

LIFE AFTER THE SCANDAL:

Thalidomide, Family, and Rehabilitation in Modern Canada, 1958-1990

By

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Abstract

In the late 1950s and early 1960s, the drug thalidomide was prescribed to pregnant women around the world as a sedative to combat morning sickness. Instead of being “completely safe,” as advertisements had promised, thalidomide caused “deformities” in children born to mothers who took the drug. In Canada thalidomide was licensed for prescription use on April 1, 1961 and remained on the market until the spring of 1962, despite knowledge of the possible connection between the medication and birth defects in newborns. This dissertation focuses on thalidomiders’ lives after the scandal. It argues that in Canada, thalidomiders’ experiences in the aftermath of the tragedy demonstrate that their disabled bodies remained political and public bodies, even in the most intimate and private aspects of their lives. Drawing on disability history and medical history, this dissertation extends the approach of patient histories to include thalidomiders’ social lives and disability as a lived experience. Because disability is always political, this case study of thalidomiders in Canada builds on the feminist critique of a public/private dichotomy and suggests that people living with disabilities do not simply blur but always transgress the public/private divide. Through an examination of rehabilitation, school, families, sexuality and reproduction, this dissertation demonstrates that thalidomiders’ lives were political as they, both inadvertently and intentionally, confronted notions of normality and engendered the limits of socially-prescribed norms. In addition, their very existence challenged ideas of humanness and belonging, and their lives were defined by their conscious and subconscious resistance to notions of abject bodies. Canadian thalidomiders have challenged the cultural importance of physical “normality” in Canada through everyday performances, and counteracted deep-seated fears of difference and “the abnormal” through their presence in communities. This dissertation is the

first study to use oral history methodology to bring the voices of Canadian thalidomiders to the attention of scholars.

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Introduction:

An Oral History of Thalidomide on a Borderland of Scholarly Inquiry

A human being without limbs is a pathetic creature completely unable to care for itself in any way. To be condemned to a life of complete inactivity and perpetual dependence on others will be constantly painful and distressing to those without limbs and a dreadful trial to their parents.¹

The first time I met Susan we had arranged to meet at a little restaurant in Perth, Ontario. A few hours before I arrived, she sent me an email saying, “In case you won’t know me, I’m the one with short arms.”² The woman has a wonderful, self-deprecating sense of humour, but deeper meanings lurk behind such statements. Susan is a thalidomider. Before she was born, she was affected by the drug thalidomide that, in the late 1950s and early 1960s, was prescribed to pregnant women around the world as a sedative to combat morning sickness. Instead of being “completely safe,” as the advertisements of the drug had promised, thalidomide caused “deformities” in children born to mothers who took the drug. Two years after that initial meeting, when I visited Susan in her home to conduct my first interview for this dissertation, she stated: “I have been through a lot myself and I feel like I survived and thrived, so I started using the term for myself. Calling myself a ‘survivor.’”³

Developed in Germany in the 1950s, thalidomide came onto the market at a time when the synthetic drugs market was soaring.⁴ What set thalidomide apart from other compounds was that it did exceedingly well in toxicity testing on animals, leading the company Chemie

¹ “As Others See It - Deformed Babies: Should We Legalize Abortions?” *Toronto Daily Star*, July 27, 1962.

² Personal email correspondence between Susan Wagner-White and Christine Chisholm, December 18, 2015.

³ Interview December 13, 2016.

⁴ Susanne Klausen and Julie Parle, “Are We Going to Stand By and Let These Children Come Into the World?: The Impact of the Thalidomide Disaster in South Africa, 1960–1977,” *Journal of Southern African Studies* 41, no. 4 (July 4, 2015): 736.

Grünenthal to declare its drug nontoxic. A drug, especially a sedative, without toxicity had enormous market potential.⁵ It seemed the perfect solution to a variety of ailments. However, in the early 1960s the drug caused an unprecedented global pharmaceutical scandal, what historian Ann Dally describes as “one of the most dramatic disasters in the history of medicine.”⁶ The thalidomide disaster affected the lives of thousands of people around the world who were harmed by the drug, as well as their families, for a lifetime. In 2011, the Thalidomide Victims Association of Canada (TVAC) provided insight into the statistics of the tragedy: “Given that no accurate census was taken during the tragedy itself, figures vary from one source to the next. However, it is claimed that between 10,000 and 20,000 babies have been born with thalidomide-caused disabilities. There are today about 5,000 surviving thalidomiders left in the world. A precise determination has never been made regarding the number of babies which were aborted or stillborn due to the effects of thalidomide.”⁷ It is also unknown how many infants born with visible deformities were killed by their families and members of the medical profession.⁸ Like TVAC, I use the term tragedy to describe the pharmaceutical disaster and the drug’s effect on Canadian lives, not to equate disability with tragedy but because the negligent marketing of the

⁵ Trent Stephens and Rock Brynner, *Dark Remedy: The Impact of Thalidomide and Its Revival as a Vital Medicine* (New York: Basic Books, 2001), 9.

⁶ Ann Dally, “Thalidomide: Was the Tragedy Preventable?” *The Lancet* 351, no. 9110 (1998): 1197.

⁷ Thalidomide Victims Association of Canada, “Report: Study on the Current Living Conditions of Canadian Thalidomide Survivors and Their Projections For Their Future,” (2011, edited in 2013), 11.

⁸ One highly publicised case of the infanticide of a thalidomide baby occurred in Belgium, where Suzanne Vandeput, along with her husband, mother, and sister, and the family doctor, Dr. Casters (who prescribed the sedative that killed the child), was arrested after putting a lethal dose of sedative in the infant’s bottle the day she was supposed to take her child home from the hospital. The young woman was acquitted of the murder of her daughter. For an overview of the legal case and euthanasia discussion that erupted in its wake see Richard Oulahan Jr., “Should One Kill a Child in Mercy ... or is Life, However Hard, too Dear to Loose?” *Life* 53, no 6. (August 10, 1962): 34-35. In Germany another murder occurred. Anna Sidorow and her doctor, Dr. Mechtilde Peterson, were brought to trial for the murder (through injection) of Sidorow’s three-year-old son in September 1963. Gert Hahn, “Mord mit Contergan vor Schwurgericht,” *Rundschau am Sonntag*, August 29, 1965.

teratogenic substance and subsequent neglect by governments caused a great deal of suffering and distress for those directly impacted, primarily thalidomiders and their parents.⁹

As scholars have shown, anxieties about bodies have profoundly shaped national histories.¹⁰ The birth of disabled “thalidomide babies,” as they were often called, also caused a great deal of uncertainty, anxiety even, about what this so-called epidemic of disabled births might mean for the provincial and national governments responsible for them. It is therefore unsurprising that the thalidomide tragedy provoked national attention in Canada in the early 1960s, the records of which provide an opportunity for historians to observe how a nation and its citizens responded to bodies that did not meet normative expectations of embodiment.¹¹ In “disfiguring” Canada’s future citizens, thalidomide created a wave of anxiety and insecurity that undermined the post-Second World War-era sense of a return to normality. The scandal had the potential to weaken Canadians’ trust in the state and the medical profession, as both institutions had enabled this tragedy to occur. With the post-war widespread availability of “wonder drugs” such as insulin, the polio vaccine, and penicillin, trust had been established between the public,

⁹ Teratogens disrupt a pregnancy or produce a congenital malformation/birth defect.

¹⁰ Patrizia Gentile and Jane Nicholas have provided a summary of the historiography of the body as it pertains to Canada in *Contesting Bodies and Nation in Canadian History* (Toronto: University of Toronto Press, 2013), 9-12. However, the collection does not include an essay that explicitly discusses disability. Other examples that speak directly to disability include Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996); Emily S. Rosenberg and Shannon Fitzpatrick, *Body and Nation The Global Realm of U.S. Body Politics in the Twentieth Century* (Durham and London: Duke University Press, 2014); and Staffan Bengtsson, “The Nation’s Body: Disability and Deviance in the Writings of Adolf Hitler,” *Disability & Society* 33, no. 3 (2018), 416-432. “Freakish” bodies in particular have been discussed in the following studies: Rosemarie Garland-Thomson, *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: New York University Press, 1996); Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997); and Thomas Fahy, *Freak Shows and the Modern American Imagination: Constructing the Damaged Body from Willa Cather to Truman Capote* (New York: Palgrave Macmillan, 2006). From the vast literature that points to the political nature of bodies I would like to flag the following as particularly influential: Angus McLaren and Arlene Tigar McLaren, *The Bedroom and the State: The Changing Practices and Politics of Contraception and Abortion in Canada, 1880-1997* (Toronto: McClelland and Stewart, 1986); Anne Fausto-Sterling, *Sexing the Body: Gender Politics and the Construction of Sexuality* (New York, NY: Basic Books, 2000).

¹¹ A comprehensive discussion of how thalidomide came to Canada and how the scandal played out in this specific national context will be provided in Chapter One.

the medical profession, and the pharmaceutical companies that helped develop these medications.¹² Yet despite these medical accomplishments as well as the state's professed interest in the personal wellbeing of its citizens, exemplified in the dramatic expansion of medical insurance coverage in the postwar years, thalidomide had found its way into Canada where it damaged and marked bodies.¹³ Its legacy, embodied in the experiences of thalidomiders, permeated Canadian culture, politics, and health care, thereby expanding its effect from individual bodies to "law, medical practices, school policies, public health programs, and patients' rights," often reshaping them entirely.¹⁴

Years after the last known Canadian thalidomider was born, a Canadian Member of Parliament (MP) still referred to thalidomide-affected children as "monstrosities."¹⁵ Such words were often used to describe the individuals who would long struggle to achieve acceptance in their communities and societies around the world. Today, with reparation payments finally being made in Canada, some might assume that the thalidomide tragedy is behind us.¹⁶ Instead, its legacies have been engraved in Canadian social infrastructure, law, medicine, as well as

¹² Susan L. Smith and Dawn Dorothy Nickel describe this time as "this optimistic age." They write: "New developments, including advances in medical technology, wonder drugs like penicillin, the expansion of hospitals, and new surgical procedure like heart surgery, seemed to suggest the limitless power of science and medicine to control and cure illness." Susan L. Smith and Dawn Dorothy Nickel, "Nursing the Dying in Post-Second World War Canada and the United States," in Georgina Feldberg, Molly Ladd-Taylor, Alison Li and Kathryn McPherson, eds., *Women, Health, and Nation: Canada and the United States Since 1945*, 330-354 (Kingston: McGill-Queen's University Press, 2003), 330.

¹³ Georgina Feldberg, Molly Ladd-Taylor, Alison Li, and Kathryn McPherson discuss how despite medical care coming within the reach of many working-class families, coverage remained uneven and incomplete. Georgina Feldberg, Molly Ladd-Taylor, Alison Li, and Kathryn McPherson, "Comparative Perspectives on Canadian and American Women's Health Care Since 1945," in Georgina Feldberg, Molly Ladd-Taylor, Alison Li and Kathryn McPherson, eds., *Women, Health, and Nation: Canada and the United States Since 1945*, 15-44 (Kingston: McGill-Queen's University Press, 2003), 23.

¹⁴ Leslie Reagan makes this statement with regards to the impact of the German measles in the U.S.A. Reagan, *Dangerous Pregnancies*, 2.

¹⁵ Grace MacInnis, House of Commons [HC] Debates, 27th Parliament, 2nd Session, Standing Committee on Health and Welfare, Minutes (3 October 1967), 4.

¹⁶ In 2015 the Harper government announced a \$180-million funding package for Canadians born with malformations because their mothers took thalidomide. In January 2019 the government under Trudeau announced an expansion of the landmark program to allow for new requests for funding from Canadians who believe they are victims of thalidomide but were previously unable to provide sufficient proof.

contemporary (body) politics.¹⁷ The experiences, struggles, and efforts of Canadian thalidomiders, their families, and the medical professionals that engaged with them, functioned as catalysts for a multitude of changes in culture and public health.¹⁸ This dissertation shares some of Canadian thalidomiders' life stories and places them into a conversation about the ways that the thalidomide tragedy impacted Canada in households, medical research, and policymaking. It considers the social, cultural, and, to an extent, political meaning of the drug's impact in a specific national context.

It is well known that the thalidomide disaster was a highly publicized scandal in Canada and elsewhere. This thesis focuses on life *after* the scandal and argues that in Canada, thalidomiders' experiences in the aftermath of the tragedy demonstrate that their disabled bodies remained political and public bodies, even in the most intimate and private aspects of their lives. Because disability is always political, this case study of thalidomiders in Canada builds on the feminist critique of a public/private dichotomy and suggests that people living with disabilities do not simply blur but always transgress the public/private divide. In addition, their very existence challenges ideas of humanness and belonging, and their lives are defined by their conscious and subconscious resistance to notions of abject bodies. This dissertation will show that thalidomiders in particular have challenged the cultural importance of physical "normality" in Canada through everyday performances, and counteracted deep-seated fears of difference and "the abnormal" through their presence in communities. It will do so through an examination of the most private aspects of thalidomiders' lives, as identified by thalidomiders themselves, and

¹⁷ In 2015 the Harper government announced a \$180-million funding package for Canadians born with malformations because their mothers took thalidomide. In January 2019 the government under Trudeau announced and expansion of the landmark program to allow for new requests for funding from Canadians who believe they are victims of thalidomide but were previously unable to provide sufficient proof.

¹⁸ Leslie Reagan has made a similar argument, regarding the legacy of the German measles epidemic in the U.S. in *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010), 1.

of the circles of proximity – the material and social contexts and interactions (social, medical, and political) – that enabled and constrained them.

To date research on the thalidomide tragedy has focussed primarily on uncovering the dimensions of the initial scandal and, more recently, on some of the socio-cultural impacts the pharmaceutical scandal itself had on drug and abortion policies.¹⁹ In addition, studies have considered its cultural implications within specific national contexts.²⁰ However, historians have

¹⁹ Henning Sjöström and Robert Nilsson. *Thalidomide and the Power of the Drug Companies* (Harmondsworth: Penguin, 1972); The Insight Team of the Sunday Times (London), *Suffer the Children: The Story of Thalidomide* (New York: Viking Press, 1979). Max Sherman and Steven Strauss, “Thalidomide: A Twenty-Five Year Perspective,” *Food, Drug, Cosmetic Law Journal* 41, no. 4 (1986), 458-466; Trent Stephens and Rock Brynner, *Dark Remedy*; Beate Kirk, *Der Contergan-Fall. Eine unvermeidbare Arzneimittelkatastrophe? Zur Geschichte des Arzneistoffes Thalidomid* (Stuttgart: Wissenschaftliche Verlagsgesellschaft, 1999); Niklas Lenhard-Schramm, *Das Land Nordrhein-Westfalen und der Contergan-Skandal: Gesundheitsaufsicht und Straffjustiz in den »langen sechziger Jahren«* (Vandenhoeck & Ruprecht, 2016); Niklas Lenhard-Schramm and Thomas Großbölting, eds, *Contergan: Hintergründe und Folgen eines Arzneimittel-Skandals* (Göttingen: Vandenhoeck & Ruprecht, 2017); Willibald Steinmetz, “Ungewollte Politisierung durch die Medien? Die Contergan-Affäre.” In *Die Politik der Öffentlichkeit – Die Öffentlichkeit der Politik*, ed. Bernd Weisbrod, 195–228 (Göttingen: Wallstein, 2003); and Alexander Von Schwerin, “1961 – Die Contergan-Bombe. Der Arzneimittelskandal und die neue risikoepestemische Ordnung der Massenkonsumgesellschaft.” In *Arzneistoffe im 20. Jahrhundert. Historische Skizzen von Lebertran bis Contergan*, ed. Nicholas Eschenbruch, Nicholas, Viola Balz, Ulrike Klöppel, and Marion Hulverscheidt, 255–82 (Bielefeld: Transcript, 2009); Martin Johnson, Raymond G. Stokes, and Tobias Arndt, *The Thalidomide Catastrophe: How it Happened, who was Responsible and why the Search for Justice Continues After More Than Six Decades* (Onwards and Upwards, 2018).

²⁰ Christine Chisholm, “The Curious Case of Thalidomide and the Absent Eugenic Clause in Canada’s Amended Abortion Law of 1969,” *Canadian Bulletin of Medical History* 33, no. 2 (January 2, 2017): 493–516; Denyse Baillargeon and Susanne Commend, “Un Médicament ‘Monstrueux’: Débats Publics et Couverture Médiaque de la Tragédie de la Thalidomide au Canada, 1961-1963,” *Canadian Bulletin of Medical History* 33, no. 1 (2016): 131-153; Barbara Clow, “Defining Disability, Limiting Liability: The Care of Thalidomide Victims in Canada,” in *Essays in Honour of Michael Bliss: Figuring the Social*, Alison Li, Elisabeth Heaman, Shelley McKellar, and Michael Bliss, eds. (Toronto: University of Toronto Press, 2008), 304-314; Ethel Roskies, *Abnormality and Normality: The Mothering of Thalidomide Children* (Ithaca: Cornell University Press, 1972); Viviane Quirke, “The Impact of Thalidomide on the British Pharmaceutical Industry: The case of Imperial Chemical Industries,” In *Ways of Regulating: Therapeutic Agents between Plants, Shops and Consulting Rooms*, ed. Jean-Paul Gaudillière and Volker Hess, 137–52 (Berlin: Max Planck Institute, 2008); Richard E. McFadyen, “Thalidomide in America: A Brush with Tragedy,” *Clio Medica* 11 (1976):79; Arthur Daemmrich, “A Tale of Two Experts: Thalidomide and Political Engagement in the United States and West Germany,” *Social History of Medicine* 15, no. 1 (2002): 137-58; Barbara Clow, “‘An Illness of Nine Months’ Duration:’ Pregnancy and Thalidomide Use in Canada and the United States,” in *Women, Health, and Nation: Canada and the United States Since 1945*, Georgina Feldberg, Molly Ladd-Taylor, Alison Li and Kathryn McPherson, eds., 45-66 (Kingston: McGill-Queen’s University Press, 2003); Clare Parker, “From Immorality to Public Health: Thalidomide and the Debate for Legal Abortion in Australia,” *Social History of Medicine* 25, 4 (2012); Susanne Klausen, “‘There is a Row about Foetal Abnormality Underway’: The Debate about Inclusion of a Eugenics Clause in the Contraception, Sterilisation, and Abortion Act, 1977-1978,” *New Zealand Journal of History* 51, No. 2 (October 2017): 80-103; Susanne Klausen and Julie Parle, “‘Are We Going to Stand By and Let These Children Come Into the World?’”; and Julie Parle, Rebecca Hodes and Thembisa Waetjen, “Pharmaceuticals and Modern Statecraft in South Africa: The Cases of Opium, Thalidomide and Contraception,” *Medical Humanities* 44 (2018): 253– 62; Julie Parle and Ludger Wimmelbucker, “‘These are the Medicines that

paid very limited attention to the every-day lived experiences of thalidomiders.²¹ This dissertation is the first study to use oral history methodology to bring the voices of Canadian thalidomiders to the attention of scholars and to conduct a long-term analysis of the aftermath of the thalidomide tragedy in this national context.²²

Historiography

The research that exists on the thalidomide tragedy to date has revealed the extent of the pharmaceutical disaster and some of its political and cultural implications in specific national contexts. (Note that previous studies do not necessarily use the term thalidomide and may instead make use of the numerous commercial names, such as Contergan and Softenon, used to advertise products containing thalidomide in various countries.²³) Two of the best-known histories of the thalidomide tragedy – Henning Sjöström and Robert Nilsson’s *Thalidomide and the Power of the Drug Companies*, published in 1972, and *Suffer The Children: The Story of Thalidomide* by the *Sunday Times* Insight Team, published in 1979 – were the first to expose in detail what had occurred.²⁴ Although published significantly later, Trent Stephens and Rock Brynner’s book

“Make” Monsters’: Thalidomide in Southern Africa, 1958–1962,” *Social History of Medicine* (published online, March 5, 2019): 1-26. <https://doi-org.proxy.library.carleton.ca/10.1093/shm/hkz011>.

²¹ Sociologist Walburga Katharina Freitag has produced a study that considers the lives of seven German thalidomiders based on oral interviews conducted between 1997 and 1998. Walburga Katharina Freitag, *Contergan: Eine Genealogische Studie des Zusammenhangs Wissenschaftlicher Diskurse und Biographischer Erfahrungen* (Waxmann Verlag, 2005). Her study is solely focused on discursive impact of rehabilitation rhetoric on the identity formation of the German thalidomiders.

²² A notable exception is Randy Warren, a Canadian thalidomider, who was interviewed for the book *Dark Remedy*. Trent Stephens and Rock Brynner, *Dark Remedy: The Impact of Thalidomide and Its Revival as a Vital Medicine* (New York: Basic Books, 2001).

²³ Publications listed below, for example, use the names “Contergan” (Germany), “Softenon” (Switzerland), and “Distaval” (UK).

²⁴ Henning Sjöström and Robert Nilsson, *Thalidomide and the Power of the Drug Companies* (Harmondsworth: Penguin, 1972); The Insight Team of the *Sunday Times* (London), *Suffer the Children: The Story of Thalidomide* (New York: Viking Press, 1979). Also interesting is a review of events published in 1986 by Max Sherman and Steven Strauss in “Thalidomide: A Twenty-Five Year Perspective,” *Food, Drug, Cosmetic Law Journal* 41, no. 4 (1986): 458-466.

Dark Remedy: The Impact of Thalidomide and Its Revival as a Vital Medicine can also be counted as part of the foundational literature on thalidomide as it chronicles the history of the drug over a period of forty years.²⁵ Beyond that, the most prolific conversation has occurred in relation to the case of thalidomide in West Germany and the United Kingdom.²⁶ Sweden, Canada, Australia, Japan, and New Zealand have also received significant scholarly attention,²⁷ and a few studies address the thalidomide scandal in the United States.²⁸ Furthermore, to date

²⁵ Trent Stephens and Rock Brynner, *Dark Remedy: The Impact of Thalidomide and Its Revival as a Vital Medicine* (New York: Basic Books, 2001).

²⁶ See Beate Kirk, *Der Contergan-Fall. Eine unvermeidbare Arzneimittelkatastrophe? Zur Geschichte des Arzneistoffes Thalidomid* (Stuttgart: Wissenschaftliche Verlagsgesellschaft, 1999); Niklas Lenhard-Schramm, *Das Land Nordrhein-Westfalen und der Contergan-Skandal: Gesundheitsaufsicht und Strafrecht in den »langen sechziger Jahren«* (Vandenhoeck & Ruprecht, 2016); Niklas Lenhard-Schramm and Thomas Großbölting, eds, *Contergan: Hintergründe und Folgen eines Arzneimittel-Skandals* (Göttingen: Vandenhoeck & Ruprecht, 2017); Willibald Steinmetz, “Ungewollte Politisierung durch die Medien? Die Contergan-Affäre,” in *Die Politik der Öffentlichkeit – Die Öffentlichkeit der Politik*, ed. Bernd Weisbrod, 195–228 (Göttingen: Wallstein, 2003); and Alexander Von Schwerin, “1961 – Die Contergan-Bombe. Der Arzneimittelskandal und die neue risikoepistemische Ordnung der Massenkongsumgesellschaft,” in *Arzneistoffe im 20. Jahrhundert. Historische Skizzen von Lebertran bis Contergan*, ed. Nicholas Eschenbruch, Nicholas, Viola Balz, Ulrike Klöppel, and Marion Hulverscheidt, 255–82 (Bielefeld: Transcript, 2009); Viviane Quirke, “The Impact of Thalidomide on the British Pharmaceutical Industry: The case of Imperial Chemical Industries,” in *Ways of Regulating: Therapeutic Agents between Plants, Shops and Consulting Rooms*, ed. Jean-Paul Gaudillière and Volker Hess, 137–52 (Berlin: Max Planck Institute, 2008); Martin Johnson, Raymond G. Stokes, and Tobias Arndt, *The Thalidomide Catastrophe: How it Happened, Who Was Responsible and Why the Search for Justice Continues After More Than Six Decades* (Onwards and Upwards, 2018). The thalidomide scandal is also discussed in other within other publications as a case study, such as in Sonia Macleod, and Sweta Chakraborty, *Pharmaceutical and Medical Device Safety: A Study in Public and Private Regulation* (Bloomsbury Publishing, 2019).

²⁷ Chisholm, “The Curious Case of Thalidomide;” Denyse Baillargeon and Susanne Commend, “Un Médicament ‘Monstrueux’: Débats Publics et Couverture Médiatique de la Tragédie de la Thalidomide au Canada, 1961–1963,” *Canadian Bulletin of Medical History* 33, no. 1 (2016): 131–153; Barbara Clow, “Defining Disability, Limiting Liability: The Care of Thalidomide Victims in Canada,” in *Essays in Honour of Michael Bliss: Figuring the Social*, Alison Li, Elisabeth Heaman, Shelley McKellar, and Michael Bliss, eds. (Toronto: University of Toronto Press, 2008), 304–314; Ethel Roskies, *Abnormality and Normality: The Mothering of Thalidomide Children* (Ithaca: Cornell University Press, 1972); Henning Sjöström and Robert Nilsson. *Thalidomide and the Power of the Drug Companies* (Harmondsworth: Penguin, 1972); Clare Parker, “From Immorality to Public Health: Thalidomide and the Debate for Legal Abortion in Australia,” *Social History of Medicine* 25, 4 (2012); Michael Magazanik, *Silent Shock: The Men Behind the Thalidomide Scandal and an Australian Family’s Long Road to Justice* (Melbourne: The Text Publishing Co., 2015); Yoichiro Yamakawa, “The Legal Settlement of Thalidomide Cases in Japan,” in *Drug-Induced Suffering’s Medical, Pharmaceutical, and Legal Aspects*, T. Soda, ed. (Amsterdam: Excerpta Medica, 1980); Susanne Klausen, “‘There is a Row about Foetal Abnormality Underway’: The Debate about Inclusion of a Eugenics Clause in the Contraception, Sterilisation, and Abortion Act, 1977–1978,” *New Zealand Journal of History* 51, No. 2 (October 2017): 80–103.

²⁸ Significantly Richard E. McFadyen, “Thalidomide in America: A Brush with Tragedy,” *Clio Medica* 11 (1976): 79; Arthur Daemmrich, “A Tale of Two Experts: Thalidomide and Political Engagement in the United States and West Germany,” *Social History of Medicine* 15, no. 1 (2002): 137–58; Barbara Clow, “‘An Illness of Nine Months’ Duration:’ Pregnancy and Thalidomide Use in Canada and the United States,” 45–66. The United States’ thalidomide scandal is also mentioned as part of Leslie Reagan’s discussion of the epidemic of the early 1960s in her

three publications discuss the case of thalidomide in Africa, two of which consider South Africa specifically while the third looks at Southern Africa more broadly.²⁹ One scholar has taken on the immense effort to study the drug's global history from the 1950s to the 1970s in an ongoing research project titled "Ways of Globalization: The International Distribution and Control of Drugs Containing Thalidomide."³⁰ This dissertation inserts the Canadian case into the existing transnational history.

Other studies discuss the impact and importance of the international thalidomide scandal with regards to pharmacology and medicine. For example, Nils Kessel's study of Doriden, a drug marketed by the Swiss manufacturer CIBA, provides a companion discussion to the literature on thalidomide, as he "sheds light on the question of how 'West Germany's worst drug disaster' was perceived by pharmaceutical companies other than Grünenthal, the German manufacturer of Contergan."³¹ Another example is the co-authored article "A Historical Argument for Regulatory Failure in the Case of Primodos and Other Hormone Pregnancy Tests," which notes how the thalidomide scandal transformed the science of birth defects (teratology) and thus raised the awareness of potentially teratogenic drugs.³²

book *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010).

²⁹ Susanne Klausen and Julie Parle, "'Are We Going to Stand By and Let These Children Come Into the World?': The Impact of the Thalidomide Disaster in South Africa, 1960–1977," *Journal of Southern African Studies* 41, no. 4 (July 4, 2015): 735–52; and Julie Parle, Rebecca Hodes and Thembisa Waetjen, "Pharmaceuticals and Modern Statecraft in South Africa," Parle and Wimmelbücker, "'These are the Medicines that 'Make' Monsters'."

³⁰ Ludger Wimmelbücker, "Ways of Globalization: The International Distribution and Control of Drugs Containing Thalidomide." In their co-authored article Julie Parle and Ludger Wimmelbücker describe the project as follows: "That wider study will illuminate the distinctiveness and/or commonalities between regions such as Southern Africa and South America (for instance)." See Parle and Wimmelbücker. "'These are the Medicines that 'Make' Monsters'," 2.

³¹ Nils Kessel, "'Doriden Von Ciba': Sleeping Pills, Pharmaceutical Marketing, and Thalidomide, 1955–1963," *History and Technology* 29, no. 2 (2013): 153.

³² Jesse Olszynko-Gryn, Eira Bjørvik, Merle Weßel, Solveig Jülich, and Cyrille Jean, "A Historical Argument for Regulatory Failure in the Case of Primodos and Other Hormone Pregnancy Tests," *Reproductive Biomedicine & Society Online* 6, (2018): 34-44.

Although there is growing interest in thalidomide within various national contexts and in the political as well as cultural implications of the scandal, there is a dearth of studies that provide a consideration of the long-term consequences of the pharmaceutical scandal in the lives of those directly impacted by it. Adding to this, thalidomide scholarship thus far has not made effective use of oral history methodology to gauge the lived experiences of those directly affected by the drug. Certainly Ruth Blue (initially with the help of her late colleague Anne Borse) has produced an extremely important oral history collection of thalidomiders' oral testimony in the United Kingdom, and Barbara Clow, Denyse Baillargeon and Susanne Commend have begun the important work of documenting the aftermath of the scandal for Canadian thalidomiders, on which my dissertation builds. However, the only other study that has effectively allowed for a consideration of the lived experiences of thalidomiders is Walburga Katharina Freitag's sociological study *Contergan: Eine Genealogische Studie des Zusammenhangs Wissenschaftlicher Diskurse und Biographischer Erfahrungen* which includes the biographical narratives of seven German thalidomiders based on oral interviews conducted between 1997 and 1998.³³ Neither patient histories nor disability histories have focused on the social disablement experienced by those whose bodies were shaped by the drug. This dissertation contributes the first long-term study of Canadian thalidomiders' life experiences to the historiography using oral history methodology (discussed below).

Historiographically, this dissertation primarily draws upon and contributes to the history of medicine and the history of disability. Thus far no works exist that tackle the important question of how scholars are to grapple with the tension between medical history and disability

³³ Walburga Katharina Freitag, *Contergan: Eine Genealogische Studie des Zusammenhangs Wissenschaftlicher Diskurse und Biographischer Erfahrungen* (Waxmann Verlag, 2005).

history in regards to thalidomiders' pasts. Thus, this dissertation is situated at the *intersection* of the histories of medicine and disability in post-Second World War Canada.

Medical history is the older of the two fields, originating in the 1930s. The pioneering historians, most notably Erwin Ackerknecht, Henry Sigerist, and Oswei Temkin, were trained physicians who were leading members of the American medical profession.³⁴ The earliest publications in medical history focused on disease histories and devised new ways of looking at the relationship between disease and society, while simultaneously foregrounding the primacy of medical progress.³⁵ The field underwent a major transformation in the 1960s and 1970s, when the advent of social history led to a questioning of a physician-centered approach. In his study of how the medical profession and American society at large imagined the human body in the mid-twentieth century, David Serlin has described the changing views on the construction of medical knowledge as follows: "Since the 1960s, an increasing number of sociologists, anthropologists, and historians have concluded that medical knowledge, far from being neutral, is socially and culturally constructed by the individuals and institutions who belong to the society in which that knowledge is generated and applied."³⁶ In 1980, American medical anthropologist Arthur Kleinman advocated for a distinction between the notions of disease and illness and wrote that while disease refers to physical pathologies, illness refers to "a person's perceptions and experiences of certain socially devalued states including, but not limited to, disease."³⁷ A few

³⁴ Charles Rosenberg, "Erwin H. Ackerknecht, Social Medicine, and the History of Medicine," *Bulletin of the History of Medicine* 81, no. 3 (2007), 511-532; Elisabeth Fee and Theodore M. Brown (eds.), *Making Medical History: The Life and Times of Henry E. Sigerist*, (Baltimore: John Hopkins University Press, 1997).

³⁵ Catherine Kudlick, "Social History of Medicine and Disability History," in *The Oxford Handbook of Disability History*, edited by Michael A. Rembis, Catherine Jean Kudlick, Kim E. Nielsen, 105-124, (Oxford University Press, 2018), 107; Beth Linker, "On the Borderland of Medical and Disability History: A Survey of the Fields," *Bulletin of the History of Medicine* 87, no. 4 (December 20, 2013): 506-514.

³⁶ David Serlin, "Built for Living: Imagining the American Body - Through Medical Science, 1945-1965," (Ph.D. diss., New York University, 1999), 8.

³⁷ Arthur Kleinman, paraphrased by Allan Young, in Young's "The Anthropologies of Illness and Sickness," *Annual Review of Anthropology* 11 (1982): 265. As cited by Serlin, *Built for Living*, 11.

years later, in 1985, British historian Roy Porter published his influential article “The Patient’s View: Doing Medical History from Below,” which focused on patient narratives and argued that historians “implicitly endorsed the view that the history of healing is par excellence the history of doctors,” which he called a “major historical distortion.”³⁸ Scholars in Canada, the United States, Great Britain, and France answered Porter’s call for a patient-centred approach in their research.³⁹

The significance of Porter’s argument for the field of medical history, and the initial forays into medical history from below that he provoked, have been surveyed.⁴⁰ In 2007 medical historian Flurin Condrauas noted that even twenty years after Porter’s intervention, and despite the initial enthusiasm caused by his article, “the history of the patient’s view is as undeveloped now as it was back in the mid-1980s when it seemed that patients’ history could turn into the new paradigm for writing history of medicine.”⁴¹ And in 2012, L. Stephen Jacyna and Stephen T.

³⁸ Roy Porter, “The Patient’s View: Doing Medical History from Below,” *Theory and Society* 14, no. 2 (1985): 175.

³⁹ Wendy Mitchinson, “Hysteria and Insanity: A Nineteenth Century Canadian Perspective,” *Journal of Canadian Studies*, 21 (1986), 87-105; Wendy Mitchinson, “Gender and Insanity as Characteristics of the Insane: A Nineteenth-Century Case,” *Canadian Bulletin of Medical History*, 4 (1987), 99-117; Wendy Mitchinson, “Reasons for Committal to a Mid-Nineteenth-Century Ontario Insane Asylum: The Case of Toronto,” in Wendy Mitchinson and Janet Dickin McGinnis, eds., *Essays in the History of Canadian Medicine* (Toronto: McClelland and Stewart, 1988), 88-109; Cheryl Krasnick Warsh, *Moments of Unreason: The Practice of Canadian Psychiatry and the Homewood Retreat, 1883-1923* (Montreal: McGill-Queen’s University Press, 1989); Mary-Ellen Kelm, “‘The Only Place Likely to Do Her Any Good’: The Admission of Women to British Columbia’s Provincial Hospital for the Insane,” *BC Studies*, 96 (Winter 1992-93), 66-89; Elaine Showalter, *The Female Malady: Women, Madness and English Culture, 1830-1980* (New York: Pantheon Books, 1985); Ellen Dwyer, *Homes for the Mad: Life Inside Two Nineteenth-Century Asylums* (New Brunswick, N.J.: Rutgers University Press, 1987); Jane Ussher, *Women’s Madness: Misogyny or Mental Illness?* (Amherst: University of Massachusetts Press, 1991); Charlotte McKenzie, *Psychiatry for the Rich: A History of Ticehurst Private Asylum, 1792-1917* (London: Routledge, 1992); Peter Rushton, “Lunatics and Idiots: Mental Disability, the Community, and the Poor Law in North-East England, 1600-1800,” *Medical History*, 32, 1 (January 1988), 34-50; Yannick Ripa, *Women and Madness: The Incarceration of Women in Nineteenth Century France*, translated by C. Menage (Cambridge: Polity Press, 1990); and Denise Jodelet, *Madness and Social Representations*, translated by Tim Pownall, edited by Gerard Duveen (Hertfordshire: Harvester Wheatsheaf, 1991). All of the above studies have been identified by Geoffrey Reaume in his article “Keep Your Labels Off My Mind! Or ‘Now I Am Going to Pretend I Am Crazy but don’t be a Bit Alarmed’: Psychiatric History from the Patients’ Perspectives,” *Canadian Bulletin of Medical History* 11, no. 2 (1994), 398.

⁴⁰ See especially K. Ernst, “Patientengeschichte. Die kulturhistorische Wende in der Medizinhistoriographie,” in *Eine Wissenschaft emanzipiert sich. Die Medizinhistoriographie von der Aufklärung bis zur Postmoderne*, Bröer R. (ed.), (Pfaffenweiler: Centaurus Verlagsgesellschaft, 1999): 97-108.

⁴¹ Flurin Condraua, “‘The Patient’s View Meets the Clinical Gaze,’” *Social History of Medicine*, 20, 3 (2007): 526.

Casper argued that despite the initial fervour, “more than twenty years after Porter’s putative gestalt shift,” the patient’s view remains “curiously underwritten,” and that historians “failed in particular to consider the impact of illness upon the patient’s economic, familial, legal, and civic status.”⁴² This was reiterated once again in 2013 by Alexandra Bacopoulos-Viau and Aude Fauvel.⁴³ Nonetheless, few studies emerged that did not place medical analyses and actors center stage. Medical history remained defined to a large extent by studies focusing on diseases such as cholera, yellow fever, and polio. Disability, when it was included, was understood almost exclusively in medical terms, as something to be treated and potentially cured.⁴⁴ The medical histories that discussed disability concentrated on disability policy and health-care costs.⁴⁵

Despite the laments about a still-underdeveloped social history of medicine several scholars have successfully followed up on Porter’s call and have written important analyses of patient experiences, including individuals with long-term disabilities.⁴⁶ An example, lauded by medical historian Beth Linker as model bottom-up history, is Daniel J. Wilson’s *Living with Polio: The Epidemic and Its Survivors*, published in 2005, which considers the emotional journey of those physically affected by polio and their families.⁴⁷ In his book, Wilson, a polio survivor himself, describes the emotional aspects of polio in detailed accounts of patient experiences and family life. By considering the medical institutions and rehabilitation of patients, but also the process of readjusting to life at home, Wilson expands the focus on purely medical

⁴² L. Stephen Jacyna and Stephen T. Casper (eds), *The Neurological Patient in History* (Rochester, NY: University of Rochester Press, 2012), 6.

⁴³ Alexandra Bacopoulos-Viau, and Aude Fauvel. “The Patient’s Turn: Roy Porter and Psychiatry’s Tales, Thirty Years On,” *Medical History* 60, no. 1 (January 2016): 1-2.

⁴⁴ Kudlick, “Social History of Medicine and Disability History,” 108.

⁴⁵ An example is Daniel M. Fox, “Policy and Epidemiology: Financing Health Services for the Chronically Ill and Disabled, 1930–1990,” *Milbank Quart.* 67 (1989): 257–87.

⁴⁶ Geoffrey Reaume’s book being one of the most cited Canadian examples. *Remembrance of Patients Past: Patient Life at the Toronto Hospital for the Insane, 1870-1940* (Toronto: University of Toronto Press, 2009).

⁴⁷ Daniel J. Wilson, *Living with Polio: The Epidemic and Its Survivors* (University of Chicago Press, 2005).

environments, an example that this dissertation follows. Similarly, this dissertation also aims to parallel Wilson's attentiveness to patient narratives and family accounts, which he explores in some instances over decades, thus providing a model for a long-term study such as my own research. Indeed, in 2007, Wilson co-published an oral history titled *Polio Voices: An Oral History from the American Polio Epidemics and Worldwide Eradication Efforts*, indicating the importance of drawing on perspectives previously neglected.⁴⁸ The importance and challenges of oral history are discussed in the methodology section below.

Parallel to the burgeoning field of the social history of medicine, the disability civil rights movement of the 1960s and 1970s spurred the "rethinking of the medical paradigm of disability."⁴⁹ The main concern of this movement has been well summarized by disability historian Catherine Kudlick, who writes: "Above all, they [disability rights activists] confronted prevailing ideas that cast disabled people exclusively as patients who passively waited to be made normal rather than as individuals struggling with inaccessible environments, prejudice, stigma, and low expectations."⁵⁰ This activism provoked the development of the field of disability studies in the 1980s. Whereas the intellectual field of disability studies emerged simultaneously in the United Kingdom and the United States, disability history has different roots in the United Kingdom, where it emerged from within medical history, and in North America, where it came into being as a subfield of disability studies in the late 1990s and early 2000s.⁵¹ As such, North American disability historians, including those in Canada, have been particularly adamant about the distinction between disability history and medical history,

⁴⁸ Julie K. Silver and Daniel J. Wilson, (eds.), *Polio Voices: An Oral History from the American Polio Epidemics and Worldwide Eradication Efforts* (Westport, CT: Praeger, 2007).

⁴⁹ Kudlick, "Social History of Medicine and Disability History," 109.

⁵⁰ Kudlick, "Social History of Medicine and Disability History," 108.

⁵¹ Kudlick, "Social History of Medicine and Disability History," 108.

whereas in the United Kingdom the divide is less marked in the scholarship.⁵² Nevertheless, in both Britain and North America, disability theorists agree that “the cause of disability is neither the illness, nor the individual in a state of tragic adaptive ‘failure’, but the oppressive society in which disabled people live.”⁵³ Whatever regional differences there may be, disability history in general is challenging the dominance of a purely medical view of disability.⁵⁴

In North America, historians aimed to solidify the arrival and parameters of the new field of disability history in works such as *The New Disability History: American Perspectives*,⁵⁵ Susan Burch’s *Encyclopedia of American Disability History*,⁵⁶ as well as in contributions to the Michigan University press book series *Corporealities: Discourses of Disability*,⁵⁷ and the

⁵² Both Beth Linker and Catherine Kudlick make this claim, citing Julie Anderson, president of the Disability History Group in the United Kingdom. The former refers to Anderson’s article “News from Beyond North America,” that appeared in the Fall of 2007 in the *Disability History Association Newsletter*, whereas the latter cites “personal correspondence”. However, neither Linker nor Kudlick refer to specific studies, articles, or books that would serve as examples of the ways that disability histories in the United Kingdom have been affected and developed differently based on their suggested closer alignment with medical history. In the newsletter, Anderson notes that during the Disability History Groups’ inaugural meeting, “We were indeed fortunate to have two leading disability scholars from the United States, Paul Longmore and David Serlin to provide the conference with insights into American disability history, as a contrast,” but she does not elaborate on what this contrast is or which studies might exemplify it. Linker, “On the Borderland of Medical and Disability History,” 501; Kudlick, “Social History of Medicine and Disability History,” 109; Julie Anderson, “News from Beyond North America,” *Disability History Association Newsletter* 3, no. 2 (Fall 2007), 5.

⁵³ Gareth Williams and Helen Busby, “The Politics of ‘Disabled’ Bodies,” in *Health, Medicine, and Society: Key Theories, Future Agendas*, edited by Simon J. Williams, Jonathan Gabe, Michael Calnan, 169-186 (Psychology Press, 2000), 175.

⁵⁴ This holds true for scholarship globally. Non-Western examples include the following: Eric Silla, *People Are Not the Same: Leprosy and Identity in Twentieth-Century Mali* (Portsmouth, NH: Heinemann, 1998); Joshua T. Malinga, “The Pan-African Movement of People with Disabilities,” in *Disability in Different Cultures: Reflections on Local Concepts*, edited by Brigitte Holzer, Arthur Vreede, and Gabrielle Weigt (New Brunswick, NJ: Transaction, 1999), 274–76; Matthew Kohrman, “Motorcycles for the Disabled: Mobility, Modernity, and the Transformation of Experience in Urban China,” *Culture, Medicine, and Psychiatry* 23 (1999): 133–55; Matthew Kohrman, “Why Am I Not Disabled? Statistics and Transnational Subject Making in Modern China,” *Medical Anthropology Quarterly* 17 (1999): 5–24; Julie Livingston, “Insights from an African History of Disability,” *Radical History Review* 2006, no. 94 (2006): 111-126; Fikru Negash Gebrekidan, “Disability Rights Activism in Kenya, 1959-1964: History from Below,” *African Studies Review* 55, no. 3 (2012): 103-122.

⁵⁵ Lauri Umansky and Paul K. Longmore, *The New Disability History: American Perspectives, History of Disability Series* (New York, New York University Press, 2001).

⁵⁶ Susan Burch, *Encyclopedia of American Disability History* (New York: Facts On File, 2009).

⁵⁷ “Corporealities: Discourses of Disability,” University of Michigan Press, accessed September 28, 2017, <https://www.press.umich.edu/browse/series/UM117>.

Syracuse University Press book series *Critical Perspectives on Disability*.⁵⁸ Important too was the founding of the Disability History Association in 2004, an “international non-profit organization that promotes the study of disabilities throughout history” by scholars “working in all geographic regions.”⁵⁹ A useful overview of disability histories with a special focus on Canadian studies has been provided by Nancy Hansen, Roy Hanes, and Diane Driedger in the introduction to their edited collection *Untold Stories: A Canadian Disability History Reader*, which outlines key publications generally and provides brief introductions to Canadian studies specifically.⁶⁰ The editors emphasize that not only is disability history “an extension of disability studies,” it has “become part of the larger *history* discipline” [emphasis in the original] indicating a commitment to historiographically-informed scholarship based in the academy.⁶¹

As Beth Linker and others have noted, many of the early publications were aimed at defining disability history as distinct from medical history.⁶² The disability activists’ outspoken rejection of the authority of the medical profession — a profession that was perceived as helping stigmatize disability — fuelled the origins in the 1980s of disability studies and motivated scholars and activists to theorize disability apart from medical understandings. (We will return to the validity of this division later.) This resulted in a disconnect between disability history and medical history, especially as disability activists and scholars alike sought to demonstrate that people with disabilities had a significant and rich history outside of institutions.⁶³ Fuelled by questions regarding identity politics and critical theory, and having been spurred by disability

⁵⁸ “Critical Perspectives on Disability,” Syracuse University Press, accessed September 28, 2017, <http://www.syracuseuniversitypress.syr.edu/subject/disability.html>.

⁵⁹ “About the DHA,” The Disability History Association, accessed June 14, 2019, https://dishist.org/?page_id=2.

⁶⁰ Diane Driedger, Roy Hanes, and Nancy E. Hansen, *Untold Stories: A Canadian Disability History Reader* (Toronto: Canadian Scholars, 2018), 2-3.

⁶¹ Driedger, et al., *Untold Stories*, 2.

⁶² Linker, “On the Borderland of Medical and Disability History,” 500.

⁶³ Catherine Kudlick, “Comment: At the Borderland of Medical and Disability History” *Bulletin of the History of Medicine* 87, no. 4 (Winter 2013): 542-3, 545.

civil rights and social justice activism, disability scholars' research often adopted (and continues to adopt) an unapologetic attitude towards the relationship between politics, advocacy, and history.⁶⁴ As Kudlick has argued, "Disability's scholarly activism expresses itself as a critique of ideas that have placed medicine, medical power, medical understandings of disability and disabled people at the center of every story that touches them."⁶⁵ Instead, disability scholars adopted a social model of disability that focuses on *social* barriers as opposed to *physical* barriers. Put another way, the efforts of disability historians to distinguish their work on disability from medical histories was grounded in an effort to de-center medical discourses.

In the late 1990s, the "second wave" of disability scholarship emerged. It was then that Judith Butler's critique of the gender/sex binary started to be applied to disability issues. Butler argued in her book *Gender Trouble: Feminism and the Subversion of Identity* that gender is performed, rather than being an essential quality of biological sex.⁶⁶ Disability scholars, including historians, paralleled Butler's feminist concerns by destabilizing the disablement/impairment binary.⁶⁷ The critique of the impairment/disability binary informed the social model of disability. Mairian Corker and Sally French wrote in 1999 that "Social model

⁶⁴ Lennard J. Davis's *Enforcing Normalcy*, published in 1995; Rosemarie Garland-Thomson's *Extraordinary Bodies*, published in 1997; and Tobin Siebers's numerous publications on disability represent the possibly most influential works in the field, all of which explored the potential of disability as an identity category. Their works helped inform the scholars discussed below. See Kudlick's article regarding the attitude of disability scholars towards the relationship between politics, advocacy, and history. Kudlick, "Comment: At the Borderland of Medical and Disability History" 542.

⁶⁵ Kudlick, "Comment: At the Borderland of Medical and Disability History," 545.

⁶⁶ Judith Butler, *Gender Trouble: Feminism and the Subversion of Identity* (Abingdon: Routledge, 1990).

⁶⁷ Ellen Samuels, "Critical Divides: Judith Butler's Body Theory and the Question of Disability," *NWSA Journal* 14, no. 3 (2002): 62. The "first wave" which emerged in the 1980s was marked by such publications as: Lennard J. Davis, *The Disability Studies Reader* (New York: Routledge, 1997); Tom Shakespeare, *The Disability Reader: Social Science Perspectives* (New York: Cassell, 1998); Lennard J. Davis, *Enforcing Normalcy: Disability, Deafness, and the Body* (Verso, 1995); Susan Wendell, *The Rejected Body: Feminist Philosophical Reflections on Disability* (New York: Routledge, 1996); Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997).

One might note that although the origins of the field lie in the mid-1980s, a series of books on psychiatry and mental illness had already begun the process of inspiring works on disability a few years earlier, Michel Foucault's book *Madness and Civilization* being the most widely known example.

theory rests on the distinction between disability, which is socially created, and impairment, which is referred to as a physical attribute of the body. In this sense it establishes a paradigm for disabled people which is equivalent to those of sex/gender and race/ethnicity.”⁶⁸ This model that foregrounds the distinction between the social exclusion of disabled individuals from their physical limitations or impairments, is contrasted against the medical model of disability which “defines disability in terms of individual deficit” rather than as a social creation.⁶⁹

While Butler’s book *Bodies that Matter* does not include the terms *disability* or *disabled*, it nevertheless enabled scholar to extend Butler’s earlier argument about the performativity of gender to include other embodied identity categories, such as race and disability.⁷⁰ The scholars who realized the potential for including Butler’s ideas into disability scholarship initially tended to utilize her work in a way that substituted “able-bodied identity” and “disability” for “heterosexuality” and “gay/lesbian.”⁷¹ One example is Robert McRuer, a crip⁷² cultural studies and critical theory scholar, who wrote in 2003 that “despite a growing awareness of the intersections between queer theory and disability studies, little notice has been taken of the connection between heterosexuality and able-bodied identity, perhaps because able-bodiedness, even more than heterosexuality, masquerades as a nonidentity, as the natural order of things.”⁷³ While the initial critique of the impairment/disability binary was certainly useful for the social

⁶⁸ Corker Mairian and Sally French, *Disability Discourse* (McGraw-Hill Education, UK, 1999), 2.

⁶⁹ Tom Shakespeare, “The Social Model of Disability,” in *The Disability Studies Reader*, edited by Lennard J. Davies, 195-203 (New York: Taylor & Francis, 2016), 197.

⁷⁰ Butler’s *Bodies That Matter: On the Discursive Limits of ‘Sex’*, appears to be the most cited among disability scholars. See Ellen Samuels, “Critical Divides: Judith Butler’s Body Theory and the Question of Disability,” *NWSA Journal* 14, no. 3 (2002): 59.

⁷¹ Robert McRuer, “Compulsory Able-Bodiedness and Queer/Disabled Existence,” in *Disability Studies: Enabling the Humanities*, edited by Rosemarie Garland-Thomson, Brenda Jo Brueggemann, and Sharon Snyder, (New York: Modern Language Association of America, 2002), 93-94.

⁷² The use of the term crip is political. Within the disability community it reflects the political reclaiming of the historically derogatory term “cripple.”

⁷³ Crip cultural studies is, in short, the study of cultures of disability and queerness. Robert McRuer, “As Good As It Gets: Queer Theory and Critical Disability,” *GLQ: A Journal of Lesbian and Gay Studies* 9, no. 1 (April 10, 2003): 79.

model of disability, in 2002 Ellen Samuels critically reviewed such applications of Butler's work and demanded a clearer engagement with and theorization of Butler's theoretical approach.⁷⁴ At that time, disability history, a field that was rooted within disability studies, remained what might be described as an undefined field of scholarly inquiry.

Subsequently, disability scholars advanced ideas surrounding disability as an identity-category worth pursuing in more careful and theorized ways. At the forefront of that discussion is Catherine Kudlick who, in 2003, wrote an influential article that served as a historiographical intervention in which she demanded that historians, like other scholars, pay attention to disability as a useful category of analysis: disability as another 'Other.'⁷⁵ Kudlick is influenced by scholars like sociologist Erving Goffman who wrote *Stigma: Notes on the Management of Spoiled Identity*, which Kudlick identifies in her footnotes as being the "most widely cited book to theorize the issue of disability."⁷⁶ Her historiographical essay, "Disability History: Why We Need Another 'Other'," builds on Joan Scott's famous call for a new category of analysis, "Gender: A Useful Category of Historical Analysis," and rivals it, if not in audience and impact, then in insightfulness.⁷⁷ Her essay argues that disability should "sit squarely at the center of historical inquiry."⁷⁸ Disability, it almost goes without saying, is not a term or category easily defined, which may be the problem that makes disability studies the rich and interesting field that Kudlick helped create. She suggests that the same academic fields that introduced studies on race, gender, and sexuality, and that spearheaded postmodernism and the linguistic turn, now

⁷⁴ Ellen Samuels, "Critical Divides: Judith Butler's Body Theory and the Question of Disability," *NWSA Journal* 14, no. 3 (2002): 58-76.

⁷⁵ Catherine Kudlick, "Disability History: Why We Need Another 'Other'," *The American Historical Review* 108, no. 3 (June 2003): 763-93.

⁷⁶ Kudlick, "Disability History: Why We Need Another 'Other'," 763; Erving Goffman, *Stigma: Notes on the Management of Spoiled Identity* (Englewood Cliffs, N.J: Prentice-Hall, 1963).

⁷⁷ Joan W. Scott, "Gender: A Useful Category of Historical Analysis," *The American Historical Review* 91, no. 5 (1986): 1053-75.

⁷⁸ Kudlick, "Disability History: Why We Need Another 'Other'," 765.

provide scholars with “valuable analytic and theoretical tools for exploring this new Other.”⁷⁹

Scholars trained as historians of women, gender, and sexuality, such as myself, are thus ideally suited to engage in this academic endeavor.

Well over ten years after the first foundational publications in the field of disability history, the divide between medical history and disability history was revisited in a closer investigation of what is at stake if the distinction is eliminated.⁸⁰ This is an important conversation that, in my opinion, is not yet resolved or sufficiently explored. In 2013 the *Bulletin of the History of Medicine* brought to the attention of scholars the “Borderland” between disability history and medical history. In the position paper that introduced the conversation, Beth Linker made the argument that the two fields should be viewed as having family resemblances, and, while pursuing their own distinct trajectories, each should pay attention to the relationship between the two, thereby focusing on commonalities rather than differences to “uncover a common family heritage.”⁸¹ Linker suggests that disability historians’ efforts to distinguish themselves from medical history have been met with complacency by medical historians. She states: “When faced with the subject of disability, medical historians frequently tend to fall back on the familiar frame of disease history. As a result, disability often lurks on the margins of medical history, but is rarely brought front and center to be fully theorized and systematically studied.”⁸² Indeed, Linker, while critiquing some medical historians’ treatment of disability as solely a medical problem, sees usefulness in considering the links to disease and epidemic research. In other words, following Linker’s suggestions, instead of demonstrating complacency by solely drawing on medical history that theorizes disease, it is important to bring

⁷⁹ Kudlick, “Disability History: Why We Need Another ‘Other’,” 763.

⁸⁰ Kudlick, “Comment: At the Borderland of Medical and Disability History,” 548-9.

⁸¹ Linker, “On the Borderland of Medical and Disability History,” 535.

⁸² Linker, “On the Borderland of Medical and Disability History,” 502.

disability into the foreground and truly assess the possibilities of combining insights from both perspectives.

Linker's position has been subsequently discussed in three response essays. Catherine Kudlick disagrees with Linker and puts forth her idea that the border between medical history and disability history is, in fact, a useful one. She suggests that although scholars of each field may discuss the same people or events, in the end, they employ different methodologies and approaches.⁸³ For Kudlick, politics defines the border between the fields.⁸⁴ In contrast, Julie Livingston, a historian who works at the intersection of history, anthropology, and public health, agrees with Linker and suggests that through the paradigm of disability, the role of medicine can be understood in critical ways.⁸⁵ A third response to Linker was provided by Daniel J. Wilson. He conducts research on the experiences of families faced with challenges of disease and disability and fully endorses Linker's suggestion.⁸⁶ He argues that "[...] both history of medicine and disability history will be stronger with fruitful intersection and cooperation. We can surely share a goal of a fuller and more complete history of how diseases, accidents, and wars gave rise to disabilities, of how patients as well as health professionals functioned in medical institutions, and of how individuals with disabilities lived, worked, and played once they walked or wheeled out of the last rehabilitation hospital."⁸⁷ This, more than any other argument, can be directly applied to the case of thalidomide. De-centering medical discourses would not provide a more comprehensive understanding of the thalidomide-induced disabilities. Rather, analyzing the

⁸³ Catherine Kudlick, "Comment: On the Borderland of Medical and Disability History," *Bulletin of the History of Medicine* 87, no. 4 (December 20, 2013): 545.

⁸⁴ Kudlick, "Comment," 541.

⁸⁵ Julie Livingston, "Comment: On the Borderland of Medical and Disability History," *Bulletin of the History of Medicine* 87, no. 4 (December 20, 2013): 560–64.

⁸⁶ Wilson, *Living with Polio*; Julie K. Silver and Daniel J. Wilson, (eds.), *Polio Voices*.

⁸⁷ Daniel J. Wilson, "Comment: On the Borderland of Medical and Disability History," *Bulletin of the History of Medicine* 87, no. 4 (December 20, 2013): 539.

medical discourses alongside socio-cultural constructions of disability and the agency of thalidomiders is the only approach that enables an understanding of the various influences that shaped perceptions of thalidomiders' bodies and lives.

This dissertation agrees with Wilson's assertion that "If disability history and the history of medicine have distinct realms of expertise, there are also sites where the two fields productively intersect."⁸⁸ Therefore, this study of the life stories of thalidomiders pays attention to these overlapping areas of expertise; while social stigmas and barriers can have little to do with medicine, and many individuals living with a disability have medicine impact their life only tangentially, thalidomiders' lives have in most cases been shaped to significant degrees by their physical ailments and interactions with medical professionals. In turn, their lives have had an impact on technological developments and rehabilitation practices.⁸⁹ Where then, on the Borderland between the histories of medicine and disability, does this dissertation lie? It occupies a space that lies primarily in the field of disability history, as it not only studies disabled individuals' lives within and outside of the medical realm, it also, importantly, considers disability as a tool and analytical framework that provides insight into new understandings of society, politics, and culture which "shape a complex web of relationships for disabled and nondisabled alike."⁹⁰ However, the dissertation stands in "productive conversation" with medical history, for it provides discursive space in the analysis for the "biological reality" that shape individual lives, thus permitting the discussion of the thalidomide-induced disabilities as medical conditions that were intermittently understood and experienced in medical terms.⁹¹ Moreover,

⁸⁸ Wilson, "Comment," 537.

⁸⁹ Wilson, "Comment," 537.

⁹⁰ Kudlick, "Social History of Medicine and Disability History," 106.

⁹¹ Catherine Kudlick has endorsed a productive conversation/dialogue between the two subfields. Kudlick, "Comment: At the Borderland of Medical and Disability History" 540; Kudlick, "Social History of Medicine and Disability History," 106.

this dissertation has the potential to bring to the attention of medical historians a way in which they may re-theorize chronicity.⁹² The thalidomide tragedy, may be reconceptualised by including a disability lens that is conducive to the long-term study of this medical tragedy.⁹³

In addition to contributing to the historiographies of medicine and disability, this thesis aims to engage with the historiography of the development of the modern Canadian state. The births of these children had a disillusioning effect on Canadian citizens when it came to the security they hoped their state would provide after the Second World War. The responsibility of the Canadian state in responding to matters related to health, and the impact on the state of concerns about healthy bodies, have been demonstrated in many studies, including Mark Humphries' *The Last Plague: Spanish Influenza and the Politics of Health in Canada* and Katherine McCuaig's *The Weariness, the Fever, and the Fret: The Campaign Against Tuberculosis in Canada 1900-1950*.⁹⁴ Both books consider the broader political context of public health measures in response to the Spanish influenza of 1918-1919 and tuberculosis, respectively, and provide examples of how transnational medical phenomena may be studied within a specific national context. In fact, *Life After the Scandal* shows how the cultural and political meaning of the thalidomide crisis provoked scientific research and body politics in a way that was informed by the rhetoric of citizenship and the welfare state.⁹⁵ After all, as political scientist Michael John Prince states, "disablement or impairment of people poses a challenge to

⁹² This potential for re-theorization was raised by Julie Livingston. Livingston, "Comment: On the Borderland of Medical and Disability History," 564.

⁹³ Ann Dally, "Thalidomide: Was the Tragedy Preventable?" *The Lancet* 351, no. 9110 (1998): 1197.

⁹⁴ Mark Humphries, *The Last Plague: Spanish Influenza and the Politics of Health in Canada* (Toronto: University of Toronto Press, 2013); Katherine McCuaig, *The Weariness, the Fever, and the Fret: The Campaign Against Tuberculosis in Canada 1900-1950* (Montréal and Kingston: McGill-Queen's University Press, 1999).

⁹⁵ See Chapter Two. Body politics here refers to the how "bodies are at the core of our families, economies, and social and political institutions more generally, shaping states, civil society, and citizenship." Georgina Waylen, *The Oxford Handbook of Gender and Politics* (Oxford: Oxford University Press, 2013), 162.

conventional notions of citizenship as participation in society, the economy, and the polity.”⁹⁶ The thalidomide scandal occurred at a time in Canadian history when the state’s relationship to disability had undergone important changes in the aftermath of the First and Second World War.⁹⁷ War, in Canada as everywhere, had challenged the masculine ideal of ability and spurred the medical profession to idealize rehabilitation practices.⁹⁸ The continuing efforts at re-making Canadian society after the Second World War serve as the backdrop against which the aftermath of the pharmaceutical scandal needs to be understood.⁹⁹ This dissertation serves as a continuation of and addition to the conversation about how disabilities and public engagement with visible impairments shifted Canadian policies and attitudes in the twentieth century.

Central to understanding government responses to the thalidomide scandal is the acknowledgement that the making of the Canadian welfare state began in the immediate post-war period but blossomed in the 1960s, at the exact time when the thalidomide babies were born. Much of the literature suggests a gradual development of the welfare state following the Second World War.¹⁰⁰ Over the course of the 1950s and 1960s, the four cornerstones of the Canadian welfare state – family allowances, contributory unemployment insurance/unemployment

⁹⁶ Michael John Prince, *Struggling for Social Citizenship: Disabled Canadians, Income Security, and Prime Ministerial Eras* (McGill-Queen's University Press, 2016), 4.

⁹⁷ For shifts in Canadians’ attitudes towards citizenship after the First World War see for instance Desmond Morton and Glenn Wright, *Winning the Second Battle: Canadian Veterans and the Return to Civilian Life, 1915-1930* (Toronto: University of Toronto Press, 1987); and for an analysis of how disability can help foster an understanding of the veterans’ experience after 1914 see David A. Gerber, “Disabled Veterans, the State, and the Experience of Disability in Western Societies, 1914-1950,” *Journal of Social History* 36, no. 4 (2003): 899-916.

⁹⁸ Kellen Kurschinski, “State, Service, and Survival: Canada’s Great War Disabled, 1914-44,” (PhD diss., McMaster University, 2015), 97.

⁹⁹ See for instance Michael Gauvreau and Nancy Christie eds., *Cultures of Citizenship in Post-War Canada, 1940-1955*, (Montréal, Quebec: McGill-Queen's University Press, 2003); Robert Allen Rutherford and Magdalena Fahmi, *Creating Postwar Canada: Community, Diversity, and Dissent, 1945-75* (Vancouver: UBC Press, 2008), Penny Bryden, *Planners and Politicians: Liberal Politics and Social Policy, 1957-1968* (Montréal, Quebec.: McGill-Queen's University Press, 1997); Michael John Prince, *Struggling for Social Citizenship: Disabled Canadians, Income Security, and Prime Ministerial Eras* (McGill-Queen's University Press, 2016).

¹⁰⁰ Alvin Finkel, *Social Policy and Practice in Canada: A History* (Waterloo, ON: Wilfrid Laurier University Press, 2006), 149; Penny Bryden, “‘Pooling Our Resources’: Equalization and the Origins of Regional Universality, 1937-1957,” *Canadian Public Administration/Administration Publique du Canada* 57, no. 3 (2014): 401-418.

assistance, a universal old-age security plan, and a national health insurance plan – were put into place.¹⁰¹ However, according to political scientist Gerard Boychuk, these early measures did not engender a significant move towards deepening state responsibility towards the well-being of Canadian citizens. Moreover, according to Moscovitch and Drover, the welfare state in Canada was in fact established in the mid-1960s, specifically between 1963 and 1968, a period of high social reform.¹⁰² Of course considerations surrounding the state’s responsibility for citizens were shaped by provincial reforms that preceded the federal implementation of welfare policies.¹⁰³ I engage with this literature in so far as it relates the case of thalidomide to the conversation about state responsibilities.

Lastly, my dissertation is located within the historiographies of gender, sexuality, and the politics of the body. I build on the feminist critique of a public/private dichotomy, thereby adding to the literature on the public/private while also drawing on the idea of abject bodies. In the 1960s, feminists began using the idea of separate spheres as a historical trope, metaphor, and tool to describe differences between men’s and women’s actions, motivations, and even physical location.¹⁰⁴ Carole Turbin describes this as follows: feminists “theorized that male domination/female subordination, the analytical equivalence of patriarchy, was structured by the strict separation of hierarchical spheres, male (public) and female (private or domestic).”¹⁰⁵

Historian Kim Warren has explained that scholars developed these ideas to understand better the

¹⁰¹ Gerard William Boychuk, *Patchworks of Purpose: The Development of Provincial Social Assistance Regimes* (Montreal and Kingston: McGill-Queen’s University Press, 1998), 42.

¹⁰² Boychuk, *Patchworks of Purpose*, 42-43; Allan Moscovitch and Glenn Drover, “Social Expenditure and the Welfare State: The Canadian Experience in Historical Perspective,” in *The Benevolent State*, 29-30.

¹⁰³ James Struthers, *The Limits of Affluence: Welfare in Ontario, 1920-1970* (Toronto: University of Toronto Press, 1994); and Dominique Marshall, *Aux Origines Sociales de l’État-providence: Familles Québécoises, Obligation Scolaire et Allocations Familiales, 1940-1955* (Montréal: Presses de l’Université de Montréal, 1998).

¹⁰⁴ Danaya C. Wright, “Theorizing History: Separate Spheres, the Public/Private Binary and a New Analytic for Family Law History,” *ANZLH E-Journal* 2, 44 (2012): 45.

¹⁰⁵ Carole Turbin, “Refashioning the Concept of Public/Private: Lessons from Dress Studies,” *Journal of Women’s History* 15, no. 1 (2003): 43.

gendered experiences of culture, labour, economic circumstances, and social interactions, all of which occur in “relationships of power.”¹⁰⁶ Since the 1960s scholars have used the public/private divide both as a physical reality as well as a metaphor and analytical framework to scrutinize state power.¹⁰⁷

By the 1980s the dichotomy came under criticism as scholars realized it was simplistic.¹⁰⁸ Spurred especially by the input of scholars who researched histories of women of color, a wide range of feminist scholars have suggested that the idea of the public/private dichotomy is misleading as it obscures not only similarities between the lived experiences of men and women, but also that the oppositional nature in which the public and private have been constructed are “not practically accurate nor theoretically helpful.”¹⁰⁹ Overall, the limitations of a rigid analysis of the public/private division have today been widely accepted.¹¹⁰ Yet, despite valuable critical re-evaluations, the importance of the public/private dichotomy has continued to resonate with

¹⁰⁶ Kim Warren, “Separate Spheres: Analytical Persistence in United States Women’s History,” *History Compass* 4 (2006): 1.

¹⁰⁷ Wright, “Theorizing History,” 46.

¹⁰⁸ Turbin, “Refashioning the Concept of Public/Private,” 43.

¹⁰⁹ Kim Warren explains: “scholars who researched histories of women of color critiqued separate spheres metaphors calling for attention to the ways in which African American women, in particular, have rarely had the privilege of occupying a strictly domestic realm.” Kim Warren, “Separate Spheres: Analytical Persistence in United States Women’s History,” *History Compass* 5, no. 1 (2007): 262. Another criticism suggests taking serious this dichotomy legitimizes the hegemony of the public. See Wright, “Theorizing History,” 47. Finally, Jürgen Habermas’s book *The Structural Transformation of the Public Sphere: An Inquiry into a Category of Bourgeois Society*, which outlined a complex spectrum of the public in his analysis of a public space separate from the emerging modern state, was influential in challenging naturalized understandings of public and private. Jürgen Habermas, *The Structural Transformation of the Public Sphere* (Cambridge, MA: MIT Press, 1989). Detailed critiques of the public/private dichotomy can be found in the following literature: Wright, “Theorizing History,” 46-47. See also Michael Warner, *Publics and Counterpublics* (NY: Zone Books, 2002); Nancy Fraser, “Rethinking the Public Sphere: A Contribution to a Critique of Actually Existing Democracy,” in Craig Calhoun, ed., *Habermas and the Public Sphere* (Cambridge, MA: MIT Press, 1992) 109-142; Carole Pateman, “Feminist Critiques of the Public/Private Dichotomy,” in *The Disorder of Women: Democracy, Feminism, and Political Theory* (Stanford: Stanford UP, 1989), 118-140; Joan B. Landes, “Further Thoughts on the Public/Private Distinction,” *Journal of Women’s History* 15/2 (2003): 28-39; Amanda Vickery, “Golden Age to Separate Spheres? A Review of the Categories and Chronology of English Women’s History,” *The Historical Journal* 36/2 (1993): 383-414; Joan B. Landes, ed., *Feminism, the Public and the Private* (Oxford: Oxford UP, 1998); Susan Gal, “A Semiotics of the Public/Private Distinction,” *Differences: A Journal of Feminist Cultural Studies* 13/1 (2002): 77-95; and the forum on public and private and the future of women’s history in *Journal of Women’s History* 15/1 (2003).

¹¹⁰ Joan B. Landes, “Further Thoughts on the Public/Private Distinction,” *Journal of Women’s History* 15, no. 2 (2003): 34.

scholars.¹¹¹ Joan Landes has suggested a semiotic approach to studying the public/private divide, grounding the public/private distinction simultaneously in material and discursive practices. She writes that “It offers an account of embodied subjectivity, which does not lose sight of social interaction or communicative processes.”¹¹² Thus, the feminist critique of the public/private divide continues to produce fruitful, if critical, analytical considerations.

This dissertation introduces the idea of disability, both in its physical reality and its analytical usefulness, into this conversation. Accepting that the public/private dichotomy is a methodological tool that is effective at certain tasks but not others, my dissertation makes use of the idea of abject bodies to consider the nature of disabled bodies as always political and public, thus never solely private. The image of the abject was originally theorized in the work of feminist psychoanalyst Julia Kristeva. In her book *Powers of Horror*, the “abject” is delineated as that which is excluded through cultural discourses.¹¹³ In essence, the self is understood in opposition to something else, the abject.¹¹⁴ While Kristeva, a disability advocate in France, does not herself utilize the term *abject* in her own essays on disability specifically,¹¹⁵ her concept has been utilized and critiqued by other scholars studying disability in recent years.¹¹⁶ Queer theorist Sara Ahmed’s writing has proven to be particularly useful in applying Kristeva’s idea of the

¹¹¹ Indeed, the *Journal of Women’s History* asked scholars to reflect on the “Public and Private” in 2003, producing a series of scholarly considerations of its shortcoming and continued usefulness. See *Journal of Women’s History* 15, no 1 (2003): 7-69.

¹¹² Landes, “Further Thoughts on the Public/Private Distinction,” 36.

¹¹³ Julia Kristeva, *Powers of Horror: An Essay on Abjection* (New York: Columbia University Press, 1982), 16.

¹¹⁴ For a condensed summary of Kristeva’s arguments see Marita Gronnvoll and Kristen McCauliff, “Bodies that Shatter: A Rhetoric of Exteriors, the Abject, and Female Suicide Bombers in the ‘War on Terrorism,’” *Rhetoric Society Quarterly* 43, no. 4 (2013): 337.

¹¹⁵ Specifically, her chapter “Liberty, Equality, Fraternity and ... Vulnerability,” in *Hatred and Forgiveness*. Translated by Jeanine Herman, 29-45 (New York: Columbia University Press, 2012).

¹¹⁶ Jan Grue, “Rhetorics of Difference: Julia Kristeva and Disability,” *Scandinavian Journal of Disability Research* 15, no. 1 (2013): 45-57; Josh Dohmen, “Disability as Abject: Kristeva, Disability, and Resistance,” *Hypatia* 31, no. 4 (2016): 762-778; Mary Bunch, “Julia Kristeva, Disability, and the Singularity of Vulnerability,” *Journal of Literary & Cultural Disability Studies* 11, no. 2 (2017): 133-150.

object to disability.¹¹⁷ Ahmed points to the ways certain bodies are commonly understood in negative terms when encountered by others, stating bluntly: “some bodies are already read as more hateful and disgusting than other bodies.”¹¹⁸ Josh Dohmen explains how the idea of the abject relates to disability specifically, as he explains that disability is excluded by the non-disabled in an affective move to reassure their own identities. He has outlined that “abjection occurs at the level of the imaginary. Thus, the exclusion to which disabled persons are subject is not (or at least not most immediately) the result of conscious, symbolic reflection; rather, it is an immediate (and affective) response intended to shore up the narcissistic boundaries of others in their interactions with disabled persons.”¹¹⁹ The concept of the abject therefore helps explain not only the othering of disabled bodies, but the significance of disability for everybody, including the non-disabled who are threatened by the vulnerability disability symbolizes.

However, the idea of the abject, as theorized by Kristeva, is not unproblematic. Kristeva has been critiqued by Jan Grue, who writes that in Kristeva’s own work on disability, published after *Powers of Horror*, she actually reaffirms the dichotomy between the disabled and non-disabled rather than challenging it. Instead of using the idea of the abject merely as a rhetorical strategy her approach suggests that vulnerability is a defining characteristic of the disabled experience, rather than a fear imposed on disabled bodies by others.¹²⁰ What we see here is a concern about dichotomous understandings that parallels scholarly critiques of the public/private divide. This has recently been echoed by Mary Bunch who states that “The psychoanalytic language, tragic tone, and essentializing claims about disability are off-putting and at times seem

¹¹⁷ Grue, “Rhetorics of Difference,” 53.

¹¹⁸ Sara Ahmed, “The Skin of the Community: Affect and Boundary Formation.” In *Revolt, Affect, Collectivity: The Unstable Boundaries of Kristeva’s Polis*, edited by Tina Chanter and Ewa Płonowska Ziarek, 95-112 (Albany: State University of New York Press, 2005), 106.

¹¹⁹ Dohmen, “Disability as Abject,” 771.

¹²⁰ Grue, “Rhetorics of Difference,” 53.

deeply problematic.”¹²¹ Yet, Grue’s reading of Kristeva has been described as “ungenerous” though not incorrect.¹²² When using the idea of abject bodies in relation to disability, it is important to remain conscious that such a discussion is to serve as an analytical goal, not to essentialise disabled experiences as vulnerable. Instead, the concept of abject bodies can actually serve to reconceptualise the meaning and potential of disabled bodies in society altogether as it challenges us to confront perceptions of embodiment that lie at the root of negative (fearful) understandings of impairment. This has been argued by Bunch, who notes that “I find that Kristeva makes an important contribution by opening up ways of envisioning a world in which forms of embodiment we today conceptualize as impaired can mean something entirely different.”¹²³ My dissertation draws on the idea of abject bodies to help theorize the ways in which the thalidomide bodies were sites of meaning-making. Kristeva’s theory of abjection, which she posits as something dangerous and transgressive, helps conceptualize the anxieties of Canadian society whose ideas of bodily superiority were vulnerable when confronted with thalidomiders. By utilizing oral history methodology, my dissertation allows for an “understanding of the experience of power and structure” among the Canadian thalidomiders whose life stories are examined.¹²⁴

Methodology

To understand how thalidomiders themselves, health experts, politicians, as well as the general population understood and responded to the consequences of the thalidomide tragedy, I have closely analyzed popular mass media, visual culture, political debates, as well as medical

¹²¹ Bunch, “Julia Kristeva, Disability, and the Singularity of Vulnerability,” 133.

¹²² Dohmen, “Disability as Abject,” 766.

¹²³ Bunch, “Julia Kristeva, Disability, and the Singularity of Vulnerability,” 134.

¹²⁴ Williams and Busby, “The Politics of ‘Disabled’ Bodies,” 174.

publications, personal correspondence, and legal documents produced during the initial court trial (1968-1970) of the German company Chemie Grünenthal that developed the drug, and documents of the various companies licensed by Chemie Grünenthal to sell thalidomide. These sources were the basis for previous studies on the history of thalidomide listed above. In addition, I have conducted interviews with Canadian thalidomiders, as well as with some of their family members.

In the summer of 2016, I took the initial step to conduct primary source research and travelled to Germany where I spend two months researching in the state archives in North Rhine-Westphalia (Landesarchiv), Rheinland division, located in Duisburg. The archive contains the relevant German court documents of the criminal trial of employees of the company Chemie-Grünenthal that developed, sold, and licenced the drug thalidomide. This trial was followed internationally and was relevant to Canadian families who had been severely affected by the decisions made by the people on trial and the company they worked for. Furthermore, in preparation for the trial a great deal of information was accumulated by the prosecutor's office regarding not only the development and sale of the drug in Germany, but also the distribution, reception, and eventual withdrawal of the drug abroad, including in Canada. As such it was extremely important for me to be familiar with the details of this trial and the documents accumulated for it.

As the court files are currently still restricted due to personal privacy considerations, and thus not accessible for the wider public, I applied for special permission to access these files.¹²⁵ On May 23, 2016 I received permission to access the four relevant collections: the files of the preliminary investigation of both the individuals and the company Chemie Grünenthal by the

¹²⁵ Refer to Appendix D for documentation.

public prosecution, the case files of the responsible prosecution office in Aachen, as well as the collection dedicated to the court trial from 1961-1971.¹²⁶ I was also able to access the open access collection containing the media coverage of the trial.¹²⁷

In addition to a detailed record of the discovery of the birth defects and other adverse effects of the drug thalidomide, the collections also house a significant number of letters between Chemie Grünenthal and its American and Canadian licensees, some correspondence between the prosecutor's office and Canadian scholars and politicians, documents produced by the Canadian companies, such as drug warnings, as well as medical journal articles. Furthermore, the monthly reports produced by Chemie Grünenthal contained information about their interactions with their licencing companies that were helpful in assessing the impact the emerging information about birth defects had on the companies operating in Canada. As such, this archive was instrumental in providing primary sources for my dissertation.

While the documents produced by the American and Canadian companies and some correspondence between Chemie Grünenthal and its American and Canadian licensees is written in English, a majority of the files are German. Any translations of these documents found in this dissertation have been produced by me and remain as close as possible to the original wording. German is my mother tongue which left me well suited to engage with the bilingual nature of the archival collections.

Although the collections allowed indirect access to materials produced by the German company, I did not gain direct access to the files collected by Chemie Grünenthal. In a seemingly

¹²⁶ LAV NRW R, NW 377 Nr. 5869 "Ermittlungsverfahren gegen Personen der Chemie Grünenthal GmbH 1962-1972" and LAV NRW R, NW 875 Nr. 14101 "Ermittlungsverfahren gegen Chemie Grünenthal GmbH Stolberg; Contergan-Verfahren 1967-1971"; LAV NRW R, Gerichte Rep. 139 Nr. 1-369; LAV NRW R, NW 1180 "Contergan-Prozess, 1961-1971."

¹²⁷ LAV NRW R, Gerichte Rep. 524 Nr. 1-19.

standardized email, I was informed by the Vice President of Public Engagement of the Grünenthal Group that the company supports academic research only very selectively and that my dissertation would unfortunately not receive such support.¹²⁸ This is one of the main obstacles in researching thalidomide: the company archives remain out of reach of historians because of gatekeeping in the interest of company profit. While I myself did not request access to the Distillers archives, the company licenced in the United Kingdom, other researchers have found the same roadblocks to be in place there.¹²⁹

Simultaneous to my efforts to gain access to the archival materials I also submitted my application to the Carleton University Ethics Research Board to interview Canadians who were affected by thalidomide.¹³⁰ I understand oral history methodology as a social research method that enables historians to uncover and reveal stories of the past from an individual perspective. As was outlined by oral historian Stevie M. Munz, “the method is predicated on gathering stories of everyday life that are undocumented and subsequently archiving them for future generations.”¹³¹ Oral history is a well-respected methodology and is utilized across disciplinary boundaries for gathering stories for a wide array of topics.¹³² In this dissertation, oral history was utilized because it would have been impossible to understand the legacy of the thalidomide

¹²⁸ Personal Email correspondence Frank Schönrock, Vice President Public Engagement, Grünenthal Group, July 5, 2014.

¹²⁹ Historians Julie Parle and Ludger Wimmelbücker provide an important, if concise comment on the difficulty of accessing archives in their article on the history of thalidomide in Southern Africa, they write: “Moreover, very few sources are available for the British Distillers Company (Biochemicals) Limited (DCBL), thalidomide’s second official distributor in Africa. The archives of DCBL are now owned by Diageo PLC and are closed.” While these scholars have pursued records of thalidomide in dozens of countries wherever available, they too have found that making use of newspaper coverage has helped supplement and enrich the available documentation. Parle and Wimmelbücker, “These are the Medicines that ‘Make’ Monsters’.”

¹³⁰ My initial application was submitted to Carleton’s University Research Ethics Board A on February 5, 2016 via email and was reviewed by the Full Board on February 12, 2016. Revisions were requested on February 19, 2016. A revised application was subsequently submitted on February 29, 2016. I received final ethics clearance on March 18, 2016.

¹³¹ Munz, “The Farmer's Wife” 66.

¹³² Rebecca Sharpless, “The History of Oral History,” in *History of Oral History: Foundations and Methodology* (Lanham: AltaMira Press, 2007), 26.

scandal without the involvement of those directly affected. (The methodological implications will be discussed below.) While policies and medical research were shaped by the discourses emerging in the aftermath of the scandal, the private lives immediately affected deserve attention. In fact, only a combined discussion of private lives and public policies can come close to capturing the significance the thalidomide scandal has for Canadian history.

From 2016 to 2018 I interviewed seventeen individuals for this dissertation. On occasion, I also draw on the previously mentioned oral history interviews conducted by researchers working in the United Kingdom. My interviews were an average of two-and-a-half hours in length. Upon receiving written consent, all but one of the interviews were audio recorded. I provided each contributor the option to receive an electronic copy of the interview recording for their personal records. One contributor preferred I take notes instead of relying on a recording device. Of the seventeen interviewed, ten are living with disabilities as a result of thalidomide, the other seven are family members whose contributions helped illuminate the consequences the thalidomide scandal and the resultant disabilities had for families during thalidomiders' childhoods or those who entered into relationships with thalidomiders as adults.¹³³

I began recruiting interviewees by contacting individuals who had publicly identified themselves as thalidomiders by providing statements or full interviews for newspaper or television coverage about thalidomide. Given that the struggle to receive compensation resulted in public interest in thalidomiders' lives there was significant media coverage. This strategy led me to speak with individuals who had, in many cases, already shared stories about their lives with interviewers. While doing so generated some interest, in several cases thalidomiders whom I had identified through media mention were not interested in speaking with me. Their answers

¹³³ Specifically, family members refer to siblings (three), spouses and partners (two), and children of thalidomiders (two).

indicated that they felt they had given enough of themselves to the public for the sake of the compensation fight and although my dissertation is not connected to their political struggle, I understand the source of the exhaustion of these individuals and respect their desire to refrain from sharing their stories. In addition to contacting private individuals, I also got in touch with representatives of the Thalidomide Victims Association of Canada (TVAC) whose contact information is available online. Not only is this how I was able to interview Mercedes Benegbi, at the time serving as the executive director of TVAC, but also how information about my research was spread among TVAC members who were then able to contact me themselves if they were interested in contributing to this research.

While I was initially open to speaking with all individuals who identified themselves as thalidomiders I made the decision to limit the scope of this dissertation to include interviews conducted with those who were members of TVAC and had already established via documentation, such as their mother's prescriptions, that it was indeed thalidomide that had caused their disabilities. Excluding individuals not officially recognized by the Canadian government as thalidomide-affected and thus unable to receive government funding was not an easy decision. Given the nature of the disabilities it can be difficult to prove that it was indeed their mothers' ingestion of thalidomide that caused their disabilities. Historian Barbara Clow wrote that "Arguing that this type of birth defect could and did develop spontaneously, independent of thalidomide use, federal and provincial officials were reluctant to accept limb deformities as sufficient proof of exposure. They consequently demanded more reliable evidence, such as hospital or pharmacy records, patient files, and/ or the testimony of prescribing physicians. As one might expect, evidence of this kind could be an exceedingly elusive

commodity.”¹³⁴ In fact, there is a group of “unrecognized thalidomide victims” actively lobbying to widen the scope of the Canadian government’s funding for thalidomide victims and in January 2019 they were successful when the Canadian government announced changes to the existing compensation program that had initially been introduced in 2015.¹³⁵ Thus, it needs to be acknowledged that at the time when interviews were being conducted, some who lacked the documentation required to be officially recognized as victims for government purposes may become recognized as thalidomide victims at a later time.

The thalidomiders who agreed to be interviewed will be briefly introduced below.¹³⁶ Their voices are the foundation for understanding the history of thalidomide in Canada and are thus privileged throughout the dissertation.¹³⁷ I am limiting introductions to their birth date, places of birth, as well as brief comments regarding their schooling and family life when applicable for the discussion in the remainder of the dissertation. These individuals are central to this dissertation and thus deserve introductions here but readers will learn more about them in the main body of this study. Many of these people suffer from a series of health conditions in addition to the visible disabilities commonly associated with thalidomide. Their physical impairments are not described in any detail and are only mentioned when relevant for the analysis in an effort to foreground thalidomiders’ own assessment of when their physical impairments played a role in shaping their lives.

Mercédes Benegbi was born in June 1962 in Montreal, Quebec. Although her parents, Colette and Marcos, divorced when she was older, Mercédes was raised in a nuclear family with

¹³⁴ Barbara Clow, “Defining Disability, Limiting Liability: The Care of Thalidomide Victims in Canada,” in *Essays in Honour of Michael Bliss: Figuring the Social*, Alison Li, Elisabeth Heaman, Shelley McKellar, and Michael Bliss, eds. (Toronto: University of Toronto Press, 2008), 304.

¹³⁵ Ingrid Peritz, “Government Opens Door to New Requests From Canadians Who Say They Are Thalidomide Victims,” *Globe and Mail*, January 9, 2019.

¹³⁶ With the exception of two who have requested to remain anonymous.

¹³⁷ Readers may also refer to the list of profiles, p. vi-vii. The subsequent introductions are sorted alphabetically.

both her parents advocating on her behalf. Her parents successfully lobbied to allow their daughter to attend regular school at the École Ernest Crépeau in Montreal. Her father actively worked on developing accessibility tools for his daughter. Mercedes attended the Montreal Rehabilitation Institute.

Ramesh Lad was born in Bradford, England in 1962 but moved to Vancouver, Canada, as an adult. While he was not one of the Canadian thalidomide children, he shared his own experiences of the ways thalidomide impacted his family unit. He was raised by his biological parents, who had moved from India to England in the 1950s. His mother stayed home, caring for the family, and his father was a labourer in a textile factory. His grandmother too was involved in his upbringing. He grew up with two older brothers, one biological and one adopted, as well as one younger sibling, also a brother. His family was very religious – Hindu – which, for them, played a large role in conceptualizing Ramesh’s disability. Many of his memories, such as meeting his wife, take place in Canada.

Alvin Law was born in July 1960 in Yorkton, Saskatchewan. His birth parents decided to give him up for adoption when he was born, and he was subsequently raised by his foster parents Hilda and Jack Law. Due to their location in Saskatchewan his foster mother travelled far to bring Alvin to various medical appointments and rehabilitation visits, for example to the rehabilitation institute in Ontario. Like Mercedes’ parents, Alvin’s foster parents also lobbied that he be able to attend public school in their community. During his school years, his parents and teachers recognized and fostered his musical ability. Eventually Alvin started his own family. In 1985, his first wife gave birth to Alvin’s son Vance. Later, Alvin met and married his second wife Darlene, and in 1995 Vance moved to stay with his father and Darlene providing Alvin with the chance of raising his son full-time.

Marie Olney was born in March 1962 in the Eastern Townships in Quebec, where she was raised by her biological parents alongside her three siblings in an English-speaking community. Her large, extended family also partook in raising her. As it was, their neighbour was on the local school board, and Marie too was enrolled in public school. Like others in Quebec she attended the Montreal Rehabilitation Institute.

The twins **Paul and Peter Settle** were born in January 1962 in Hamilton, Ontario. They were raised by their biological parents, Maxene and John in a Roman Catholic family alongside their two older brothers and two older sisters. When they were born at St. Joseph's Hospital in Hamilton, Peter arrived first. Paul was born six minutes later. Growing up, the two boys attended public school and became Easter Seals. Both were fitted with prosthetics in the rehabilitation center in Toronto and went through a number of difficult medical procedures. Later in life the twins both married and then went through divorces. Paul became a single-father to a daughter and a son. Peter has a daughter whom he raised with his late second wife.

Aline Vachon was born in April 1963 in Montreal, Quebec. She stayed in the Montreal Hospital until the age of three, at which point she was adopted by her biological uncle and his wife who lived closer to the Montreal Rehabilitation Institute where she spent a lot of time during her childhood than her birth parents. Aline eventually got married and gave birth to her daughter, though her body would not have endured a second pregnancy and childbirth. Sadly, years later, her husband passed away young and she became a widow and single mother.

Susan Wagner-White was born in January 1963 in Perth, Ontario. As a child she was raised by her biological parents alongside one brother and one sister. Her mother suffered from mental health problems which led to physical absences due to hospitalization and an inability to parent when she was at home. Susan's father eventually left the family to pursue another

relationship, though his absence was not permanent. As a result of her difficult home life, Susan experienced changing living circumstances, including temporary homelessness. She also needed to negotiate coming out to her family as lesbian during her teenage years. While growing up she attended public school and spend time in the rehabilitation center in Toronto. Later in life she met and married her wife Rae.

The individuals above have chosen to attach their names to their narratives within this dissertation. However, some have stipulated that parts of their narrative may be included as long as they remain anonymous. In addition, two participants chose to remain entirely anonymous. In these cases, their names and as much identifiable information as possible have been omitted to ensure their privacy. The small size of the thalidomide community in Canada makes it difficult to ensure complete anonymity. Indeed, one of the two anonymous contributors noted that it was fine if other thalidomiders would be able to identify them, but that for the broader public it should not be made easily apparent who they are. As such, instead of using pseudonyms that would allow readers to connect various stories of one person to a specific unnamed individual, the reader will find various memories, anecdotes, and quotes throughout the dissertation that are not associated with a name. In some instances, the gender of the speaker is identified, at other times it is obscured. Any of these accounts may belong to one of the ten individuals interviewed in an effort to obscure the identity of these individuals to the best of my abilities.

The ethnographical account, *Oral History Off the Record: Toward an Ethnography of Practice* edited by Stacey Zembrzyki and Anna Sheftel, was particularly helpful as I prepared for the interviews, as it includes insights into the actual interviewing processes and challenges that

can arise.¹³⁸ Indeed, during the interview process several challenges arose that require discussion. Conducting oral history interviews is a performative process for both the narrator and the interviewer.¹³⁹ The process of receiving ethics clearance, in some sense, may be understood as preparing for the role of interviewer with prepared steps that need to be taken during specific scenarios. In fact, one issue that required consideration is the potential of a participant to experience distress during the interview. Yet, the reality of being confronted with memories of the sexual abuse of a child and the sudden onset of severe nausea I personally experienced was not something you can prepare for. Even though I strove to redirect the conversation in a sensitive manner to foreground the narrators' personal perceptions, it became apparent that my reaction, however subtle, to the recollection of experienced abuse served to build trust during the interview process.

The memories of physical and emotional abuse were difficult and present a dark, yet important part of this research. It is important to acknowledge that several contributors who stated that they did not experience physical abuse were hesitant to frame their experiences as representative for the broader thalidomide community. They felt that the experience of physical abuse had been central to many thalidomiders' lives and worried that their participation in my research as someone who did not experience physical abuse may misrepresent the community. Several of these participants ended up sharing anecdotes during the interview that may have been understood as instances of abuse by others, but were often framed as not abusive as the contributors compared them to the perceived more traumatic experiences others had to endure.

¹³⁸ Stacey Zembrzycki, and Anna Sheftel, *Oral History Off the Record: Toward an Ethnography of Practice* (New York: Palgrave Macmillan, 2013). Similarly, helpful was Alistair Thomson, and Robert Perks's *The Oral History Reader* (New York: Routledge, 2016).

¹³⁹ Della Pollock, "Introduction: Remembering," in *Remembering: Oral History Performance*, ed. Della Pollock (New York: Palgrave Macmillan, 2005), 2.

Due to the extreme situations and abuse some thalidomiders endured, particularly during their childhoods, some felt their own relative positive experiences would take away from the tragedy that thalidomide had caused in Canada. In these instances, I acknowledged that I understood their desire to emphasize their knowledge about abuse and trauma that was part of the legacy of thalidomide, and that their life-story was nonetheless relevant and important for me to hear as I was interested in all types of experiences. I emphasised that I was there to listen to happy memories as well, and that they were equally important to understanding the history of Canadian thalidomiders.

Considering the consequences of baring to the public the information entrusted to me during personal interviews, even when the narrator had knowingly declared that the information could be used in my research and that they did not seek to remain anonymous, became a challenge as I went through the recordings and chose which anecdotes ought to be included in this study. No extensive reading of reflections on oral history methodology could have prepared me for the concerns and, at times, even unease, I felt about using some of the information given to me. Opening up for interpretation incidents of exploitation, abuse, mistreatment, neglect, disagreements, but also exposing moments of joy, intimacy, and sheer happiness previously shared as personal memories between individuals felt, despite the consent granted, like a dangerous form of trespassing. In her essay “Ethics and Interpersonal Relationships in Oral History Research,” oral historian Valerie Yow has aptly written that “As we pry into our narrators’ private lives or the secrets of their public or professional lives, we often have to consider the effects of making public the whole story.”¹⁴⁰ As a researcher such deliberations can be extremely difficult. In the end, I acknowledged the desire of my interview partners that their

¹⁴⁰ Valerie Yow, “Ethics and Interpersonal Relationships in Oral History Research,” *The Oral History Review* 22, no. 1 (1995), 53.

stories be heard in this study, while simultaneously remaining aware of the responsibility I have in integrating them within a framework that provides context and scholarly analysis.

The reader may find a greater use of my personal voice during certain parts of the analysis of interview segments. While an acknowledged practice by some, such integration of reflexive writing may still remain frowned upon by others. Steven High wrote in his foreword to *Oral History Off the Record* that “writing in the first person makes reflexive writing possible, yet there remains considerable resistance to personalizing our voice, at least within disciplines such as history.”¹⁴¹ This research aims to find a balance between the scholarly tone required for an academic study and the occasional use of reflexive writing in an effort to devise the most suitable and ethical means of addressing particular memories shared with me.¹⁴²

In addition to the thalidomiders who contributed directly to this research through their participation in interviews, other Canadian thalidomiders have their voices included in the following discussion as well. The use of statements quoted in media, specifically newspapers, documentaries, and magazines, allowed for the inclusion of an even broader range of narratives. In addition, sixteen interviews from an existing oral history project led by Anne Borsay (since deceased) conducted by Ruth Blue, specifically, *Thalidomide: An Oral History* housed at the Wellcome Library, were also reviewed and are selectively cited in the following chapters.¹⁴³ Although these interviews were conducted with thalidomiders from the United Kingdom, the

¹⁴¹ Steven High, “Foreword,” in *Oral History Off the Record: Toward an Ethnography of Practice*, Stacey Zembrzycki and Anna Sheftel eds. (New York, NY: Palgrave Macmillan, 2013).

¹⁴² Here I am drawing on the practice of reflexive writing that has been adopted by oral historians such as Pamela Sugiman in “Memories of Internment: Narrating the Life Stories of Japanese Canadian Women,” *Canadian Journal of Sociology* 29, no. 3 (2004): 359-88.

¹⁴³ Anne Borsay (with Ruth Blue as project research assistant and interviewer). *Thalidomide: An Oral History (16 Series record levels.)* Swansea University, in collaboration with the Thalidomide Trust, funded by Wellcome Trust. London, England: Wellcome Library.

insights gained from them allowed me to draw parallels and understand differences from the experiences specific to Canadian thalidomiders.

Overall, those that chose to participate in oral history interviews are interesting and different in many ways. Broadly speaking these narrators are not famous, nor are most of them even public figures. Many are ordinary citizens and yet each one of them recognized their special place within Canadian history and their ability to contribute valuable insight into the past by agreeing to partake in the interviews for this study. Some consciously chose to be visible to the public eye. Some, like Mercedes joined TVAC and led the political fight for compensation; others like Alvin have taken up public speaking, and still other, such as Susan, Peter and Paul, are featured in a variety of news stories, as well as on radio and television. Others preferred to remain unnamed, though they know they too are part of an important chapter in Canadian history.

While the ethics process demanded a detailed plan for my interviews as well as dedicated engagement with the question of how these interviews were to contribute to my analysis, the following discussion will outline how the interviews themselves disrupted the carefully set direction the research was embarking on and how my narrators helped re-shape the focus of this dissertation in invaluable ways. This is relevant to the discussion of oral history but also relates to methodological considerations expressed by medical historians who have pursued patient histories. Geoffrey Reaume, for example, wrote that when considering the perspective of patients, it is an important scholarly ambition to “redress the balance in a field where much of the scholarship has been written from the perspective of observers rather than the observed.”¹⁴⁴ Allowing the voices of my narrators to direct me to relevant issues helps redress the power

¹⁴⁴ Reaume, “Keep Your Labels Off My Mind!” 397.

imbalance experienced by individuals with disabilities. Scholars contributing to the field of disability history, such as Karen Hirsch, concur. Hirsch has argued pointedly: “Scholars in the humanities are just beginning to discover that disabled people have a unique perspective on life informed by their disability experience.”¹⁴⁵ As such, oral history may be one way disability historians and medical historians who study the interactions between people with disabilities and the medical profession can find common ground.

Before conducting my official interviews, it was clear to me from secondary research and conversations with other scholars that thalidomide’s history demands attention be paid to questions of reproduction and family planning. Having focused much of my course work and research projects during my academic career on gender and sexuality in history, issues related to reproduction seemed not only appropriate but necessary for me to focus on. Inevitably, in the early 1960s, a great deal of attention in newspapers and magazines was paid to the experience of pregnancy and birthing of the women who ingested the drug. Since the teratogenic effects of the drug were discovered, the wombs of pregnant women had been turned into ticking bombs in the public’s imagination. Given this past fascination with pregnancy and thalidomide, I set out to explore whether the disabilities resulting from the ingestion of thalidomide by mothers shaped the lived experiences of thalidomiders to the extent that it was a significant factor in determining their own reproductive futures. In other words, I wanted to see if this pharmaceutical disaster had an impact on their desire or decision to create their own families and experience parenting.¹⁴⁶

As such, my initial application to Carleton University’s Ethics Research Board outlined that my research would answer the following question: “My research will consider the

¹⁴⁵ Karen Hirsch, “Culture and Disability: The Role of Oral History,” *The Oral History Review* 22, no. 1 (1995), 6.

¹⁴⁶ I choose to use the phrase “non-parenting” in the preliminary discussion, not to paint the choice to parent as the natural or normal decision, but rather to paint a trajectory of family influences.

transgenerational impact of the drug thalidomide, which caused a range of severe birth defects including phocomelia, on families in Canada. It will discuss the lived experiences of thalidomiders themselves and the ways their childhoods shaped their lives, including their later experiences of parenting or non-parenting. Family and private life, including stories of everyday survival, sexuality, and familiar relations will take center stage, in order to shed light on the aspects of thalidomide and disability that often remain hidden.”¹⁴⁷

In the *Letter of Information* that I distributed to my interviewees the project was described as follows: “My current academic research investigates 1) the lived experiences of thalidomiders in Canada and their perspectives on those experiences, and 2) the impact thalidomide had on families and family planning.”¹⁴⁸ The first part communicated that I was interested in individuals’ life stories and their perspectives on them, which was meant to provide me with insight and context, and the second part conveyed my particular interest in private family life and reproductive choices.

Based on the initial twelve oral interviews conducted between December 2016 and April 2017, it became apparent early on that there was no universal experience regarding thalidomiders’ reproductive choices as I had, perhaps naively, anticipated there would be. At that point, I realized that a social history of thalidomide solely focused on family and private life, including stories of everyday survival and sexuality, would fail to accurately convey the long-term impact of the drug in Canada. While reproductive choices are, of course, extremely relevant and highly important, and are thus included as part of the larger conversation surrounding body-

¹⁴⁷ The initial application was submitted to Carleton’s University Research Ethics Board A on February 5, 2016 via email and was reviewed by the Full Board on February 12, 2016. Revisions were requested on February 19, 2016. A revised application was subsequently submitted on February 29, 2016. I received final ethics clearance on March 18, 2016.

¹⁴⁸ See Appendix B for Letter of Information.

politics, familial experience or even moments of sexual exploration and/or exploitation, did not emerge as universally relevant in thalidomiders' own assessments of the impact the drug had had on their lives.

Before beginning the interview, whether during a pre-interview conversation or during the set-up of the voice recorder, many spoke about compensation payments and particularly the financial challenges they faced as their aging bodies require increasing attention and accommodations. However, what became most relevant for the direction of this dissertation was that during interviews, it was the rehabilitation procedures and visits thalidomiders made to hospitals and rehabilitation centers as children that produced the most passionate responses.¹⁴⁹ Linda Shopes has argued that oral history interviews are “open-ended, subjective, historically inflected” and “let the narrator define the plot of his or her own story for the historical record.”¹⁵⁰ In fact, my interview partners often re-directed the discussion to the topics of rehabilitation and prosthetics whether in the home environment or in medical facilities. The question catalogue I used to lead my interviews included, besides questions regarding childhood, family, relationships, challenges and successes in life, a question about rehabilitation, therefore, I did not need to revise my ethics application and instead continued with the same set of questions once I realized the importance of rehabilitation to interviewees. In addition to the question about their rehabilitation visits, I began taking careful note of the ways that rehabilitation was also brought up when asking seemingly unrelated questions. Della Pollock has called the process of allowing

¹⁴⁹ Refer to Appendix D for the question catalogue.

¹⁵⁰ Linda Shopes, “Oral History,” in *The Handbook of Qualitative Research*, 4th ed., Yvonna S. Lincoln and Norman K. Denzin, eds. (Thousand Oaks: Sage, 2011), 452.

the narrator to take such a guiding role in interviews as “making history in dialogue” or “the heart of oral history.”¹⁵¹

Although generally guided by my questions, the contributors often deviated and provided insight into a lifespan of subjective life experiences related to the consequences of the scandal or their disabilities. As the interviews unfolded, I encouraged my participants to share other stories that they felt would help me understand their lives. In fact, at the end of each interview, I asked the participant if there was anything that I had failed to ask about that they felt was relevant. Although a simple question, it resulted in many participants sharing additional and meaningful stories. As a consequence, this dissertation shifted from a focus on reproduction and private lives to the question of how private lives and public influences, particularly those of the medical profession but also those of policy makers and community members, intersected in the lives of thalidomiders. This allowed for an interesting engagement with the ideas surrounding the distinction often drawn between disability and impairment but also the blurred boundaries between private and public matters.

In 1990 Michael Frisch’s book, *A Shared Authority: Essays on the Craft and Meaning of Oral and Public History* sparked an important scholarly discussion about the ethics, merits, and dilemmas of the collaborative potential of oral history.¹⁵² Frisch was path-breaking in his call to historians to consider if and how it is possible to create an oral history research methodology that is built on a shared authority between the historian and the narrator in oral history research.¹⁵³

Karen Hirsch subsequently urged historians and disability scholars to include disability as an

¹⁵¹ Della Pollock, “Introduction: Remembering,” in *Remembering: Oral History Performance*, ed. Della Pollock (New York: Palgrave Macmillan, 2005), 2.

¹⁵² Michael H. Frisch, *A Shared Authority: Essays on the Craft and Meaning of Oral and Public History* (Albany: State University of New York Press, 1990).

¹⁵³ Alistair Thomson, “Introduction: Sharing Authority: Oral History and the Collaborative Process,” *The Oral History Review* 30, no. 1 (2003), 23.

analytic category in academic scholarship and to explore the potential of oral history in the development of disability studies and disability history.¹⁵⁴ Since then, public historians and oral historians have engaged closely with the notion of shared authority, yet it is only during the research process that the implication of this ethical consideration truly becomes visible. By being challenged and re-directed by the narrators, oral historians can uncover potential research avenues of which they were previously unaware.¹⁵⁵ In my dissertation this approach encouraged the inclusion of rehabilitation visits and schooling experiences as topics of analysis.

Rehabilitation visits were a significant aspect of thalidomiders' experiences.¹⁵⁶ This insight, gained through a shared authority approach to oral history, was tremendously important. In fact, medical environments were places in which intimacy was breached in very profound ways. The private (family) and public (medical) environments were interlinked in the life experiences of Canadian thalidomiders, and it became apparent that I needed to address the medical environments in which the thalidomide-affected bodies were policed alongside questions about the ways in which thalidomide bodies were policed in the domestic realm; doing so demonstrates thalidomide bodies continuously moved between public and private spaces while retaining their political significance as markers of difference.

¹⁵⁴ Hirsch, "Culture and Disability," 2.

¹⁵⁵ Liz Linthicum, who engaged in an oral research project with people with physical disabilities, has noted, "It [oral history] also, crucially, enabled respect for individuals' own criteria for what issues mattered to them."¹⁵⁵ She continues, "The material gathered during oral history interviews could allow sources themselves to influence the direction of research, on occasions dramatically uncovering much larger themes or perspectives to work with." Liz Linthicum, "Integrative Practice: Oral History, Dress and Disability Studies," *Journal of Design History* 19, no. 4 (2006): 311-312. Of course, In order for this type of collaboration to occur, "both parties may need to cede some interpretive authority, [but] neither party needs to relinquish it altogether." Linda Shopes, "Commentary: Sharing Authority," *The Oral History Review* 30, no. 1 (2003), 108.

¹⁵⁶ This is further supported by medical publications which reiterated the assumption of medical professionals that two long arms and legs would improve thalidomide childrens' lives by making them "normal" and able to do "normal" things, which will be discussed in Chapter Two.

It is also relevant to acknowledge that the memories of thalidomiders are both private as well as shaped through public discussions, specifically within a small, largely politicised community. Historians David Glassberg, Alon Confino, Pierre Nora, and Maurice Halbwachs have carefully ensured that the importance of collective memory and memory politics cannot be ignored by oral historians.¹⁵⁷ Given the politicized nature of the fight for compensation that has only recently (in 2015 and again in 2019), resulted in a new compensation system that includes annual pensions and a medical assistance fund, an important question emerges: Is it possible that thalidomiders emphasize stories about the harm that came to them at the hands of the medical profession and the Canadian government, because doing so aids them in their long struggle for monetary compensation? After all, as oral historian Pamela Sugiman has argued, “As a social process, memory [...] is selective. We remember what we need to remember, what is safe to remember, that for which we have the cultural tools to express. Memory is shaped by its audience. It is formed and presented with a reading of this audience, one that may hear or dismiss, listen or ignore, accept or punish. In each of these ways, memory is too a political project.”¹⁵⁸ To address this concern I embraced communications scholar Arthur Bochner’s belief that the importance of self-narratives is to derive insight from “experiences rather than to depict an experience exactly as it was lived.”¹⁵⁹ It is important to consider the narratives thalidomiders offered as accounts of the past and as memories shaped by life experience. Memories provide insight into the importance the recalled moments have for the individuals at the center of this

¹⁵⁷ David Glassberg, “Public History and the Study of Memory,” *The Public Historian* 18, no. 2 (1996): 7-23; Alon Confino, “Collective Memory and Cultural History: Problems of Method,” *American Historical Review* 102, no. 5 (1997): 1-18; Pierre Nora, “Between Memory and History: Les Lieux de Mémoire,” *Representations* 26 (1989): 7-24; Maurice Halbwachs, *On Collective Memory*, trans. Lewis A Coser (Chicago: University of Chicago Press, 1992).

¹⁵⁸ Pamela Sugiman, “Memories of Internment: Narrating the Life Stories of Japanese Canadian Women,” *Canadian Journal of Sociology*, 29(3): 359-88.

¹⁵⁹ Arthur P. Bochner, “Criteria Against Ourselves,” *Qualitative Inquiry* 6, no. 2 (2000): 270.

study.¹⁶⁰ Regardless of what a “collective memory” among thalidomiders may be, allowing for the inclusion of medical and rehabilitation visits into this analysis revealed that thalidomiders clearly recall the overt manipulation of their bodies that occurred in an attempt to make them ‘normal.’¹⁶¹

This research cannot do justice to the unique and differing experiences of all those harmed by thalidomide in Canada, nor does it attempt to. The research does not include the voices of all those harmed or impacted by the drug in Canada, nor does it provide a window into the complete life cycle of those who participated in the interviews. What it does do is listen to and take seriously voices that have, until now, been mostly ignored by historians. It was the visibility of their bodies in the media, and the emotion-evoking depictions of their disabilities that caused outrage, public demands, and expectations that would lead to changes in Canada’s socio-cultural structure. Therefore, it is necessary for ethical and historiographical reasons to place these individuals center stage, because they, above anyone else, have lived with the consequences of the poorly-tested and negligently marketed drug.

¹⁶⁰ As the author, I am not deciding between an accurate or inaccurate memory, instead the study allows the self-narratives of my contributors to stand as important markers of how thalidomide shaped the lived experiences of Canadian thalidomiders in the aftermath of the scandal. This is particularly important in a study that includes the life stories of people with disabilities which have largely been excluded from the grand narrative of Canadian history. People with disabilities have been underrepresented and, at times, even muted in history. As such this dissertation embraces the principle that gathering these stories is not done to “mirror or directly reflect history, but to provide participants a space to share their lived experiences.” Stevie M. Munz, “The Farmer’s Wife: An Oral History Project” (PhD diss., Ohio University, 2016), 56.

¹⁶¹ This dissertation thus agrees with Mark Freeman, scholar of narrative psychology, who suggests, use of self-narratives has “aims of practicing fidelity to the human experience.” Mark Freeman, “Autobiographical Understanding and Narrative Inquiry,” in *Handbook of Narrative Inquiry: Mapping a Methodology*, ed. Clandinin, D. Jean (Thousand Oaks, Sage, 2007), 134.

Chapter Overview

This dissertation does not offer a linear narrative about the lives of Canadian thalidomiders. Nor does it provide a chronological assessment of the intersections of medical science and government policies since the 1960s. Instead, it is a set of several interconnected, historically-located case studies regarding the impact of thalidomide in Canada. The division of topics into these chapters must be understood as being superimposed on issues that were interconnected. Indeed, the separation of chapters into two sections, the first focusing on public institutional environments and the latter on private domestic environments, actually serves to underscore the interconnectedness of the public and private sphere. By attempting to separate the discussions of (experiences in) public institutions and private lives, it becomes clear how interwoven the two spheres were in the lives of thalidomiders. This dissertation is organized as follows:

Chapter One provides an overview of the ways the thalidomide scandal unfolded in Canada. It provides the historical context for both the pharmaceutical scandal itself as well as the ways in which the rhetoric about thalidomiders and their bodies initially developed in Canada. What will be made clear is that for the pharmaceutical sector, including the Germany-based company that licensed thalidomide, Canada served as a research ground for the drug *after* other countries had taken it off the market. Furthermore, the chapter outlines how, in the aftermath of the initial scandal, the Canadian public turned to the government for a solution to problems raised by the “deformed” babies that had been born. The public’s expectation that the state should take the lead in addressing the needs of the thalidomiders must be understood in the context of the developing welfare state and new ideas about the responsibility of the state towards its citizens.

Chapter Two analyzes the rehabilitation programs for thalidomiders, with an emphasis on prosthetics specifically. The Canadian government reacted to the scandal by emphasizing rehabilitation and medical intervention as a solution to the crisis. The focus in this chapter is the public discourse that positioned medical intervention as the solution to the perceived problems of thalidomiders' disabilities. As the fates of the thalidomide children were heavily publicized in the Canadian press, the Canadian government's reaction can be understood, at least in part, as a demonstration of a deliberate approach to health care and what it could offer Canadians. As such, the chapter outlines how thalidomide children became entangled in the post-war conversation about the Canadian government's role in defining the emerging welfare state at a time when health care was being negotiated between the federal and provincial levels. In addition, the chapter analyzes the treatments thalidomiders experienced, for better or worse, at the hands of the medical profession, and what repercussions these engagements had for them as individuals. The children's embodied experiences of the rehabilitation efforts contradicted state rhetoric of the benefits of prosthetics. As the chapter shows, the social construction of ideal citizen bodies did not hold up against the scrutiny of the young thalidomiders. Emphasis, in this chapter, is placed on the period between 1963 and 1980, although certain experiences occurred afterwards. Importantly, Chapter Two documents the predominance of medical authority in thalidomiders' lives.

Chapter Three continues to investigate the reach of the medical profession in institutional settings, in particular the non-medical institutions that played a major role in thalidomiders' lives. These institutions were, first and foremost, schools. Here the discussion outlines ways in which thalidomiders learned to measure their capacities beyond the rehabilitation setting. The thalidomide children enrollment in public schools was based on the (unintentionally political)

activist work of their parents, which links the thalidomide case to larger developments in disability right and children's welfare. In the chapter, the role of the medical profession in negotiating thalidomiders' access to education as well as the role parents played in navigating the education of their children is contrasted with the lived experiences of the children. The thalidomiders determined what opportunities were open to them based on drawing comparisons to those around them, including a differentiation between physical and intellectual disabilities. Yet, while this discussion provides a theoretical contrast between the social disablement and medical understandings of disability, it also notes children's embodied experiences during attempts to overcome the barriers they encountered in educational settings.

Chapter Four turns to private settings and domestic lives, particularly family life in the aftermath of the scandal. The timeframe of this chapter is measured primarily by thalidomiders' residency with parents, thus covering chiefly thalidomiders' childhoods and adolescence. A discussion of how families experienced their thalidomide children's coming home from the hospital is followed by an analysis of every-day family life that involved parents, siblings, and, at times, other community members. This chapter addresses explicitly if, how, and when social disablement was experienced in domestic environments and in what ways thalidomiders and their families collaborated with and resisted attempts at social and embodied management of the disabled children. It emphasises the role of children as historical actors and provides insights into the ways family lives were organised. This is important as medical histories have often fallen short in considering the implications of medical involvement and experiences for patients after they return home from hospitals and rehabilitation facilities.

Chapter Five extends the analysis of private lives by discussing sexuality and intimacy, as well as (sexual) abuse. This chapter spans thalidomiders' childhoods and their growth into

adulthood. The insights gained in this chapter allow for a continuation of the discussion of how the domestic sphere shaped thalidomiders' perceptions of ability; furthermore, the chapter parallels the discussion of thalidomide children's resistance to interpretations of their bodies as lacking in Chapter Two, as it allows a window into the very distinct ways that embodiment and social discourse were negotiated by individuals. The investigation of the intersections of socially constructed discourses of normality and able-bodiedness, as well as heteronormativity and gender, serves to expose the way that disabled bodies not only transgress the hypothesised boundary between public and private but that disability eliminated the possibility of separating, even theoretically, private aspects of disabled experiences.

Chapter Six builds on this discussion of intimacy by analyzing thalidomiders' experiences of (in-)fertility and fertility control as well as the experiences of becoming a parent and raising children. It demonstrates that embodied experiences of bearing and rearing children were shaped by and negotiated against social discourses and perceptions of ability. The chapter highlights that whereas thalidomide had an immense impact on the reproductive experiences of women who took the drug, the long-term consequences of thalidomide also shaped the reproductive experiences of the next generation. The narratives of thalidomiders demonstrate the complexity of sexual politics that is key to understanding the intersection of sexuality and disability, while also highlighting that disability was not the only or even the central factor in determining the experiences of fertility control, birthing, or (non-) parenting.

Overall, the dissertation demonstrates that the long-term consequences of the thalidomide tragedy were shaped, and continue to be shaped, primarily by the political nature of disabled bodies rather than the physical impairments that were caused by the drug. With age, thalidomiders' bodies are beginning to present new challenges, many of a medical nature. These

problems are not addressed in this dissertation. The dissertation also does not engage with the political activism or the employment and professional lives of thalidomiders. While these are important areas to consider for future research, their exclusion from this dissertation does not impede analysis of the ways thalidomiders' bodies, and therefore their lives, were inherently political.

Note Regarding Terminology

The discussion of thalidomide demands a careful attention to the language used in the analysis. This dissertation will draw on the language and terminology used during the time under investigation found in primary sources, because the terminology chosen by historical actors carries particular meanings and connotations that are essential to be retained in this analysis. This means that this dissertation utilizes words no longer considered appropriate or acceptable and may be hurtful to some readers. This should not be misconstrued as a disregard for the often eugenic implications of the terms adopted or the destructive impact that language can have on social structures and individual well-being. Instead, favouring the use of historically accurate terms helps convey the socio-cultural context in which Canadians and their national government understood disability and thalidomiders' experiences. However, the dissertation endeavours to make use of contemporary terminology whenever possible. I acknowledge that language has shifting and diverse meanings for different individuals and that terminology that is considered acceptable, even appreciated, by some may not be tolerated by others. I want to emphasize that in no way does this dissertation or the terminology used intend to (further) victimize thalidomiders.

Chapter 1: The Canadian Thalidomide Tragedy

By November, Canadians will know how much damage has been done. It will all be over, all but the crying.¹

The Canadian thalidomide story is a tragic one. As the introduction has noted, in the early 1960s an international pharmaceutical tragedy occurred that resulted in the births of thousands of babies born with serious physical disabilities around the world. Among the countries affected, Canada stands out for two reasons: the late withdrawal of the drug from the market and the reaction of the public that placed blame on the Canadian government rather than on the two pharmaceutical companies selling the pills. Increasing pressure from the medical profession, the public, and states resulted in the withdrawal of the drug from the markets in Germany and the United Kingdom in November 1961. Meanwhile, in Canada the drug remained on the market until the spring of 1962 despite knowledge of the possible connection between the drug and birth defects in newborns.²

This chapter will outline how the drug first entered the market, how the Canadian licensing companies reacted to concerns about the drug and its effects, and how the withdrawal of the drug finally took place. The subsequent financial settlements and compensation programs will briefly be noted as well. The chapter draws on a range of primary sources to demonstrate that the two Canadian companies selling thalidomide, Richardson-Merrell and Frank W. Horner

¹ June Callwood, "The Unfolding of Drug-Deformed Babies: A Report On a Nightmare of Error and Neglect," *MacLean's Magazine*, May 19, 1962, 68.

² Canada is not alone in its late withdrawal of the drug, although given the fact that the United States did not approve thalidomide, it is curious that the dangers of the drug were not taken more seriously by the Canadian authorities. Trent Stephens and Rock Brynner note in their book *Dark Remedy* that, as an example, "In Italy and Japan, thalidomide remained on the market a further nine months." They do not, however, explain why some nations were slow in removing the drug from the market. Instead they simply note: "The fact that the United States and a few other countries had not approved thalidomide was extremely embarrassing to all the nations that had." *Dark Remedy: The Impact of Thalidomide And Its Revival As A Vital Medicine* (New York: Basic Books, 2001), 67.

Ltd, remained in contact with Chemie Grünenthal as well as the Canadian Food and Drug Directorate in the aftermath of the initial scandal in Europe, assuring the Canadian government that the evidence against thalidomide remained inconclusive, which ensured the continued sale of the drug in Canada. Put simply, Canada was one of the places that the pharmaceutical sector used to study the potential of the drug despite existing knowledge of its probable dangers. Importantly, this chapter will demonstrate the curious reaction of the Canadian media to the revelations about the dangerous drug, which allowed the two companies operating in Canada to stay surprisingly distant from the lime-light of the scandal. The delayed withdrawal of the drug in Canada is one of the most disturbing facets of the Canadian thalidomide scandal and, along with the reaction of the Canadian public, it shaped the actions of the governments in the aftermath of the scandal. In fact, the events outlined in this chapter shaped the lived experiences of Canadian thalidomiders in years to come. The reactions of the Canadian Food and Drug Directorate (slow in requesting the recall of thalidomide), the media (which allowed the companies to avoid public scrutiny and placed blame on the Canadian government), and the companies (which slyly avoided compensating the victims of their products fairly) determined the support offered to thalidomiders and their families as they tried to adjust to life after the scandal.

By the time the drug thalidomide started to be officially sold in Canada in 1961, concern about the drug's effect on fetuses had already begun to spread in Europe and North America. Yet, doubt had not permeated into pharmaceutical, medical, and political circles deeply enough to prevent the influx of pills into Canada. Ordinary Canadians across the country had no reason to suspect that the dangerous substance they were given by doctors and sold by pharmacists

would result in babies with disabilities. The ways in which thalidomide came to impact Canadian lives remains largely unexplored, unlike in Germany and the United Kingdom in particular, which have received much more detailed attention from journalists and scholars alike.³ Indeed, the origins of thalidomide's history lie in Stolberg, West Germany, and thus the story of Canadian thalidomiders begins, like that of all those harmed by the drug, in Germany. In 1954, when the German company Chemie Grünenthal (today Grünenthal GmbH) synthesized the drug, it was referred to by the laboratory name K 17. The name was given to the substance because it was the seventeenth substance identified by the drug-discovery pharmacist Wilhelm Kunz during his employment at Grünenthal. The drug stood out because it produced no apparent toxic effects when administered orally to animals, even in massive doses. That meant that in addition to being an effective sleeping aid, it was seemingly and unusually safe in comparison to barbiturates which, in the 1950s, served as popular sedatives. Thalidomide could be ingested in large quantities without causing death.⁴ In fact, Chemie Grünenthal later referred to the drug as being "harmless like sugar cookies."⁵

³ See Beate Kirk, *Der Contergan-Fall. Eine unvermeidbare Arzneimittelkatastrophe? Zur Geschichte des Arzneistoffes Thalidomid* (Stuttgart: Wissenschaftliche Verlagsgesellschaft, 1999); Niklas Lenhard-Schramm, *Das Land Nordrhein-Westfalen und der Contergan-Skandal: Gesundheitsaufsicht und Strafjustiz in den »langen sechziger Jahren«* (Vandenhoeck & Ruprecht, 2016); Niklas Lenhard-Schramm and Thomas Großbölting, eds, *Contergan: Hintergründe und Folgen eines Arzneimittel-Skandals* (Göttingen: Vandenhoeck & Ruprecht, 2017); Willibald Steinmetz, "Ungewollte Politisierung durch die Medien? Die Contergan-Affäre." In *Die Politik der Öffentlichkeit – Die Öffentlichkeit der Politik*, ed. Bernd Weisbrod, 195-228 (Göttingen: Wallstein, 2003); and Alexander Von Schwerin, "1961 – Die Contergan-Bombe. Der Arzneimittelskandal und die Neue Risikoepistemische Ordnung der Massenkonsumgesellschaft," in *Arzneistoffe im 20. Jahrhundert. Historische Skizzen von Lebertran bis Contergan*, ed. Nicholas Eschenbruch, Nicholas, Viola Balz, Ulrike Klöppel, and Marion Hulverscheidt, 255-82 (Bielefeld: Transcript, 2009); Viviane Quirke, "The Impact of Thalidomide on the British Pharmaceutical Industry: The Case of Imperial Chemical Industries," in *Ways of Regulating: Therapeutic Agents between Plants, Shops and Consulting Rooms*, ed. Jean-Paul Gaudillière and Volker Hess, 137–52 (Berlin: Max Planck Institute, 2008).

⁴ Barbara Clow, "Defining Disability, Limiting Liability: The Care of Thalidomide Victims in Canada," in *Essays in Honour of Michael Bliss: Figuring the Social*, Alison Li, Elisabeth Heaman, Shelley McKellar, and Michael Bliss, eds. (Toronto: University of Toronto Press, 2008), 305.

⁵ In the original: "unschädlich wie Zuckerplätzchen." Jürgen Serke, "Vom Schlafmittel zur Schreckenspille," *Osfriesen-Zeitung*, May 21, 1968.

The testing of the substance, the introduction of the drug to the market, and the initial reactions by medical professionals regarding its effects have all been addressed in detail in previous studies.⁶ Those books and journalistic accounts are primarily located within the field of medical history. Although they include some stories of the thalidomide children, these accounts are very much top-down considerations of the tragedy with a focus on the pharmaceutical scandal, the medical discourses that occurred, and the compensation payments negotiated afterwards. Lawyer Henning Sjöström and biochemist Robert Nilsson published their book *Thalidomide and the Power of the Drug Companies* in 1972, in which the authors uncompromisingly outline how Chemie Grünenthal ignored or dismissed the growing concerns about the toxicity of thalidomide and how the company engaged in a smear campaign to discredit doctors who tried to bring attention to the problem.⁷ The book contains a chapter that discusses the history of thalidomide in Sweden and Canada as the two countries that stand out for their negligence, since thalidomide remained on the market there much longer than elsewhere despite damning evidence that it was causing harm.⁸ Seven years later *Suffer the Children: The Story of Thalidomide* by the *Sunday Times* Insight Team was published. Credited as the most comprehensive study of the thalidomide tragedy to date, the book is based on the team's campaign to uncover the history of the thalidomide scandal, which ultimately helped secure financial settlements for British thalidomiders.⁹ In 1986, Max Sherman and Steven Strauss summarized the chemistry, pharmacology, and teratology of thalidomide and reviewed the regulatory processes that resulted from the thalidomide tragedy, focusing on the United States,

⁶ I intentionally use the term *effect* as opposed to *side-effect* to emphasize the importance of making pharmaceutical products and their impact on human bodies transparent.

⁷ Henning Sjöström and Robert Nilsson. *Thalidomide and the Power of the Drug Companies* (Harmondsworth: Penguin, 1972).

⁸ Sjöström and Nilsson. *Thalidomide and the Power of the Drug Companies*, 131-148.

⁹ The Insight Team of the *Sunday Times* (London), *Suffer the Children: The Story of Thalidomide* (New York: Viking Press, 1979).

with a special note on the surprising resurrection of thalidomide's usage in the treatment of leprosy and other conditions.¹⁰

Another highly cited contribution to the literature on thalidomide was published in 2001. Professor of anatomy and embryology Trent Stephens and historian Rock Brynner chronicled the history of thalidomide over a period of forty years, from its initial appearance on the market and the subsequent scandal, to the time when the drug reappeared as a prescription product for certain medical conditions.¹¹ While these earlier books have been essential in providing information about, and a spotlight on what occurred, I would credit Niklas Lenhard-Schramm's *Das Land Nordrhein-Westfalen und der Contergan-Skandal: Gesundheitsaufsicht und Strafjustiz in den langen sechziger Jahren* as the publication with the most accurate discussion of the early development and marketing of the drug in Germany. Lenhard-Schramm corrects mistaken dates and facts widely assumed in these earlier publications, which primarily drew on the indictment produced for the criminal trial in Germany, thus citing files that relied on second-hand accounts. In contrast, Lenhard-Schramm conducted his own research and provides a very detailed engagement with the archival sources available in German archives.¹² This Chapter is based on my own review of these archival collections.

In addition to the accounts primarily concerned with uncovering the extent of the pharmaceutical scandal, there is a growing number of publications that address the initial scandal

¹⁰ Max Sherman and Steven Strauss, "Thalidomide: A Twenty-Five Year Perspective," *Food, Drug, Cosmetic Law Journal* 41, no. 4 (1986): 458-466.

¹¹ Trent Stephens and Rock Brynner, *Dark Remedy: The Impact of Thalidomide and Its Revival as a Vital Medicine* (New York: Basic Books, 2001).

¹² Lenhard-Schramm reviews and critiques previous publications (an emphasis is placed on German-language studies and accounts), as well as critiques how certain inaccurate information has subsequently been reiterated in newspaper and media coverage. Whenever such studies or articles are cited in this dissertation, I have consulted my own archival material and taken Lenhard-Schramm's corrections into consideration. Niklas Lenhard-Schramm, *Das Land Nordrhein-Westfalen und der Contergan-Skandal: Gesundheitsaufsicht und Strafjustiz in den »langen sechziger Jahren«* (Vandenhoeck & Ruprecht, 2016), 45-53. His critique of *Suffer the Children* and *Thalidomide and the Power of the Drug Companies* can be found specifically on pages 43-44.

and the aftermath of the discovery of thalidomide's teratogenicity in a variety of national and regional contexts, no doubt spurred by increased media attention due to the Australian class action lawsuit (led by Lynette Rowe, 2011–2012), the subsequent settlement benefitting victims of the drug in Australia and New Zealand (2014), and the recent fight by Canadian thalidomiders to receive compensation. This is true especially of the Rowe case that led to the assembling of primary sources housed at the State Archives of North-Rhine Westphalia, which were temporarily made available online in the aftermath of the trial. The 2012 study of Clare Parker, for instance, focuses on the Australian context and argues that the thalidomide scandal had an impact on ethical considerations surrounding abortion and infanticide, essentially leading to acceptance of the idea that any woman, of any class, might find herself requiring access to an abortion under certain circumstances.¹³ In 2015, Michael Magazanik published his book *Silent Shock: The Men Behind the Thalidomide Scandal and an Australian Family's Long Road to Justice* because he had been inspired by the Australian thalidomider Rowe's successful legal action against parent drug manufacturer Chemie Grünenthal, and the Australian distributor, Distillers, in 2011, during which he served as a lawyer.¹⁴ The book further uncovers the corporate negligence that led to the worldwide thalidomide tragedy, as well as the subsequent denial of responsibility or reasonably fair compensation to the drug's victims.

Susanne Klausen and Julie Parle published an article in 2015, which, like previous studies, is also firmly located within the field of medical history. It discusses how although South Africa narrowly missed the thalidomide tragedy within its own borders, the scandal unfolding

¹³ This idea has been raised by the media in a variety of national contexts in the immediate aftermath of the scandal. Clare Parker, "From Immorality to Public Health: Thalidomide and the Debate for Legal Abortion in Australia," *Social History of Medicine* 25, 4 (2012): 879

¹⁴ Michael Magazanik, *Silent Shock: The Men Behind the Thalidomide Scandal and an Australian Family's Long Road to Justice* (Melbourne: The Text Publishing Co., 2015).

elsewhere in the world had a significant impact on the passage of the Medicines and Related Substances Control Act (No. 101) of 1965 in the country and on the debate over abortion law reform in the early 1970s.¹⁵ Susanne Klausen next assessed the issue in New Zealand in the article “‘There is a Row about Foetal Abnormality Underway’: The Debate about Inclusion of a Eugenics Clause in the Contraception, Sterilisation, and Abortion Act, 1977-1978,” in late 2017, where she outlines how the thalidomide scandal contributed to the passing of a eugenic abortion clause by New Zealand’s parliament, despite its controversial nature.¹⁶ Parle also co-authored with historian Ludger Wimmelbücker, an assessment of how thalidomide impacted Southern Africa more broadly and address the questions of “intended, explored, initiated or sometimes thwarted markets for thalidomide-containing preparations outside ‘the West’.”¹⁷ They point to “colonial legacies and circuits of commerce” as explanations for the absence of notable thalidomide scandals in the region.¹⁸

There have also been a few publications on the history of thalidomide in the United States.¹⁹ In his article “A Tale of Two Experts: Thalidomide and Political Engagement in the United States and West Germany,” Arthur Daemmrlich considers the role played by Widukind Lenz, the German doctor who was among the first to recognize the relation between increasing

¹⁵ Susanne Klausen and Julie Parle, “‘Are We Going to Stand By And Let These Children Come Into the World?’: The Impact of the ‘Thalidomide Disaster’ in South Africa, 1960-1977,” *Journal of Southern Africa Studies* 41, no.4 (2015): 735-752.

¹⁶ Susanne Klausen, “‘There is a Row about Foetal Abnormality Underway’: The Debate about Inclusion of a Eugenics Clause in the Contraception, Sterilisation, and Abortion Act, 1977-1978,” *New Zealand Journal of History* 51, No. 2 (October 2017): 80-103.

¹⁷ Julie Parle and Ludger Wimmelbücker, “‘These are the Medicines that ‘Make’ Monsters’: Thalidomide in Southern Africa, 1958–1962.” *Social History of Medicine* (published online, March 5, 2019): 1. <https://doi-org.proxy.library.carleton.ca/10.1093/shm/hkz011>.

¹⁸ Parle and Wimmelbücker, “‘These are the Medicines that ‘Make’ Monsters’,” 1.

¹⁹ Significantly Arthur Daemmrlich, “A Tale of Two Experts: Thalidomide and Political Engagement in the United States and West Germany,” *Social History of Medicine* 15, no. 1 (2002): 137-58; Barbara Clow, “‘An Illness of Nine Months’ Duration:’ Pregnancy and Thalidomide Use in Canada and the United States,” in *Women, Health, and Nation: Canada and the United States Since 1945*, Georgina Feldberg, Molly Ladd-Taylor, Alison Li and Kathryn McPherson, eds., 45-66 (Kingston: McGill-Queen’s University Press, 2003).

numbers of birth defects and thalidomide, and Frances Kelsey, who blocked FDA approval of the drug in the United States in her role as reviewer for the U.S. Food and Drug Administration. He compares how Kelsey, a Canadian, received some protection in her efforts to delay thalidomide's marketing approval in the United States, while Lenz was subjected to sharp criticism from the German company as well as colleagues, particularly while providing testimony during the lengthy court trial.²⁰ Although a teaching tool with guiding questions for students rather than a scholarly, historical account, Lisa A. Seidman and Noreen Warren also consider the interesting case of the United States, where Frances Kelsey played a key role in protecting American citizens from the drug, in their article "Frances Kelsey & Thalidomide in the US: A Case Study Relating to Pharmaceutical Regulations."²¹ More importantly for this dissertation, Leslie Reagan also discusses thalidomide in her book *Dangerous Pregnancies – Mothers, Disabilities, and Abortion in Modern America*. While the main focus of her book is on the German measles epidemic of the early 1960s, she examines the perception and impact of the global thalidomide scandal in the United States to strengthen her arguments regarding the occurrence of national anxiety about disabled, and "dangerous" babies. In fact, Reagan suggests that the images of thalidomide children caused many women to procure abortions when faced with the possibility that their children might be born with disabilities.²²

In addition to the chapter in *Thalidomide and the Power of the Drug Companies*, there have been a few publications on the thalidomide scandal and its aftermath in Canada. Ethel Roskies' 1972 study *Abnormality and Normality: The Mothering of Thalidomide Children* is a

²⁰ Arthur Daemmrich, "A Tale of Two Experts."

²¹ Lisa A. Seidman and Noreen Warren, "Frances Kelsey & Thalidomide in the US: A Case Study Relating to Pharmaceutical Regulations," *The American Biology Teacher* 64, no. 7 (2002): 495-500.

²² Leslie Reagan, *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010).

psychological study that, based on interviews with twenty Québécois mothers, is concerned with the mothering of Canadian thalidomide children. She considers specifically mothers' decisions regarding bearing and raising (including the choice not to raise) thalidomide children in the aftermath of the thalidomide scandal. While she focuses specifically on the twenty mothers whose children, with the exception of one, were enrolled in a rehabilitation program at the Rehabilitation Institute of Montreal, Roskies' conclusions are insightful regarding the mothering of all children who are born with some type of physical disability or, as the title states, abnormality.²³

Historian Barbara Clow has contributed two chapters to the Canadian historiography of thalidomide. “‘An Illness of Nine Months’ Duration:’ Pregnancy and Thalidomide Use in Canada and the United States,” discusses the Canadian thalidomide scandal alongside the developments in the United States.²⁴ In “Defining Disability, Limiting Liability: The Care of Thalidomide Victims in Canada,” Clow considers the relationship between ideas about congenital malformations and decisions about access to state sponsored programs of care.²⁵ In “Un Médicament ‘Monstrueux’: Débats Publics et Couverture Médiatique de la Tragédie de la Thalidomide au Canada, 1961-1963” Denyse Baillargeon and Susanne Commend contribute an “analysis of the public debates provoked by babies born with phocomelia in order to better assess the conception Quebec and Canadian societies had of disabled persons at the beginning of the

²³ Ethel Roskies, *Abnormality and Normality: The Mothering of Thalidomide Children* (Ithaca: Cornell University Press, 1972).

²⁴ Barbara Clow, “‘An Illness of Nine Months’ Duration:’ Pregnancy and Thalidomide Use in Canada and the United States,” in *Women, Health, and Nation: Canada and the United States Since 1945*, Georgina Feldberg, Molly Ladd-Taylor, Alison Li and Kathryn McPherson, eds., 45-66 (Kingston: McGill-Queen’s University Press, 2003).

²⁵ Barbara Clow, “Defining Disability, Limiting Liability: The Care of Thalidomide Victims in Canada,” in *Essays in Honour of Michael Bliss: Figuring the Social*, Alison Li, Elisabeth Heaman, Shelley McKellar, and Michael Bliss, eds. (Toronto: University of Toronto Press, 2008), 304-314.

1960s.”²⁶ This is an important contribution to the literature as it reviews Canadian newspaper coverage as well as the documents housed at Library and Archives of Canada that had not previously received scholarly attention. Finally, my own article, “The Curious Case of Thalidomide and the Absent Eugenic Clause in Canada’s Amended Abortion Law of 1969,” discusses the impact of thalidomide on the development of Canadian abortion law reform in the late 1960s and explains why, unlike in other Commonwealth countries, the thalidomide scandal in Canada did not generate political support for a eugenic clause in the amended federal *Criminal Law Amendment Act, 1968-69*.²⁷

No study to date has discussed the thalidomide tragedy from a social history perspective focusing on disability in any depth. Indeed, none of the publications cited above has provided a truly comprehensive discussion of the events in Canada. This Chapter aims to remedy this by drawing on not only original primary sources detailing the correspondence between Chemie Grünenthal and its licensees operating Canada, housed at the State Archives of North-Rhine Westphalia, as well as the relevant collection housed at Library and Archives of Canada, but also Canadian media coverage, federal and provincial government records, and, importantly, oral history testimonies. A comprehensive review of these sources is essential to the understanding of the individual lives at the center of this study. The history of the drug will now be traced from its beginnings in Germany to its market release in Canada, and finally to the withdrawal of the pills from Canadian pharmacies and private homes.

²⁶ Denyse Baillargeon and Susanne Commend, “Un Médicament ‘Monstrueux’: Débats Publics et Couverture Médiatique de la Tragédie de la Thalidomide au Canada, 1961-1963,” *Canadian Bulletin of Medical History* 33, no. 1 (2016): 131-153.

²⁷ Christine Chisholm, “The Curious Case of Thalidomide and the Absent Eugenic Clause in Canada’s Amended Abortion Law of 1969,” *Canadian Bulletin of Medical History* 33, no. 2 (January 2, 2017): 493-516.

In October 1957, the drug arrived on the German market under the name Contergan, primarily as a sedative and sleeping pill, although thalidomide was also an ingredient in a variety of other types of medication sold over-the-counter and as a prescription medicine to people suffering from a variety of bothersome issues like hypertension, asthma, and headaches.²⁸ Most infamously, however, thalidomide was given to pregnant women as a treatment to alleviate morning sickness. As the sales of thalidomide sky-rocketed domestically – by 1959 it had become the most sought after sleeping pill in the Federal Republic of Germany and by March of 1960, it was officially the most-sold sedative in West Germany – Chemie Grünenthal opted to license companies outside of Germany to market the drug.²⁹ Between 1958 and December 1961 a significant number of sample tablets had been distributed in North America.³⁰ According to Michael Magazanik’s book *Silent Shock*, the Cincinnati-based drug company that became Grünenthal’s licensee partner in the United States, William S. Merrell (after a merger the company would later be referred to as Richardson-Merrell), distributed as many as 2,528,412 thalidomide pills to more than 1,200 doctors across the country.³¹ Indeed, William S. Merrell was running clinical trials as a way to shore up interest for their new product.³² According to others sources, samples also crossed the border into Canada. This is unsurprising given that Grünenthal was intent on creating interest for their product, including in the Canada market.³³ In

²⁸ Klausen and Julie Parle, “‘Are We Going to Stand By and Let These Children Come into the World?’” 736.

²⁹ Barbara Clow, “‘An Illness of Nine Months’ Duration’,” 47; Anklageschrift (indictment) from 1967, today archived at the National Archives of North Rhine-Westphalia in Duisburg, Germany, LAV NRW R, Gerichte Rep. 139, No. 1–396, 80.

³⁰ The NRW Staatsarchiv in Germany holds detailed information in this regard, including doctor and patient evaluations of Kevadon samples from January 1961, Interdepartmental memos, as well as information about the Kevadon Hospital Clinical Program. “Kevadon Clippings,” Drug Coordination, 274, LAV NRW R, Gerichte Rep. 139 Nr. 166, 275.

³¹ Magazanik *Silent Shock*, 143.

³² Stephens and Brynner, *Dark Remedy*, 70.

³³ In fact, Chemie Grünenthal had requested a patent (patent application # 701,891) with the Canadian Patent Office, which was allotted on 20.10.1959. See Letter from Frederic D. Lamb, Secretary, The Wm. S. Merrell Company, Cincinnati, Ohio, to Hanswerner von Schrader-Beielstein Dr. Med. Dr. Rer. Nat. Dipl. Chem., Assistant Director of

fact, they requested support from their American licensing company Merrell by sending representatives to Montreal in order to share positive studies about Contergan.³⁴

Sources suggest that the drug became available to Canadian women as early as 1959, as it was distributed in sample form before its official introduction into the Canadian market.³⁵

According to the Thalidomide Victims Association of Canada (TVAC), Merrell informed the Food and Drug Directorate of Canada's Department of National Health and Welfare that clinical investigation of their thalidomide-containing samples would be carried out in Canada by "qualified investigators."³⁶ Frank W. Horner, the Montreal-based pharmaceutical company also distributed samples freely. Vice-President Leonard Mitchell informed the German manufacturer about significant promotion of the drug underway in Canada, before the brand Talimol's official release onto the market:

We are now distributing this brochure and a good supply of samples to about two or three hundred physicians across the country. At the same time we are asking them a number of questions about their use of sedatives and hypnotics and what they consider the shortcomings of barbiturates, etc. In about six weeks' time we will go back to these same physicians asking a number of questions about Talimol and what particular points impressed them most with the product. We hope that this bit of market research will give us an effective way of introducing Talimol, sometimes before the end of the year. In this preliminary distribution we are labelling the product as a 'new drug' in the hope that this will overcome the difficulty of physicians wanting to start prescribing the product before we are ready. [...] I am sending you samples of the first few batches of Talimol tablets, prepared for this

Research, Chemie Grünenthal GmbH, Stolberg, Rheinland, Germany, December 2, 1960, LAV NRW R, Gerichte Rep. 139 Nr. 249/23, 23212.

³⁴ Letter from Chemie Grünenthal (Dr.Dr. v. S.) to Dr. Woodward, Messrs. The Wm. S. Merrell Company c/o Mr. Robert H. Woodward, Vice President, Cincinnati 15, Ohio, USA, December 22, 1960, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24407.

³⁵ Thalidomide Victims Association of Canada "The Many Faces of Thalidomide (from 1957 to 1966) compiled by Randolph Warren May 7, 1999.

³⁶ "Timeline," *No Limits – The Thalidomide Story*, accessed on July 5, 2019, <http://thalidomidestory.com/story/timeline/timeline/+1959-canada/>.

pre-marketing distribution, and we will look forward to having a report from your control or analytical laboratories on these tablets.³⁷

Health Canada first licensed thalidomide for prescription use on April 1, 1961. Two companies received the rights to manufacture and sell thalidomide in Canada: the Montreal-based pharmaceutical company Frank W. Horner Limited and the United States-based company Richardson-Merrell. The Merrell product Kevadon went on sale as a prescription drug on April 1, 1961, while the Horner product followed suit, also as a prescription-only product, seven months later on October 23, 1961.³⁸ The U.S. based Merrell company and Grünenthal had agreed on sub-licensing thalidomide to the Canada-based Horner Limited through Merrell, though the raw materials would be directly obtained from the German manufacturer.³⁹ In a letter dated January 25, 1961 from Merrell to Dr. v. Schrader of Grünenthal, Robert H. Woodward wrote Merrell was convinced that given Horner's good reputation in Canada, and their approximately sixty-man strong sales structure, the two companies combined would be able to "cover the Canadian doctors thoroughly."⁴⁰

Between the release of Kevadon and the subsequent release of Talimol, discussion about thalidomide's possible side-effects was ongoing (this included a variety of issues beyond birth defects). For example, the Medical Director of William S. Merrell, Dr. John N. Premi, writing from Weston, Ontario, contacted Chemie Grünenthal in July 1961 when he inquired about the

³⁷ Letter from Leonard Mitchell, Vice-President Frank W. Horner Limited, Montreal Canada, to Dr. H. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, August 25, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24073.

³⁸ Letter to all physicians by The Wm. S. Merrell Company, Division of Richardson-Merrell, Inc., Cincinnati, Ohio, August 10, 1962, pp.121-123, "Sequence of events," Drug Coordination, 122, LAV NRW R, Gerichte Rep. 139 Nr. 166 p. 123.

³⁹ "Bericht über die Besprechung mit der Firma Richardson-Merrell/USA am 20.3.61 in Stolberg," LAV NRW R, Gerichte Rep. 139 Nr. 250/24b p. 24155; Letter to Dr. Gerlach of Richardson-Merrell Inc. dated 29 March 1961 LAV NRW R, Gerichte Rep. 139 Nr. 249/23, 23665.

⁴⁰ "Übersetzung des Schreibens The Wm. S. Merrell Company, Cincinnati, vom 25.1.61," LAV NRW R, Gerichte Rep. 139 Nr. 249/23, 23683. (Please note that I am translating to English a German-language translation of a letter that was originally composed in English, thus the phrasing might deviate slightly from the original words used.)

autoimmune disease thrombocytopenic purpura, a condition that causes a rash and increased tendency to bleed, which he came across when following a number of clinical investigations of thalidomide.⁴¹ In a letter dated August 9, 1961, “S” of Grünenthal, presumably Dr. Schrader-Beielstein, responded to Premi reassuringly regarding purpura, stating that this was not a known side-effect of the drug.⁴² Warning signs about the drug’s effects were therefore not completely ignored. However, given the diverse studies that were being produced about the drug, the pharmaceutical companies were not likely to immediately trust concerns that they came across. Instead they inquired with their German counter-part, as the licensing company was likely to have compiled a more comprehensive overview of studies from inside and outside their own laboratories.

Similarly, meetings were held in Stolberg, Germany, on September 4 and 5, 1961, which were attended by representatives of the licensing company.⁴³ During these meetings, it was noted that in Canada, unlike in the United States and England, no case of “polyneuritis” (a condition affecting the peripheral nerves) had been recorded.⁴⁴ The meeting was in fact a two-way exchange during which Dr. Carl Bunde, Director of Medical Research of Merrell, who was “thoroughly familiar with the clinical findings obtained in the United States and Canada with Kevadon,” shared insights with Chemie Grünenthal. This visit to Germany that served to inform

⁴¹ It is noteworthy that thalidomide caused concerns beyond birth defects, most notably nerve damage, but other problems were discussed in the medical literature as well. Letter from John N. Premi, Medical Director of Canada, The Wm. S. Merrell Company, Weston Ontario, to Dr. H. W. V. Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, July 18, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24328.

⁴² Letter from Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, to John N. Premi, Medical Director of Canada, The Wm. S. Merrell Company, Weston Ontario, August 9, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24335.

⁴³ The archival records do not indicate if representatives from both Merrell and Frank Horner or just one of the companies were present.

⁴⁴ The Chemie Grünenthal notes only refer to “representatives of the licencing companies from [...] Canada” (Vertreter der Lizenzfirmen), as such it is not clear if representatives from both companies or just one were in attendance. LAV NRW R, NW 377 Nr. 5869 “Ermittlungsverfahren gegen Personen der Chemie Grünenthal GmbH 1962-1972,” 109.

the Germany company about the information gained about the drug by Merrell, demonstrated that North America, and Canada in particular, was one of the places that the pharmaceutical sector used to study the effects of the drug.⁴⁵ Canada, beyond being a potentially profitable market for the drug was therefore also a place that the pharmaceutical sector used to study the effects of the drug. While this was a common practice for pharmaceuticals at the time, the following discussion will demonstrate that the clinical investigation of the thalidomide-containing samples and later prescription medication would continue well after the medical studies of negative effects of the drug became established with enough authority to cause the withdrawal of the drug from the market elsewhere.

That Merrell was well-aware of the concerns surrounding thalidomide in Germany at the time is made explicitly clear in a letter from Merrell's Managing Director, who wrote to Dr. von Schrader on September 27, 1961: "I might mention at this point that we are not receiving the Contergan mailings, however, this may be temporary in view of the present unsettled climate for Contergan in Germany."⁴⁶ Moreover, only a few weeks before the release of Talimol on the Canadian market, the Director of Medical Research of Merrell, Dr. Carl A. Bunde, wrote to Grünenthal regarding polyneuritis, that "There are still no cases reported from Canada."⁴⁷ Frank W. Horner Limited was also in touch with Grünenthal directly. While one letter to the German company noted that "I was rather disturbed to read the two reports [...] dealing with the polyneuritic syndrome attributed to long term therapy with thalidomide [...]" it goes on to note

⁴⁵ Letter from Robert H. Woodward, The Wm. S. Merrell Company, to Dr. H. W. Von Schrader, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, August 8, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24332.

⁴⁶ Letter from F.H. Wadey, Managing Director The Wm. S. Merrell Company, to Dr. H. W. Von Schrader, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, September 27, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24338.

⁴⁷ Letter from Dr. Carl A. Bunde, Director of Medical Research, The Wm. S. Merrell Company, to Dr. H. W. Schrader-Beielstein, Chemie Grünenthal G.m.b.H., October 3, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24347.

that more information would be appreciated as the Canadian representative was conscious that this would likely have to be commented on when Talimol was released onto the Canadian market.⁴⁸ While disturbing, suggestions that the drug caused nerve damage were apparently not considered sufficiently serious to warrant a delay of the product's release or the withholding of the drug from the market. After all, as one critical report by reporter June Callwood reminded readers in the immediate aftermath of the scandal, "Thalidomide had been tested more carefully than most new drugs. Over a three-year period, it had been found harmless to vital organs. It was later found to be so safe that even massive doses didn't harm would-be suicides."⁴⁹ The advantages of the product seemed to outweigh the still elusive side-effects. The drug was deemed acceptable by the Canadian Food and Drug Directorate with the understanding that the medical profession was to be made aware of the possibility of nerve damage as a side effect.⁵⁰

The continued commitment to thalidomide was, unsurprisingly, encouraged by the German creator of the drug. Chemie Grünenthal provided scientific studies to Frank W. Horner to keep them informed of the scientific developments, but made sure to note that such information was solely for internal purposes and was not to be used for publications of any kind.⁵¹ More importantly, however, Chemie Grünenthal lauded Vice-President of Frank W. Horner, Dr. Leonard Mitchell, for his immediate discussion of the periphery polyneuritis, and reassured him that such side-effects, when monitored, did not present a problem as long as the dose was adjusted or use of the product discontinued.⁵² Despite ongoing conversations about

⁴⁸ Letter from [unreadable], Frank W. Horner Limited, Montreal, Canada, to Export Department Grünenthal G. m. b. H. Stolberg im Rheinland, Germany, June 5, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24077.

⁴⁹ Callwood, "The Unfolding of Drug-Deformed Babies," 66.

⁵⁰ Callwood, "The Unfolding of Drug-Deformed Babies," 66.

⁵¹ Letter from Chemie Grünenthal G.m.b.H., to Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, 28.9.1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24070.

⁵² Letter from (?) to Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, 29 August 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24071.

side-effects and concerns raised abroad, the sale of thalidomide continued and expanded in Canada. Chemie Grünenthal's licencing department produced a report in November 1961 that indicated that "since market introduction, Kevadon has practically become Merrell, Canada's number one product."⁵³

By mid-November 1961 the German Doctor Widukind Lenz, one of the medical professionals credited for pushing the company and medical profession to take seriously the concerns about birth defects, raised alarm about the drug. He phoned the German company, followed by a detailed letter summarizing his concerns, and proceeded to make his suspicions public when attending a congress of the "Association of Pediatricians of North Rhein-Westphalia" on November 19, 1961, in Düsseldorf, Germany. His efforts had been preceded by various warnings and questions posed to Grünenthal in previous years. The German company remained reluctant to acknowledge a correlation between their product and any negative effects. Soon after, also in November of 1961, Australian doctor William McBride echoed the concerns about birth defects voiced by Dr. Lenz.⁵⁴ Yet it was not until a newspaper article broke the story of their scary suspicions that Grünenthal was willing to withdraw the drug from the German market. In fact, it was on November 26, 1961, that the German newspaper *Welt am Sonntag* published an article that raised public awareness of the situation, which has been credited with providing the impetus for the German company to take action.⁵⁵ The day following the publication of this newspaper article, on November 27, 1961, Grünenthal informed the German authorities about its intention to withdraw the drug from the market.

⁵³ "Monatsbericht der Lizenzabteilung," Chemie Grünenthal (November 1961), LAV NRW R, Gerichte Rep. 139 Nr. 16b, 16335.

⁵⁴ For a detailed account of McBride's experiences refer to: Magazanik, *Silent Shock*, 241-249.

⁵⁵ Avoiding legal complications, the article, like Widukind Lenz, who alerted the world to the dangers of the drug, did not name Contergan, the most popular of Grünenthal's thalidomide products, or thalidomide specifically, although the consequences for the company remained the same. "Missgeburten durch Tabletten? Alarmierender Verdacht eines Arztes gegen ein weitverbreitetes Medikament," *Welt am Sonntag*, November 26, 1961.

In a letter to Dr. Leonard Mitchell, of Frank W. Horner, and Robert H. Woodward, of Merrell, dated November 29, 1961, Grünenthal informed the in-Canada operating companies about their decision to remove thalidomide from the German market and to stop any sales of their thalidomide-containing products outside of Europe from their warehouses, writing that: “As an ethical, pharmaceutical company we arrived at this measure, as we believe that despite the scientifically non-founded allegations, we should not proceed the distribution of Contergan until the raised accusations have been resolved.”⁵⁶ Thus, the message to Canada was clear: the withdrawal of the drug by the German company was not based on the occurrences of or any correlation to birth defects which had caused resistance towards Grünenthal’s products, but rather was an effort to counter the bad publicity currently circulating. As long as Canada did not face the same problem, the letter appeared to imply, the two companies had no reason to follow suit.

In Grünenthal’s November 1961 monthly report the company reflected on the impact of recent developments on the Canadian distribution of thalidomide: “How Merrell will react to the situation, cannot yet be determined from the visit of their representatives. Everything will depend on the impact the British newspaper coverage will have on the attitudes of the Canadian officials. Horner, who began sales of Talimol in mid-November, do not plan on pulling their product from the market for now, but instead intend to advise doctors to refrain from prescribing Kevadon during pregnancy by means of warning-leaflets.”⁵⁷ Therefore, it is clear that despite events in Germany, Kevadon and Talimol remained available on the Canadian market. In fact, it was only

⁵⁶ Letter from Chemie Grünenthal G.m.b.H. to Frank W. Horner Ltd. Pharmaceuticals c/o Dr. Leonard Mitchell, Vice President and Research Director, Montreal Canada, November 29, 1961. The archival file, part of the trial documents, contains a typed note indicating that the same letter was mailed to The Wm. S. Merrell Company c/o Mr. Robert H. Woodward, Cincinnati, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24063.

⁵⁷ “Monatsbericht der Lizenzabteilung,” Chemie Grünenthal (November 1961),” LAV NRW R, Gerichte Rep. 139 Nr. 16b, 16335.

on December 1, 1961, that the drug companies informed the Canadian Food and Drug Directorate of the possible congenital malformations related to the drug.⁵⁸ Shortly after, on December 5 and 7, letters were sent to Canadian physicians warning them not to prescribe the thalidomide-containing pills to pregnant women, and outlined occurrences of congenital malformations.⁵⁹ These letters had been carefully drafted; in fact, while visiting Ottawa on December 1, Merrell's representative had actually agreed upon the text with the members of the Canadian Food and Drug Directorate present.⁶⁰ Below the letter head, Frank W. Horner's letter read: "CONTRAINDICATION to use of thalidomide (TALIMOL, Horner and KEVADON, Merrell) Do not administer to pregnant patients or to premenopausal women who may become pregnant."⁶¹ The actual text of the letter continued:

Dear Doctor:

We have just received sketchy information from abroad on the occurrences of congenital malformations in the offspring of some mothers who had been taking thalidomide early in pregnancy. The number of cases involved, types of malformation, and whether or not thalidomide is responsible are all unknown to us at this time.

This development, the first to be suggested in several years of thalidomide usage, will be investigated most thoroughly, we assure you [...].

In the meantime we are taking this precautionary step of advising that the drug should not be used in pregnant patients or in premenopausal women who may become pregnant. [...]

Sincerely yours,
J.R. MacDougal, M.D.

⁵⁸ A memorandum housed at the NRW Staatsarchiv, submitted by the The Wm. S. Merrell Co. medical director on June 11, to the House Antitrust Committee "as part of the record of hearings on H.R. 6245": "Summary," Drug Coordination, 118, LAV NRW R, Gerichte Rep. 139 Nr. 166, 119.

⁵⁹ See Letter titled "Drug Warning – Kevadon" to Canadian Doctors from John N. Premi, Medical Director, The Wm. S. Merrell Co., Division of Richardson-Merrell, Inc., Department of Medical Research, Pharmaceutical Manufacturers Since 1828, Cincinnati, Ohio, February 21, 1962. Drug Coordination, Appendix A, 118, LAV NRW R, Gerichte Rep. 139 Nr. 166, 119.

Letter to Canadian Doctors from Dr. J.R. MacDougal, Medical Director, Frank W. Horner Ltd. Pharmaceuticals, Montreal Canada, December 7, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24062.

⁶⁰ Drug Coordination, 116, LAV NRW R, Gerichte Rep. 139 Nr. 166, 123.

⁶¹ Letter to Canadian Doctors from Dr. J.R. MacDougal, Medical Director, Frank W. Horner Ltd. Pharmaceuticals, Montreal Canada, December 7, 1961, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24062.

Medical Director⁶²

It is, however, unclear how many doctors received the letter. The attitude of the Canadian authorities was captured in a statement made by Dr. C. A. Morrell, at the time Director of the Food and Drug Directorate, to the *Globe and Mail*, who declared that the letters sent to doctors were adequate given that the evidence against the drug was “only statistical.” In fact, Dr. Morrell further noted that “You shouldn’t jump off the deep end.”⁶³ The “sketchy information,” which in hindsight could have prevented the plight of many families had it been taken more seriously, remained a matter of contestation even during the 1968-1970 criminal trial that will be discussed below.⁶⁴ Thus, thalidomide remained available to Canadian doctors, pharmacists, and pregnant women.

The Canadian distributors remained in contact with the German company. In fact, in late December 1961 a letter was sent to the Director of Scientific Relations at Merrell, Dr. F. Jos. Murray, notifying him that the Canadian embassy in Bonn requested information about thalidomide (Kevadon) from Chemie Grünenthal. The letter indicates that a man by the name of De Salabery, who introduced himself as working in the commercial services department of the Canadian embassy, asserted that he had heard about the withdrawal of thalidomide (Contergan) in Germany and would like to request information directly from the manufacturing company. De Salabery was informed about the concerns raised by Dr. Lenz as well as the contraindication note added to prescriptions, but it was made clear to him that this was a precautionary measure that was likely unnecessary given the notice to doctors and the patient leaflet. The fact that Chemie

⁶² Letter to Canadian Doctors from Dr. J.R. MacDougal, Medical Director, Frank W. Horner Ltd. Pharmaceuticals, Montreal Canada, December 7, 1961. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24062.

⁶³ As cited by Callwood, “The Unfolding of Drug-Deformed Babies,” 67.

⁶⁴ In fact, one shocking defence of the Grünenthal employees was the suggestion that the disabilities were the fault of mothers who had failed to induce abortions. Another suggestion made was the “grotesque and far-fetched theory” that instead of harming the fetus, thalidomide actually stopped the miscarriage of already deformed fetuses. Stephens and Brynner, *Dark Remedy*, 73.

Grünenthal contacted Merrell to inform them about this inquiry is telling. The letter to Merrell's Director of Scientific Relations notes that Mr. De Salabery had limited medical knowledge thus discrediting any concerns the man may have noted about the drug, demonstrating the continued efforts of the German company to reassure its licensee. Mr. De Salabery had assured his contact at Chemie Grünenthal that he was not intending to produce any publications but that he was simply aiming to forward the information to his government in Canada.⁶⁵ It seems apparent that Chemie Grünenthal felt that it was in their own and their licensees' interest that any information reaching the Canadian government regarding thalidomide ought to be monitored. A generous interpretation would suggest the German company aimed to reassure and support its licensee in continuing the sale of thalidomide in Canada. A sceptical evaluation suggests that Chemie Grünenthal wished that Merrell would remain the predominant party to relay information about thalidomide to the Canadian government given their economic interest in the drug. The Canadian Food and Drug Directorate seems to have accepted this flow of information as acceptable, working alongside the company to mediate the incoming information between the pharmaceutical and medical sectors.

A few months later, on February 21, 1962, the Merrell company followed the initial warning letter with another cautioning doctors that observance of the contraindication continued to be necessary.⁶⁶ This follow-up letter was likely based on the seemingly low impact the initial warning had had on the Canadian medical profession. In a summary document compiled for the German trial that addressed civil claims for compensation for damages caused by thalidomide,

⁶⁵ Letter to Mr. F. Jos. Murray, Director of Scientific Relations, The Wm. S. Merrell Company, Cincinnati, Ohio, USA, from [unknown], Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, 22 Dezember 1961. LAV NRW R, Gerichte Rep. 139 Nr. 250/24b p. 24287, December 22, 1961.

⁶⁶ Letter to Canadian Doctors from John N. Premi, Medical Director, The Wm. S. Merrell Co., Division of Richardson-Merrell, Inc., Department of Medical Research, Pharmaceutical Manufacturers Since 1828, Cincinnati, Ohio, February 21, 1962. Drug Coordination, Appendix B, p. 119. LAV NRW R, Gerichte Rep. 139 Nr. 166 p. 119.

Chemie Grünenthal noted that in a reply to a letter dated January 11, 1962, Horner had indicated to the German company that the warning did not cause alarm among the Canadian doctors. Indeed, the Canadian distributor explained that the majority of the medical profession seemed to be unimpressed by the warnings they received about the teratogenic effects of the drug. Despite the letters that had been sent out in early December 1961, Horner remarked that the sales of Talimol in December did not decline, despite Horner's decision to discontinue promotion of the product.⁶⁷

In the meantime, Dr. Günther Sievers, of Chemie Grünenthal, noted as late as January 1962, that thalidomide was available in Canada since early 1961 and that its "development" there was "remarkable."⁶⁸ Nonetheless, just over a week after that letter had been sent, on March 2, 1962, both Kevadon and Talimol were finally withdrawn from the Canadian market by the licensee companies at the request of the Food and Drug Directorate.⁶⁹ The Food and Drug Directorate had stepped in to reach an agreement with the companies. Significantly, the directorate had no legal authority to issue a drug recall, instead it relied on the cooperation of the companies.⁷⁰ The decision to withdraw the drugs should not be mistaken for an

⁶⁷ Summary document included in the German trial files. 24 004. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24004.

⁶⁸ Dr. Günther Sievers, *Euromed*, Heft 1, January 16, 1962. In its original: "Zwar ist das Präparat seit drei Jahren sehr umfangreich klinisch geprüft worden, wurde jedoch seit Anfang 1961 auf dem amerikanischen Kontinent zunächst in Kanada ausgeben. Seine dortige Entwicklung war bemerkenswert."

⁶⁹ The simultaneous withdrawal was not coincidental. As Frank W. Horner was a sub-licence holder through Merrell, C.A. Merrell, Director of Wm. S. Merrell Company himself contacted Mr. H. Horner, president of Frank W. Horner Limited, on March 02, 1962, requesting the withdrawal of thalidomide in a letter that was, in fact, composed in Ottawa, Canada. The letter states: "A meeting was held at the Directorate on Wednesday, March 1, 1962, to discuss the advisability of temporarily withdrawing the drug Thalidomide from the Canadian market. In view of increasing demands from Canadian physicians, as well as certain other pressures, we have decided to ask you to withdraw your product TALIMOL from the Canadian market until such time as we can be certain of its possible association or lack of association with congenital deformities in children." Letter from C.A. Merrell, Director, The Wm. S. Merrell Company, to H. Horner, President, Frank W. Horner Ltd, Montreal, Canada, Tunney's Pasture, Ottawa, Ontario, March 2, 1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24038.

⁷⁰ Matthew Herder, Elaine Gibson, Janice Graham, Joel Lexchin, and Barbara Mintzes, "Regulating Prescription Drugs for Patient Safety: Does Bill C-17 Go Far enough?" *CMAJ: Canadian Medical Association Journal/Journal De l'Association Medicale Canadienne* 186, no. 8 (2014): 287.

acknowledgement of the drug's dangers, according to a letter from Merrell to Grünenthal: "This step was taken as a consequence of our thorough review of all data available to us from abroad and was considered necessary as a precaution to the future use of the drug until the unresolved question of its association with congenital malformation is answered. We sincerely hope that at some time in the future the drug may be reintroduced [...]"⁷¹

Whatever the motivation for the withdrawal of the drug, physicians were informed of the decision by the companies.⁷² In fact, in the immediate aftermath of thalidomide's withdrawal from the market, the drug companies' efforts in this endeavor were reported on favourably by the Canadian media. One article informed Canadians: "The alarmed drug companies did a thorough job. The Canadian distributors of the William S. Merrell Company on March 5 telegraphed its salesmen to pick up the drugs, sent two telegrams to wholesalers, instituted meetings of sales executives to ensure that hospital and institutional pharmacies weren't overlooked. Frank W. Horner Limited put sixty sales-men to work picking up supplies, sent letters to 20,457 physicians, 5,209 drug stores and 1,985 hospitals."⁷³ Also eager to emphasize their effective involvement in helping retrieve the pills, Merrell later stated in a letter to physicians that they had checked "even on drug stocks of deceased physicians."⁷⁴ However, as will be outlined below, despite such efforts, the drug remained elusive during attempts to eradicate its presence in places where consumers could access it.

⁷¹ Letter from Robert H. Woodward, The Wm. S. Merrell Company, to Dr. H. W. V. Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, March 12, 1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24b p. 24303 / LAV NRW R, Gerichte Rep. 139 Nr. 250/24b p. 24304.

⁷² One letter to physicians housed at the NRW state archives: Letter from Mr. H. Horner, president, Frank W. Horner Limited, to "Doctors", March 5, 1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24036

⁷³ Callwood, "The Unfolding of Drug-Deformed Babies," 67.

⁷⁴ Letter to all physicians by The Wm. S. Merrell Company, Division of Richardson-Merrell, Inc., Cincinnati, Ohio, August 10, 1962, pp.121-123, "Follow up on supplies," Drug Coordination, 123. LAV NRW R, Gerichte Rep. 139 Nr. 166 p. 123.

In addition, while individuals in the pharmaceutical sector and the government were seemingly alarmed at this point, other factors likely played a more important role in finally initiating the withdrawal of the drug. Not unlike in Germany and the United Kingdom, media awareness of the situation likely spurred the Food and Drug Directorate to act. Indeed, a *Time Magazine* article had been published in late February noting the continued availability of thalidomide in Canada.⁷⁵ In a letter to Chemie Grünenthal, a Frank W. Horner vice-president explained:

At the 'request' of our Food & Drug Directorate we are taking Talimol off the market. This request is undoubtedly based on the Time Magazine article of last week, which I am sure you have now seen. As recently as last Friday (February 23) I spoke to our Food & Drug Directorate and was assured that no such action was contemplated, and that our and Merrell's warnings were considered adequate. Although there has been remarkably little newspaper follow up to the Times article, the Food & Drug Directorate seem to have received a number of emotional letters, and it has been hinted too that the Minister of National Health & Welfare – a cabinet position in our country – might be afraid of the political embarrassment that he might suffer in this situation. In any event we are complying with the Food & Drug Directorate's request.⁷⁶

Instead of medical research and investigation, it had been the fear of sensational media coverage and political embarrassment that had finally motivated the Canadian government to initiate action that would protect its citizens. The delayed reaction of Canadian authorities and the two companies had alarming consequences. As reporter June Callwood aptly observed: "What the

⁷⁵ "Sleeping Pill Nightmare," *Time Magazine*, Vol. LXXIX, no.8, February 23, 1962.

⁷⁶ Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. H. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, March 2, 1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24039.

A response to Mitchell's letter was written on March 15, 1962. In this letter a Chemie Grünenthal G.m.b.H. representative expresses his regret that the products Talimol and Kevadon had to be withdrawn as a result of the Times article. Letter from Chemie Grünenthal G.m.b.H., to Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, 15.3.1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24031.

delay has done, in Canada, is prolong the threat through the months of summer and autumn.”⁷⁷ A survey conducted in the early 1960s found 115 children born in Canada in 1961 and 1962 with congenital malformations of the type associated with the use of thalidomide.⁷⁸ An editorial of the *Canadian Medical Association Journal* had previously outlined where thalidomide children had been born:

Data in the possession of the Department of National Health and Welfare indicate that there are some 96 surviving infants who have been born in Canada with congenital malformations after ingestion of thalidomide by the mothers during pregnancy. To date the Department has received information concerning 55 babies born in Quebec with deformities attributed to the effects of thalidomide, 23 in Ontario, six in British Columbia, six in Saskatchewan, four in Alberta, one in Manitoba, and one in Nova Scotia. No known cases of this nature have been reported to the Department from New Brunswick, Prince Edward Island, or Newfoundland. It is emphasized that these are preliminary figures and that a detailed epidemiological study of this problem is continuing.⁷⁹

According to a 2015 publication, there were at least thirty Canadian thalidomiders whose mothers took the drug after it was taken off the market in Germany.⁸⁰

⁷⁷ Callwood, “The Unfolding of Drug-Deformed Babies,” 13.

⁷⁸ “Of this number eight were stillborn and 33 died in the neonatal period or in the early months of life; the remaining 74 infants were alive at the time of reporting, which extended from August 1962 to May 1963.” Jean F. Webb, “Canadian Thalidomide Experience,” *Canadian Medical Association Journal* 89 (1963): 989-990.

⁷⁹ “Rehabilitation of Thalidomide-Deformed Children.” *Canadian Medical Association Journal* 88, no. 9 (1963): 488-489. The disproportionately high number of thalidomide births has been noted by Denyse Baillargeon and Susanne Commend, suggesting that “In the absence of documents on this subject, it is difficult to explain with certainty why the majority these children are born in Quebec. The fact that one of the two companies pharmaceutical companies that produced the drug was based in Montreal, facilitating its distribution to Quebec doctors could be involved.” [Translated from French]. Denyse Baillargeon and Susanne Commend. “Un Médicament ‘Monstrueux’: Débats Publics et Couverture Médiaque de la Tragédie de la Thalidomide au Canada, 1961-1963,” *Canadian Bulletin of Medical History* 33, no. 1 (2016): 148.

⁸⁰ Magazanik, *Silent Shock*, 164.

TABLE I.—CASE INCIDENCE BY MONTH OF BIRTH

Month	Cases
November 1961.....	3
December 1961.....	3
January 1962.....	12
February 1962.....	3
March 1962.....	9
April 1962.....	10
May 1962.....	14
June 1962.....	13
July 1962.....	19
August 1962.....	12
September 1962.....	5
October 1962.....	9
November 1962.....	2
December 1962.....	1
Total.....	115

Of the total number of cases, six were born late in 1961 and 109 in 1962 (Table I). Fig. 1 shows graphically the case incidence by month of birth.

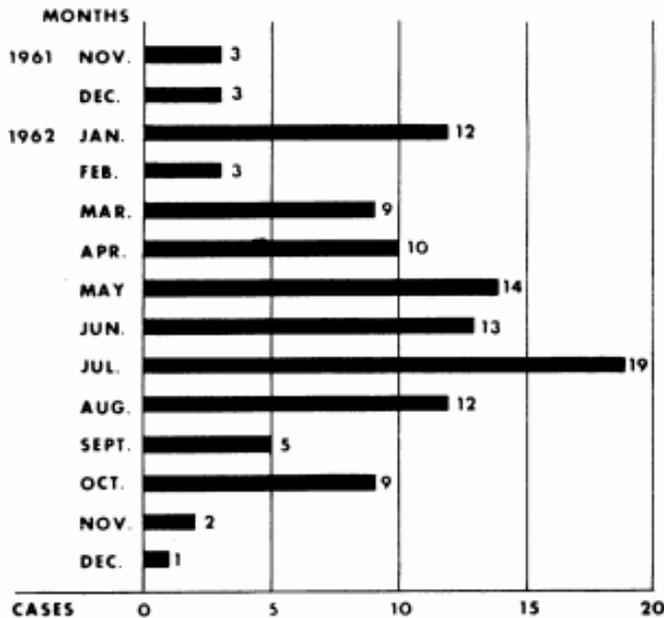


Fig. 1.—Cases of congenital malformations associated with maternal thalidomide intake by month of birth—Canada, 1961-1962.

Illustration 1: Overview of Canadian thalidomide babies born by months in 1961 and 1962. Jean Webb, "Canadian Thalidomide Experience," *Canadian Medical Association Journal* 89 (1963): 990.

While Canadian authorities had been slow in requesting the drug's withdrawal from the market, the official investigation into the drug's impact in Canada began almost immediately. On April 10, 1962, a letter to physicians from Dr. Morrell, Director of the Food and Drug Directorate, requested that samples on hand be returned to the supplier or destroyed, and that side-effects of new drugs be reported to him.⁸¹ However, an article published in the *Canadian Medical Association Journal* on April 21, 1962, indicated that, "'samples' of thalidomide (Kevadon) undoubtedly still remain in some physicians' offices and, as such, should be discarded unused."⁸² The request from April 1962 was thus followed-up by Morrell three months later, on July 20, 1962, with another letter to physicians in which he requested that they review their files and advise their patients who might have a supply of the drug in the home to destroy it.⁸³ This was an effort that we today know was not entirely successful as some women still consumed the drug, unaware of the warnings that were circulating.

Indeed, as noted earlier, removing thalidomide was more difficult than expected. In a letter to Grünenthal, the removal steps were outlined by Merrell:

In connection with this visit, Dr. Murray intends to inform you of our decision to withdraw Kevadon (thalidomide) from the market in Canada. As you may already know, Frank W. Horner Limited also decided to withdraw Talimol at the same time. Attached is a copy of our letter of March 5 addressed to all Canadian physicians announcing the withdrawal, as well as a copy of a letter received from the Canadian Food and Drug Directorate. We are, in addition to advising physicians of this step, requesting all wholesale druggists, retail pharmacists, and hospitals to return their total stock of Kevadon to us for credit. In this way, we expect to empty the 'pipeline' of supplies.⁸⁴

⁸¹ Callwood, "The Unfolding of Drug-Deformed Babies," 67.

⁸² A. E. Rodin, L. A. Koller, and J. D. Taylor, "Association of Thalidomide (Kevadon) With Congenital Anomalies," *Canadian Medical Association Journal* 86, no. 16 (April 21, 1962): 745.

⁸³ Jean Webb, "Canadian Thalidomide Experience," *Canadian Medical Association Journal* 89 (1963): 988.

⁸⁴ Letter from Robert H. Woodward, The Wm. S. Merrell Company, to Dr. H. W. V. Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, March 12, 1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24b p. 24303 / LAV NRW R, Gerichte Rep. 139 Nr. 250/24b p. 24304.

Contrary to expectations of a swift recall of the drug, the *Toronto Daily Star* summed up some of the difficulties. In July 1962 the newspaper quoted Frank W. Horner, president of the Canadian company that sold thalidomide under the name Talimol, who noted that “a number of druggists at first refused to give up their supplies,”⁸⁵ because it had been an effective drug for certain ailments. In a letter sent on April 12, 1962, doctors were advised that “Any pharmacist who continues to dispense the drug is open to seizure of all stocks and/or prosecution.”⁸⁶ Horner further elaborated on the problems associated with retrieving the drug from the market when he stated that, as paraphrased by a journalist interviewing him, “his firm’s pills will be difficult to identify. He describes them as ‘plain white, about a third smaller than an aspirin with some scoring in the center.’”⁸⁷ The pills of the second company that had marketed thalidomide in Canada were described in only slightly more helpful terms: “Kevadon pills were described as being bluish-turquoise, circular, about the size of an aspirin and inscribed with an ‘M’ contained in two circles.”⁸⁸

⁸⁵ “Baby-Deforming Thalidomide Believed Off the Shelves,” *Toronto Daily Star*, 30 July 1962, 4.

⁸⁶ Howden Horner, President, Frank W. Horner Ltd, Montreal, Canada, “Urgent that you destroy or return all stocks or samples of thalidomide (Talimol, Horner),” letter to Canadian doctors, April 12, 1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24025.

⁸⁷ “Baby-Deforming Thalidomide Believed Off the Shelves,” *Toronto Daily Star*, July 30, 1962, 4.

⁸⁸ “Baby-Deforming Thalidomide Believed Off the Shelves,” *Toronto Daily Star*, July 30, 1962, 4.

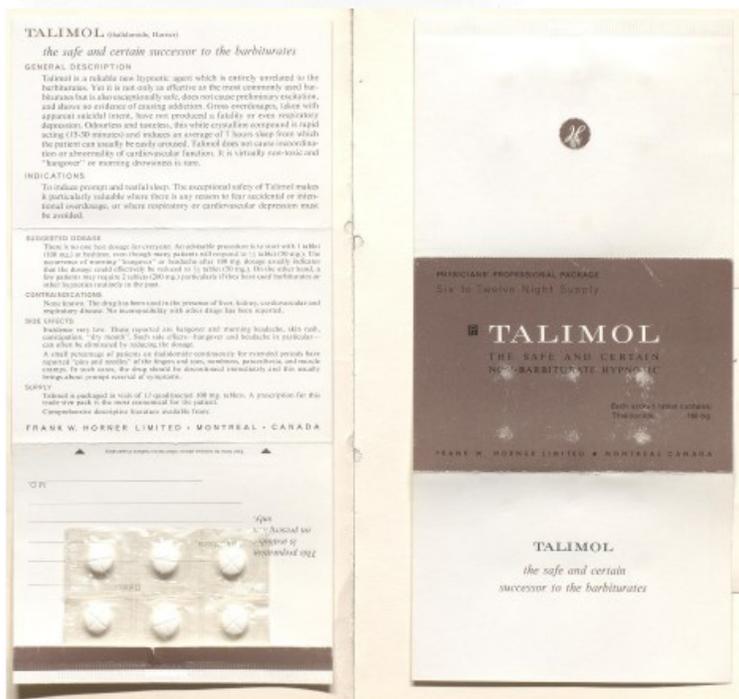
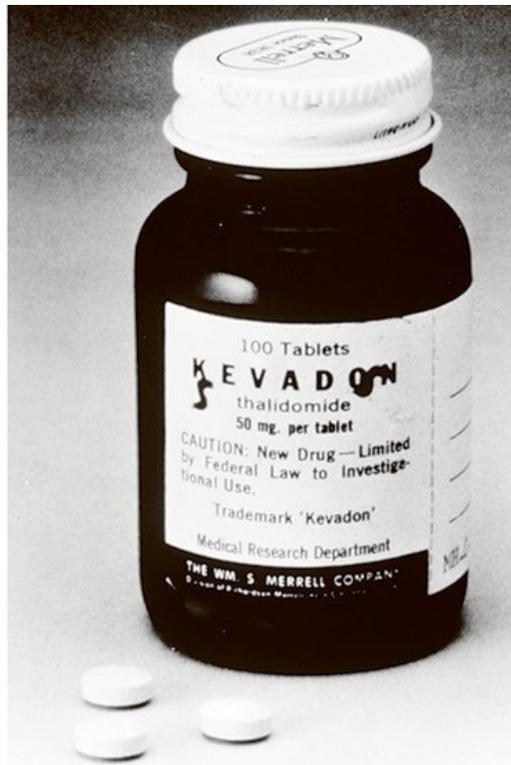


Illustration 2: Kevadon and Talimol packaging and pills. (Top) A sample of Kevadon pills used in the clinical trials conducted by William S. Merrell. Source: Thalidomide Victim’s Association of Canada, “About Us,” <https://thalidomide.ca/> [accessed 06 July 2019]. (Bottom) A sample of Talimol as it was distributed to doctors in Canada. Source: LAV NRW R, Gerichte Rep. 139 Nr. 374/70.

While the difficulties in retrieving thalidomide were being acknowledged, the Frank W. Horner Ltd. president carefully positioned their role in this process. Instead of acknowledging themselves as key players in this problematic situation, the letter sent to doctors in mid-April noted that their efforts in informing the medical profession about the withdrawal process was “just one means of our helping the [Food and Drug] Directorate achieve these ends,” referring to the government’s efforts at having all thalidomide tablets in Canada returned or destroyed.⁸⁹ The government did take a leading, if not entirely effective, role in the process of locating the thalidomide supplies throughout Canada. Sources indicate that on April 10, 1962, federal inspectors were sent to visit drugstores in an effort to inquire about stocks of the drug left on shelves. Investigators were apparently astonished by what they discovered: “One of them incredulously reported back that the first pharmacist he called on not only had thalidomide in supply, but had just received a new prescription for it.”⁹⁰ A *MacLean’s* reporter made a similar discovery when he called a drug store in the west end of Toronto. In response to the reporter’s surprise that thalidomide was still on the shelves there, the pharmacist responded by saying ““Why not? [...] It’s safe for an adult male, isn’t it? [...] I am not sending back the rest of my supply until people stop asking for it.””⁹¹ Clearly the severity of the situation had not resonated with parts of the medical and pharmaceutical professions enough to protect women from the dangers the drug posed to them and their unborn children. When informed by this, a Merrell official responded by saying “I am shocked. [...] but there is a point where our responsibility ceases.”⁹² Also shocking were the numbers published by *MacLean’s Magazine*. On April 10,

⁸⁹ Howden Horner, President, Frank W. Horner Ltd, Montreal, Canada, “Urgent that you destroy or return all stocks or samples of thalidomide (Talimol, Horner),” letter to Canadian doctors, April 12, 1962. LAV NRW R, Gerichte Rep. 139 Nr. 250/24a p. 24025.

⁹⁰ Callwood, “The Unfolding of Drug-Deformed Babies,” 67.

⁹¹ Callwood, “The Unfolding of Drug-Deformed Babies,” 67.

⁹² Callwood, “The Unfolding of Drug-Deformed Babies,” 67.

1962, 108,748 tablets that had been distributed by Horner as samples were still unaccounted for, while only 14,304 had been returned.⁹³

The difficulties did not end there. The process of removal was further complicated by unsuspecting Canadians who may simply have been unaware that the product they harboured in their medicine cabinet was the infamous drug they had read about, since thalidomide was sold under a variety of names. In 1963, *The New England Journal of Medicine* published an article by Professor Helen B. Taussig of Johns Hopkins Hospital in Baltimore who critiqued the “masquerading” of the drug under different names. She noted that “what makes things even worse in some countries [...] is the fact that the name of the drug is withheld from the patient by the pharmacist who only provides a label with the name of the patient and a number.”⁹⁴ This explains how even those who were aware of the problems with thalidomide did not always realize that the drug could be found in their own home. The impossibility of tracing the drug is further demonstrated by a letter addressed to Dr. Hilmar von Veltheim and Grünenthal’s parent company Dalli-Werke, dated October 25, 1963, in which Dr. Walter Herzfeld (an attorney at law in New York) pointed out that thalidomide was sent to the Philippines from Canada. The letter reads: “Richardson-Merrell, Inc. of Canada did indeed send small amounts of thalidomide to the Philippines, however, solely for the personal use of employees of the sales department of the organisation.”⁹⁵ Thus, the ease with which the pills were distributed not only in Canada but across national borders becomes apparent.

While the removal process of the drug was on-going, company representatives of Merrell and Frank W. Horner remained in communication with Grünenthal to receive and exchange

⁹³ Callwood, “The Unfolding of Drug-Deformed Babies,” 67.

⁹⁴ Sjöström and Nilsson. *Thalidomide and the power of the drug companies*, 132-133.

⁹⁵ Letter from Dr. Walter Herzfeld to Herrn Dr. Hilmar von Veltheim c/o Dalli-Werke Maeurer & Wirtz K.G. Stolber/Rheinland, Germany, October 25, 1963, LAV NRW R, Gerichte Rep. 139 Nr. 380/77b.

information about its product and new scientific developments.⁹⁶ On May 4, 1962, von Schrader-Beielstein sent a letter to Mr. F. Hugh Wadey, the Managing Director of William S. Merrell Company in Weston, Ontario. In it he reported the findings of the Convention of the North-West German Association of Paediatrics which had been held in Hamburg, Germany, the previous weekend on the subject of thalidomide and congenital abnormalities. The letter states: “The question of whether thalidomide was or was not responsible for the abnormalities remained completely open, and we regard the Congress as being of great importance.”⁹⁷ The letter continues:

At the present stage of the investigations here in Germany on the subject of malformations, one might summarise as follows:

- 1) There are cases of extreme malformation in which the anamnesis of the mother reveals not only other drugs and diseases, but also thalidomide in early pregnancy.
- 2) There are cases of extremital malformation in which the anamnesis of the mother reveals no thalidomide. (At the moment, it might be said that in 50% of the cases covered there is no thalidomide in the anamnesis of the mother).
- 3) Cases are known of normal children with mothers whose anamnesis reveals thalidomide.

All this data refers to early pregnancy; to be exact, to the period between the 20th and 42nd days following conception.⁹⁸

The connection between thalidomide and birth defects thus remained contested. According to a letter sent back to Chemie Grünenthal on June 4, 1962, by F. Hugh Wadey, the publications of the Convention that von Schrader-Beielstein referred to in his letter of May 4, 1962, were only

⁹⁶ See for example: Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, January 17, 1962 in which the Canadian distributor shares information about the availability of articles on congenital malformations, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24053; Letter from Chemie Grünenthal G.m.b.H. to Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, January 22, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24049; Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, January 30, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24043.

⁹⁷ Letter from Dr. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, to Mr. F.H. Wadey, Managing Director, The Wm. S. Merrell Company, Weston, Ontario, May 4, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24237.

⁹⁸ Letter from Dr. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, to Mr. F.H. Wadey, Managing Director, The Wm. S. Merrell Company, Weston, Ontario, May 4, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24237.

received in German and not in English, causing the Merrell representative to wonder how he might obtain English language copies.⁹⁹ Frank W. Horner too struggled at times with the lack of proper English translations, indicating some of the difficulties faced by the companies to evaluate the stream of information coming from their German partner company and published in medical journals and newsletters.¹⁰⁰

Beyond external scientific research, the companies themselves pursued further medical trials of the drug. Frank W. Horner, for example was testing pregnant rats in January 1962 and by mid-May 1962 Robert M. Woodward of Richardson-Merrell submitted the formula of Kevadon 100mg to Dr. H. W. v. Schrader-Beielstein of Grünenthal for testing.¹⁰¹ While Woodward indicated that he was doubtful that there was a relationship between certain ingredients, which he emphasized are inactive, and malformations, he noted that “regardless of this, however, we shall be much interested in learning whether Dr. Muecker finds differences in side effects from the tablet material as compared with thalidomide itself.”¹⁰² Given such interest

⁹⁹ Letter from Mr. F.H. Wadey, Managing Director, The Wm. S. Merrell Company, Weston, Ontario, to Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, June 4, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b 24215.

¹⁰⁰ Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. H. Mueckter, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, January 18, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24052; A response to Dr. Leonard Mitchell inquiry from January 18, 1962 was send swiftly by Grünenthal, see letter from Chemie Grünenthal G.m.b.H. to Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, January 24, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24046; Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. W. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, May 31, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24015.

¹⁰¹ Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. W. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, January 9, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24057; and Letter from Robert H. Woodward, The Wm. S. Merrell Company, to Dr. H. W. Von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, May 16, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24197.

¹⁰² Letter from Robert H. Woodward, The Wm. S. Merrell Company, to Dr. H. W. Von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, May 16, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24b, 24197.

Indeed, Chemie Grünenthal G.m.b.H. had themselves requested to receive samples from Frank W. Horner Ltd. Pharmaceuticals on 23.1.1962, thus it is likely that Merrell received the same request. Letter from Chemie Grünenthal G.m.b.H. to Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, January 23, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24048.

it appears reasonable to suspect that the licencing company was still hopeful that the drug's name could be cleared. However, in a letter written in March 1962 Frank W. Horner's Vice President wrote to Chemie Grünenthal, "I am extremely doubtful that we will want to re-introduce it in the future even if this should be permitted."¹⁰³ All the companies' doubts and discussions were conducted secretly, without the knowledge of the families that would soon be facing the consequences of the drug.

In fact, the companies stayed surprisingly absent from the limelight of the scandal in Canada. Horner's vice-president wrote in a letter to Grünenthal: "It is rather interesting that Talimol and Horner have not been mentioned in any of the Canadian publicity. This is rather surprising [...] However, I must say that under the present circumstances I am just as glad we are not receiving any more attention."¹⁰⁴ Yet, while the pharmaceutical sector pursued its own questions in regard to the drug, the Canadian government was starting to be faced with a highly public scandal.¹⁰⁵ The scrutiny of the government rather than the drug companies was surprising even to the pharmaceutical representatives. One letter from Horner to Grünenthal written in May 1962 noted: "While I was away from Montreal there was apparently a fair amount of newspaper and radio comment on the situation, and strangely enough most of the criticism has been levelled at the Food & Drug Directorate and not at Merrell or ourselves."¹⁰⁶ The featured article in the May 1962 edition of *MacLean's Magazine* declared: "The drug had been on the Canadian market

¹⁰³ Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. H. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, March 2, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24039.

¹⁰⁴ Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. W. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, March 15, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24032.

¹⁰⁵ Key here was the MacLean's featured article: June Callwood, "The Unfolding of Drug-Deformed Babies: A Report On a Nightmare of Error and Neglect," *MacLean's*, May 19, 1962, 13, 65-68.

¹⁰⁶ Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. H. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, May 8, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24023.

for eight months when the medical directors of both companies manufacturing it visited Ottawa to warn officials that doctors in Europe suspected thalidomide of damaging human embryos. More than three months later, on March 2, the Department of Health decided the drug should be withdrawn. But six weeks later, on April 11, it was still being sold over drug store counters.”¹⁰⁷ The way the article frames the events clearly places the burden of delayed reaction onto the government, framing the pharmaceutical companies as among those distraught by the discovered impact of the drug. The article read: “Their ordeal is shared by [...] two pharmaceutical companies who manufactured the tablets under the names Kevadon and Talimol in the belief they were bringing Canadians the safest sedative ever devised. It is also shared by government officials who were warned of the risk of the drug three months before they took any action, and four months before their decision was enforced.”¹⁰⁸ The portrayal of the government’s reactions and shortcomings will play a significant role in the events presented in Chapter Two, as it resulted in pressures placed on the government to supply a solution to the problems caused by the drug.

By mid-1962 many women across Canada were aware of the threat caused by the drug and anxiously wondering what might happen to their unborn children. *MacLean’s Magazine* reporter June Callwood described women’s worries at the time: “Across Canada, expectant mothers who used the pill containing a new drug, thalidomide, to relieve morning sickness in early pregnancy are waiting now to discover whether or not their babies will be massively deformed.”¹⁰⁹ Healthcare journalist Jacky Law describes the initial impression of the public: “[They] saw pictures of a previously unknown congenital malformation whereby babies were

¹⁰⁷ Callwood, “The Unfolding of Drug-Deformed Babies,” 13.

¹⁰⁸ Callwood, “The Unfolding of Drug-Deformed Babies,” 13.

¹⁰⁹ Callwood, “The Unfolding of Drug-Deformed Babies,” 13.

being born with arms and legs that seemed to belong more to a water creature than a human being and with a whole host of associated internal problems. Indeed, the condition was christened phocomelia because its limb malformations were so similar to the flippers of a seal” [emphasis added].¹¹⁰ Clearly, the Canadian government had to address the issue. By August 1962, the Hon. J. W. Monteith, the Minister of National Health and Welfare, proposed a meeting with representatives of provincial governments as it became apparent that the federal government needed to develop a strategy to address the births of so many disabled children.¹¹¹ He called for a meeting that would discuss a program of assistance for families affected, in which the national government would share the financial responsibilities with the provinces. The Federal-Provincial Conference was held on August 17, 1962, and is discussed in more detail in the following chapter.¹¹² The decisions reached by the Canadian state regarding funding for thalidomide children would impact the lives of these individuals in significant ways and must be understood as a catalyst for many of the accounts recalled and analyzed in this dissertation.

Parents too posed questions and pursued solutions to the challenges they faced as a result of the disabilities and health concerns that thalidomide had caused. In 1965, an international congress of thalidomide parents was hosted on June 18-19 in Cologne, Germany. Newspapers indicate that Canadian parents participated.¹¹³ At the Congress, questions about prosthetics as

¹¹⁰ Jacky Law, *Big Pharma: Exposing the global healthcare agenda* (New York, NY: Carroll & Graf, 2006), 95.

¹¹¹ “Thalidomide - Assistance to parents of deformed children - Co-operation with provinces,” August 1, 1962.LAC, RG2, Privy Council Office, Series A-5-a, Volume 6192 Access Code 90, 21333.

This was preceded by statistical investigations in the provinces to determine the extend of thalidomide births. Given the tragedy transcended provincial borders a conference would provide room to develop a strategy to address the support for thalidomide children demanded in the media. See for example a letter noting Alberta’s Department of Public Health’s interest in receiving support from Horner Ltd. in their efforts. Letter from Dr. Leonard Mitchell, Vice President and Research Director, Frank W. Horner Ltd, Montreal, Canada, to Dr. H. von Schrader-Beielstein, Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, May 28,1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24018.

¹¹² Webb, “Canadian Thalidomide Experience,” 988.

¹¹³ “Contergan-Eltern beraten - Internationaler Kongress mit 4000 Teilnehmern,” Aachener Zeitung, April 26, 1965.

well as school enrollment and educational futures seemed to have preoccupied participants. These were conversations that were sparked and supported by lectures given by experts from the fields of science and education.¹¹⁴ Solutions were sought at the private and the public level, sometimes in harmony, other times causing conflict, something that will be discussed throughout this dissertation. However, one avenue of solution-seeking was largely excluded from the discussion at the time, as highlighted in the Introduction: the legal pursuit for financial compensation, whether those were directed at the private sector or the government. A brief overview will be included here.

While it took many years, the thalidomide case went to trial in Germany 1968. Nine men were charged with intent to commit bodily harm and involuntary manslaughter.¹¹⁵ The proceedings of this criminal trial were to assess whether the responsible individuals at Grünenthal were guilty of not, or only insufficiently, testing the substance. Hearings began on May 27 in Alsdorf, Germany, where the trial was conducted in the casino, as the nearby Aachen court house was not spacious enough to accommodate the number of people required and expected for the trial.¹¹⁶ While there had originally been nine defendants, in the end seven company employees stood trial.¹¹⁷ Questions about the impact the drug had had in Canada were considered briefly. For example, the German archives contain a file noting that Carl-Hermann Schulte-Hillen, one of the lawyers representing German thalidomide children and their families,

¹¹⁴ “Erster Internationaler Kongress des Contergankinder-Hilfswerks,” LAV NRW R, NW 1180 “Contergan-Prozess.”

¹¹⁵ Anklageschrift (indictment) from 1967, today archived at the National Archives of North Rhine-Westphalia in Duisburg, Germany, LAV NRW R, Gerichte Rep. 139, No. 1–396.

¹¹⁶ This included witnesses and onlookers as well as the legal professionals involved in the trial.

¹¹⁷ Hermann Wirtz, Chemie Grünenthal owner, and the company’s former head of the scientific department, Dr. med. Heinz Kelling, were both excused due to health issues. The following seven men stood trial: Heinrich Mückter, Jakob Chauvistré (excluded from the trial in August 1970s for health reasons, he passed away soon after), Klaus Wienandi, Josef Leufgens, Dr. med. Günther Sievers, Dr. rer. Nat. Dr. med. Hans Werner von Schrader-Beielstein, and Dr. med. Gotthold Erich Werner (separated from the main trial in October 1970 for health reasons). For a brief summary of these men see “Auseinandersetzung im Conterganprozeß,” *Handelsblatt Düsseldorf*, May 28, 1968.

apparently learned that in the initial sales period of thalidomide in Canada, when only a few pills were being sold, the number of children with dysmelia was exaggerated because of the unreliability of record keeping.¹¹⁸ The file reads: “He asserts to know that a single case was registered fourteen times and thus recorded fourteen times.”¹¹⁹ Throughout the files, different estimates appear in regard to the number of babies born with birth defects in Canada.¹²⁰

The trial captured the attention of Canadians. In fact, the German legal representatives actively reached out to Canadians, as well as other nationals, while building and making their case. According to German newspaper coverage, at least two Canadian women served as witnesses at the German trial.¹²¹ Furthermore, the prosecuting lawyer in the German trial, Dr. Havertz, was in touch with Dr. F. Clarke Fraser, working at the Department of Genetics at McGill University.¹²² In November 1962, Dr. Fraser informed Dr. Havertz that “we still have no exact count of the number of cases of malformations caused by thalidomide.”¹²³ At that time, based on a survey by the Canadian Paediatrics Society, Dr. Fraser reports between thirty to forty babies whose mothers took thalidomide were known to have been born disabled.¹²⁴ Indeed, earlier that year, in January 1962, Dr. Mitchell of Frank W. Horner Limited had mentioned in a letter to Dr. von Schrader-Beielstein, that Horner too had reached out to “a geneticist at McGill

¹¹⁸ Dysmelia is an umbrella term for all types of congenital limb differences.

¹¹⁹ “Vermerk,” Menden/Sauerland, den 10. Mai 1963, LAV NRW R, Gerichte Rep. 139 Nr. 187. 187086.

¹²⁰ See for example: LAV NRW R, NW 875 Nr. 14101, 24.

¹²¹ “Eine Mutter Will Noch Einmal Contergan Nehmen,” *Rheinische Post*, August 21, 1968.

¹²² Dr. Havertz reached out to Dr. Fraser in a letter dated 20 November 1962, in which he wrote that investigations in regard to thalidomide were underway in Germany and that the prosecution was not only considering the damaged caused in Germany but also in other countries. The prosecution was requesting Dr. Fraser’s assistance in gathering information. Letter from Dr. Havertz, Staatsanwalt, Aachen, Germany, to Dr. F. Clarke Fraser, Department of Genetics, McGill University, Montreal, 20 November 1962, LAV NRW R, Gerichte Rep. 139 Nr. 167a, 167034.

¹²³ Letter from Dr. F. Clarke Fraser, Department of Genetics, McGill University, Montreal, to Dr. Havertz, Staatsanwalt, Aachen, Germany, November 26, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 167a, 167036.

¹²⁴ Letter from Dr. F. Clarke Fraser, Department of Genetics, McGill University, Montreal, to Dr. Havertz, Staatsanwalt, Aachen, Germany, November 26, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 167a, 167036.

University” in their efforts to investigate the possible teratogenicity of thalidomide.¹²⁵ Canadian scientists were actively involved in monitoring and evaluating the consequences of the drug in Canada. Dr. Fraser noted that “I am not aware of any scientists in our country who oppose the view that thalidomide or some constituent of the pills containing thalidomide resulted in a number of malformed children, though not all children born with phocomelic-type malformations result from pregnancies in which it is possible to establish that the mother took thalidomide.”¹²⁶ In fact, the difficulty of establishing whether a woman had taken thalidomide continues to be an ongoing issue among Canadians who are seeking compensation and financial assistance but are unable to produce a paper trail documenting their mothers’ use of the drug. In Germany, the trial ended on December 18, 1970, after Grünenthal’s compensation offer to the German thalidomide children of 100 million D-Mark (about \$30 million CDN at the time) was accepted by parents who agreed to the condition that they could not pursue any further legal action against the company.¹²⁷

While Canadians followed the German criminal trial with interest and a few Canadians even contributed to the proceedings in some way, they did not benefit from the compensation offered by Grünenthal because the company had not operated in Canada. At the time, the question of the company’s guilt was overshadowed by the acute need for financial support. Initially the U.S.-based company Richardson-Merrell pursued a pre-emptive strategy and agreed to a quick out-of-court settlement with ten Ontario families who were represented by

¹²⁵ Letter from Leonard Mitchell, Vice-President Frank W. Horner Limited, Montreal Canada, to Dr. H. von Schrader-Beielstein, , Chemie Grünenthal G.m.b.H., Stolberg im Rheinland, Germany, January 9, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 250/24a, 24057.

¹²⁶ Letter from Dr. F. Clarke Fraser, Department of Genetics, McGill University, Montreal, to Dr. Havertz, Staatsanwalt, Aachen, Germany, November 26, 1962, LAV NRW R, Gerichte Rep. 139 Nr. 167a, 167036.

¹²⁷ “Timeline,” *No Limits – The Thalidomide Story*, accessed July 5, 2019, <http://thalidomidestory.com/story/timeline/timeline/+a-settlement-is-reached/>.

Spangenberg Traci of Cleveland.¹²⁸ The families received a lump sum of two million dollars, although it is not clear how the money was distributed amongst the families. This settlement came with two conditions: that Spangenberg Traci could not represent more families and that the amount of money received remained confidential. The secrecy was intended to prevent other affected families from becoming aware of the possibility of taking legal action before the statute of limitations expired in their province. The strategy was successful in Quebec where the statute expired twelve months after the injury occurred.¹²⁹ The company operated strategically to avoid financial responsibility for those harmed by their product. A second legal battle was fought with the test case of eleven-year-old Denis Henry in New Jersey, where Richardson-Merrell had a subsidiary. While it was not a straight-forward legal case, it led to a second out-of-court settlement of 15 million U.S. dollars for twenty-six Quebecois thalidomiders and additional settlements for three other children.¹³⁰

Besides these settlements, financial support for Canadian thalidomiders specifically needed to be addressed within Canada's national borders if help from the Canadian government was to be successfully requested. In 1987 TVAC was founded, assisted by the Canadian War Amps.¹³¹ TVAC was created to assist the efforts of the War Amps' Thalidomide Task Force that had been set up to seek compensation for Canadian-born thalidomide victims.¹³² One newspaper recorded, "The task force decided the government was 40 per cent responsible for the tragedy because it licensed the drug and failed to heed the growing warning signs about its dangers."¹³³ (TVAC is still operating today, and it has, since 1992, been recognized as a charitable

¹²⁸ Stephens and Brynner, *Dark Remedy*, 68.

¹²⁹ Stephens and Brynner, *Dark Remedy*, 68-69.

¹³⁰ Stephens and Brynner, *Dark Remedy*, 69.

¹³¹ The Thalidomide Victims Association of Canada, "Mission and History," accessed July 5, 2019, <https://thalidomide.ca/en/mission-and-history/>. TVAC was officially incorporated on June 23, 1988.

¹³² The Thalidomide Victims Association of Canada, "Mission and History."

¹³³ "Thalidomide kids – 30 years later," *The Toronto Star*, February 13, 1993.

organization.¹³⁴) In 1991, the federal government paid survivors of thalidomide a one-time sum between \$52,000 and \$82,000 per person, depending on their level of disability.¹³⁵ The government had created a \$21 million assistance package for this purpose – thirty years after the children had been born.¹³⁶

In 2012, Grünenthal offered an apology to thalidomiders. However, Grünenthal's chief executive Harald Stock who spoke at the unveiling of the accompanying (controversial) sculpture, emphasized Grünenthal's shortcomings in reaching out to survivors while carefully avoiding any statements that could have been interpreted as an admission of guilt.¹³⁷ As a result, many thalidomiders (if not all) do not accept the apology and are offended by the continued shortcomings of the company in acknowledging their responsibility in the tragedy.

At the same time, grievances among thalidomiders continued in Canada. In December 2014, the Canadian House of Commons unanimously passed the opposition federal New Democratic Party's motion 'to right the wrong' and compensate Canada's survivors. The *Globe and Mail* reported the emotional response of those thalidomiders and TVAC representatives that were present in the parliamentary gallery during the vote and who stated to the media: "While the hard work of hammering out a financial package remains ahead, Parliament's all-party endorsement represented a powerful symbolic step, they said: Canada was finally acknowledging that victims deserved support for a mistake made by their country a half century ago."¹³⁸ Both Susan Wagner-White and Mercedes Benegbi were present: "I feel like all of Canada was standing up for us tonight,' said Susan Wagner-White, a thalidomide survivor who watched the

¹³⁴ The Thalidomide Victims Association of Canada, "Mission and History."

¹³⁵ Numbers here differ between sources. Some sources, like No Limits (2016), suggest that the lever per person was \$30,000 to \$80,000 per survivor.

¹³⁶ "Thalidomide Survivor Hopes Ongoing Help Around the Corner," *Winnipeg Free Press*, Nov 28, 2014.

¹³⁷ "50 Jahre Schweigen (50 Years of Silence)," *Spiegel Online*, August 31, 2008.

¹³⁸ "Parliamentary motion for 'full support' for thalidomide survivors passes unanimously," *Globe and Mail*, December 1, 2014.

proceedings from the gallery. Ms. Benegbi called the vote a ‘moment of pure joy’ after years of heartache.”¹³⁹

In 2015, the government revisited the compensation and assistance payment and agreed on a new compensation system that includes annual pensions and a medical assistance fund managed by a third-party administrator. The Thalidomide Survivors Contribution Program (TSCP) was announced on May 22, 2015. Initially the Canadian thalidomiders had requested \$250,000 lump-sum payments, in addition to annual pensions that would provide them with the freedom to determine how to manage their medical and financial needs independently. While not acceding to that request, the long-awaited compensation package of \$180 million to which the government in Ottawa committed was nonetheless met with great excitement. The package outlined that a \$125,000 tax-free lump-sum payment would be provided for each survivor plus an annual tax-free pension for the rest of their lives of \$25,000, \$75,000 or \$100,000 depending on the severity of their disability.¹⁴⁰ The main concern expressed by thalidomiders, after the initially vague announcement by the Canadian government on March 6, 2015, was that the \$168 million that would remain to be disbursed after lump-sum payments was thought to be only for medical expenses. It was, however, established that this was not the case and Mercedes, representing TVAC, stated in an interview with *The Globe and Mail* that “I am reassured that Health Canada is considering a broad range of needs of thalidomiders and they are open to developing this program with the collaboration of [our] task force.”¹⁴¹

In the aftermath of the 2015 compensation package frustration persisted among thalidomiders regarding the hard-won financial support. One of the primary concerns was the

¹³⁹ “Parliamentary motion for ‘full support’ for thalidomide survivors passes unanimously,” *Globe and Mail*, December 1, 2014.

¹⁴⁰ “Thalidomide victims to receive funding for variety of expenses,” *The Globe and Mail*, March 10, 2015.

¹⁴¹ “Thalidomide victims to receive funding for variety of expenses,” *The Globe and Mail*, March 10, 2015.

limited access to the benefits, especially given the difficulty for many of proving their status as thalidomiders. The TSCP required that applicants met very specific criteria to receive recognition and compensation, which resulted in the rejection of many self-identified Canadian thalidomide victims. In January 2019 Canadian thalidomiders succeeded in convincing the Canadian government to change the existing compensation program. On January 9, 2019, the Minister of Health announced a new program called the Canadian Thalidomide Survivors Support Program for Thalidomide Survivors (CTSSP). This program expanded the benefits to a payment of \$250,000, ongoing tax-free annual payments based on level of disability, and an Extraordinary Medical Assistance Fund (EMAF). Thalidomiders who were already registered under the 2015 were automatically transferred to the 2019 CTSSP. However, access to the program remained difficult for some people unrecognized by authorities as thalidomiders.

A Canadian law firm leading a class-action legal proceeding claimed the accessibility criteria of the 2015 TSCP were unlawful and asserted that the 2019 CTSSP was a revision, not a replacement of the TSCP, and stated the following in regards to the January changes: “While the announcement stated that the 2019 CTSSP would ‘provide a fair and comprehensive approach to identifying thalidomide survivors that is based on international best practices’ no details of the eligibility criteria or evidentiary requirements of the 2019 CTSSP were announced.”¹⁴² The government reacted quickly and in April 2019, an additional broadening to the eligibility criteria occurred, as a three-step probability-based medical assessment process was announced, resulting in the new CTSSP.¹⁴³

¹⁴² Koskie Minsky LLP, “Thalidomide Survivors Contribution Program Class Proceeding Q&A,” accessed on April 12, 2019, https://kmlaw.ca/wp-content/uploads/2019/03/Thalidomide_FAQ_20190329.pdf.

¹⁴³ Health Canada, “The Canadian Thalidomide Survivors Support Program for Thalidomide Survivors (CTSSP),” accessed on April 12, 2019, <https://www.canada.ca/en/health-canada/news/2019/04/the-canadian-thalidomide-survivors-support-program-ctssp.html>.

The Canadian thalidomide scandal is defined by the federal government's marked delay of the drug's withdrawal in this country. Chemie Grünenthal continued to receive reports from the Canadian licensees about the success of the drug, which seems initially to have raised the company's hopes for a future return of the product to the market. Clearly the ongoing conversations between Chemie Grünenthal and Richardson-Merrell and Frank Horner Ltd. raise serious questions regarding the ethics (or lack thereof) of testing and regulation of drugs in Canada. However, an entirely separate aspect of the scandal was key for the way the thalidomide scandal unfolded in Canada after the spring of 1962 when the drug was finally withdrawn from the market: the curious reaction of the Canadian public that placed blame primarily on the Canadian government rather than the drug companies. The next Chapter will discuss the implications of these developments and outline how, in an effort to come to terms with the tragic impact of the drug, the Canadian government reacted to the crisis by emphasizing rehabilitation and medical solutions.

Part 1 – Thalidomide and Institutional Settings

Chapter 2: Rehabilitation and Artificial Limbs

What is important is that we take advantage of the knowledge gained from the tragedy.¹

The best known visual representations of the thalidomide scandal were the bodies of children that were affected by what was referred to by scientists as skeletal anomalies, notably amelia and phocomelia, that is, the short or “missing” limbs newspapers and parents described.² These visible disabilities indicated to the public that both the state and medical profession had failed to protect Canadian citizens from harm. The previous Chapter has noted the curious choice of the Canadian media to place the blame for the thalidomide scandal primarily on the government rather than focusing on the pharmaceutical companies. As the focus of the public’s scrutiny intensified immediately after the crisis became public knowledge, the Canadian government recruited the medical profession to resolve the problems now faced by families whose babies were born with various disabilities by funding medically-controlled rehabilitation centers.³ This Chapter will discuss the way rehabilitation emerged as a response to the thalidomide tragedy and focus on two issues specifically. First, the Chapter will demonstrate that

¹ “On the Positive Side... Thalidomide Babies Spurred On Research,” *Hamilton Spectator*, April 20, 1964.

² The word “phocomelia” is composed of the Greek words phokr~, meaning a seal, and meh, a limb, because the short extremities it describes were said to resemble the flippers of a seal. P.M. Dunn, A.M. Fisher, H.G. Kohler, “Phocomelia,” *American Journal of Obstetrics and Gynecology* 84, no. 3 (01 August 1962): 348.

³ These rehabilitation centers were specifically aimed at addressing the (perceived) challenges caused by the best-known and most visible disabilities caused by thalidomide, the short or missing limbs, but it is important to note here that thalidomide caused other physical complications too. These include “congenital heart disease, microphthalmos and coloboma, intestinal atresia, renal malformations, abnormal pinnae, and facial naevus.” R.W. Smithells and C.G.H. Newman, “Recognition of Thalidomide Defects,” *Journal of Medical Genetics* 29, no. 10 (October 1992): 716.

the thalidomide babies and their care coincidentally became part of a larger consideration of the responsibility of the modern Canadian state to care for its (disabled) citizens. And second, the experiences of Canadian thalidomiders demonstrate that the promotion of prosthetics served to ease public anxiety about non-normative bodies, rather than assist thalidomiders in their everyday lives. Despite the intensive attempts to provide thalidomide children with prosthetics and medical interventions meant to assure them a place as functioning members of society, most children resisted drastic medical interventions early on and fully rejected prosthetics in their teens, because the rehabilitation efforts contradicted the embodied experiences of the children who were able to participate in everyday life without the aid – and hindrance – of prosthetic devices. Overall, this Chapter addresses the overarching argument of this dissertation by demonstrating that the thalidomide bodies had political significance. Building on Michel Foucault’s contention that “the body is the inscribed surface of events,” the prosthetics and the rejection of the alteration of their bodies by thalidomiders can be read as a reflection of socio-political discourses that correlated with the thalidomiders’ childhoods.⁴

Historians, as well as scholars in other disciplines, have made great strides towards studying the history of rehabilitation and prosthetics.⁵ Many of these studies take into account that, in 1990, Foucault highlighted the political processes involved in the establishment of ‘normal bodies’ through the medical categorization of bodies.⁶ Foucault’s later works and those

⁴ Michel Foucault, “Nietzsche, Genealogy and History,” in *Language, Counter-Memory, Practice* (Ithaca, NY: Cornell University Press, 1983), 148.

⁵ Some contributions to this scholarship are: Glenn Gritzer, and Arnold Arluke, *The Making of Rehabilitation: A Political Economy of Medical Specialization, 1890-1980* (Berkeley: University of California Press, 1985); David Harley Serlin, *Replaceable You: Engineering the Body in Postwar America* (Chicago, London: University of Chicago Press, 2004); Beth Linker, *War’s Waste: Rehabilitation in World War I America* (Chicago: The University of Chicago Press, 2011).

⁶ Michel Foucault, *The History of Sexuality* (Vintage Books, 1990).

who have drawn on his ideas emphasise that medicine does not provide neutral assessments but is central in defining what is normal; it produces discourses of normal and in need of protection, and abnormal, in need of treatment.⁷ Furthermore, building on Foucault's critical work on technologies, as part of which he discusses how machines can help determine human subjectivity, studies such as Celia Lury's *Prosthetic Culture* and Gabriel Brahm and Mark Driscoll's *Prosthetic Territories*, as well as others, have demonstrated the usefulness of understanding human relations with their material surroundings through the metaphorical use of prostheses.⁸ Discussions of Donna Haraway's concept of the cyborg have also been prolific.⁹ However, as Katherine Ott points out, cyborgs are "divorced from disability and are commissioned by needs other than physiological."¹⁰ Historians of technology, in turn, have emphasized that technologies are not simply material tools, but have to be understood within their socio-cultural contexts.¹¹ More recently, an interdisciplinary group of scholar, including medical historians, sociologists, queer studies theorists, and anthropologists, aimed to re-focus the discussion and enter analyses of the complex historical and social origins of prosthetics. Published in 2002, *Artificial Parts, Practical Lives: Modern histories of Prosthetics*, edited by Katherine Ott, David Serlin, Stephen Mihm, contains various essays that emphasize the

⁷ For example: Peter Conrad, "Medicalization and Social Control," *Annual Review of Sociology* 18, no. 1 (1992): 209-232; Peter Conrad, and Joseph W. Schneider. *Deviance and Medicalization: From Badness to Sickness* (New York: Macmillan, 1980).

⁸ Robert Scott Leventhal, *Reading After Foucault: Institutions, Disciplines, and Technologies of the Self in Germany, 1750-1830* (Detroit, Mich: Wayne State University Press, 1994); Celia Lury, *Prosthetic Culture: Photography, Memory and Identity* (London: Routledge, 1998); Mark Driscoll, and Gabriel Brahm, *Prosthetic Territories: Politics and Hypertechnologies. Vol. 3* (Boulder: Westview Press, 1995).

⁹ Donna Jeanne Haraway, *Simians, Cyborgs and Women: The Reinvention of Nature* (London: Free Association Books, 1991); Mark Seltzer, *Bodies and Machines* (New York: Routledge, 1992); Chris Hables Gray, *The Cyborg Handbook* (New York: Routledge, 1995).

¹⁰ Katherine Ott, "The Sum of Its Parts – An Introduction to Modern Histories of Prosthetics," in *Artificial Parts, Practical Lives: Modern Histories of Prosthetics*, eds. Stephen Mihm, David Harley Serlin, and Katherine Ott (New York: New York University Press, 2002), 21.

¹¹ For example, Carroll W. Pursell, *The Machine in America: A Social History of Technology. 2nd ed.* (Baltimore: Johns Hopkins University Press, 2007).

intersections between science, technology, and disability and examine the materiality and representation of the body. They, unlike other studies, include the role of people with disabilities.¹² This chapter adds to this literature by combining a history of medicine approach that traces the emergence of the Canadian Prosthetic Research and Training Units in the early 1960s as a response to the thalidomide tragedy, with a consideration of the lived experiences of rehabilitation within and outside these institutions that draws on both patient histories and a disability lens.

Rehabilitation medicine is a relatively recent field of practice and the emphasis placed on medically-led rehabilitation after the thalidomide tragedy symbolizes the successful integration of rehabilitation within medical institutes. From the eighteenth to the nineteenth century, the use of mild electronic stimulation was still widely rejected by the medical profession as quackery. The discovery of X-rays in 1895 led to an enthusiastic acceptance of the therapeutic use of rays.¹³ However, it was the First World War that truly helped to expand rehabilitation medicine.¹⁴ In fact, veterans drove the design of prosthetics in the post-war period. However, it was only during the Second World War that the term “rehabilitation” became commonly associated with the increasingly standardized practices of the profession. Only in the 1950s and 1960s, the decades associated with the polio outbreaks and the thalidomide tragedy, did the rehabilitation of people truly become institutional and move into hospital settings.¹⁵ The first part of this chapter will consider how and why rehabilitation became a central aspect in thalidomiders’ lives by outlining the emphasis placed on rehabilitation as a solution to the

¹² Stephen Mihm, David Harley Serlin, and Katherine Ott eds., *Artificial Parts, Practical Lives: Modern histories of Prosthetics* (New York: New York University Press, 2002).

¹³ Ott, “The Sum of Its Parts,” 15.

¹⁴ Beth Linker’s *War’s Waste: Rehabilitation in World War I America* (Chicago: The University of Chicago Press, 2011).

¹⁵ This history has been succinctly summarized by Katherine Ott. Ott, “The Sum of Its Parts,” 15-16.

“thalidomide problem” by politicians and doctors, only then will the experience of thalidomiders in the rehabilitation programs receive attention.

In order to understand how central rehabilitation was to thalidomiders’ lives, it is necessary to emphasize that Canadian thalidomide families, unlike elsewhere, had few other recourses to receive substantial and continuous support. Canadian thalidomiders were unfortunate in the lack of public support in pursuing litigation against the companies marketing thalidomide in Canada. As outlined in the previous chapter, only two settlements were reached between Merrell and Canadian thalidomiders. This differed from the experience of thalidomiders in Germany where the criminal trial of the company employees generated immense media interest and pressure to find a solution that would help these children. The large number of *Nebenklägern* (joint plaintiffs to the prosecution in the case) made up of thalidomide parents put further pressure on the company and state. In April 1970, Grünenthal reached a settlement with thalidomide parents that led to the establishment of a trust fund in the amount of 100 million D-Mark (about \$30 million CDN at the time) that would benefit all children certified by a medical panel to be eligible (not limited to those whose families signed the settlement).¹⁶ As a result of the settlement, the trial ended in December 1970 with no criminal verdict rendered. In December 1971, spurred by the federal legislature, the funds provided as part of the Grünenthal settlement were transferred into the Foundation for the Assistance of Handicapped Children (today referred to as *Conterganstiftung für behinderte Menschen*) which took over the distribution of funds to victims.¹⁷ The foundation received additional funds (initially 50 million D-Mark) from the

¹⁶ William B. Fisch, “European Analogues to the Class Action: Group Action in France and Germany,” *The American Journal of Comparative Law* 27, no. 1 (1979): 73.

¹⁷ Bund Contergangeschädigter und Grünenthalopfer e.V., “Stiftungsverhandlungen,” <http://www.gruenenthal-opfer.de/Stiftungsverhandlungen>, accessed July 10, 2019.

federal budget.¹⁸ The money was transferred to the victims in the form of pensions and one-off capital settlements. While the criminal trial in Germany, and the media and public pressure it caused, resulted in the first national attempt to address the problems faced by thalidomiders, other nations too experienced the power of public scrutiny. In the United Kingdom, the media campaign of the *Sunday Times* in September of 1972, the support for thalidomiders expressed in the boycott of Distiller products (Distiller was a Grünenthal licensee) by several distributing chains in England and the United States, as well as pressure exerted by share-holders fearing for their reputation given the media interest, played a significant role in paving the way for relatively fair compensation, even though the support British thalidomiders received has certainly been far from perfect.¹⁹ The heightened media attention can be attributed to the large numbers of thalidomiders born in these two countries (numbers vary in sources but initially 455 thalidomiders registered in the United Kingdom, while in Germany at least 5000 thalidomide babies were born, of which forty percent did not survive beyond infancy and early childhood) and the significant public uproar caused by the massive trial in Germany.²⁰

In a much less dramatic fashion, the Swedish company Astra eventually agreed to a settlement after a trial that, similar to events in Germany, had no criminal verdict. The settlement has been described as being “more than [Swedish victims] could have received under the law from a trial.”²¹ In Japan the importance of public opinion has been recognized by scholars as

¹⁸ Bund Contergangeschädigter und Grünenthalopfer e.V., “Stiftungsverhandlungen,” accessed July 10, 2019, <http://www.gruenenthal-opfer.de/Stiftungsverhandlungen>.

¹⁹ Bund Contergangeschädigter und Grünenthalopfer e.V., “Entschädigung im Ausland,” accessed July 10, 2019, http://www.gruenenthal-opfer.de/Entschaedigung_Ausland.; Sunday Times, London, *Suffer the Children: The Story of Thalidomide* (London: Deutsch, 1979).

²⁰ Bund Contergangeschädigter und Grünenthalopfer e.V., “Entschädigung im Ausland;” Bundesverband Contergangeschädigter e.V., “Zahlen un Fakten,” accessed July 10, 2019, https://www.contergan.de/images/zahlen-daten-fakten/20140317113301CON_Zahlen-Daten-Fakten_140311_mit_links.pdf.

²¹ Trent Stephens and Rock Brynner, *Dark Remedy: The Impact of Thalidomide and Its Revival as a Vital Medicine* (New York: Basic Books, 2001), 67.

well. In a comparative analysis of drug injury compensation plans that were created in the aftermath of the thalidomide tragedy in West Germany, Sweden and Japan, legal scholar John G. Fleming states that “Most pervasive seems to have been the recognition that public sentiment will not in the long run condone the heavy expenditures of adversary litigation or indeed protracted settlement negotiation,”²² and adds, “Japanese reform was propelled as much by public opinion aroused over the long delays in the settlement of the thalidomide [...] disasters as by a government anxious to avoid in the future the stigma of culpability in respect of its licensing.”²³ We see here that Canada was not alone in facing public demands to ensure the well-being of the thalidomide children.

Not only was the delayed reaction of the Canadian government, in comparison to the German and U.K. governments, an international embarrassment for the state, as it was described by Stephens and Brynner in their book *Dark Remedy*, but the Canadian media actually focused on an even greater shame.²⁴ The United States Food and Drug Administration never released the drug into official use, an outcome that is credited mostly to Frances Oldham Kelsey, a Canadian pharmacist and reviewer for the US Food and Drug Administration, who had effectively withstood the pressure of the pharmaceutical industry to allow the drug into the US market.²⁵ As a result, Canadians were confronted with the example of a governing body that had successfully protected its citizens, under the guidance of a Canadian no less. Thus, instead of turning to Europe as examples of how the thalidomide tragedy ought to be addressed, it seems that Canadians focused on an example that was, both geographically and perhaps culturally, closer to

²² John G. Fleming, “Drug Injury Compensation Plans,” *The American Journal of Comparative Law* 30, no. 2 (1982): 297.

²³ Fleming, “Drug Injury Compensation Plans,” 303.

²⁴ Stephens and Brynner, *Dark Remedy*, 67.

²⁵ *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010), 59.

home, the United States. In July 1962, the *Globe and Mail* published a statement by Carl Beeston, the twenty-four-year-old father of thalidomide baby Kim Beeston, born January 20, 1962: “The Federal Government accepted the drug for the Canadian market when the United States turned it down. I think it is the government’s duty to cover expenses above the normal.”²⁶ Whatever motivated Canadians, public outcry over the plight of Canadian victims of the drug and accusations aimed at the federal government of negligence due to the slow process of removal from the market, meant that a political solution was urgently needed.

It therefore became the responsibility of the state to fix the mistake of allowing the drug onto the Canadian market. Alongside the requests for help from parents, the media also reported that politicians called on the federal government to support the children. When the federal government replied it would not provide financial assistance because it had done everything in its power to protect the public once the danger was realized, Stanley Knowles, New Democratic Party (NDP) Member of Parliament for Winnipeg North Center, spoke up in parliament in July 1962, requesting that the federal government “bear full responsibility for babies crippled by the drug thalidomide.”²⁷ Knowles pointed at the negligence of the Honourable Jay Waldo Monteith, the Minister of National Health and Welfare, who had failed to act quickly enough to pull the drug off the market after the first warning signs had reached Canada from Europe.²⁸ As the newly appointed chairman of the NDP’s caucus Committee on Health and Welfare, Knowles insisted that the government bear the expenses that were “occasioned by its ghastly error in allowing thalidomide on the market and then its negligence in allowing Canadian sale months

²⁶ “Form Association to Fight for Aid, Drug Baby’s Father Urges Parents,” *Globe and Mail*, July 31, 1962.

²⁷ See Stanley Westall, “Knowles Charges Negligence, Calls Government Responsible,” *Globe and Mail*, July 31, 1962.

²⁸ Stanley Westall, “Knowles Charges Negligence, Calls Government Responsible,” *Globe and Mail*, July 31, 1962.

after its evil effects were known.”²⁹ Eventually such publicity did spur Health Minister Monteith into action.

However, Canadian thalidomiders were facing distinct and significant challenges in receiving state support and monetary compensation from the start. Not only was responsibility for the thalidomide children split between the federal and the provincial governments, there were also distinct regional laws and differences in the respective provincial legal systems that needed to be respected. In addition, the relatively small number of thalidomiders born in Canada, as opposed to the numbers in Germany and the United Kingdom, and the difficulties associated with having two official languages also played a role in the ways the Canadian government approached the issue.³⁰ It is clear that Canadian thalidomiders faced many hurdles when it came to receiving fair and equal support. Political scientist Alexandra Niblock, herself born in the early 1960s with bilateral phocomelia as a result of thalidomide, outlined such challenges in 2014.³¹

Nonetheless, in 1962, it appeared that the government was taking strides in addressing the thalidomide tragedy. Health Minister Monteith invited and met with representatives of provincial governments to develop a strategy to address the births of so many disabled children. This can be described as an example of “cooperative federalism,” which, at the time, was described by Prime Minister Pearson in November 1963, as based on mutual respect of the federal and provincial jurisdictions, with close cooperation the defining feature of their shared

²⁹ Stanley Westall, “Knowles Charges Negligence, Calls Government Responsible,” *Globe and Mail*, July 31, 1962.

³⁰ TVAC explains on their website: “Rather, families were forced to settle out-of-court with gag orders imposed on them not to discuss the amounts of their settlements. This resulted in wide disparity in the compensation amounts, with settlements for individuals with the same levels of disability varying by hundreds of thousands of dollars.” Thalidomide Victims Association on Canada, “The Tragedy of Thalidomide in Canada,” accessed April 12, 2019, <https://thalidomide.ca/en/the-canadian-tragedy/>.

³¹ Alexandra Niblock, “The Hurdles of Federalism: the Canadian Experience of Thalidomide,” presentation given at Carleton University, Ottawa, September 24, 2014.

responsibilities for Canadians.³² Five provincial governments – Quebec, Ontario, Manitoba, Alberta, and British Columbia – responded to Monteith’s invitation to “work out joint programs of care and financial assistance” for people affected by thalidomide, and they met during a federal-provincial conference held on August 17, 1962.³³ At the time, based on unofficial reports cited by newspapers, fifty-five thalidomide births were known to have occurred in Canada, excepting the Atlantic provinces.³⁴ The provincial and federal governments agreed to share the financial responsibility of caring for the thalidomide children. Conditional cost sharing programs were a defining feature of federal provincial diplomacy at the time.³⁵ While hospital and diagnostic services were already covered as part of the publicly-funded insurance plan introduced in 1957, the cost of “managing thalidomide deformities, including such items as doctors’ fees, surgery, drugs, prosthetic devices, psychological assessment and support, special education or vocational training, custodial care, and even income supplements” were to be shared.³⁶ The federal government additionally made close to half a million dollars available to help thalidomide victims and their families, although, as discussed below, this money was primarily channeled towards rehabilitation and prosthetics research.³⁷

While such funding was theoretically made available, accessing government support was in reality difficult. The government aimed to limit its liability by making it difficult to be

³² Richard Simeon, *Federal-Provincial Diplomacy: The Making of Recent Policy in Canada - With a New Preface and Postscript* (Toronto: University of Toronto Press, 2006), 172.

³³ “Ottawa, Five Provinces – Meeting Aug. 17 On Drug Baby Aid,” *The Hamilton Spectator* August 3, 1962, 1.

³⁴ “Ottawa, Five Provinces – Meeting Aug. 17 On Drug Baby Aid,” *The Hamilton Spectator* August 3, 1962, 1.

³⁵ Richard Simeon, *Federal-Provincial Diplomacy: The Making of Recent Policy in Canada - With a New Preface and Postscript* (Toronto: University of Toronto Press, 2006), 315.

³⁶ Health Protection Branch, Health Canada (HPB), ‘Memorandum: Aid for Thalidomide Babies,’ John E. Osborne, Director, Research and Statistics, to G.D.W. Cameron, Deputy Minister of Health (MOH), August 1962. See Barbara Clow, “Defining Disability, Limiting Liability: The Care of Thalidomide Victims in Canada,” in *Essays in Honour of Michael Bliss: Figuring the Social*, Alison Li, Elisabeth Heaman, Shelley McKellar, and Michael Bliss, eds. (Toronto: University of Toronto Press, 2008), 307.

³⁷ HPB, ‘Chronology re Thalidomide,’ 16–17. See Clow, “Defining Disability, Limiting Liability,” 308.

officially recognized as a thalidomide victim, and thus qualify for government aid.³⁸ In other words, although families of thalidomiders were seeking out financial aid and material support, there were hurdles to qualifying for federal and provincial aid. The federal government emphasized that phocomelia was not only caused by the drug but was also a naturally occurring congenital malformation. This justified a strict demand for families to carry the burden of proof that their babies were indeed harmed by the drug, which required the difficult task of producing documentations such as hospital or pharmacy records. This has been well-summarized by historian Barbara Clow:

The demand for professional evidence of thalidomide use [...] dramatically reduced the numbers of children who qualified for federal and provincial aid. Among thousands of deformed babies born in Canada between 1960 and 1963, only 115 met the strict criteria of eligibility established by the government, and more than 40 of these children had died as a result of severe congenital malformations long before the habilitation programs became available. Consequently, though the government had set aside hundreds of thousands of dollars to care for the victims of thalidomide, only a tiny fraction of this money was expended for drugs, surgery, prosthetic devices, and support. Between 1963 and 1971, for example, Ontario's habilitation program served fewer than twenty children at a total cost of less than \$34,000.³⁹

Despite the shortcomings of such funding, thalidomiders emphasised during our interviews that rehabilitation and medical research of prosthetics did emerge as central to the support the government offered to those who did qualify to be beneficiaries of the government programs. In his book *Replaceable You*, which discusses the development and widespread use of new medical technologies in the aftermath of the Second World War, David Serlin argues that “in the late 1940s and early 1950s, medical procedures used to rehabilitate or alter the human body enabled a new alignment of civic goals and national imperatives, of material form and ideology, of private

³⁸ Clow, “Defining Disability, Limiting Liability,” 304.

³⁹ Clow, “Defining Disability, Limiting Liability,” 310-311.

possibility and public responsibility.”⁴⁰ Discussing the United States, Serlin explains how in the American context, physical rehabilitation, including the use of prosthetics, became an allegory of national rehabilitation in the post-Second World War period.⁴¹ The importance of rehabilitation and prosthetics in the Canadian case also requires understanding the specific historical context in which they gained prominence. In the words of historian Cay-Rüdiger Prüll: “Scientific knowledge and practice can [...] be viewed as local and contingent phenomena, which depend on the time and place in which they develop.”⁴²

In fact, the relationship between state financial compensation for British thalidomiders and the United Kingdom’s welfare system is of immediate interest here because of its stark contrast to the Canadian case. In the United Kingdom, the government funded the Lady Hoare Thalidomide Fund, a private organization set up to support thalidomiders, with a three-million-pound donation.⁴³ This move to channel funds into a private, charitable organization that had been set up by Lady Mary Hoare, wife of the Lord Mayor of London, has been criticised by scholar Jameel Hampton. He argues that the British government thereby managed to evade instituting new statutory provisions benefitting the general classes of disabilities, whom he defines as “adult disabled people under 65 whose disablement had not come about as a result of war or industrial injury.”⁴⁴ In other words, the British government avoided a more comprehensive review and enhancement of social assistance for individuals with disabilities.⁴⁵

⁴⁰ Serlin, *Replaceable You*, 1.

⁴¹ Serlin, *Replaceable You*, 2.

⁴² Cay-Rüdiger Prüll, “Scientists, Doctors and Drug Development: the history of Raymond P. Ahlquist’s receptor theory, 1948-1988,” in Viviane Quirke, and Judy Slinn eds., *Perspectives on Twentieth-Century Pharmaceuticals* (Oxford; New York: Peter Lang, 2010), 150.

⁴³ This amount has been described as “shamefully low” by journalists. See John-Paul Flintoff, “Thalidomide: The Battle for Compensation Goes On,” *The Sunday Times*, March 23, 2008.

⁴⁴ Jameel Hampton, *Disability and the Welfare State in Britain. Changes in Perception and Policy 1948–1979* (Bristol: Policy Press, 2016), 2.

⁴⁵ Hampton, *Disability and the Welfare State in Britain*, 167.

Based on an analysis of declassified Prime Ministerial files at the national archives in Britain, Hampton demonstrates there was a keen awareness on the part of the United Kingdom's government that thalidomide children were in some ways no different from other individuals disabled as a result of congenital conditions, diseases, or amputations. By channelling support through a private body like the Lady Hoare Thalidomide Fund, the government chose an avenue that allowed it to frame thalidomiders' need of support as unique. Thalidomiders were treated as a distinct case unrelated to the general classes of disabilities, and the British government emphasised this support as exceptional, thus avoiding taking on a broader responsibility for disabled individuals in British society. Indeed, Hampton outlines how the government slyly managed to keep disabled people out of the state welfare settlements, an aim they had successfully ingrained in welfare politics and which the government seemed unwilling to see derailed as a result of the unusual media attention received by the thalidomide tragedy.⁴⁶ The British case provides an interesting juxtaposition to the Canadian case, where it was emphasised early on by state-appointed experts that the funding for thalidomiders by the federal government would be directed in a way that would provide benefits for disabled individuals generally.

In the aftermath of the thalidomide tragedy, the Canadian government directed its financial support to one ostensible solution for everyone with physical disabilities: artificial limbs. On January 25, 1963 Health Minister Monteith, tabled the report of the Expert Committee on the Habilitation of Congenital Anomalies Associated with Thalidomide in the House of Commons.⁴⁷ The Expert Committee was one outcome of the joint effort on the part of provincial

⁴⁶ Hampton, *Disability and the Welfare State in Britain*, 164-165.

⁴⁷ Report, dated December 1962, of Expert Committee on Habilitation of Congenital Anomalies Associated with Thalidomide, Sess. Paper No. 268A.

and federal authorities to cooperate in supporting the thalidomide babies.⁴⁸ The recommendations of the Expert Committee were aimed specifically at rehabilitation measures, an aim that, in the words of Monteith, “coincide[ed] to a considerable degree with actions the government is already taking.”⁴⁹ While the intention may have been benevolent, the measures proposed to help thalidomiders were drastic (the implications this had for thalidomiders will be discussed below). In their historical overview study of artificial arms research, David J. A. Foord, and Peter Kyberd, describe the report as “an aggressive approach to rehabilitation, including the rehabilitation for infants, novel in terms of its approach and the devices that would be used.”⁵⁰ The report of the Expert Committee stated:

If the normal development pattern of the infant is to be met, these cases must be immediately referred to other specialists for the early provision of limb prostheses; probably as early as two months of age. The fitting of the such apparati is only the beginning: training the child to use and live with his new limbs will demands years of care and supervision through the resources of a rehabilitation centre. Social, vocational and psychiatric problems, in addition to recognized paediatric and orthopaedic disabilities, will arise and co-operation between the many specialties involved in the team will be essential.⁵¹

To meet this goal of providing prostheses, in 1963, the Canadian government committed \$200,000 specifically “to establish regional prosthetic research and training centers to meet the problems presented by children with congenital limb deficiencies.”⁵² While phrased in a way to allow for a general application of the funds for prosthetics research, the annual grant has been

⁴⁸ Hon. J. W. Monteith, House of Commons [HC] Debates, 25th Parliament, 1st Session, Minutes (25 January 1963), 3108.

⁴⁹ Hon. J. W. Monteith, House of Commons [HC] Debates, 25th Parliament, 1st Session, Minutes (25 January 1963), 3109.

⁵⁰ David J. A. Foord, and Peter Kyberd, “Ideas and Networks: The Rise and Fall of Research Bodies for Powered Artificial Arms in America and Canada, 1945-1977,” *Scientia Canadensis: Canadian Journal of the History of Science, Technology and Medicine* 38, no. 2 (2015): 44.

⁵¹ Department of National Health and Welfare, *The Report of the Expert Committee of the Habilitation of Congenital Anomalies Associated with Thalidomide* (Ottawa: 1962), 2.

⁵² Canada Department of National Health and Welfare, Annual Report for the fiscal year ended 31 March 1964, Medical Rehabilitation and Crippled Children Grant, 63.

described by R. N. Scott, who reviewed the prosthetics research programs in 1995, as having been set aside to address the “thalidomide problem” specifically.⁵³ This money was supplementary to the funds available through the existing Medical Rehabilitation and Crippled Children Grant. This grant was the outcome of the merging of two previously existing grants in the 1960-61 fiscal year. The Crippled Children Grant, called to life in 1948 as part of the National Health Grant Program that allocated federal grants to the provinces to develop public health and hospital services, was merged with the Medical Rehabilitation Grant, which had been established several years later, in 1953, after a review of the first five years of the National Health Grant Program. The combining of the two previously existing grants into the federal Medical Rehabilitation and Crippled Children Grant was supposed to provide a more flexible measure of financial assistance to Canadians through the provinces by providing access to larger amounts of funds.⁵⁴ The addition of the \$200,000 was directly applied to address the perceived problems faced by thalidomiders.

The funds were channelled into three new Prosthetic Research and Training Units, all of which were chosen because they were connected with teaching hospitals associated with medical schools.⁵⁵ Specifically the funding went to the Rehabilitation Institute of Montreal, the Ontario Crippled Children’s Centre in Toronto, and the Rehabilitation Hospital in Winnipeg. Almost as an afterthought, based on a paper prepared by the Department of Veteran Affairs that emphasized the importance of engineering expertise, which was included in the last appendix to the Expert Committee’s report, a fourth Prosthetic and Research Training Unit was included in

⁵³ R. N. Scott, “Lessons for Researchers from the Canadian Thalidomide Experience,” Proceedings of the 1995 MyoElectric Controls/Powered Prosthetics Symposium, Fredericton, New Brunswick, Canada: August, 1995.

⁵⁴ To my knowledge, the history of this grant is yet to be discussed by scholars. National Health Grant Program, Subsection 1. – National Health Grant Program, 223, accessed August 5, 2018, https://www66.statcan.gc.ca/eng/1962/196202410223_p.%20223.pdf.

⁵⁵ Foord and Kyberd, “Ideas and Networks,”: 44.

the funding.⁵⁶ The University of New Brunswick's Bioengineering Institute was called on to conduct and coordinate prosthetics research, with a particular focus on electrical engineering. In addition to the funds channeled to the rehabilitation centers and research, provinces were able to receive training for local specialists, indicating why teaching hospitals were chosen.⁵⁷ Each of these rehabilitation institutions holds significance for the Canadian thalidomiders who spent significant amounts of time in them. The image of a young thalidomide girl being fitted with artificial arms, published in *The Montreal Star* on May 24, 1968, depicts the devices that were, for better or worse, developed in the Prosthetic Research and Training Units (Illustration 3). The way these devices were experienced by the young children will be discussed below, but it is worthwhile noting that some thalidomiders (as will be discussed in Chapter Four), actually considered the rehabilitation institutions home because of the long periods of time they spent there.

⁵⁶ R.E. Gilpin, Department of Veterans Affairs, Canada Prosthetic Services Centre, *The Prosthetic Treatment of Children with Congenital Deformities of the Extremities, Report No. 28* (Ottawa: Government of Canada, 1962). Foord, and Kyberd, "Ideas and Networks," 44.

⁵⁷ "The Federal Government will bear the cost of the course per se and will share with the Provinces the expenses entailed in the attendance of their delegates." "Rehabilitation of Thalidomide-Deformed Children," *Canadian Medical Association Journal* 88, no. 9 (1963): 488.



The above image shows Denis Cote, chief of the training unit at the Rehabilitation Institute of Montreal, fit a new harness with two artificial arms on a six-year-old Canadian girl. Such fittings had to occur frequently to accommodate the children's growing bodies.

Illustration 3: Chief of the training unit at the Rehabilitation Institute of Montreal fitting thalidomide girl with artificial arms. This was one of the institutions that received federal funding. The caption of the image notes that the child had to visit the Institute frequently, indicating the time-consuming role these rehabilitation programs played in the children's lives. The process of fitting prosthetics specifically could take hours at a time and was often uncomfortable, even painful, for the children. Source: *The Montreal Star*, 24 May 1968.

A number of important questions emerge as a result of these funding developments. First, why did medical experts and the Canadian government determine that rehabilitation should become the primary resource for Canadian thalidomiders? Second, what motivated the governments to imagine the need for research and rehabilitation advances that would benefit *all* individuals with physical disabilities, and not just thalidomiders? Third, what did “rehabilitation” mean for Canadian thalidomiders and their families? And, finally, what impact did the decision to channel funding to rehabilitation and artificial-limb research have on the individuals who attended these programs and institutions? In order to begin answering these major questions, this chapter seeks to assess, on the one hand, the ideas and intentions of the federal government and relevant medical professionals, as well as public discourses regarding disability, and on the other hand, the experiences of the individuals who attended the rehabilitation centers. The aim here is to not only address the question of *why* funds were channeled in this manner, but also what implications this decision had for the lives lived by thalidomiders in the aftermath of the scandal.

Before determining the importance of a rehabilitation solution to the thalidomide tragedy in Canada specifically, it is important to acknowledge that there was an international interest in developing powered upper-limb prosthetics at the time. In 1966, the *Toronto Daily Star* interviewed Dr. Gringas, who worked at the Rehabilitation Institute of Montreal, which had received funding for research as a result of the thalidomide tragedy, and reported that “[Dr. Gringas] mentions the recently established research departments of his Institute, where highly skilled electronic engineers and craftsmen are experimenting with new types of prosthetics. Staff members have travelled the world in search of ideas. A Russian electronic hand is being simplified for use by Canadian children. German and French appliances are being improved in the Institute’s prosthetic workshop. More efficient models of carbon-dioxide powered limbs are

being developed.”⁵⁸ Canada’s funding enabled engineers and doctors at the research institute to join international research initiatives and, ultimately, to play a leading role in developing a prosthetics-centred solution to the thalidomide scandal. Thus, while for Canada, the choice to channel funding into Prosthetic Research and Training Units had specific relevance, it is important to acknowledge that there was an international community of scientists pursuing research similar to that funded by the Canadian government.

Yet, while part of an international interest in prosthetics, the thalidomide scandal occurred at a particularly interesting moment in the history of Canadian health care that determined the way thalidomiders’ perceived needs were addressed. Before the Second World War, health care had been, for the most part, a private matter. Then, in 1947, Saskatchewan introduced a province-wide, universal hospital care plan, a change that began to widen Canadians’ accessibility to health care and underscored the importance of health care in the provincial and federal governments’ relationship to their citizens. Leading the way once more, Saskatchewan introduced a universal, provincial medical insurance plan in 1962, which was followed by the passing of the *Medical Care Act* in 1966 by the federal government.⁵⁹ With the passage of the *Medical Care Act*, the federal government assumed a cost-sharing responsibility with the provinces for services rendered by doctors outside of hospitals, a move that built on its earlier *Hospital Insurance and Diagnostic Services Act* from 1957, which had only offered cost-sharing for certain hospital and specific diagnostic services. It took six years for all provinces and territories to adopt the universal physician services insurance plans.⁶⁰

⁵⁸ *Toronto Daily Star*, March 26, 1966, 4.

⁵⁹ The term universal is somewhat misleading as health care services did not extend to all Canadians equally. Notably First Nations received drastically lower standard of medical care. See Maureen K. Lux, *Separate Beds: A History of Indian Hospitals in Canada, 1920s-1980s* (Toronto, Ontario: University of Toronto Press, 2016).

⁶⁰ Government of Canada, *Canada's Health Care System*, accessed June 18, 2018, <https://www.canada.ca/en/health-canada/services/health-care-system/reports-publications/health-care-system/canada.html#a3>.

These changes were not unrelated to emerging reactions to the thalidomide scandal. For example, in response to the federal-provincial meeting in August of 1962, one newspaper article paraphrased the president of the Canadian Labor Congress, Claude Jodoin, as having said that “current activity to discover how to provide care for drug-deformed babies underlines the urgent need for a nation-wide medical care plan.”⁶¹ The thalidomide scandal, therefore, influenced the national discussion underway regarding a broadening of health care access in Canada.⁶² Put another way, thalidomide babies and their care coincidentally became part of a larger consideration of the responsibility of the modern Canadian state to care for its citizens. Rehabilitation and prosthesis quickly played important roles within such considerations. Returning here to David Serlin’s argument that rehabilitation was linked closely with the alignment of “civic goals and national imperatives,” and that prosthetics actually became a signifier for national rehabilitation in the post-Second World War United States, it becomes apparent that thalidomiders had inadvertently brought such considerations, if indirectly, into public consideration in Canada.⁶³ The bodies of thalidomide children were thus thrust, at birth, into a political environment in which medical consideration went unequivocally beyond physical need to become part of a larger social discourse.

Instead of being solely concerned with the well-being of the thalidomide children, from the beginning, it was made apparent by politicians that the money used to fund prosthetics

⁶¹ “Ottawa, Five Provinces – Meeting Aug. 17 On Drug Baby Aid,” *The Hamilton Spectator*, August 3, 1962, 1.

⁶² In comparison, Britain had already experienced a broad consensus that health care should be made available to all in the wake of World War II, a public belief that had led to the establishment of the National Health Service (NHS) there. Donald W. Light, “Universal Health Care: Lessons from the British Experience,” *American Journal of Public Health* 93, no. 1 (2003): 26. In Germany, such considerations had even longer roots, reaching back to 1883 when Otto von Bismarck’s *Health Insurance Law* benefitting industrial workers helped turn Germany into a pioneer of state welfare. An interesting discussion about the developments in these two countries can be found in Lutz Leisering, “Nation State and Social Policy: An Ideational and Political History,” in *Variations of the Welfare State: Great Britain, Sweden, France and Germany between Capitalism and Socialism*, edited by Franz-Xavier Kaufmann (Heidelberg: Springer-Verlag Berlin, 2013), 1-22.

⁶³ Serlin, *Replaceable You*, 1-2.

research in Canada would, benefit not only thalidomiders. This was acknowledged in the House of Commons, when Health Minister Monteith stated in 1963 that prosthetics research would “benefit not only children with disabilities associated with thalidomide, but others with severe disabilities from other causes.”⁶⁴ The same sentiment that public funding and research would benefit disabled individuals at large was reasserted years later, in the mid-1990s, when R. N. Scott of the Institute of Biomedical Engineering and Department of Electrical Engineering at the University of New Brunswick assessed the thalidomide rehabilitation programs in the early 1990s and wrote: “When we spend public funds in research and development programs, we must do our best to ensure that public benefit results. It may be, as it was almost universally in the Thalidomide Program, that the benefits do not accrue to the intended persons. In such a situation, it is better that some other part of the public benefits than that the program be stopped.”⁶⁵ Thus, support for thalidomiders was inextricably bound up in the intention of creating measures of support that would serve not only thalidomiders themselves, but all Canadians with physical disabilities.

The same rationale, that the programs had significance beyond providing rehabilitation and accessibility tools to thalidomide children, was later used to justify the shortcomings of the efforts made. In other words, when it became clear that many thalidomiders did not reap the benefits that had been anticipated, authorities justified the programs’ existence by stating that others with physical disabilities could benefit. Indeed, newspaper coverage reported on the issue. In an article titled “On the Positive Side... Thalidomide Babies Spurred On Research,” published on 20 April 1964 in the *Hamilton Spectator*, the author posed the question: “What can be said

⁶⁴ Hon. J. W. Monteith, House of Commons [HC] Debates, 25th Parliament, 1st Session, Minutes (25 January 1963), 3109.

⁶⁵ R. N. Scott, “Lessons For Researchers From The Canadian Thalidomide Experience.”

today to put the thalidomide episode in perspective, now that the sensational publicity it prompted has died down?”⁶⁶ An answer to this question was supplied by Dr. Jean Webb, then head of the federal health department’s Child and Maternal Health Division: “Probably the most encouraging practical result of the tragedy, is that our knowledge of how to help child amputees will be greatly increased due to special research on mechanical arms and legs being developed to aid the babies.”⁶⁷

As much as the rehabilitation institutes were part of larger political consideration, they were also, and primarily, a direct reaction to the images of babies born with phocomelia. Canadians were being exposed to images of severely disabled newborns, such as the image of baby Kimberly under the headline “Drug-Baby Parents Must Be Helped” and the image of the same child with her parents under the headline “Abortion Bid Hinted, Despite U.S. Ruling.”⁶⁸ Both images display baby Kimberly’s short upper limbs clearly and appear to demand compassion from the viewer. In the first the baby holds a toy, happily playing (Illustration 4), in the second her father holds his daughter’s hand while she sits on her mother’s lap, her parents looking at her lovingly (Illustration 5). Her bodily difference is displayed at the same time as she is depicted as loved by her parents and engaging in play as any other, “normal” baby would be. The image of baby Kimberley sitting alone, playing with her rattle accompanied an article in which her parents make public their need for government assistance. Indeed, Kimberley’s father actively recruited the help of newspapers to make visible the need experienced by their own and other thalidomide families. The image displaying the whole family suggests that although

⁶⁶ “On the Positive Side... Thalidomide Babies Spurred On Research,” *Hamilton Spectator*, April 20, 1964.

⁶⁷ “On the Positive Side... Thalidomide Babies Spurred On Research,” *Hamilton Spectator*, April 20, 1964.

⁶⁸ Dorothy Howarth, “Drug-Baby Parents Must Be Helped,” *The Telegram*, July 30, 1962; “Abortion Bid Hinted, Despite U.S. Ruling,” *The Globe and Mail* on July 31, 1962. Photo by Harold Robinson. Other times these “images” were actually physical descriptions in newspaper articles.

abortion may have been considered by her parents had they known about the deformities before she was born, they would now keep and raise her as part of their family. The words of Kimberley's mother cited below the image share the mother's sorrow with the reader. She states: "They are outcasts. ..."⁶⁹ As a result of such coverage, there emerged a concern among the Canadian public regarding the federal government's responsibility to provide financial aid to these young citizens and their parents.⁷⁰



Illustration 4: Canadian thalidomide child – Kimberly – holding a rattle with her short arm. The caption reads: "Healthy, happy and loved, Kimberley chews on a baby held in her rudimentary left arm." Source: Dorothy Howarth, "Drug-Baby Parents Must Be Helped," *The Telegram* 30 July 1962.

⁶⁹ "Abortion Bid Hinted, Despite U.S. Ruling," *The Globe and Mail*, July 31, 1962.

⁷⁰ "We Love Him, Say Drug Baby's Parents, But How Can We Pay For His Needs?" (Newspaper clipping, date and source unknown.)



Illustration 5: Parents Carl and Anne Beeston holding their six-month-old daughter in 1962. The caption to the image read: “Anne and Carl Beeston say they will keep their 6-month-old daughter, Kimberley, but Mrs. Beeston said she could see no reason for bringing deformed babies into the world knowingly. ‘They are outcasts. ...’” Source: “Abortion Bid Hinted, Despite U.S. Ruling,” *The Globe and Mail* on July 31, 1962. Photo by Harold Robinson.

The seeming contradiction between the ways Kimberley’s image was displayed on several occasions in newspapers alongside her parents’ request for help, insinuating that her image would elicit support by evoking feelings of sympathy or pity, and the words of her mother that note that Kimberley’s disabilities made her into a social outcast is important to acknowledge. Indeed, disability scholar Bill Hughes acknowledges that “Compassion for the

wounded and repulsion in the presence of the wound are often co-located.”⁷¹ This relates to Julia Kristeva’s idea that staring at and ‘abjectifying’ damaged bodies is a process by which people try to restore their symbolic capacities as human subjects.⁷² The depiction of individuals with disabilities as vulnerable exists alongside ideas of disability as inherently dangerous and impure.⁷³ Charitable impulses towards the vulnerability of disability can serve to function in an almost redemptive manner at the same time as disability poses a threat to the onlooker. Disability scholar Bill Hughes describes this phenomenon as follows: “The propriety of both individual and social bodies is challenged by the presence of potentially contaminating impairment in the midst of community. Vulnerability is an opportunity for normative redemptive agency, but it is also represented as a threat to the constitutional integrity of persons and polity.”⁷⁴ Such a dual perception of disability had implications for individuals with disabilities as it stirs confusion in regards to the place people with disabilities ought to take in society. Madeline Burghart writes: “the interplay between psychic, emotive and categorical understandings of both vulnerability and threat has recurring repercussions in the lives of people with disabilities as it contributes to the ongoing confusion and anxiety regarding the place of disability in modern culture.”⁷⁵ This anxiety is important to acknowledge here because it helped shape the social context in which prosthetics were suggested as the ideal solution to help the thalidomide children. Indeed, the rhetoric employed by doctors, discussed below, illuminates that prosthetics could help not only relieve the vulnerability of disability to some extent, by making thalidomiders more independent, but they could also assuage the threat posed by the abnormal bodies by re-making

⁷¹ Bill Hughes, “The Abject and the Vulnerable: The Twain Shall Meet: Reflections on Disability in the Moral Economy,” *The Sociological Review* 67, no. 4 (2019): 839.

⁷² Julia Kristeva, *Powers of Horror: An Essay on Abjection* (New York: Columbia University Press, 1982), 46.

⁷³ Hughes, “The Abject and the Vulnerable,” 839.

⁷⁴ Hughes, “The Abject and the Vulnerable,” 839.

⁷⁵ Madeline Burghardt, “Common Frailty Constructed Oppression: Tensions and Debates on the Subject of Vulnerability, Disability and Society.” *Disability & Society* 28, no.4 (2013): 558.

them in the image of the able-bodied, thereby mitigate the psychological discomfort experienced as a result of being faced with disabled embodiment.

Indeed, the language doctors used to express what thalidomiders might gain through rehabilitation and prosthetics requires attention, as it demonstrates the underlying attitudes towards disability at the time. The disabled bodies of the thalidomide children were assumed to be insufficient, lacking in ability, and therefore they were manipulated and adjusted through surgeries and prosthetics in order to be repaired. The aim of prosthetics was to overcome the difference from what was considered normal. One of the medical experts working with and researching the young Canadian thalidomiders in Canada, was Dr. John E. Hall, who had been one of the experts appointed by the Minister of Health and Welfare to be a member of the Expert Committee on the Habilitation of Congenital Anomalities Associated with Thalidomide. Hall was based at the University of Toronto and came to work at the Ontario Crippled Children's Centre as an Orthopedic Consultant.⁷⁶ He stated as early as May 1963 that "Many thalidomide-deformed children will not have been severely affected, and with capable management should be able to compete with normal children on a very nearly equal basis."⁷⁷ Clearly then, the prosthetics were seen as a normalization measure for the thalidomide children. The children would not become normal, but they would, at least become competitive. However, he continued, thalidomide had quite an extensive impact on many bodies, often involving more than one limb. Hall elaborated: "The most severely disabled children, on the other hand, are unlikely by present standards to reach a competitive level, except possibly in intellectual endeavours. If it is not possible to do anything more for them than make them sufficiently independent to take care of

⁷⁶ John E. Hall, "Habilitation of Patients with Congenital Malformations Associated with Thalidomide: Surgery of Limb Defects," *The Canadian Medical Association Journal* 83 (May 11, 1963): 1.

⁷⁷ Hall, "Habilitation of Patients with Congenital Malformations Associated with Thalidomide," 1.

their own personal needs, a great deal will still have to be accomplished. With present methods of prosthetic fitting even this modest goal is out of reach.”⁷⁸ By referring to their (lack of) competitiveness, Hall essentially indicated that there were different ways of existing, and the bodies of thalidomiders meant they did not belong to those fully capable of participating in society. Another doctor, Dr. Gringas made the following observation regarding developments in prosthetics research at the Montreal Rehabilitation Institute in 1966: “With every leap forward, it’s becoming more socially acceptable to be born crippled.”⁷⁹ In his emphasis on what is socially acceptable he highlights indirectly that by fitting children with the new prosthetics, society would not be confronted with the potential (psychological) disruption posed by disabled bodies. By utilization prosthetics to make the thalidomide bodies appear closer to the non-disabled ideal, these bodies would be less threatening to social expectations of humanness and acceptability. Social expectations of acceptability are, of course, socially contingent. As put succinctly by disability scholar Josh Dohmen, “insofar as disability or particular disabilities are abject, this is contingent and capable of revision [...] the exclusion of disabled subjects that results from abjection is itself a product of existing social relations.”⁸⁰ In the medical profession and much of the public, attitudes towards thalidomiders existed in a space between rejection and pity, resulting in a drive to adjust their bodies to relieve the discomfort experienced by those confronted with images of these children.

While the doctors had clear ambitions regarding what the prosthetics could mean for the thalidomide children, such expectations need to be contrasted against the lived experiences of the children who spend much of their childhoods in the Rehabilitation Institutes. It is important to

⁷⁸ Hall, “Habilitation of Patients with Congenital Malformations Associated with Thalidomide,” 1.

⁷⁹ “A Shock – The First Day of School,” *Toronto Daily Star*, March 26, 1966, 4.

⁸⁰ Josh Dohmen, “Disability as Abject: Kristeva, Disability, and Resistance,” *Hypatia* 31, no. 4 (2016): 774.

consider what “rehabilitation” meant for thalidomiders and their families. Some children spend several years living in the hospitals, but most moved between their family homes and the institutions, spending up to six weeks at a time in the Rehabilitation Institutes having their prosthetics fitted and learning how to use them. Dr. Hall explained in 1963 that, “The general rehabilitation measures for all of these children will follow a similar pattern which has the eventual aim of integrating [the children with thalidomide-induced deformities] into society as productive members.”⁸¹ This aim of producing productive members of society meant for the children that they were supposed to learn to participate in every-day life through the help of their prosthetics, instead of relying on the help of others. Dr. Hall noted that “These children can be taught to do simple tasks such as feeding themselves,”⁸² a goal that was no doubt considered to be in the best interest of the children. Indeed, an image of two-and-a-half-year-old Judith Pilote appeared in the press depicting her eating with her artificial arms (Illustration 6). The caption suggests that the prosthetic provided Judith with a level of independence and ability that was hardly imaginable when her disabilities had left her immobile for her first year of life. Yet, looking at the image more closely, it becomes apparent that Judith is straining to reach the food. Ironically, a lot of effort was put into teaching children to use their prosthetics to eat, when in many cases having short limbs did not, in fact, prevent the children from feeding themselves. One example is the image of thalidomider Mercédes Benegbi from 1969, showing her using her own limb to direct the spoon to her mouth (Illustration 7).⁸³ Alvin recalls that eating with his feet, which was only allowed during dinner at the Toronto Rehabilitation Center would take him

⁸¹ Hall, “Habilitation of Patients with Congenital Malformations Associated with Thalidomide,” 1.

⁸² Hall, “Habilitation of Patients with Congenital Malformations Associated with Thalidomide,” 9.

⁸³ The image, was part of an uplifting article meant to reassure Canadians that the thalidomide children who had reached school age were adjusting well with the help of medical professionals, which will be discussed in Chapter Three.

about six minutes, whereas eating lunch and breakfast, when he was forced to use his arm prosthetics, would take him over an hour, turning these meals into an ordeal.⁸⁴ While Alvin was perfectly able to feed himself, using his feet and legs, he spent copious amount of time in rehabilitation facilities because his approach to eating with his feet was differed and thus viewed as in need of repair. Indeed, the negative impact some rehabilitation procedures had on thalidomiders is something that Stephens and Brynner capture in their following statement in regard to forced use of prosthetics: “It is hard to exaggerate the psychological damage inflicted by these years of futile effort. It was a hideous and almost universal mistake that undoubtedly diminished their lives and haunted some victims as their first failures – theirs because, of course, it *couldn't* be the experts' fault” [Emphasis in the original].⁸⁵

⁸⁴ Interview conducted on February 14, 2017.

⁸⁵ Stephens and Brynner, *Dark Remedy*, 113.



s bras
Elle
l'une
sser à
Man-
le sol
pieds
ouvoir
age 56

A voir Judith Pilote, âgée de 2 ans et demi, on ne dirait pas qu'elle a dû passer sa première année de vie alitée et immobile.

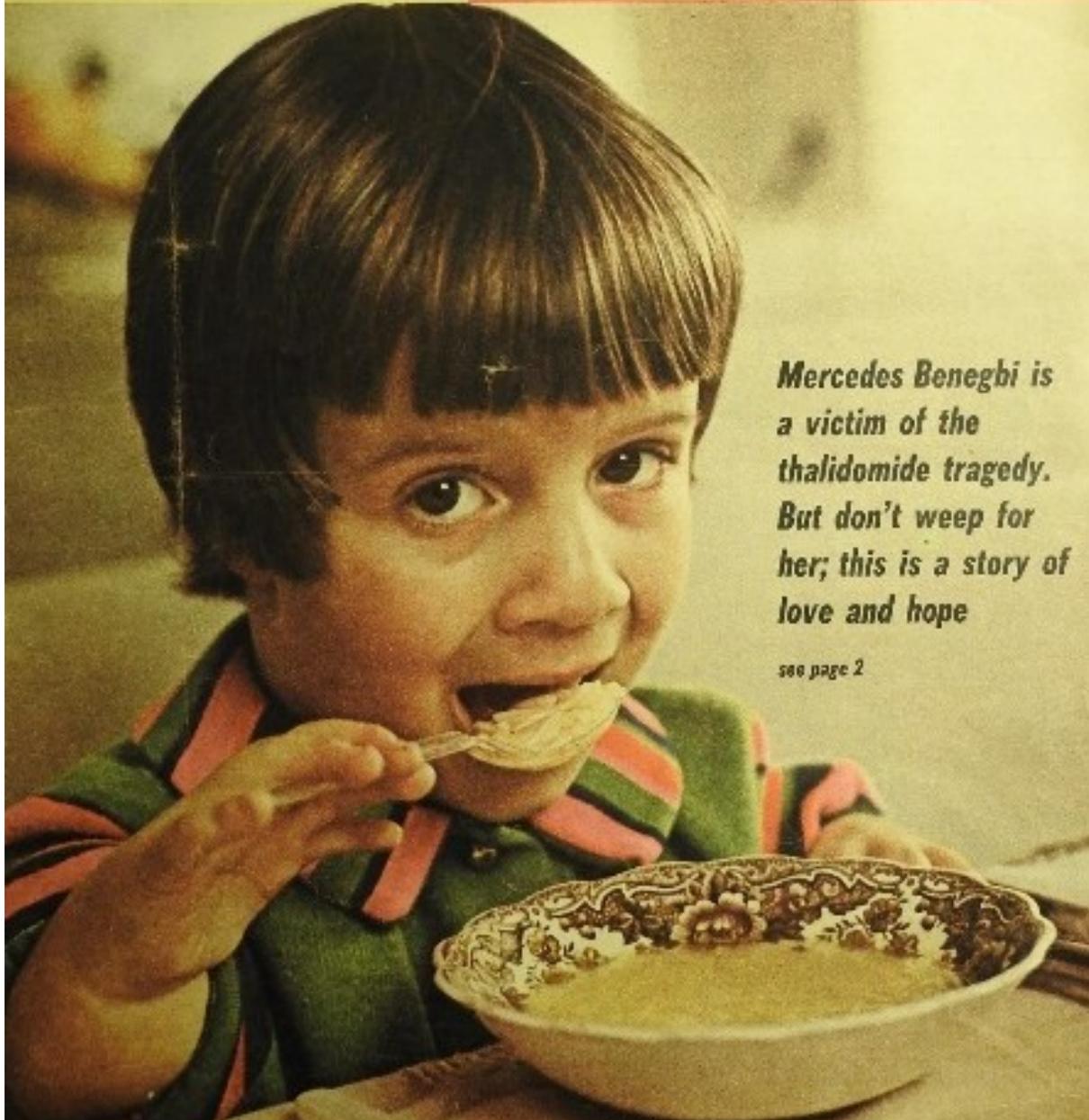
Illustration 6: In comparison, thalidomider Judith eating with artificial arm. The caption reads: “To see Judith Pilote [sic] aged two-and-a-half, no one would say that she had to spend her first year of life lying motionless.” The image and its caption suggests, incorrectly, that Judith gained a measure of independence through the use of her artificial arms. Source: Ian Adams, “There is Hope – and Help – for Thalidomide Babies,” *Weekend Magazine* (newspaper clipping, unknown date, circa 1965). Photo by Bert Beaver.

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Weekend Magazine



*Mercedes Benegbi is
a victim of the
thalidomide tragedy.
But don't weep for
her; this is a story of
love and hope*

see page 2

Illustration 7: Canadian thalidomider Mercedes Benegbi eating without the help of artificial limb. Source: Charlie King, *Weekend Magazine*, Feb. 15, 1969.

Besides mealtimes, an additional challenging experience that thalidomiders shared relates to their subjection to the medical gaze. The thalidomide children underwent medical examinations in auditoriums while large groups of doctors, nurses and therapists watched. The experience of being on display is captured in the following statement: “They had a grand stand of doctors. So you would walk in and they would have a round stage [...] and there would be the doctors, and our mother would be there too.”⁸⁶ The children were quite literally put on a stage to perform their disability in front of doctors and medical professionals. Indeed, the experience of being subjected to the medical gaze was recalled in even grimmer memories of having their pictures taken for medical records and publications, in the form of individual portraits or to document thalidomiders’ bodies being manipulated in a process of ‘normalization’. Susan describes the process this way: “A lot of times when we got our pictures taken, we had to go [...] down these stairs into a basement, there was a large workshop there and the man that was taking the pictures, I referred to him as the gnome, he was really short and kind of hunched over and he was creepy [...] and ahm, I felt objectified, you know, there is no question about it.”⁸⁷ The twins remember being on display. Peter explained to me: “They took nude pictures of us. They’d put us on a table and hold us up and take nude pictures of us.”⁸⁸ Paul, unlike his twin and Susan, emphasised that the children, at least when they were a little older, tried to exert some control over the experience: “We’d use to have these cubicles that we would walk into and they’d have a table were they’d say ‘Okay, take your clothes off.’ But we were like ‘No, we will keep our underwear on.’”⁸⁹ Nonetheless, nude images of older children also appeared in medical

⁸⁶ Paul Settle, Personal Interview, January 14, 2017.

⁸⁷ Susan Wagner-White, Personal Interview, January 19, 2017.

⁸⁸ Peter Settle, Personal Interview, January 14, 2017.

⁸⁹ Paul Settle, Personal Interview, January 14, 2017.

publications, demonstrating that resistance was not always effective (Illustration 8).⁹⁰

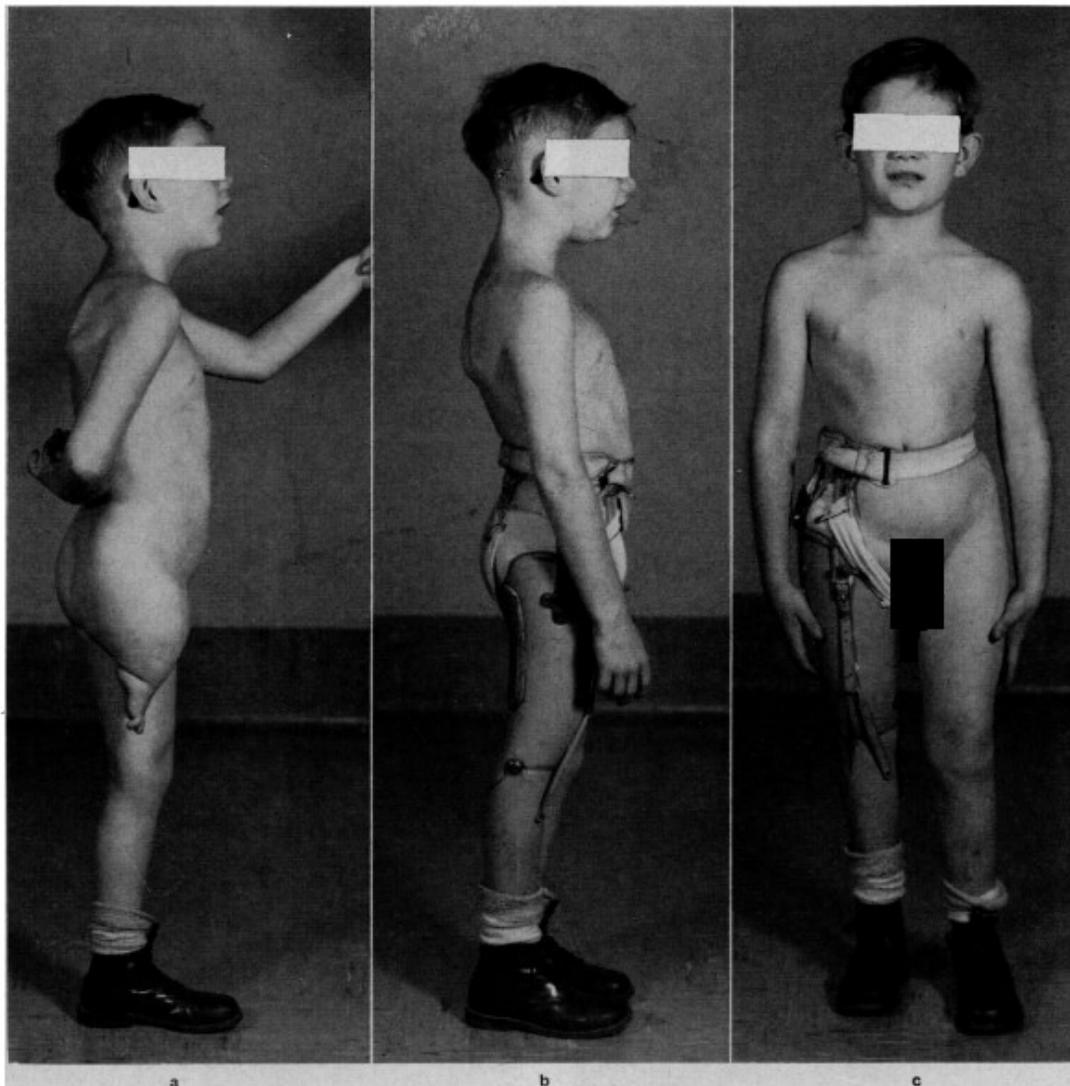


Fig. 5a, b and c.—This lad has phocomelia of his right leg. He has been fitted with a limb similar in many ways to the standard above-knee type of prosthesis with a slightly higher lateral wall to give him more stability.

Illustration 8: Pictures of a naked boy published in a medical article discussing developments in prosthetic technologies that would supposedly be applicable for thalidomide children. The image depicts the boy with and without his leg prosthesis. Interviewees have confirmed that they were photographed in the exact same positions. Disturbingly, the image captures not only the boy's impairment, it also exposes his genitals in the frontal view of the original image. Source: John E. Hall, "Habilitation of Patients with Congenital Malformations Associated with Thalidomide: Surgery of Limb Defects," *Canadian Medical Association Journal* 88 (1963): 968.

⁹⁰ The reproduction of the image of a naked boy here threatens to reproduce the staring and abjection the children were subjected to when the images were initially taken. I have chosen to manipulate the image to obscure the boy's genitals, but it was the short limb that resulted in the scrutiny imposed on this bodies. I have chosen to include the image, because such photographs themselves are a long-term consequence of the tragedy and represent important evidence of the way disabled bodies were viewed. Indeed, the inclusion of the image may make visible the way staring occurs.

In her renowned study *On Photography*, writer, filmmaker, and political activist Susan Sontag discusses how photographing someone or something can be an exertion of power. She writes: “To photograph is to appropriate the thing photographed. It means putting oneself into a certain relation to the world that feels like knowledge – and therefore, like power.”⁹¹ In the case of the thalidomiders, the processes of being photographed and brought into an auditorium for display purposes were experiences of being stared at that threatened to reduce them to a state of abjection. Kristeva writes: “Voyeurism is a structural necessity in the constitution of object relation, showing up every time the object shifts towards the abject.”⁹² The thalidomide children were literally subjected to the medical gaze, not, for the most part, because of medical need, but because their bodies did not meet the expectation placed on functioning bodies and were therefore perceived as threatening to social order.

In addition to photographs and medical examinations, thalidomiders were pressured to undergo unnecessary surgical procedures. One extremely disturbing example of how the medical profession’s putative failure “haunted” children is the story of Randy Warren, the son of a Canadian military officer who had been stationed in the 1960s in Soest, West Germany. Randy had been born with short arms, four fingers on each hand, feet attached to his hips and stomach malformations.⁹³ He spent large portions of his young life in Montreal’s Shriners’ Hospital, where he began cutting his legs with a razor blade in order to avoid being forced into his artificial legs. When doctors planned another surgery to cut off his feet, he refused to eat and even threatened suicide.⁹⁴ Given his experience, and taking into consideration that there are

⁹¹ Susan Sontag, *On photography* (London: Penguin, 1977), 4.

⁹² Julia Kristeva, *Powers of Horror: An Essay on Abjection* (New York: Columbia University Press, 1982), 46.

⁹³ Colin McGregor “A Thalidomide Baby’s Story: Guilt at Being Whole,” *The Social Eye*, accessed April 30, 2017, <http://tse2015.ca/2016/05/13/a-thalidomide-babys-story-guilt-at-being-whole/>.

⁹⁴ Stephens and Brynner, *Dark Remedy*, 116.

many others who felt that the reach of the medical profession into their lives, and more specifically onto their bodies, had a drastically negative impact, it is reasonable to question how this disconnect between the aim to “expiat[e] medicine’s sins to these children” and the continued failure of the medical profession to alleviate or prevent harm done to them was allowed to occur.⁹⁵

Ultimately, the experiences of thalidomiders demand questions about whom these prosthetics were actually helping. Imagining the thalidomide children eat without the help of prosthetics (which emulated the arms of a non-disabled person) or accepting that a thalidomide child might prefer his body over the body he could have with medical intervention had the potential to disrupt the perceived superiority of able-bodied onlookers. Disability scholar Ingunn Moser discusses how rehabilitation measures serve those confronted with disabilities to define what it means to be a human. She writes: “Rehabilitation is essentially about the question of what is ‘human’. It is a discourse and practice that in everyday situations and confrontations constitutes what it means to be an ‘able’ and ‘competent’ person. Currently, this is achieved by normalisation.....[T]he definition of ‘the human’ as that which is ‘normal’ leads to a sharp delimitation and exclusion of that which is not normal.”⁹⁶ We see then, that the insistence on prosthetics and other unnecessary medical procedures was likely a result of social assumptions that perceived the thalidomide bodies as being problematic. The vigor with which thalidomide children were pressured in medical institutions speaks to the vulnerability of society when it is faced with disability, rather than the actual need of the thalidomide children.

Instead of unusual occurrences, medical visits became part of ordinary life. There was

⁹⁵ Stephens and Brynner, *Dark Remedy*, 113.

⁹⁶ Ingunn Moser, “Against Normalisation: Subverting Norms of Ability and Disability,” *Science as Culture* 9, no. 2 (2000): 206.

never a clear end to the rehabilitation of their impaired bodies nor was a precise method of determining what, exactly, constituted successful rehabilitation ever provided. This made it difficult to distinguish between patient and non-patient experiences. For this reason, the definition of “rehabilitation” for thalidomiders and their families was unclear, muddled by questions of identity and self-perception. It would be extremely problematic to view thalidomiders’ lives as defined by their role as patients even though some remained in the care of the medical profession throughout much of their lives, because visits to medical facilities did not necessarily mean that these individuals considered themselves in need of medical attention. Here we see how disability scholarship can usefully intersect with medical patient histories. Disabled bodies, more so than sick bodies, provide historians with the possibility to critically assess medical ideas of what constitutes successful treatment and to reflect clearly on the social discourses that shape notions of what bodies are perceived as normal. Catherine Kudlick has rightfully pointed out that “Disability historians are in a unique position to frame ‘cure’ as a fragile promise, more a belief than a certainty, a driving force that determines everything from individual attitudes to spending priorities to the way social structures do and don’t deal with disabled people.”⁹⁷ The solution offered to thalidomiders to address their disabilities was certainly not a cure for the short limbs of thalidomiders. Instead, the prosthetics and the funding channeled into research and rehabilitation programs were markers of how the thalidomide bodies were *perceived* of in Canadian society at the time. The efforts to make thalidomide bodies ‘normal’ demonstrate how genuine attempts to help these children intersected with political ideas about acceptable bodies. Within this context, the thalidomide children themselves often developed their own benchmarks of what their bodies were capable of.

⁹⁷ Catherine Kudlick, “Comment: On the Borderland of Medical and Disability History,” *Bulletin of the History of Medicine* 87, no. 4 (December 20, 2013): 544.

Most of the children were not alone in navigating their experiences with the rehabilitation programs. One experience thalidomiders shared as a group was that they moved in and out of the patient role intermittently during their childhoods. Besides brief and lengthy stays at clinics for prosthetic fittings, surgeries, and rehabilitation, thalidomiders also negotiated patient experiences at home, as they left the hospitals and clinics with different bodies after amputations, with new technological extensions of their bodies, or with ongoing health struggles. Although Chapter Four will focus on domestic settings and family life, it is impossible to separate the experiences of the children in the rehabilitation centres from their home environments where they continued to practice using their prosthetics under the watchful eyes of parents, guardians and siblings. Doctors were aware of the importance to gain the support of parents in their efforts to rehabilitate the children. In 1958, Doctor MacDonell published the results gained from a clinical study that he had conducted at the Area Child Amputee Clinic at Grant Rapids. In the report he suggested that the “parental acceptance of early fittings has been excellent.”⁹⁸ Susan, one of the thalidomiders interviewed for this study, recalls, that “they told my parents, and this is how they got – you know – the agreement to do it, was that it would make my life better. Yeah. It would make my life better and I would be more normal.”⁹⁹ The bodies of thalidomiders had marked them as abnormal, in need of adjustment.

As expected by doctors responsible for overseeing thalidomiders’ rehabilitation process, parents did encourage their children to use their prosthetics in the hopes that doing so would help their child succeed in life. Paul remembers how his parents implemented training that had been suggested in the rehabilitation institute for his twin brother, Peter, who had only one long leg:

My parents had a picnic bench and they had two-seat benches, they were long

⁹⁸ J. A. Macdonell, “Age of Fitting Upper-Extremity Protheses in Children; a Clinical Study,” *The Journal of Bone and Joint Surgery. American Volume* 40–A, no. 3 (June 1958): 655–62.

⁹⁹ Interview conducted on December 13, 2016.

and you could move them. It wasn't a permanent picnic table. My parents used to take the long benches that you sit on. One here and one here. And Peter would be with his artificial leg [Paul demonstrates how little Peter would have used a bench on each of his sides to help himself stand up and move forward.] They would put a glass of water at the end and if he wanted a glass of water he had to go down and get it. And he was mad because if it was juice or water or whatever it was, he wanted it and he would ache about it. 'I want it, I want it.' And I guess one of the neighbours came over and said 'that is so cruel what you are doing to your kid.'¹⁰⁰

Both twins assured me that they understood that their parents had their son's best interest at heart. Similarly, Susan's parents encouraged her for a long time to use her prosthetic arms, trusting in and extending the doctor's advice and rehabilitation center's regimen at home, despite Susan's displeasure. Such efforts were approvingly acknowledged by the doctors at the Rehabilitation Institutes. Dr. Davidson, medical director at the Crippled Children's Center in Toronto, stated that: "The parents are an excellent group: they are co-operative and have a good understanding [...]."¹⁰¹ What parents were, for the most part, unable to anticipate was that, in the words of Professor of Anatomy and Embryology Trent Stephens, and historian Rock Brynner: "The artificial limbs were among the greatest sources of misery for almost all the victims, and consumed much of their young lives while remaining, for all but a few, completely useless."¹⁰²

While many parents collaborated with doctors whom they trusted, they also needed to negotiate the discomfort of their children. When Alvin would arrive home from his usually three to six-week stays at the rehabilitation center, his mother would take off the painful and enclosing prosthetic arms, throw them in the closet and send him out to play.¹⁰³ In fact, families, at times, challenged physicians' authorities in different ways after witnessing the children's misery. They

¹⁰⁰ Paul Settle, Personal Interview, January 14, 2017.

¹⁰¹ "Drug Victims Learn to Live," *Hamilton Spectator*, April 21, 1964.

¹⁰² Stephens and Brynner, *Dark Remedy*, 113.

¹⁰³ Alvin Law, "Thalidomide: Some Truth," 09 March 2015. <https://alvinlaw.com/2015/03/09/thalidomide-some-truth/>.

did so, not by directly addressing the doctors, but by modifying daily approaches to so-called rehabilitation. This affirms Mona Gleason's observation about the lives of children who were ill, namely that "children and their families complied with, and troubled, the desires of experts, variously supporting, interrupting, rejecting, and transmuting their attempts at embodied management."¹⁰⁴ The role parents took in the rehabilitation treatment of their children emphasizes the importance of de-centering the importance placed on doctors and medical institutions often found in medical histories. This builds on Joan Lynaugh argument that medical historians need to de-center and stop privileging doctors' diagnoses when attempting to understand the history of illness experience.¹⁰⁵ Nursing historian Karen Buhler-Wilkerson concurs, stating medical diagnoses have little saliency in the home because they do not effectively help to negotiate a patient's experience outside a medical environment.¹⁰⁶ A broader approach to studying medical treatment that includes domestic environment helps provide nuance to historians' understanding of rehabilitation histories.

In many cases, there was undoubtedly a shared interest in the well-being of the children, shared by parents and doctors at the rehabilitation institutes, that came from a place of concern and care. One man recalls his challenging experiences in the rehabilitation center by emphasizing the well-meaning nature of the medical personnel he encountered there, including some doctors but also nurses and physio-therapists: "They were not bad people, they were just doing a job I could not relate to. [...] I was never treated inappropriately; [they] treated me with respect. I think it was just a really tough spot for all of us to be in. I don't know that a lot of them felt

¹⁰⁴ Mona Gleason, *Small Matters: Canadian Children in Sickness and Health, 1900-1940* (Montreal and Kingston: McGill-Queen's Press - MQUP, 2013), 20.

¹⁰⁵ Joan E. Lynaugh, "Nursing the Great Society: The Impact of the Nurse Training Act of 1964," *Nursing Hist. Rev.* 18 (2008): 13–28, as quoted in Fairman and D'Antonio, "Reimagining Nursing's Place" (n. 111), 436.

¹⁰⁶ Karen Buhler-Wilkerson, *No Place Like Home: A History of Nursing and Home Care in the United States* (Baltimore: Johns Hopkins University Press, 2001).

comfortable pushing the prosthetics, that's just the way the policies went at the time.”¹⁰⁷ Note that, instead of being a medical issue, prosthetics are described as a political issue. The efforts to provide children with prosthetics despite the discomfort many experienced during fittings and practice seems to have been based on the honest, if in many cases misguided, belief that this was in the best interest of the children.

Despite good intentions, negotiations between parents, the federal government, the medical and scientific communities, and the still very young disabled individuals themselves regarding the perceived needs of children with disabilities often failed. Collaboration in the name of providing thalidomide children with the best care possible was unquestionably difficult given that assumptions about what constituted ideal measures differed not only between the adults involved, but also between adults and the children. The significance of thalidomiders' problematic experiences in the rehabilitation centers underlines that evaluating government funding is central to understandings of the socially condoned policing of disabled bodies. When tabling the report of the Expert Committee on the Habilitation of Congenital Anomalies Associated with Thalidomide in January 1963, the Honourable Monteith noted that “The committee also considers that the whole problem of the training of prosthetics should be reviewed [...]”¹⁰⁸ Yet, despite the explicit awareness that further reviews were needed, thalidomide children served many years as test subjects for the prosthetics and rehabilitation measures that were being funded – a process that extended beyond the rehabilitation centers themselves and reached into private household and schools.

¹⁰⁷ Alvin Law, Phone Interview, February 14, 2017.

¹⁰⁸ Hon. J. W. Monteith, House of Commons [HC] Debates, 25th Parliament, 1st Session, Minutes (25 January 1963), 3109.

The experiences in the Prosthetic Research and Training Units had a profound impact on the young thalidomiders. Alvin now says this about his time in the rehabilitation programs: “It wasn’t something that I was in denial about, but I had no reason to want to remember that. [...] You know, you try to forget a bad thing in your life, and you put it out of your mind.”¹⁰⁹ While trying to forget the experience may have been a strategy some used as they were older and no longer attended the programs, the programs and institutions definitely had implications for the ways the children learned to think about themselves during their times there. Some thalidomiders say they were forced to accept a perception that their body was not sufficient.¹¹⁰ Despite the pervasiveness of this message, most children resisted the prosthetics early on and fully rejected them in their later teens. The inconvenience and pain resulting from the prosthetics and their fitting ensured, paradoxically, that instead of making the thalidomide bodies whole, the prosthetics fostered certainty that their thalidomide-affected bodies were a superior version of themselves.¹¹¹ The perceptions thalidomiders formed about their bodies during their years in the rehabilitation programs remained significant throughout much of their lives, as will become apparent in the following chapters.

Listening to thalidomiders’ experiences with prosthetics reveals that doubts projected onto the children’s bodies and reservations in regard to their capabilities were mostly unwarranted and seemed to serve the purpose of making the *social environment* more comfortable with the disabled children in their midst rather than improving the lives of the

¹⁰⁹ Alvin Law, Phone Interview, February 14, 2017.

¹¹⁰ Interview conducted on January 19, 2017.

¹¹¹ It needs to be noted, however, that it is easy to overstate such confidence in their bodies. Still ingrained in some minds to this day is the notion that certain actions look weird or awkward, and are accompanied with shame; some do not like to eat or smoke using their feet, while others feel uncomfortable hugging because they do not have the arms to embrace the other person in the same way as an individual with long arms. This is one of the long-term consequences, not of the drug itself but of the socio-cultural disablement that was strengthened through the medical ideologies that were (and in many cases still are) dominant.

thalidomiders. This idea was similarly expressed by historian Henri-Jacques Stiker who writes: “Rehabilitation marks the appearance of a culture that attempts to complete the act of identification, of making identical. This act will cause the disabled to disappear and with them all that is lacking, in order to assimilate them, drown them in the greater and single social whole.”¹¹² Instead of allowing the thalidomide children to practice every-day tasks using their own bodies, the medical profession attempted to make the thalidomide bodies fit ‘normal’ expectations. The rejection of prosthetics, and thereby the rejection of one body shape as being superior over others, was not only a dismissal of societal expectations, it also meant the opening up of new possibilities and ways of understanding how to negotiate their environment. By rejecting the medical approach to their bodies pursued by the medical profession and supported, to an extent, by parents, thalidomiders chose to leave the path envisioned for them. They rejected the “drive” to create “normal” bodies and pursued lives lived by their own standards of how their bodies should function.

It is certain that understanding the state’s and the medical profession’s shared aim of rehabilitating thalidomiders is only one side of the coin. As medical historian Daniel J. Wilson put it, “A full history of asylums and rehabilitation hospitals needs to take into account the goals and practices of the professionals running them *and* the needs, desires, and experiences of the patients who were treated there.”¹¹³ Disability scholars might add that decentering the importance of medical discourses is also key to understanding the experience of disability. The stories of thalidomiders indicate that the existence of genuine concern among rehabilitation and medical personnel does not absolve the medical profession. The challenges faced by the children

¹¹² Henri-Jacques Stiker, *A History of Disability* (Ann Arbor: The University of Michigan Press, 1999), 128.

¹¹³ Daniel J. Wilson, “Comment: On the Borderland of Medical and Disability History,” *Bulletin of the History of Medicine* 87, no. 4 (December 20, 2013): 537.

as part of the rehabilitation programs are closely connected to the federal government's choice to make rehabilitative measures and prosthetics the only consistent access point for thalidomiders and their families seeking governmental aid. The insistence of the state and doctors on rehabilitation overlooked in many instances how the *individual* children (and the thalidomide children as a group) whom they tried to help actually experienced these processes, and served instead to emphasize the *universal* applicability of the research to which funding was being committed. In the end, it is apparent that patient experiences contrasted in interesting and complicated ways with the promises of the advances in medical technologies that were federally funded in the early 1960s. While new prosthetics were being developed, the thalidomide children grew into teenagers, a period of their lives when many chose to abandon the uncomfortable, at times painful, tools that they had not wanted and found confining and impractical. In sum, rehabilitation sadly came at a high price for the individuals who were forced into the medical treatments that may have done them more harm than good.

Chapter 3: Thalidomide and Canadian Education

Thirty years ago, thousands of babies with flipper-like hands and feet squeezed out of their mother's wombs into a world that wasn't ready for them.¹

In addition to rehabilitation hospitals, another institutional setting in which thalidomiders spent significant time during their childhood and adolescence was school. For the thalidomide children, attending “normal” schools, a term used during interviews, alongside non-disabled peers, as opposed to schools specifically intended for children with disabilities, was not always the obvious option for parents. The thalidomide children's entry into public schools was part of a longer history of transition away from segregation of persons with disabilities in Canadian public institutions. In their interviews, thalidomiders emphasized that enrolling them in public school was frequently a difficult task for parents who as a consequence, inadvertently, became activists asserting their children's right to education. This chapter argues, in part, that the importance attributed to thalidomiders' access to “normal” schools is deeply political because it illuminates the hierarchical understanding of disabilities. Thalidomiders gained social capital, measured in their claim of belonging, by defining themselves as different from those with intellectual disabilities. As such this chapter builds on the insight of Josh Dohmen, who explains: “persons with different disabilities may be narcissistically wounded by and therefore also exclude others identified as disabled. A person with a physical disability may reject a person with an intellectual disability, for example, especially if the physically disabled person's intellectual prowess is central to her self-image.”² Therefore, the chapter demonstrates how thalidomiders themselves

¹ “Thalidomide kids – 30 years later,” *The Toronto Star*, February 13, 1993.

² Josh Dohmen, “Disability as Abject: Kristeva, Disability, and Resistance,” *Hypatia* 31, no. 4 (2016): 771.

experienced abject encounters that both challenged and helped position them as worthy of access to public education.

Once thalidomiders established their belonging in schools, disability nonetheless determined children's embodied experiences while there. Thalidomide children understood their own physical abilities by looking to those around them, including their non-disabled friends and foes in the schoolyard. The lived experiences of disability are always necessarily public as they depend on self-perceptions built through interpersonal-interactions. Furthermore, the chapter highlights that, although parents were instrumental in opening the doors to public education for their thalidomide-affected children, doctors continued to assert their role as intermediaries between the children and their successful participation in Canadian society, this time by paving the way for their charges' success at school. The continued involvement of doctors outside of rehabilitation institutes shows the falseness of a private/public divide, as doctors got involved in parents' decision-making regarding their children's education. By drawing on the oral history interviews, the chapter examines the ways that the thalidomide children themselves understood their participation in public schools. In doing so, this chapter gives voice to a marginalized group of Canadians whose stories about school have not yet been heard.

The history of education has produced fruitful scholarship, but the schooling of children with disabilities remains under-represented in the historiography. Thus far, book length studies have traced the history of schooling legislation in Canada.³ Furthermore, the regulation of children within Canadian schools and schooling as a moral regulator have also received scholarly

³ J. Donald Wilson, Robert M. Stamp, and Louis-Philippe Audet, *Canadian Education: A History* (Scarborough: Prentice-Hall of Canada, Ltd., 1970); F. Henry Johnson, *A Brief History of Canadian Education* (Toronto: McGraw-Hill, 1968).

attention.⁴ However, in 2006 disability historian Richard J. Altenbaugh has lamented that people with disabilities are not well-represented in the context of the history of education. In fact, he referred to them as “virtually invisible.”⁵ Within Canadian historiography, scholars such as Jason Ellis, Karen K. Yoshida, Fady Shanouda, Nick Clarke, and Mona Gleason have begun in the past decade to address this problem with important studies of education that include the voices and experiences of children with disabilities.⁶ This chapter adds to these studies the voices and stories of the Canadian thalidomiders.

Several thalidomiders recount how their enrollment in public school hinged entirely on their parents’ advocacy on their behalf. Methodologically noteworthy is that such memories are shaped by their parents’ accounts of their efforts; accounts that were shared with the thalidomiders when they were adults. Oral historians have considered the challenges of the ways the past gets re-constructed in oral narratives and how it is important to recognize that present concerns get embedded in accounts of the past.⁷ Thalidomiders who have, in some cases, been dedicated to assuage their mother’s guilt for taking the drug that resulted in their disabilities may be motivated to emphasize their mother’s actions and importance in an effort that resembles an

⁴ Bruce Curtis, *Building the Educational State: Canada West, 1836-1871* (Lewes, Sussex: Falmer Press 1988); Mona Gleason, “Disciplining the Student Body: Schooling and the Construction of Canadian Children’s Bodies,” *History of Education Quarterly* 41, no. 2 (2001): 189–215.

⁵ Richard J. Altenbaugh, “Where Are the Disabled in the History of Education? The Impact of Polio on Sites of Learning,” *History of Education* 35, no. 6 (2006): 705.

⁶ Jason Ellis, “Early Educational Exclusion: ‘Idiotic’ and ‘Imbecilic’ Children, their Families, and the Toronto Public School System, 1914–50,” *The Canadian Historical Review* 98, no. 3 (2017): 483-504. Karen K. Yoshida, Fady Shanouda, and Jason Ellis. “An Education and Negotiation of Differences: The ‘Schooling’ Experiences of English-Speaking Canadian Children Growing Up with Polio during the 1940s and 1950s.” *Disability & Society* 29, no. 3 (2014): 345-358; Nick Clarke, “Opening Closed Doors and Breaching High Walls: Some Approaches to Studying Intellectual Disability in Canadian History,” *Social History/Histoire Sociale* 3 (2006): 467–485; Mona Gleason, “Navigating the Pedagogy of Failure: Medicine, Education and the Disabled Child in English Canada, 1900 to 1945,” in *The End of Children? Changing Trends in Childbearing and Childhood*, edited by Graham Allan and Nathanel Lauster (Vancouver: UBC Press, 2012), 140–160.

⁷ Paul Thompson, “Believe It or No: Rethinking the Historical Interpretation of Memory,” in *Memory and History: Essays on Recalling and Interpreting Experience* ed. Jaclyn Jeffrey and Glenace Edwall (Lanham, New York: University Press of America, 1994), 6-7.

attempt at constructing narratives of redemption. With this caveat in mind, the emphasis on mother's efforts to include thalidomiders in public schools remain significant. While these memories may not be first-hand accounts, they are nonetheless key as they demonstrate the importance attributed by the thalidomiders and their families to parents' success at opening up this particular public space previously difficult to access for children with disabilities.

Alvin, Marie, Susan, Mercédes, Peter and Paul, all note that their parents, mainly the mothers, contacted the principal of their respective schools to make the case that their children ought to be allowed to attend public school.⁸ Paul recounts: "My mum had to fight to get us to a normal school, because this school board did not want anything to do with us. [...] My mum said, 'No, they're going to a regular school.'" In fact, the twins' mother established relationships with local politicians to be able to ensure her sons' access to public school. Knowing the mayor and city councillors helped Mrs. Settle put pressure on the school board to make sure the boys' education was made accessible in their community. Marie's mother reached out to their neighbour, who was on the local school board, and Marie too was enrolled in public school.⁹ Mercédes' mother lobbied on behalf of her daughter, as well as the other thalidomide children she often visited along with her daughter at the Montreal rehabilitation hospital, demonstrating that while a mother's activism on behalf of her own child is significant, the efforts made by parents had an impact on the rights of thalidomide children at large.¹⁰ Melanie Panitch has produced an in-depth analysis of the ways that "homemakers have become activists through the experience of having a disabled child," and the case of thalidomide children is another example

⁸ Sometimes through an intermediary such as a local politician.

⁹ Marie Olney, Phone Interview, November 13, 2017.

¹⁰ Mercédes Benegbi, Personal Interview, October 13, 2017.

that supports this observation.¹¹ As a result of such efforts thalidomide children attended local, public schools alongside their non-disabled peers.

This importance attributed to thalidomiders' access to public schools is deeply political, not only in terms of accessing public spaces and opportunities, but in its emphasis on a hierarchical understanding of disabilities. Concerns about the education available to their children demonstrate that the choice of school was not solely dictated by the question whether the thalidomide children should study in public schools alongside children without disabilities, but also by parents' insistence that their children should not be placed in the same institutions as children with *intellectual* impairments. The distinction between intellectual and physical ability has historical ties. In the late nineteenth and early twentieth century Cartesian dualism asserted that "the mind and body are distinct and coexist in a hierarchical, mind-over-body relationship."¹² This understanding proved relevant for thalidomiders. In their experiences, there was indeed a hierarchy of disabilities that placed those with minor physical disabilities, especially those who could somehow mask their physical disabilities, at the top, and those who had intellectual and mental disabilities at the bottom. Janice Brockley explains this in her work: "Physical disability, while stigmatized, was not as disturbing as intellectual disability. [...] In line with this hierarchy, those physical disabilities that appeared to have an intellectual component, such as cerebral palsy and epilepsy, were also some of the most stigmatized."¹³ The distinction of thalidomiders from those with intellectual impairments began right after their births, as a 1962 newspaper article quoted then Health Minister Matthew Daymond: "If they are normal mentally

¹¹ Melanie Panitch, *Disability, Mothers, and Organization: Accidental Activists*, New Approaches in Sociology (New York: Routledge, 2008), 3.

¹² Mona Gleason, "Size Matters: Medical Experts, Educators, and the Provision of Health Services to Children in Early to Mid-Twentieth Century English Canada" in Cynthia Comacchio, Janet Golden, and George Weisz, eds., *Healing the World's Children: Interdisciplinary Perspectives on Child Health in the Twentieth Century*, (Montreal-Kingston: McGill-Queen's University Press, 2008), 183.

¹³ Janice A. Brockley, "Martyred Mothers and Merciful Fathers," 294.

they should be given every opportunity to develop normally.”¹⁴ Discourses of normality were therefore working to distinguish not only between non-disabled and disabled members of society, but also between individuals with physical and intellectual or mental disabilities. The successful emphasis of this difference would help secure social opportunities, as the quote by Daymond makes apparent. Thalidomiders’ difference from children with intellectual disabilities was henceforth emphasized by both parents and the thalidomiders.

Emphasizing the difference between physically and intellectually disabled children was an international occurrence. Barbara Sherman Heyl has recorded the testimony of a German teacher: “Then in 1962-63 came the great medicine scandal – the sleeping medicine, Kontradon (Thalidomide), and the Kontradon children. The parents said, ‘We can’t send our children there [to the Hilfsschule that educated intellectually disabled children¹⁵].’ So the first special schools for the physically handicapped were founded!”¹⁶ In Germany, like in Canada, parents seem to have been adamant that their physically disabled children ought not to be grouped together with those that suffered from intellectual disabilities. One Canadian mother emphasized in 1962 that: “I don’t want Kim to go to an institution. She is not mentally retarded, she is as bright as a button. I think they belong in a home where they are loved and cared for.”¹⁷ Implied in this statement is that a child with mental or intellectual disabilities may be less likely to be loved and wanted within a family and therefore more likely to be institutionalized.

It is noteworthy that institutions offering schooling solely for the physically disabled existed in Canada. Tracy Odell has conducted an oral history about the experiences of physically

¹⁴ Val Sears, “Province Gets Advice on Crippled Babies,” *Toronto Daily Star*, July 31, 1962.

¹⁵ “The Hilfsschule appeared to be a dumping ground for children who did not keep up or did not conform. It was negatively stigmatized as a place for children from the lower classes whom school authorities viewed as unruly, slow, or troublesome.” Cited in Barbara Sherman Heyl, “Parents, Politics and the Public Purse: Activists in the Special Education Arena in Germany,” *Disability & Society* 13, no. 5 (November 1, 1998): 705.

¹⁶ Barbara Sherman Heyl, “Parents, Politics and the Public Purse,” 688.

¹⁷ “Form association to fight for aid, drug baby's father urges parents,” *The Globe and Mail*, July 31, 1962.

disabled children (of whom she herself had been one) who attended the Bloorview Hospital, Home and School, located in Toronto, between the years 1960 and 1989. She writes that “Bloorview admitted children with physical disabilities from across Ontario, Canada in order to provide care, treatment and education that were not offered to children who remained at home.”¹⁸ In fact, the Bloorview Hospital (which changed its name several times between the late 1950s and mid-1970) was the same institution that, in 1962, became the home of the Ontario Crippled Children’s Centre, the rehabilitation institute that Susan, Peter, Paul, and other thalidomiders attended in Toronto. Odell’s study, however, includes participants who lived at Bloorview full-time for a minimum of two years. She suggests that parents actually chose to send their children there because they had been told that schooling would be made accessible for their children. Odell concludes that segregated education was not ideal in comparison to attending public schools: “Thirteen respondents expressed dissatisfaction with the quality of Bloorview’s school experience, especially when accessible schooling had been given as a key reason for their admission. The respondents who went to school in the community, either before arriving at Bloorview or during their stay there, had generally positive comments to make about their integrated experience.”¹⁹ While oral testimonies indicate that schooling there did not compare favourably to integrated education in public schools, this example of the Bloorview Hospital, Home and School, as analyzed by Odell, is relevant to this study because it shows that the parents of thalidomiders who did not want their physically disabled children segregated to institutions that would place them together with children with intellectual disabilities potentially had the option of choosing an institutional setting solely for the physically disabled. Bloorview

¹⁸ Tracy Odell, “Not Your Average Childhood: Lived Experience of Children with Physical Disabilities Raised in Bloorview Hospital, Home and School from 1960 to 1989,” *Disability & Society* 26, no. 1 (2011): 50.

¹⁹ Odell, “Not Your Average Childhood,” 51, 61.

actually conducted pre-admission testing to screen out children with an Intelligence Quotient (IQ) considered low (below 80,4) to, in the words of Odell, “retain the integrity of the facility as a place for children with physical disabilities.”²⁰ It is likely that Bloorview was not considered an option by the parents of thalidomiders because it involved full-time institutionalization. Indeed, as will be discussed in the next chapter, influenced by shifting social discourses regarding the importance of families and, potentially, due to political considerations regarding the expense caring for thalidomide children could potentially impose on the welfare state, doctors encouraged the integration of the thalidomide children within their families, albeit it under the watchful eyes of the medical profession.

Thalidomide parents’ activism was part of a larger move to integrate children with physical disabilities within the public educational system.²¹ When, in the 1940s and 1950s, the Canadian public school system was confronted with an influx of disabled children as a result of the polio epidemic, no consistent approaches for educating disabled children existed. While “auxiliary education” (the term used at the time) was addressed sporadically in education legislation in the first half of the twentieth century, as has been outlined by historian Jason Ellis, many schools in the 1940s and 1950s continued to developed their own informal accommodations.²² By the late 1940s and the 1950s the idea of extending educational

²⁰ Odell, “Not Your Average Childhood,” 51.

²¹ For a discussion of how physical disabilities were treated in the school system before the de-segregation movement, see Jason A. Ellis, “Chapter 5. ‘Mental equality where physical equality has been denied’: orthopaedic and sight saving classes in Toronto schools, 1920-1945,” in *‘Backward and Brilliant Children’: A Social and Policy History of Disability, Childhood, and Education in Toronto’s Special Education Classes, 1910 to 1945* (PhD Dissertation, Department of History, York University, 2011), 254-300. And Jason Ellis, “Early Educational Exclusion: ‘Idiotic’ and ‘Imbecilic’ Children, their Families, and the Toronto Public School System, 1914–50,” *The Canadian Historical Review* 98, no. 3 (2017): 483-504.

²² Jason Ellis, “Early Educational Exclusion: ‘Idiotic’ and ‘Imbecilic’ Children, their Families, and the Toronto Public School System, 1914–50,” *The Canadian Historical Review* 98, no. 3 (2017): 484; Karen K. Yoshida, Fady Shanouda, and Jason Ellis, “An Education and Negotiation of Differences: The ‘Schooling’ Experiences of English-Speaking Canadian Children Growing Up with Polio during the 1940s and 1950s,” *Disability & Society* 29, no. 3 (2014): 349.

opportunity to all children started to truly take hold in Canada, and the idea of integrating children with disabilities into mainstream schools was reflected in school reforms. Karen Yoshinda, Fady Shanouda, and Jason Ellis, who have studied the experiences of polio survivors in Canadian public schools, note that after 1945 Canadian “school reform extended educational opportunity [...] by expanding special education services for Canadian children with disabilities.”²³ However, Ellis cautions that it was not until the 1960s that effective strides towards de-segregation within public schools were made.²⁴ Nonetheless, the example of polio survivors demonstrates that even before the thalidomide children were born, the integration of physically disabled children in schools was well under-way. Yoshinda and her colleagues write: “new discourses of educational opportunities were being implemented that expected children with disabilities to participate in schooling just like every other child.”²⁵ De-segregation in education was part of an ideological shift that has been described by disability scholars Roy Hanes and Allan Moscovitch as follows: “For many decades, particularly in the post-World War II era until the 1960s, government policy was primarily directed by policies that more or less focused on the development of institutional/segregated programs for people with disabilities – special schools, hospitals, training programs, educational programs, etc. Gradually there was a shift in ideology to one that challenged the dominant theme of segregation and resulted in a greater focus on policies directed at integration of people with disabilities.”²⁶ What will become apparent in the discussion below is that at least some of the thalidomide children felt that their

²³ Karen K. Yoshida, Fady Shanouda, and Jason Ellis, “An Education and Negotiation of Differences: The ‘Schooling’ Experiences of English-Speaking Canadian Children Growing Up with Polio during the 1940s and 1950s,” *Disability & Society* 29, no. 3 (2014): 348.

²⁴ Ellis, “Early Educational Exclusion,” 503.

²⁵ Yoshida, Shanouda, and Ellis, “An Education and Negotiation of Differences,” 356.

²⁶ Roy Hanes and Allan Moscovitch, “Disability Supports and Services in the Social Union,” in *Federalism, Democracy and Disability Policy in Canada*, Alan H. Puttee, ed., 121-152 (Montreal: McGill-Queen's University Press, 2002), 134.

inclusion into ‘normal’ classes was central to their identity. Both the parents’ and the thalidomiders’ motivation behind ensuring and emphasizing their belonging in ‘normal’ classes will be discussed below.

In contrast to Canada, in countries such as the United Kingdom and Germany, segregated learning environments were a common experience for thalidomide children and were welcomed by many parents. Ramesh, who grew up and attended a school specifically for disabled children in the United Kingdom before moving to Canada, found that the type of schools many parents sought to avoid for their children in Canada, referred to in the interviews as “special schools”, was actually a positive environment for him. He feels that his education was well served.²⁷ However, the “special schools” were not always appreciated by Britons. In an oral interview conducted with British thalidomiders, Simone Baker recalls her mother’s attitude: “So she couldn’t understand why I had to be in this special school at all. And they said, ‘No, you’re doing the wrong thing if you take her out of here,’ you know. ‘We need to make sure she’s properly looked after’ and my mum had a real battle to get me out of that school and into a regular primary school.”²⁸ The interview, conducted by Ruth Blue, does not, unfortunately, indicate why the mother felt so strongly about resisting her daughter’s enrollment in a school specifically for disabled children, a form of education Ramesh’s parents had embraced. Although the Canadian case is distinct in many ways, the thalidomide tragedy in this country was nonetheless part of an international event that produced similar questions about the best way to raise and educate their children among parents across national borders.

²⁷ Ramesh Lad, Phone Interview, February 22, 2017.

²⁸ Ruth Blue interviewed Simone Baker for *Thalidomide: An Oral History (16 Series record levels.)* (London, England: Wellcome Library).

The inclusion of the thalidomide children in public schools, whether their memories of the experience were positive or negative, was part of a larger politically-charged history. In 1975, special education teachers Jack Birch and Kenneth Johnstone argued in the American context that the matter of disability inclusion in educational institutions was of national interest.²⁹ Disability scholar Wa Munyi elaborates: “The greatest challenge in education today [...] is ensuring that all schools are as readily and fully accessible to persons with disabilities as to the non-disabled. From every standpoint, whether that of human rights, economic efficiency, or social desirability, the national interest should be to serve children with disabilities equally with all others.”³⁰ Indeed, Birch travelled internationally to promote his conviction that disabled children ought to be allowed to “display skills society assumed they were incapable of developing.”³¹ In the long term, the inclusion of thalidomiders in public schools was in line with the general political developments in Canada regarding the treatment of individuals with disabilities that eventually culminated in ideas foregrounding social inclusion.³² In 1996 the *Equal Citizenship for Canadians with Disabilities: The Will to Act* (Canada 1996a), a report prepared by the Federal Task Force on Disability Issues, “argued strongly for a renewed leadership role by the Government of Canada on disability issues.”³³ In 1998 the shared statement by federal and provincial governments, as well as territorial social service ministers and governments, titled *In Unison: A Canadian Approach to Disability Issues* (Canada 1998),

²⁹ Jack Birch and Kenneth Johnstone, “Mainstreaming a New Public Policy in Education,” *Annual Convention of the American Association of School Administrators* (Dallas, Texas: 1975). Cited in Chomba Wa Munyi, “Past and Present Perceptions Towards Disability: A Historical Perspective,” *Disability Studies Quarterly* 32, no. 2 (April 9, 2012): Education.

³⁰ Munyi, “Past and Present Perceptions,” Education.

³¹ Cecil R. Reynolds, Elaine Fletcher-Janzen, and Kimberley J. Vannest, *Encyclopedia of Special Education: A Reference for the Education of Children, Adolescents, and Adults with Disabilities and Other Exceptional Individuals / Volume 1* (New Jersey: Wiley, 2014), 298.

³² Of course, this is a matter of ongoing political activism and work.

³³ Michael John Prince, *Absent citizens: Disability Politics and Policy in Canada* (Toronto: University of Toronto Press, 2009), “Political Context”.

noted the vision of full participation of persons with disabilities in all segments of Canadian life.³⁴ Since then further political initiatives have pursued the same goal. What can surely be argued is that by including children with disabilities in public schools and “normal classes,” the thalidomide children’s experience of public schooling is a mark of the move away from the segregation of persons with disabilities.

Yet, even as thalidomiders were integrated in public schools, the distinction between intellectual, mental, and physical disabilities, raised when they were born and when they first entered the schools, continued to matter. This has historical parallels to polio survivors who used intellectual endeavours to compensate for physical disability.³⁵ During the interviews, the thalidomiders contrasted mental illnesses sharply against the experiences of living with physical disabilities.³⁶ Physical and mental impairments were not viewed or experienced by thalidomide children as being on a spectrum of ability, rather they were perceived, at least by some, as distinctly different, with the former being superior to the latter. Drawing this distinction helped thalidomiders affirm their self-image as competent and as belonging with their non-disabled peers. Indeed, Dohmen acknowledges this phenomenon: “abject encounters with others identified as disabled may also serve as opportunities to form new identifications. By opening up the imaginary space in which boundaries are blurred, the abject might provide the impetus for forming new boundaries, for identifying (oneself and others) differently, for problematizing the slippery associations between others with whom one disidentifies.”³⁷ Drawing parallels between physical and mental illness was perceived as problematic by several of the participants; a form of

³⁴ Michael John Prince, *Absent Citizens: Disability Politics and Policy in Canada* (Toronto: University of Toronto Press, 2009), “Political Context”.

³⁵ Daniel J. Wilson, *Living with Polio: The Epidemic and Its Survivors* (University of Chicago Press, 2005), 169.

³⁶ I choose here to adopt the language of the interviewees, using mental illness as opposed to newer designations such as intellectual impairments etc.

³⁷ Josh Dohmen, “Disability as Abject: Kristeva, Disability, and Resistance,” *Hypatia* 31, no. 4 (2016): 773.

dis-identifying from the ‘other’. For example, Peter and Paul remember their negative reaction to the change in school board policy that required them to take the yellow bus with children with cognitive disabilities: “And then all of a sudden they got this idea that we’re going to yellow bus them with other disabled children. Right? Well these other disabled children were mentally challenged. A lot of retarded children. You don’t use that word anymore. [...] We felt offended. We did. This car-load of children that were screaming, yelling, and spitting and drooling and we found nothing good about being with this group. We tried, but they were in another world.”³⁸ By the 1960s, disability activism may have begun working on changing social perceptions of disability, yet specific types of disability remained stigmatized in significant ways, based on individuals’ perceived ability to contribute to society. Clearly, some of the thalidomiders found it helpful to define their disability against intellectual disabilities to underline their distinct status in their community and school environments. Given normative assumptions about disability, there was social capital to be lost if the thalidomide children did not distinguish themselves from those defined as having intellectual disabilities.³⁹ Social capital refers here to the measure of humanness attributed to a person, measured on perceptions of ‘normalcy’. Emphasizing their belonging ‘in this world’ with non-disabled peers by suggesting the exclusion of children with intellectual disabilities to a different realm of existence served to stress thalidomiders’ humanness. Sociologist Ingunn Moser writes that “the definition of ‘the human’ as that which is ‘normal’ leads to a sharp delimitation and exclusion of that which is not normal.”⁴⁰ By

³⁸ Paul and Peter Settle, Personal Interview, January 14, 2017.

³⁹ Nic Clarke has considered the impact of such ideas on families with children with intellectual disabilities. His work on the history of British Columbia demonstrates the struggles of parents of “mentally deficient” children and their advocacy that opposed institutionalization. Clarke’s book thereby demonstrates the ways in which such hierarchies could have a profound impact on individuals and their families. See Nic Clarke, “Sacred Daemons: Exploring British Columbian Society’s Perceptions of ‘Mentally Deficient’ Children, 1870-1930,” *BC Studies*, no. 144 (Winter /2005 2004): 61–89.

⁴⁰ Ingunn Moser, “Against Normalisation: Subverting Norms of Ability and Disability,” *Science as Culture* 9, no. 2 (2000): 206.

emphasizing their intellectual ‘normality,’ thalidomiders claimed their humanness and belonging.

Importantly, being included into public school classrooms meant that instead of segregating the thalidomide children, the communities they lived in played a part in creating accessibility strategies. Mercedes’ desk, for example, was outfitted with a basket on the side so she could reach her things. One magazine exposé recounts the circumstances of Mercedes’ entrance into the public school, which she attended at six years old.⁴¹ It begins with an explanation of the role the rehabilitation institute and doctors played in the thalidomide children’s transition to schools and then recounts the experience of Mrs. Leblanc, Mercedes’ teacher:

Last fall, as the children came of school age, the plan was extended to cover teachers. They had to be shown how to help pupils with their prosthesis – and like the parents, how to cope with questions. Mrs. Leblanc, for example, faced up to questions the first day Mercedes came to class. Mercedes wore her prosthesis for writing and later took it off for drawing, which she usually likes to do with her own little hands. Classmates became curious and one boy asked, ‘Why is it that sometimes her arms are long and sometimes they’re short?’ ‘Because,’ Mrs. Leblanc replied with the frankness she had been told to use at all times, ‘she was born without arms. And for certain work, she has to wear her prosthesis.’⁴²

Two interesting issues arise in this report about Mercedes’ first day at school. First, the young thalidomider was not required to wear her prosthetic arm at all times; also apparent in the image of the Mercedes showing one of her drawings to her teacher (Illustration 9). Not unlike eating lunch in the rehabilitation institutes, it appears that at school thalidomiders were also permitted breaks from undertaking tasks with their artificial limbs. It is possible that by age six

⁴¹ She attended the École Ernest Crepeau in Montreal.

⁴² Trent, Bill. “‘If I Had a Baby, How Would I Be Able to Carry It Around?’” *Weekend Magazine*, edition 19, no. 7 (February 15, 1969), 2-3.

thalidomiders had effectively resisted the full-time use of their artificial limbs or that certain tasks or times, such as eating lunch and drawing, were considered less threatening to social norms if they were conducted without prosthetics, though it is not clear from either rehabilitation reports or interviews why thalidomiders were allowed certain tasks and times without their prosthetics.

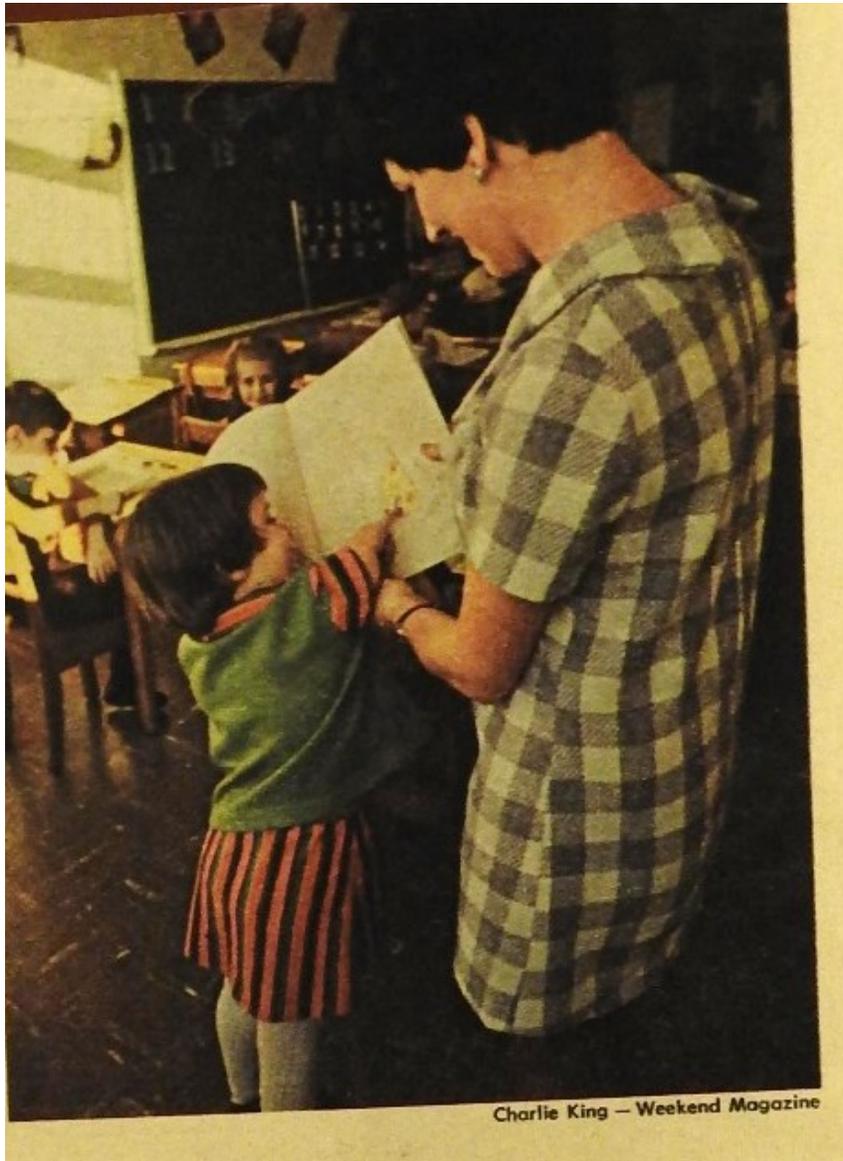


Illustration 9: Teacher Mrs. Leblanc with Mercedes. The image depicts six-year-old Mercedes pointing at one of her drawings with her own hand, as opposed to wearing her prosthetic arm. Her teacher, holding the drawing, appears to be smiling at her. Other children are seated in the background. Source: Charlie King, *Weekend Magazine*, Feb. 15, 1969, 4.

The second interesting issue that emerges is the way in which the medical profession was also part of the ways in which thalidomiders were introduced into schools. Mrs. Leblanc had been instructed by Mercédes' doctor about the ways she ought to address questions surrounding the young girl's disability, similar to the ways that parents were receiving guidance from doctors through the rehabilitation programs.⁴³ It was the medical professionals' authority in making education possible by instructing not only parents at home but also teachers in the public domain that was emphasised. As such, there existed an interconnection between the two primary institutional environments that children like Mercédes navigated. Indeed, one article lauded the Montreal-based doctor Maurice Mongeau, chief of the local rehabilitation facility, stating: "These children have now started their schooling, with much credit in this area going to Dr. Maurice Mongeau [...]."⁴⁴ And the doctors themselves affirmed their own importance in thalidomiders' ability to attend public schools. Dr. Gringas, who worked alongside Dr. Mongeau in Montreal, stated that the thalidomiders' enrollment in school would be one of his proudest moments and continued "We will demonstrate that these children are prepared to make their own way in life [...]."⁴⁵ The "we" in this quote indicates his belief that it was the involvement of the medical profession that bridged the physical disabilities and the potential of the thalidomide children to partake in Canadian public education.

What becomes particularly significant are the ways in which school environments contrasted with the rehabilitation settings when it came to providing accessibility tools. Like the desk Mercédes used at school noted earlier, other children too received material support that

⁴³ I was unfortunately unable to determine how doctors instructed teachers. While teacher Mrs. Leblanc and Mercédes' school were located in Montreal, making an in-person visit from Dr. Maurice Mongeau of the Montreal rehabilitation institute possible, instructions may also have been relayed through phone calls or via training sessions for teachers at the institutes.

⁴⁴ "Fighting the handicap," *The Montreal Star*, May 24, 1968.

⁴⁵ *Toronto Daily Star*, March 26, 1966, 4.

made their education more accessible. This contrasts with the prostheses that were imposed on children. Alvin, who had a talent for music, received the help of both his parents and his teacher in making playing the trombone in the school band possible. The band director, Blaine McClary, mounted the instrument on the side of a wooden chair so that Alvin, who does not have the arms that other musicians use to hold the instruments, could play the instrument with his mouth and foot. In fact, Alvin eventually moved on to become the lead chair trombonist for Canada's National All Star High School Jazz Band, enabled by his foster parents' encouragement and his teacher's willingness to support the boy's musical aptitude.⁴⁶ Here the accessibility tool was created as a result of Alvin's interest and inclinations, determined specifically by his personal needs, rather than as a result of a generic solution based on perceptions of ideal embodiment.

Once the thalidomide children entered public schools, some found their time there to be a positive experience, because it was a place to meet friends and be encouraged by teachers. Mercedes recounts the times on the schoolyard when a balloon game was particularly popular. Being unable to catch the balloon, a seemingly essential aspect of the game and an unproblematic aspect of the other children's play time, became a moment in this young girl's life that could have been disabling in experiencing and asserting normality. As Strong-Boag has put it: "Many youth and children have been handicapped in some aspect of their physical and mental functioning and disabled in their performance of normality. Pervasive prejudice in most times and places has further deepened vulnerability."⁴⁷ However, Mercedes who still looks amazed today when recounting the story, notes that the other children still wanted her to be on their team. When she explained to them how she would not be able to play, since she was unable to catch the balloon, her classmates replied that she could still join the game and run around the play-

⁴⁶ Alvin Law, Phone Interview, 14 February 2017.

⁴⁷ Strong-Boag, "'Forgotten People of All the Forgotten,'" 33.

ground. Her social environment made the game accessible. This is how it came about that Mercedes was literally performing as a player in the game that her impairments may have disqualified her from, had her social environment not encouraged her inclusion. Indeed, Mercedes had other option for participating in the game, such as blocking other players or using her torso and head to move the ball through the air. Her friends viewed her inability to catch a ball as a surmountable barrier to participate in the game. They pointed out that there were other ways in which she could engage in it, such as by performing the running and probably laughing, which was just as much part of the game as the actual act of throwing and catching. Reiterating the view of the social model of disability, Strong-Boag writes: “Disadvantage and disability are always socially constructed.”⁴⁸ Similarly notions of normality are socially constructed and can, at times, be flexible. Indeed, in a consideration of how norms of ability and disability can be subverted, Moser writes: “There are always different discourses that intersect and interfere with one another; in the overlaps and contradictions between them, we find possibilities for action, interruption, interference and displacements, and there we find possibilities to participate in the struggles to refigure and re-articulate what it is to be abled and disabled.”⁴⁹ Like in rehabilitation settings thalidomiders experienced moments during their times in school when they were required to negotiate their physical impairments with, oftentimes contradictory, discourses regarding their ability. Mercedes’s fond memory of being included in this game does allude to the fact that this was a time that helped her articulate her belonging with her peers.

The oral history interviews revealed that the way school was experienced oftentimes hinged on factors outside the educational context. Susan, for example, experienced school as a

⁴⁸ Strong-Boag, “‘Forgotten People of All the Forgotten,’” 34.

⁴⁹ Moser, “Against Normalisation,” 202.

“safer, a better place than home.”⁵⁰ Since at home she had to negotiate an often angry and drunk father and the manic episodes of her heavily medicated mother, school seemed a reprieve. Yet, this did not mean that things were easy for Susan at school. In fact, a daily need all children share was one that made Susan’s life extremely difficult. Having hands that are attached to her shoulders, Susan, like many thalidomiders, was unable to use the washroom at school without help. In Susan’s case this meant many years of suppressing her own bodily needs to get through her school days:

I never used the washroom from the time I was in kindergarten until the time I finished high school. Not once. Ever.”

Christine: “How did you make that possible?”

Susan: “I didn’t drink a lot I guess and I just trained my bladder and bowels to not have to go there. Yeah. [...] It was very hard. I mean as a little girl, you know, or even having my period at eleven in junior high, you know those were situations that need to be dealt with and [...] I went to school back when they didn’t have assistance. [...] They didn’t want to have to add anybody or they didn’t really know what was going to be needed. [...] And I was embarrassed and independent and I was damned if I was going to ask for help, so I didn’t.”⁵¹

While Susan made a conscious effort to train her body to suppress needs that would expose her vulnerability, she was not always successful and her sister would have to take her home early so Susan could appease her body in the safety of her own house. Susan was not alone in facing this hurdle of an inaccessible public school.

Despite her good experiences while attending to her education, Mercedes too needed to negotiate personal hygiene at school. Like Susan she would often go home to use the washroom, something she had received permission for from the school. Other times teachers helped her, though, she emphasised, never making her feel uncomfortable. It may be hypothesised that

⁵⁰ Susan Wagner-White, Personal Interview, December 13, 2016.

⁵¹ Susan Wagner-White, Personal Interview, December 13, 2016.

Mercédes who grew up in a supportive home environment was more likely to place her trust in teachers and was less likely to view a request for help as a vulnerability rather than one of many tools she made use of to succeed throughout her days, whereas Susan was shaped by experiences of abuse, as will be discussed later, and was thus not comfortable with the potential risks of exposing herself, quite literally, to teachers who did not themselves pay attention to their student's needs. It is also possible that some teachers were better prepared by doctors regarding what physical needs the thalidomide children may require assistance with. It is furthermore likely that Mercédes' parents were key in ensuring the school paid attention to their daughter's needs, while Susan's parents did not take on this responsibility. However, both girls shared the experience of being aware and reminded of their difference due to their inability to use the washroom unassisted. The inaccessible physical space of the school served to accentuate the difference between the thalidomide children and their able-bodied peers in uncomfortable ways. Indeed, it is worthwhile here to think beyond the social disablement of these young girls.

Women's and Gender scholar Stacey Clifford Simpican who studies intellectual impairments writes "Because many disability scholars and activists embrace the social model of disability – which centers on the cultural production of disability and de-emphasizes the body – some scholars argue that the dominance of the social model works to silence individuals' experiences of pain, shame, or frustration with their impairment."⁵² Thalidomiders' stories confirm that it is essential to consider both the social barriers as well as physical hurdles they faced. Although Susan's and Mercédes' experiences of sanitary care at school differ in some ways, they nonetheless show that both girls had to, at times, interrupt their education in order to retreat to their homes to be able to care for their physical needs.

⁵² Stacey Clifford Simpican, *The Capacity Contract – Intellectual Disability and the Question of Citizenship*, (Minneapolis: University of Minnesota Press, 2015), 15.

Public schools brought other difficulties. Bullies were something that almost all the participants recounted to varying degrees. When the Hamilton twins were in grade four they were confronted with the misguided remarks of a child at their school, an experience they brought home. Paul recounts, speaking to his brother: “If you recall, when we were in grade four, there was this kid [...] and he came up to me and said: ‘You’re a freak!’ He was a couple years older than we were. ‘My mum and dad said that your parents did it wrong.’ I came home wondering what this kid had been talking about and I asked my mother. She sat us down and she explained: ‘You’re going to run into people like that and they don’t understand that you can do whatever you want. And that your parents didn’t do anything wrong.’”⁵³ The boys’ mother, Maxene, put the experience into perspective for the young boys. While the Hamilton twins would not shy away from a fight on the school yard, Mercedes was not a fighter. She says that she had “little bodyguards.”⁵⁴ Her friends provided a wholesome barrier between her and other children’s hurtful remarks, such as the one girl that attempted to convince everyone on the schoolyard that her “condition” was contagious. We cannot say for sure whether the girl said those things out of malevolence or potentially fear, however, Kristeva’s concept of abjection, as applied by Mary Bunch, suggests that the rejection of disabled bodies is not about the impairment but rather about the vulnerability and anxiety of the onlooker.⁵⁵ This anxiety can result in the rejection of the other, in this case Mercedes. As put succinctly by Josh Dohmen, “To be sure, the ambivalence of abjection means there is also always the possibility of violent rejection.”⁵⁶

⁵³ Paul and Peter Settle, Personal Interview, January 14, 2017.

⁵⁴ Mercedes Benegbi, Personal Interview, October 13, 2017.

⁵⁵ Mary Bunch, “Julia Kristeva, Disability, and the Singularity of Vulnerability,” *Journal of Literary & Cultural Disability Studies* 11, no. 2 (2017): 142.

⁵⁶ Josh Dohmen, “Disability as Abject: Kristeva, Disability, and Resistance,” *Hypatia* 31, no. 4 (2016): 775.

Instead of remembering this as a negative and hurtful episode in her school-life, Mercédes now frames it differently. After her friends had stood up to the girl, defending Mercédes, she remembers consoling the girl and says: “I was able to do that, because I was raised with great confidence.”⁵⁷ Mercédes has been able to contextualize a memory which she describes as a “rejection of her” into a positive lesson about herself and friendship. She was a child whose parents and friends provided an environment in which she developed as a confident individual that could rise up against social stigma. Indeed, this story alludes to Kristeva’s suggestion that abject encounters have the potential to disrupt repressed anxieties. This idea was well-summarized by Bunch: “Interaction makes it possible to transform the repressed anxiety of encountering different modes of embodiment to ‘attention, patience, and solidarity’ in a way that is ‘capable of refining [ones] being in the world’. As such, disability has the power to serve as the catalyst toward a ‘new humanism’.”⁵⁸ While we do not know what impact Mercédes actions had on the girl, the story opens up room to consider that abject encounters, while painful and difficult at times, also have the potential to evoke change. After all, at least according to Mercédes, the girl allowed herself to be comforted by the thalidomider despite her earlier rejection.

However, not all the thalidomide children were as fortunate in having friends and family to support them during difficult times. Aline was outright tormented at school. She states: “At school it was difficult because I was bullied. Often, I came from the school crying. Almost every day. I was crying. I knew my difference. ‘*Oh, look at her!*’”⁵⁹ Being in a public school placed her in an environment that not only exposed her to the social stigma of her disability, it also fostered

⁵⁷ Mercédes Benegbi, Personal Interview, October 13, 2017.

⁵⁸ Bunch, “Julia Kristeva, Disability, and the Singularity of Vulnerability,” 143.

⁵⁹ Aline Vachon, Personal Interview, October 13, 2017.

a self-awareness of herself as different. She was stared at, excluded, othered. Psychoanalyst Jane France writes: “When looking occurs without sympathy, without resonance, without some kind of interaction or reciprocity, it is as if the looker is doing something to the looked-at, and the qualities of distance, superiority and authority which accompany this kind of looking deprive the looked-at (person or people) of any kind of meaningful reciprocation or redress.”⁶⁰ Aline suffered under this rejection of her. By stating that she knew her difference, Aline acknowledges that her private and personal understanding of herself was shaped by public interactions with others.

Public discourses continued to locate disability as something to be stared at. Indeed, it has to be taken into consideration that at the time that Aline and the other thalidomide children attended school, freak shows continued to be part of Canadian culture. In Canada freak shows were offered as entertainment well into the 1960s, the 1970s, and, in some cases, even into the 1980s, although declining in prominence and certainly facing criticism.⁶¹ Nicholas and Chambers have pointed out that freak shows “remained one of the few profitable live shows, as carnivals in the 1950s, 1960s, and 1970s transitioned to offer more mechanical rides and games.”⁶² Their work has revised earlier understandings of the end-date of freak shows operating, which had been placed in 1940 by Garland-Thomson.⁶³ One of the arguments made at the time, problematically so, and which was raised in court proceedings in the United States, was that working in the freak shows was the right of people with disabilities, which would prevent their dependence on government welfare, and that these shows were one of few avenues to

⁶⁰ Jane Frances, “Damaged Or Unusual Bodies: Staring, Or Seeing and Feeling,” *Body, Movement and Dance in Psychotherapy* 9, no. 4 (2014): 202.

⁶¹ Nicholas and Chambers, “In Search of Monkey Girl,” 643, 649.

⁶² Nicholas and Chambers, “In Search of Monkey Girl,” 641.

⁶³ Rosemarie Garland-Thomson, *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 70.

employment for people with disabilities. While true for some, this minimizes the lack of choice and agency on the part of many ‘performers.’⁶⁴ In fact, in 1973 a man by the name of Sealo, whose arms were described as flippers, thus similar to those of thalidomide children, was part of the Canadian National Exhibition.⁶⁵ Canadian children and adults therefore continued to be confronted with disability as the ‘other’, allowing us to understand how children were raised in environments that made pointing at and talking about disabled bodies possible. Mercedes herself had been elected ‘Queen of the Carnival’ at her school. She framed it as a fun and positive memory, indicating that carnivals and staring were not only motivated by repulsion and abjection, but also attraction and intrigue.

This chapter has demonstrated that thalidomiders’ attendance of public schools was part of a slow process of de-segregation in Canadian education that remained hinged upon the differentiation of physical from intellectual and mental disabilities. The repeated story of parent activism retold by the thalidomiders may be a way of acknowledging and emphasizing that they succeeded in being accepted as intellectually competent, drawing attention away from the abjection they experienced based on their physical disabilities and laying claim to their humanness. Stressing their acceptance into mainstream public education appears to be a shared memory that has identity-affirming importance for thalidomiders.

Medical professionals and parents worked with, and at times against, teachers and local politicians to integrate thalidomiders into public schools. Once the children were integrated in public schools, some felt they belonged, while others’ experiences were more difficult. The

⁶⁴ Nicholas and Chambers, “In Search of Monkey Girl,” 656. See also, Brigham A. Fordham, “Dangerous Bodies: Freak Shows, Expression, and Exploitation,” *UCLA Entertainment Law Review* 14, no. 2 (Summer 2007): 207-45.

⁶⁵ Nicholas and Chambers, “In Search of Monkey Girl,” 652.

thalidomide children continued to negotiate an environment that required careful consideration of both social barriers and embodied needs. Educational settings provided thalidomiders with an opportunity to reflect on their social belonging. As disability scholar Stacey Clifford Simpican wrote: “Defining disability thus always incites a parallel question: disabled in comparison to what or whom?”⁶⁶ Thalidomide children not only drew comparisons between their own embodiment and the expectations placed on them by the medical profession, as discussed in the previous Chapter, they also developed understandings of their belonging and their abilities based on their understanding of themselves in comparison to those around them, including children with intellectual disabilities, bullies, and friends. As the next Chapter demonstrates, even at home, thalidomiders as well as their families continued to negotiate the children’s disabilities as well as the social legacies of the thalidomide scandal.

⁶⁶ Stacey Clifford Simpican, *The Capacity Contract – Intellectual Disability and the Question of Citizenship*, (Minneapolis: University of Minnesota Press, 2015), 7.

Part 2 – Thalidomide and Family Life

Chapter 4: Childhood

The apology is for us and it's for our parents, who felt massacred when they saw their mutilated children enter the world.¹

Part One of this dissertation, which focused on public institutional environments, has begun to demonstrate that it is impossible to separate discussions of experiences in public institutions and presumed private environments, such as domestic life. The most private aspects of thalidomiders' lives, their bodies, and the ways they understood themselves, were shaped and understood through thalidomiders' experiences in the public sphere. Families provided a forum in which both collaboration with and resistance to social norms, expectations, and practices occurred. In turn, doctors instructed and monitored parents' engagement with their children in the home. We have seen that the medical profession, policy makers, and educational staff were involved in navigating the tragedy's consequences, sometimes in helpful, at other times in detrimental ways. This chapter continues to challenge the notion of home and domestic life as a private setting sealed off from public influence, by demonstrating that not only thalidomiders, but also their entire families, were impacted by the challenges the thalidomide-induced disabilities presented. Whereas the dissertation began with Susan's statement about being a survivor, this chapter considers Mercedes' belief that if the thalidomiders are the survivors of the tragedy, then their parents were the victims. It will examine how families experienced their

¹ Mercedes Benegbi cited in "The government 'washed its hands, like Pontius Pilate,'" *The Globe and Mail*, February 6, 2010.

thalidomide children's coming home from the hospital, their ongoing interactions with doctors thereafter, and every-day family life that involved parents, siblings, and, at times, other community members. It will argue that the domestic lives of the thalidomide children were entwined in political, social, and medical relations, and that family life was, in fact, inherently interconnected with these influences.² In other words, the thalidomide bodies never left the realm of the political, even when they moved into seemingly private environments. By studying everyday experiences alongside public debates, it becomes apparent that thalidomiders' childhoods were embodied and political manifestations of such public discourses.

Responsibility for the thalidomide children's immediate welfare was given, for better or worse, to their families, albeit under the constant surveillance of state policies and medical discourses. While some thalidomiders remained in hospital settings after their births for longer than others, in some cases for years, eventually all Canadian thalidomide children moved into domestic settings.³ As historian Veronica Strong-Boag concludes from her overview of children with disabilities in nineteenth and twentieth-century English Canada, "The fate of all youngsters is inextricably tied to families, and this is especially true for those with disabilities."⁴ The belief in the pre-eminence of family obligation is deeply enshrined in North American ideas about child welfare, and embracing socially-accepted norms and roles, such as key ideas of responsible

² Scholar of childhood and family Joy Parr has made this argument about the interconnectedness of the family in her own work. See Joy Parr, *Childhood and Family in Canadian History* (Toronto: McClelland and Stewart, 1982), 8-10.

³ In some instances, children stayed in hospital settings for their entire childhoods and only then moved in with their families. Randy Warren was sixteen years old when he left the Shriner Hospital in London, Ontario; Trent Stephens and Rock Brynner, *Dark Remedy: The Impact of Thalidomide and Its Revival as a Vital Medicine* (New York: Basic Books, 2001), 114.

⁴ Veronica Strong-Boag, "'Forgotten People of All the Forgotten': Children with Disabilities in English Canada from the Nineteenth Century to the New Millennium," in *Lost Kids: Vulnerable Children and Youth in Twentieth-Century Canada and the United States*, edited by Mona Lee Gleason, 33-50 (Vancouver: UBC Press, 2010), 36.

gendered parenting, often provided the basis for disabled children's access to resources and support.⁵ In his 2006 historiographical review of studies about mental illness and intellectual disabilities, Nic Clarke argues that historians need to extend their research beyond institutions when discussing people with disabilities to consider the role families played in their lives.⁶ Similarly, Mona Gleason, a scholar of education, children, and youth in the nineteenth and twentieth centuries in Canada, has noted that "Oral testimony from adults who grew up with a physical disability [...] suggest[s] that while medical professionals held considerable power, the values and capacities of individual families were also important."⁷ The same can be argued in the case of the ten Canadian thalidomiders who partook in this oral history-based research, and this chapter contributes new insights into the ways family life matters when studying the history of children with disabilities, including thalidomiders.

Before the specific case of thalidomide families can be approached, however, it is essential to highlight the relevant policy context in which families took charge of these children. The thalidomide children's early life is anchored in an interesting time regarding family policy internationally as well as in Canada specifically. The 1970s represented a critical turning point in views and policies regarding child welfare in Canada.⁸ During that decade the doctrine of the best interests of the child, which became a rhetoric used particularly in divorce proceedings regarding the custody of a child, emphasized the notion of a child as an individual rather than the

⁵ Mona Gleason, Tamara Myers, Leslie Paris, and Veronica Strong-Boag, "Introduction," in *Lost Kids: Vulnerable Children and Youth in Twentieth-Century Canada and the United States*, edited by Mona Lee Gleason, 1-12 (Vancouver: UBC Press, 2010), 6.

⁶ Nic Clarke, "Opening Closed Doors and Breaching High Walls: Some Approaches for Studying Intellectual Disability in Canadian History," *Histoire Sociale / Social History* 39, no. 78 (November 1, 2006): 471, 481.

⁷ Gleason, *Small Matters*, 19.

⁸ Jane Nicholas, and Lori Chambers, "In Search of Monkey Girl: Disability, Child Welfare, and the Freak Show in Ontario in the 1970s," *Journal of Canadian Studies/Revue d'études Canadiennes* 50, no. 3 (September 8, 2017): 641.

property of parents.⁹ Children, it was now acknowledged in courts, had rights and needs that were distinct and ought to be respected. This was a continuation, to some extent, of the human rights discussions that permeated Canada, and much of the Western world, in the post-Second World War period. Historian Dominique Marshall explains how “a peculiar version of human rights informed postwar social policy-making in Canada. The focus on children had an impact on the material and ideological world of young Canadians of the post-war years, and on the formation of the Canadian state in ways that marked the political culture of the country.”¹⁰ Simultaneously – and it is not unrelated – by the time of the Second World War, a disabled children’s rights advocacy had demanded that “special needs youngsters,” whose unmet needs began to receive increased public attention, ought to gain “inclusion with full civil and legal rights.”¹¹ However, as Marshall explains, throughout the 1940s and 1950s the evolution of children’s rights in Canada was flawed, as policy makers who sought to promote such rights simultaneously “subordinate[d] them to more immediate political and social objectives.”¹² Indeed, Chapter Two has already demonstrated that the well-being of the thalidomide children was part of political concerns regarding the welfare state, with detrimental consequences to the children who were subjected to rehabilitation practices that my interviewees have described in negative terms.

Considerations of child welfare are particularly important in understanding the socio-political context in which thalidomide children and parents operated. While biological families are generally the primary carer for children, and this held true for most thalidomide children, the

⁹ Nicholas and Chambers, “In Search of Monkey Girl,” 645.

¹⁰ Dominique Marshall, “Reconstruction Politics, the Canadian Welfare State, and the Ambiguity of Children’s Rights, 1940-1950,” in *Histories of Canadian Children and Youth*, edited by Nancy Janovicek and Joy Parr, 255–65 (Oxford University Press, 2003), 258.

¹¹ Strong-Boag, “‘Forgotten People of All the Forgotten,’” 39.

¹² Dominique Marshall, “Children’s Rights: The influence of War on Peace, 1940-1960s,” in *Histories of Canadian Children and Youth*, edited by Nancy Janovicek and Joy Parr, 255–65 (Oxford University Press, 2003), 265.

thalidomide scandal initially placed this ideal into question in its immediate aftermath. Media attention to the births of the disabled infants raised questions of the role biological parents would play as the needs and welfare of the infants were being considered. One newspaper article explained: “A baby deformed by thalidomide elicits sympathy that is especially poignant. [...] There are large ‘ifs,’ which indicate that the responsibility for the care of a child, born without arms or legs because of the drug, belongs to the community as well as to the parents.”¹³ At least rhetorically, biological parents alone could not be held responsible for providing the children with the anticipated care they would need. In turn, by acknowledging a shared responsibility for these children, it also allowed for the oversight of parents’ care for their children. This oversight was largely taken on by medical professionals, a phenomenon discussed below.

In 1893, Canada introduced its first comprehensive child protection policy, the *Ontario Act for the Prevention of Cruelty to and Better Protection of Children*.¹⁴ This was followed by the adoption of legislation modeled on the Ontario Act by six other provinces.¹⁵ The legislation aimed at protecting children and preventing neglect and mistreatment by parents. Particularly, it provided for the legal authority to remove children from their home and place them in foster families. Indeed, Nicholas and Chambers have argued that it empowered the Children’s Aid Society (CAS) to remove children from parental custody. They explain that “Under the Act, anyone ‘having the care, custody, control or charge of a child’ who ‘wilfully ill- treats, neglects, abandons, or exposes such child, or causes or procures such child to be ill- treated, neglected, abandoned, or exposed, in a manner likely to cause such child unnecessary suffering or serious

¹³ “The Baby Belongs To All.” (Newspaper clipping, date and source unknown.)

¹⁴ “An Act for the Prevention of Cruelty to and better Protection of Children,” Ontario, Statutes, 1893, 56. Revised and consolidated 1897 with the 1898 *Laws of Ontario Dealing with Neglected and Dependent Children, Revised and Consolidated 1897*.

¹⁵ Manitoba and British Columbia in the spring of 1898, Halifax in 1905, Saskatchewan and Alberta in 1909, and New Brunswick in 1913. Cited in Charlotte Neff, “Government Approaches to Child Neglect and Mistreatment in Nineteenth-Century Ontario,” *Histoire Sociale/Social History* 41, no. 81 (2008): 165-214.

injury to its health' could be charged with a summary offence."¹⁶ However, the removal of a child from parental custody remained rare among non-racialized groups until the late 1950s.¹⁷ Indeed, by the mid-1960s, child welfare, as applied by the CAS, was firmly oriented towards maintaining children's wellbeing within their homes, including for children with disabilities.¹⁸ Here, the thalidomide case presents a particularly interesting situation, as newspaper coverage conversely suggested that courts and the public initially believed a removal of thalidomide children from their parents' custody to be in the best interest of both the children as well as parents overwhelmed by the birth of their thalidomide child.

The public discourse of need and sympathy for the babies was contrasted with initial declarations of shock and horror that the idea of such severe physical disabilities provoked in parents, medical staff, and politicians quoted in newspaper coverage of the births of thalidomide children. As a result, parents were often considered unprepared for the burden of a disabled child. In fact, on July 20, 1962, a *Globe and Mail* story reported: "Kitchener, July 19 – A deformed baby today was made ward of the Waterloo County's Children's Aid Society because the strain of caring for the child could undermine the mother's health."¹⁹ Both parents wanted CAS to assume responsibility for their baby. As historian Veronica Strong-Boag aptly observed: "Birth announcements invite public celebration. Some new arrivals, such as the thalidomide-affected infant born to a Kitchener, Ontario, couple in the spring of 1962 [...] also

¹⁶ "An Act for the Prevention of Cruelty to and better Protection of Children," Ontario, Statutes, 1893, s. 13; cited by Nicholas and Chambers, "In Search of Monkey Girl," 645.

¹⁷ Nicholas and Chambers, "In Search of Monkey Girl," 645. It ought to be noted that certain children, such as those of First Nations' heritage and those from other racialized groups, were more likely to be removed from parental custody. See Marlee Kline, "Child Welfare Law, 'Best Interest of the Child' Ideology, and First Nations," *Osgoode Hall Law Journal* 30, no. 2 (1992): 375-425. Furthermore, international discussions of child welfare informed such social changes. A useful, condensed discussion of the events has been provided by Nicholas and Chambers as recently as September of 2017. Nicholas and Chambers, "In Search of Monkey Girl."

¹⁸ John McCullagh, *A Legacy of Caring: A History of the Children's Aid Society of Toronto* (Toronto: Dundurn Group, 2002), 155.

¹⁹ "Deformed Baby Put Under Foster Care," *The Globe and Mail*, July 20, 1962.

invoke consternation and, sometimes, state intervention.”²⁰ Two months old at the time, the child’s future was determined by judge J. R. H. Kirkpatrick at a Family Court Hearing. The parents had not brought their child home from the hospital. The mother, who had only seen the baby’s head, was described as “under a severe strain.”²¹ The wardship was made permanent because in the judge’s opinion the child was “not adoptable,” though the parents would be allowed to regain guardianship of the child if they wished to do so in the future. This case indicates that both children’s welfare as well as the perceived burden on parents played a role in placing children into the care of the state and the Children’s Aid Society.

Given the concern for parents, their emotional and psychological well-being became subject to monitoring during the initial move of babies from institutional to domestic, familial care. In fact, most mothers of thalidomide children were confronted with the suggestion from medical staff to leave their children behind in the hospital; doctors expressed concern mainly about the mothers’ emotional well-being. Understandably, in some cases, the birth of a thalidomide child was indeed a significant shock to women. On July 17, 1962, for example, one mother was observed by the hospital staff after having given birth to her thalidomide child. A hospital spokesperson shared with a reporter that “the mother was in a severe state of shock ‘for some time after she first saw her child.’”²² Judith Pilote recalls today that “When I was young, when my mother had me, she was so shocked, she lost consciousness, because she had a nervous breakdown, and she told the doctor to dump me in the garbage.”²³ This meant that some parents were happy, at least at first, to rely on the resources and support available to them in hospital settings. One mother lamented that hospital officials would keep the baby only twenty-two days:

²⁰ Strong-Boag, “‘Forgotten People of All the Forgotten,’” 33.

²¹ “Deformed Baby Put Under Foster Care,” *The Globe and Mail*, July 20, 1962.

²² “5 More Deformed Babies Include Hamilton Twins.” *Toronto Daily Star*, July 28, 1962.

²³ Judith Pilote in *Right The Wrong*, TVAC documentary, 2013.

“‘The Hospital commission was kicking up a fuss about him taking up bed space,’ said the young mother. ‘We didn’t have much choice but to bring him home.’”²⁴

The initial shock of parents when faced with their thalidomide children was acknowledged and addressed by doctors who viewed the mental health of parents, particularly mothers, as an extension to their medical responsibility to the thalidomide children. In fact, Doctor Mongeau in Montreal developed a special approach to dealing with the thalidomide mothers, which was referred to as the “flying squad.”²⁵ He explained his approach as follows: “We want to be the ones to break the news to the mother. We want to be with her during the hours of crisis. We can help her express her grief and disappointment. We can also supply her with the positive side of the picture – namely, that her child, with training, will be able to do many things. We want to calmly give her all the facts and then let her make her own decisions.”²⁶ Doctors took on the leading role in negotiating the abject reactions mothers experienced when first confronted with having a child with disabilities. In 1966 the *Toronto Daily Star* published an article that explained the importance of providing support to parents. The article noted that while working at the Rehabilitation Institute in Montreal, “It’s part of his job to tell a mother her baby is deformed.”²⁷ It continued: “The ‘flying squad’ approach has already been tested on mothers with newborn defective children and it seems to work well. Social workers and doctors [...] have consoled mothers during long periods of weeping. They have assured fathers who shouted ‘I wish that kid were dead,’ that they understand their feelings.”²⁸ The involvement of a social worker was described as functioning as a “buffer”

²⁴ “Mother Wept All Day,” *Toronto Daily Star*, July 26, 1962.

²⁵ *Toronto Daily Star*, March 26, 1966, 4.

²⁶ *Toronto Daily Star*, March 26, 1966, 4.

²⁷ *Toronto Daily Star*, March 26, 1966, 4.

²⁸ *Toronto Daily Star*, March 26, 1966, 4.

between emotional parents and doctors who were preoccupied with “reality and its acceptance.”²⁹ However, it was a doctor who headed the “thalidomide team.”³⁰ Beyond the initial breaking of the news, doctors at the Rehabilitation Institute of Montreal published an article in 1966 stating that the “Psychological evaluation of both child and parents” were both key aspects of the evaluation program for thalidomide children.³¹ The article was accompanied by an image in which Doctor Mongeau is seen sitting on the floor, intently looking at a young thalidomide girl (Illustration 10). He is positioned as the professional protector and carer of the children, dressed in his doctor’s coat and with the expert knowledge to counteract the emotional reaction of parents. In sum, the thalidomide scandal led to consideration of the welfare of both children and their families.

²⁹ “There’s Hope – And Help – For Thalidomide Babies,” *Weekend Magazine* No. 17 (1968), 16.

³⁰ “There’s Hope – And Help – For Thalidomide Babies,” *Weekend Magazine* No. 17 (1968), 16.

³¹ M. Mongeau, G. Gringas, E.D. Sherman, B. Herbert, J. Hutchinson, and C. Corriveau, “Medical and Psychosocial Aspects of the Habilitation of Thalidomide Children,” *Canadian Medical Association Journal* 95 (Aug. 27, 1966): 390.



Illustration 10: Dr. Maurice Mongeau with a thalidomide girl, Bernadette Bainbridge, at the Rehabilitation Institute in Montreal. The image was part of an article discussing the ‘flying squad’ approach to helping mother’s cope with the news of having given birth to a child with disabilities. Source: *Toronto Daily Star*, March 26, 1966. Photographed by Len Sidaway.

The way medical professionals interacted with parents was also a continuation, to some extent, of the ways in which mothers had been distrusted by experts since the 1930s. In fact, in contrast to the normalized expectation of a mother’s natural bonding with a non-disabled child, women’s devoted care of their disabled children, at times, challenged social ideas about the value of disabled children’s lives. This phenomenon was also observed by social historian Janice A. Brockley who writes that the history of intellectually disabled children in American history “point out the difficult position of mothers, who were utterly essential to the functioning of the

private nuclear family and deeply distrusted by experts at the same time.”³² The perceived burden of caring for a child with a disability was contrasted against the sentiment, increasingly gaining credit during the 1960s, that it was the well-being of the child that needed to be prioritized. Yet, the case of thalidomide babies posed the question: Should the infants begin their lives under the care of medical experts and be considered as wards of the experts, or should they be turned over to their parents as members of a family unit? This question continued to be relevant for the medical profession throughout the early childhood years of the thalidomide children; indeed, experts pondered the issue in a medical journal in 1966 when members of the Rehabilitation Institute in Montreal wrote: “Frequent visits by the parents were encouraged to maintain the family ties. The children’s visits to their homes had to be carefully considered according to the individual case and his attachment to his environment. No concern was felt about sending a child home when the parents were well adjusted and emotionally stable and where the child received love and attention. However, when the parents were still emotionally disturbed, a visit home might have a negative effect.”³³ This demonstrates there was the desire to integrate disabled children into families, albeit it under the watchful eyes of the medical profession.

The case of the thalidomide children demonstrates a continuation of the medical profession’s reach into the domestic realm of child rearing. Examples of the Canadian medical professions’ interest in asserting their role in child rearing has a longer history, with an exceptional example from the interwar period standing out: The Dionne quintuplets born in Ontario were the first quintuplets known to have survived their infancy. In a study of the Dionne

³² Janice A. Brockley, “Martyred Mothers and Merciful Fathers – Exploring Disability and Motherhood in the Lives of Jerome Greenfield and Raymond Repouille,” in Lauri Umansky and Paul K. Longmore, *The New Disability History: American Perspectives*, History of Disability Series, 293-312 (NYU Press, 2001), 296.

³³ M. Mongeau, et al., “Medical and Psychosocial Aspects of the Habilitation of Thalidomide Children,” 394.

quintuplets, Katherine Arnup argued that “during the interwar years, men and women in the fields of medicine, child psychology and social work intervened in an increasingly aggressive manner in the traditionally maternal domain of raising children.”³⁴ What we see in the case of the thalidomide children was that the medical profession, by the 1960s, continued the standard practice of medical involvement in “training mothers” (and, as we saw in Chapter Three, teachers). Simultaneously, the growing importance of families was supported by newspaper articles such as the one published in the *Toronto Daily Star* on July 31, 1962, which quoted Dr. A. L. Chute, chief of pediatrics at the Hospital for Sick Children in Toronto, speaking about the thalidomide babies: “‘If parents are unable to care for the children, then they would have to be placed in an institution,’ he said. ‘But the home is the best place to raise any child.’”³⁵ In other words, efforts were made to emphasise doctors’ importance in supporting and directing parents in efforts to integrate the thalidomide children into family homes. Indeed, the ‘flying squad’ that had been developed in Montreal to help mothers’ cope with the initial shock of bearing a thalidomide child, was credited by reporter Catherine Sinclair in a *Chatelaine* article in 1962 with negotiating parents’ acceptance of their thalidomide children:

When twenty-two-year old Mrs. Anne Beeston, of Willowdale Ont., gave birth to a deformed baby girl last January, her initial guilt-stricken reaction was that she’d already done her baby enough damage and that the child could be best cared for in a nursing home. Doctors convinced her and her husband Carl that there was no room in their lives for guilt because she had taken thalidomide, and that they would feel much guiltier if they gave up their daughter. The Beestons now agree but are finding that the pain of watching their baby trying to move about is growing no less.³⁶

³⁴ Katherine Arnup, “Raising the Dionne Quintuplets: Lessons for Modern Mothers,” *Journal of Canadian Studies* 29, no. 4 (1994): 66.

³⁵ “Need Special Baby Homes,” *Toronto Daily Star*, July 31, 1962.

³⁶ Catherine Sinclair, “What Future for Thalidomide Babes?” *Chatelaine* (November 1962), 110.

Mrs. Beeston's child, Kimberley was living with her parents, due to, as the article suggests, the convincing words of doctors. The girl would continue to visit the same doctors mentioned in the article for years to come in the Montreal Rehabilitation Institute, and they would continue to discuss parenting of the child with her parents.

What stands out in the excerpt above is the notion of guilt carried by mothers for having taken the drug and inadvertently caused their children's disabilities. Another mother, Maxene Settle collected a newspaper clipping from sometime in the 1960s of a cartoon depicting parents with an infant walking up a hill with the weight of a large cross labelled "thalidomide" placed on their shoulders (see Illustration 11).³⁷ While the cross may represent many of the burden experienced by thalidomide parents in the years to come, some of which are discussed below, it may also stand as a representation for guilt weighing down parents. This, too, was addressed by doctors, as described by Dr. Mongeau in an interview in 1968: "Sometimes a parent would break down and weep in my office. Or a father would tell me that he honestly wished the child were dead. Well, you know these are unacceptable things to say in our society and the father would feel terribly guilty. But you can't repress this kind of guilt. And I could only agree and say, 'Yes, I understand how you feel.'"³⁸ Indeed, Dr. Mongeau continued: "The primary treatment in these cases of congenital deformation is to treat the parents first."³⁹ Neither feelings nor key parental decisions, such as whether a child would be kept or given into an institution or up for adoption, were apart from medical guidance. Private family lives were not separate from public concerns about the care for children with disabilities, instead the care that would be offered at home was

³⁷ This was part of a large collection of newspaper clippings Maxene Settle saved in a suitcase which Paul Settle generously allowed me to borrow when I visited him in Hamilton for this research. I was unable to determine where or by whom the cartoon had been published, though all other clippings collected by Mrs. Settle were of Canadian origin, most from local newspapers in and around Hamilton, Ontario, so it is reasonable to believe that this cartoon was of Canadian origin.

³⁸ "There's Hope – And Help – For Thalidomide Babies," *Weekend Magazine* No. 17 (1968), 16.

³⁹ "There's Hope – And Help – For Thalidomide Babies," *Weekend Magazine* No. 17 (1968), 16.

subject to the public gaze of medical professionals, judges, the journalists, and all Canadians who followed the story of these children in newspapers and magazines.



Illustration 11: “Thalidomide – Too Great A Burden.” In the cartoon drawing, parents are depicted with a supposedly disabled infant walking up a hill with the weight of a large cross placed on their shoulders. The cross is labelled “thalidomide”. Source: Newspaper clipping of unknown origin collected by Maxene Settle.

Despite doctors’ initial offers of institutional care or state guardianship, eventually the aim was for all thalidomide children to be integrated into families, and most parents opted to bring their children home sooner rather than later. As Strong-Boag explains: “Families everywhere constituted the first line of support. Even if they sometimes yearned for respite from

responsibility they have often taken for granted the need to shelter and protect dependents, and the great majority has not readily surrendered offspring who did not match the standard of the day.”⁴⁰ This reflects the acknowledgement of families as primary caregivers, though, as has already been demonstrated, the guiding hand of the medical profession reached into the private homes. Almost exactly ten months after the official withdrawal of thalidomide from the Canadian market on January 3, 1963, Susan was born in the Perth District Hospital, Ontario. She was the third child of a young family. The parents, Barbara Jane and John Norman, already had a boy, Roger, and another girl, Christine. Susan would not join the family until six weeks after her birth because she was kept in the hospital for medical supervision. Susan represented an interesting medical case for the staff of the hospital: Her disabilities stood out as unusual, but because she was one of the later thalidomidiers born, her case was already part of an emerging medical conversation. Prolonged hospitalization after birth was not uncommon for thalidomide babies given the extent of the physical impact of the drug, with many children suffering from internal problems as well as those visible on the body. Thus, the initial care of the infant fell to doctors and nurses. However, in Susan’s phrasing of the events, the framing of her early hospitalization emphasizes not medical care, but the disruption of her integration into her family. She says: “I was *taken away* for six weeks right at birth” [emphasis added].⁴¹ Taken away from what, one wonders. Susan’s words indicate that to her, the medical profession began, immediately after her birth, to infringe upon her family’s right to be the primary caregivers. It is not clear whether medical necessity or other reasons determined her prolonged stay in the hospital; given her mother’s mental health problems it may have been a concern for the mother rather than the child that encouraged doctors not to discharge the infant sooner. But Susan has

⁴⁰ Strong-Boag, “‘Forgotten People of All the Forgotten,’” 36.

⁴¹ Susan Wagner-White, Personal Interview. December 13, 2016.

seemingly concluded that her early hospitalization interfered with her timely integration into her family. She was “taken away” from them. Given her later experiences of extensive and lengthy periods spent at rehabilitation centres, as discussed in Chapter Two, it seems she has identified a pattern of medical involvement that began at birth. Here we see how thalidomide children’s bodies were always political, as their care in public institutions and in private homes remained under the consistent surveillance of medical professionals as well as the public who remained informed about the development of the children through newspaper coverage.

Born exactly a year before Susan, Paul and Peter, the thalidomide twins, were born on January 3, 1962 in Hamilton, Ontario, and present another example of the ways thalidomiders conceptualize the medical profession’s role in their early lives. They also did not return home from the hospital with their mother immediately after they were born. Neither did the boys join their large Roman Catholic family together. Instead, Paul went home first. In their case it is clear that the timing of their release from hospital was determined by the medical needs of the infants, which were more extensive for Peter. Peter’s body required medical attention in a way that determined a prolonged hospital stay. Interestingly, like Susan, Paul’s phrasing of his and Peter’s homecoming places the twins’ move from the institutional to the domestic setting as a *return*, rather than an *arrival*. He says: “I came home within two weeks, he [Peter] stayed in the hospital for about three months. When we finally did come home, and then we were all family *again* [...]” [emphasis added]. Like in Susan’s account, between being born and coming home, the twin’s belonging to the family had been interrupted. This is significant as it demonstrates a shared sentiment of medical intervention, however necessary, as something that was disruptive to the domestic setting.

The inclination of the medical profession to insert itself into family life went beyond the physical separation of families for medical purposes. Historian Cynthia Comacchio outlined in her study of a national campaign by Ontario physicians to reduce infant and maternal mortality in the early twentieth century that the medical profession used printed information, targeted specifically at mothers, to help shape an understanding of motherhood through a scientific lens. Comacchio states: “Far from being purely informative, however, the advice literature served as propaganda for the experts’ cause. It strove to establish the physician as maternal mentor and child saviour, to associate child welfare with national interest, and to define anew the experiences of childhood and motherhood.”⁴² This was part of a larger effort on the part of doctors to retain access to the modern family and ensure their services rendered would remain needed. In the case of disabled families, the medical professionals claimed access to families, which helped define relationships between medical profession, parents, and children/patients. Doctors at the Montreal Rehabilitation Institute observed: “Psychological assessments have not been completed but the following impressions have been gathered: (1) Children taken home directly from hospital after birth have shown greater capacity for adaptation than those who were institutionalized. (2) Institutionalized children improved significantly under the constant stimulation provided at the Institute.”⁴³ Thus, the benefits of family integration were medically assessed and, although found favourable, the importance of continued medical supervision was emphasized. As the previous two chapters have demonstrated, many doctors took pride in their role as mediators between physical impairments and social opportunities. Furthermore, as was noted with the example of the “flying squad” approach of informing parents of their babies’

⁴² Cynthia R. Comacchio, *Nations Are Built of Babies: Saving Ontario’s Mothers and Children, 1900-1940* (McGill-Queen’s Press - MQUP, 1993), 92.

⁴³ M. Mongeau, et al., “Medical and Psychosocial Aspects of the Habilitation of Thalidomide Children,” 394.

disabilities discussed above, parents became part of that equation, as doctors integrated the supervision of parents, based on notions of mental health and training, into the rehabilitation programs for the thalidomide children. Medical expertise, based on a claim to authority, was continuously used to justify the medical reach into the family unit.

While the nuclear family was an important support structure for many children, not all thalidomiders experienced immediate belonging to one. As we saw, some parents decided to place their children into the care of adoptive parents or foster families, and the stories of these children differ as much as those who remained with their biological parents. Alvin, for example, considers his childhood in a foster family a positive experience and explains on his website (writing in the third person) that:

Alvin's birth family courageously gave him up for adoption. They hoped and prayed that their sickly, deformed newborn would somehow find a family more capable of caring for his needs. Luckily, their prayers were answered.

Hilda Law was a fifty-five year old foster mother who, along with her husband, Jack, took in neglected and abused children. They loved and encouraged them back from their hopelessness and, through social service programs, sent them to couples yearning for adoptions. They were truly special people.

One day in 1960, the most disturbing case they had ever seen was presented to them – Alvin. They were warned he'd never possess any quality of life and would likely need to be institutionalized.

Not only did Hilda nurse him back to health, but her intuition told her that lurking inside this impossible scenario was... hope. Through the Law's faith, dedication and infinite belief, little Alvin learned to use his feet for hands. Suddenly, his world opened up.⁴⁴

While this is an idyllic, possibly romanticized description of his foster parents, Alvin's depiction of events speaks to the difficulties of finding placements for Canadian children with disabilities, an issue that historian Veronica Strong-Boag has analyzed. She writes about the rejection of disabled children by potential parents: "the overwhelming majority of would-be adopters, much

⁴⁴ Law, Alvin. "Rewrite Your Story," accessed October 25, 2017, <https://alvinlaw.com/about/>.

like their biological peers, have favored healthy and attractive offspring [...].”⁴⁵ By the 1960s, likely tied to the promises of public health care, a shift in perceptions was apparent.⁴⁶ As was noted by Strong-Boag citing a pediatrician who stated in 1967 that “infants need no longer be guaranteed defect-free. Would-be adopters were now ‘more willing to take their chances as do natural parents and will still love and look after a child that turns out to have a health problem.’”⁴⁷ Alvin’s foster parents are an example of people opening their homes to take in a child with disabilities.

However, while some families were willing to care for a child with disabilities, others chose not to. Part of Alvin’s narrative of being embraced by new and supportive foster parents is the story of different parents, his biological parents who, as Alvin suggests, experienced fear, confusion, and social pressure when confronted with a disabled child. In our interview, Alvin explained how he came to know his biological mother later in life. His biological mother lived in the same area, which enabled her to follow Alvin’s story through the media reports about him.

He explains:

My birth family already knew where I was. But they couldn’t reach me because of the rules. When the laws changed I expected that I would hear from them, because I was famous, but I never did. They got so embarrassed. They felt uncomfortable. [...] They almost felt like they were chasing a celebrity. [...] So that was what really made them keep away. So when I approached them, and I suggested a meeting, it was probably maybe a month [...] I did not make a phone call. My wife found her address, she sent her a letter, she [his biological mother] got the letter and she sat down with her sister and they talked about it and then they eventually sent a letter back and we arranged a meeting in her home.⁴⁸

⁴⁵ See particularly her article “Children of Adversity.” Veronica Strong-Boag, “‘Children of Adversity’: Disabilities and Child Welfare in Canada from the Nineteenth Century to the Twenty-First,” *Journal of Family History* 32, no. 4, (2007): 416-7.

⁴⁶ Strong-Boag mentions the first provincial hospital insurance plan in Saskatchewan in 1947, a national hospital insurance program in 1957, and a national medicare program in 1966 as a possible explanation for a decline in fatalistic views. Strong-Boag, “‘Children of Adversity,’” 452.

⁴⁷ Strong-Boag, “‘Children of Adversity,’” 419.

⁴⁸ Alvin Law, Phone Interview, February 14, 2017.

Whatever the motivations behind her distance from Alvin, his biological mother, Sophie, finally met him in May 1993. It was undoubtedly a strange experience for Alvin's mother, who had only held her child once, when he was four days old, to see the man he had become. Although the meeting was an emotional experience for Alvin, he had a pragmatic reason to contact his birth mother. When he had been given up for adoption his health records had been sealed, an issue he needed to address as part of the struggle for compensation; as explained previously, the federal government required detailed proof of the mother's ingestion of thalidomide before compensation would be granted. Important here, however, was the way this meeting with his biological mother reaffirmed something about his familial identity. Alvin wrote in a blog post: "I wouldn't be alive if it weren't for Sophie but because of what she innocently did, I have no arms! And what I observed, learned, and had a profound conversation with Darlene [Alvin's wife] about following that heavy meeting in 1993 was incredibly powerful. Hilda Law made me who I am!"⁴⁹ It was his foster mother that had shaped his identity, more so than the woman whose action of taking the drug, albeit unknowingly, had resulted in his physical disability. Alvin identified his social environment as the predominant factor in shaping his outlook on life, much more than any embodied experiences or achievements linked to his disability. Both his birth family and his foster family lived with the consequences of the thalidomide tragedy. One woman gave her son up for adoption, another woman became his advocate and mother. They were all subjected to social pressures due to Alvin's disability at one point or another.

While Alvin was embraced by caring, supportive foster parents, the experience of being integrated into a family was not a positive event for all thalidomide children. The transition between institutional settings and domestic family life illuminates the fragile distinction between

⁴⁹ Alvin Law, "For Mom," May 8, 2015, <https://alvinlaw.com/2015/05/08/for-mom/>.

public and private spaces. In fact, seemingly public institutions, such as rehabilitation hospitals, were conceived of by some thalidomiders as “home”, a term usually associated with the private sphere. The assumption that the idea of being at home, and the notion of safety associated with it, is associated with family life must be problematized. As Aline explained, “The hospital was my real home, because when I was born I stayed at the hospital until the age of three, so for me the smell of the hospital, seeing doctors and nurses, all the care that I had being very young. So, for me that was safe, I was safe, and I was home. Then they took me from that, my safety, my refuge.”⁵⁰ In fact, it was not only the children who defined their every-day lives at the rehabilitation institute in terms of family life. Margaret Owens, a nurse working at the Montreal Rehabilitation Institute at the time when Aline was there, explained the way she understood her relationship to the thalidomide children in an interview in 2016: “People ask me if I got married and had kids. I say well, actually, I have 35 children. [...] You weren’t just nursing. You were dealing with all the other problems that kids needed.”⁵¹ Home, usually associated with the private sphere could be located in an institution, such as a rehabilitation hospital, usually associated with the public sphere.

In retrospect, Aline’s positive memory of her first few years of life in the hospital are likely coloured by the contrasting difficulties she experienced when she transitioned into the domestic setting of the extended family she moved in with. Aline revealed her wish to die when she was confined in the rehabilitation institute.⁵² However, her assertion of the hospital as feeling safer than moving into a domestic setting is not unusual. Disability historian Geoffrey Reaume has

⁵⁰ Aline Vachon, Personal Interview, October 13, 2017.

⁵¹ Margaret Owens quoted in Matthew McCully, “Margaret Owens: The things that stay with us,” *The Record* (22 August 2016), accessed July 15, 2019, <https://www.sherbrookerecord.com/margaret-owens-the-things-that-stay-with-us/>.

⁵² Aline Vachon in *Right The Wrong*, TVAC documentary, 2013.

noted in a similar vein that, at times, institutional settings could serve as a “security blanket” and that a transition out of a hospital could seem like the “cold, cruel world.”⁵³ While Reaume refers to older individuals transitioning out of institutions, it is nonetheless reasonable to suggest that the rehabilitation hospital where everything was familiar and where those around the thalidomide children were accustomed with their needs and physical appearance, was a refuge compared to the world they entered when leaving. Indeed, Randy Warren’s transition to living at home, captured by Stephens and Brynner in *Dark remedy*, was described as a shock since until then his “whole world” had been the hospital.⁵⁴

In the experiences of some thalidomiders, families caused them to feel rejected. Aline, for example, unlike Alvin, did not have a positive adoption experience. She considers the explanation given for her adoption an excuse. Aline, who needed to carefully compose herself when recounting her story to me, left the hospital at three years of age to move in with her adoptive parents, her biological uncle and his wife.⁵⁵ Given the family relation to her biological parents, she learned who her birth mother was. Her extended hospital stay, she implied, was based less on medical need, and more on her family’s apparent reluctance to bring her home. Her adoptive parents explained to her that her biological parents lived too far from Montreal, and it was therefore decided that Aline would be better off staying in Montreal with her uncle and aunt, who lived close to the hospital where she would have her surgeries and where she could receive special care. Instead of accepting this explanation, Aline considers her biological parents’ behaviour as the rejection of a disabled child. “They knew they were going to have a handicapped baby. They decided, ‘no we don’t want to.’ So, it’s okay. I can’t judge that [...]

⁵³ Geoffrey Reaume, *Lyndhurst: Canada’s First Rehabilitation Centre for People with Spinal Cord Injuries, 1945-1998*, Vol. 28 (Montreal: McGill-Queen’s University Press, 2007), 171.

⁵⁴ Stephens and Brynner, *Dark Remedy*, 68, 115.

⁵⁵ Aline kindly spoke English, as opposed to French, throughout the interview although this is not her first language.

Was it the better decision? I don't know."⁵⁶ Other children did travel long distances for treatment; Jane Rogerson, for example, travelled from the Maritimes to Montreal on a regular basis.⁵⁷ It is impossible to assess her parent's motivations, but Aline's interpretation of events is clear: the choice was a rejection based on her disability. Whether it was motivated by a specific factor, such as financial concerns, shame, or guilt, or possibly a combination of all three, was not apparent to the young girl, who suffered as a result. Aline bravely shared: "All my life I was crying to have my mother back."⁵⁸ Looking back, now a mother herself, Aline's evaluation of her parents' decision remains an emotional one. She concedes that "I can't judge her [biological mother's] decision, but I think most of the time when parents decide to adopt, they adopt out of love, because they want [children] so much, but for me it was not the case."⁵⁹

Beyond speaking to the challenges of negotiating her biological parents' choice, her words indicate that the domestic setting she entered was a challenging one. The emotions displayed on Aline's face as she discusses her childhood reflect the impact this experience had on her life. Every-day life with her adopted parents was very trying for the young thalidomide-affected girl. Emphasising the challenging nature of that experience, Aline recalls: "Being adopted was very difficult. Painful. It was a nightmare."⁶⁰ The long stays at the rehabilitation hospital bear parallels to institutionalized living for disabled children. It has been suggested that "Institutions might, under certain conditions, support relations and development better than single households. Adult failure and abuse occur after all in both domestic and institutional settings."⁶¹ Thus, while disability historians have tried to move away from favouring analyses centered around

⁵⁶ Aline Vachon, Personal Interview, October 13, 2017.

⁵⁷ Ian Scott, "Thalidomide: 'Wonder drug' victim worries about future," *Mailstar*, February 15, 1989.

⁵⁸ Aline Vachon, Personal Interview, October 13, 2017.

⁵⁹ Aline Vachon, Personal Interview, October 13, 2017.

⁶⁰ Aline Vachon, Personal Interview, October 13, 2017.

⁶¹ Strong-Boag, "'Forgotten People of All the Forgotten,'" 43.

institutions, there are ways in which institutional settings need to be re-assessed and analysed as home environments and places of family creation. At the same time, placement of thalidomide children as wards of the state in rehabilitation hospitals for years at a time, may also be understood in the context of state agencies and medical professionals acting to protect children from their biological families; as one historian put it, to protect “the vulnerable from the near, if not the dear.”⁶² In other words, it would be wrong to generalize the reach of the medical profession as solely negative and the care of families as uniformly positive experiences. Substance abuse, fears, and other stresses experienced by parents, at times the direct result of being faced with the challenging task of caring for a disabled child, meant that the rehabilitation centers could also serve as a refuge and a safe haven.

Abuse and neglect were indeed negative experiences shared by some of the thalidomide children once they joined families. After being left by Susan’s father, her mother, struggling with mental health issues, spiralled into a psychological breakdown that became so severe that she was admitted to the Kingston Psychiatric Hospital. Susan was living alone in the house for a couple of months until her father informed her that her home, which was a rental house, was to be torn down obligating her to vacate the building. Susan then moved to her grandmother’s home, who passed away soon after, leaving her stranded. It was winter, both her siblings lived elsewhere, and they were not particularly close emotionally at the time. Susan began sleeping in her car. Susan recalls: “I felt abandoned. Like that fear of abandonment, like I was all alone. No one wanted me kind of thing. That was tough. That’s how that felt.”⁶³ Susan’s experience of homelessness is important for two reasons: it demonstrates that sometimes integrating thalidomiders into families did not serve them well (although this does not imply that staying in a

⁶² Strong-Boag, “‘Children of Adversity’,” 421.

⁶³ Susan Wagner-White, Personal Interview, December 13, 2016.

hospital setting would have served Susan better), it also provides insight into the ways that the thalidomiders were not only a distinct group, but they also shared experiences with other groups of people with disabilities. “Deinstitutionalization” occurred in the latter half of the twentieth century and meant the move of individuals from institutional to community settings or family homes. Strong-Boag has suggested that this did not necessitate better care and writes that “Although institutions produced obvious tragedies, deinstitutionalization offered its own betrayals. Growing rates of homelessness and inadequate supports for community living were far from the dream of integration.”⁶⁴ While thalidomiders, for the most part, were not part of the deinstitutionalization in Canada, their vulnerability to the same problems is obvious. Not unlike Aline’s experience, family, for Susan, was a place of abandonment.

Depression and substance abuse meant that some parents were present and absent at the same time. Historian Jonathan Metzl has discussed the use of tranquilizers by mothers and writes that: “In the 1960s and 1970s, psychopharmacological medications seemed to burst onto the American scene. Popularized and problematized in the notion that these drugs were ‘Mother’s Little Helpers’, the pills became known as the treatments of choice for the pressures of motherhood [...].”⁶⁵ This was the case for Susan’s mother, who suffered from depression and was heavily addicted to tranquilizers. She spent her days locked away in her bedroom, leaving her children responsible for her physical well-being; at times they even called ambulances for their unconscious mother. Their father, an alcoholic, was away at work the majority of the time and had trouble controlling his anger when at home. Susan’s siblings moved out early on, leaving their younger sister to negotiate the volatile home environment on her own. While

⁶⁴ Strong-Boag, “‘Forgotten People of All the Forgotten,’” 43.

⁶⁵ Jonathan M. Metzl, “‘Mother’s Little Helper’: The Crisis of Psychoanalysis and the Miltown Resolution,” *Gender & History* 15, no. 2 (2003): 228.

disability literature addressing childhood has made an effort to move “beyond the discussion of impairment, inequality and abuse to enable children to step out from under the shadow of normative expectations that have clouded their lives,” it is nonetheless essential to acknowledge that the thalidomide children did experience a particular vulnerability to challenging social environments.⁶⁶

Ideas circulating outside the family homes had significant impact on the ways life with a child with disabilities was experienced in private homes. Parents faced a variety of stresses due to their children’s thalidomide-induced physical disabilities, including harassment of people in the community. Thalidomider Judith Pilote has recalled in an interview with the *Globe and Mail* that when she was born her “mother thought I was the Devil. She said she wanted to throw me in the garbage.”⁶⁷ Religious understanding of disability had diminished with the growing trust in the medical profession and science, yet such religious sentiments clearly continued to exist. Other families were confronted with religious interpretations of the thalidomide tragedy from outside the family unit. Maxene Settle, the twin’s mother, received harassing phone calls that wore her down so much she eventually had to contact the police to combat the harassment. Peter recounts: “When we were babies my mum would get a phone call saying ‘They are evil. They’re born from the devil. They have got to be sacrificed. They have got to be murdered.’” And his brother Paul continues: “So my mum kept getting these phone calls, from this evil lady. She lived two houses up, a neighbour. She had a mental illness.”⁶⁸ Thus in at least two instances thalidomiders’ disabilities were associated with ‘evil.’ Disability as a marker of something bad,

⁶⁶ Kirsty Liddiard, Tillie Curran, Katherine Runswick-Cole, “Introduction” in *The Palgrave Handbook of Disabled Children's Childhood Studies*, xxi-xxiv (London: Palgrave Macmillan, 2018), xxiii.

⁶⁷ Ingrid Peritz, “Special Report - The Fight of Their Lives: After Years of Neglect, Canadian Thalidomide Survivors Make a Plea for Help,” *The Globe and Mail*, November 21, 2014.

⁶⁸ Paul and Peter Settle, Personal Interview, January 14, 2017.

sometimes perceived as a divine judgement, served to reassure people that things were as they were supposed to be. There was a reason for disability that in some way justified the difficulties of those affected and it rationalized peoples' feelings of unease when confronted with physical differences.⁶⁹ Anomalies were perceived as dangerous. However, as we see in Paul's statement this rejection was contextualized by him as being about the woman who made the statement. Whereas this neighbour suggested he was 'evil' due to his physical disabilities, he emphasised her mental illness to suggest her judgement was not valid. Here we see the way thalidomiders used their perceptions of different types of disabilities to reflect on their own worth, as was discussed in the previous chapter. The context in which thalidomiders' families experienced harassment was thus one that must be understood as closely related to prevailing social discourses that were part of an evolving way in which the value of those with disabilities were being understood. Whether in religious terms or in terms of their value as productive citizens (discussed in Chapter Two), social discourses determined the varied reactions to the thalidomide children.

Besides targeted harassment, one specific issue that weighed on families and caused friction in households was the lack of financial support provided by the government. This too, shows the consequences of the thalidomide tragedy on families and illuminates how public policies determined experiences of families. In Canada, financial help for families began first in Ontario in the 1920s with the provincial government's Mothers' Allowances.⁷⁰ Cynthia R. Comacchio has pointed out that while "the medical supporters recognized that 'while called the

⁶⁹ Rosemarie Garland-Thomson, *Freakery: Cultural Spectacles of the Extraordinary Body* (New York: New York University Press, 1996), 121.

⁷⁰ The Ontario Mothers' Allowance Act, 1920, section 3, subsection (f): "A monthly allowance may be paid towards the support of dependant children of a mother who '(f) Is a fit and proper person to have the care and custody of her children'" (The Ontario Mothers' Allowance Act, 1920, Statutes of Ontario, First Session of the 15th Legislature of Ontario, Chapter 89).

Mothers' Allowance Act, it is in reality an Act to provide home life and care for fatherless children'.⁷¹ This program of assistance was indicative of new ways in which the Canadian state entered into contractual responsibility with their citizens.⁷² The financial assistance came, as one might suspect, tied to moral regulations imposed on the biological, adoptive and foster-mother that qualified for it. In the seven of the nine provinces that granted payment of allowances to mothers, it was carefully outlined that "If she is not a fit character the children may be cared for by a children's aid society, financed by the province or municipal authority."⁷³ This form of family assistance was expanded in the 1940s through the implementation of Family Allowance at a federal level. Yet, the case of children with disabilities often placed additional financial strain on families. Indeed, Strong-Boag asserts that "The slow and patchwork evolution of federal and provincial allowances and tax benefits for rearing youngsters with disabilities rarely matched needs."⁷⁴ Parents of thalidomiders had to travel to medical and rehabilitation appointments, and reimbursements for visits provided through the rehabilitation institutes had to be applied for. The burden was placed squarely on the shoulders of parents and care-givers.

Given the prominence of the thalidomide scandal, questions regarding financial assistance were addressed in the media. An "indirect aid" was announced by newspapers in 1962. For example, the *Toronto Daily Star* announced on July 28, 1962 that: "The federal health department will give 'indirect' financial assistance to the parents of thalidomide-deformed babies, a department spokesman said last night. [...] The department spokesman said funds would go to provincial welfare agencies 'if any of them come to us for assistance.'"⁷⁵ The

⁷¹ Cynthia R. Comacchio, *Nations Are Built of Babies: Saving Ontario's Mothers and Children, 1900-1940* (McGill-Queen's Press - MQUP, 1993), 86.

⁷² Nicholas and Chambers, "In Search of Monkey Girl," 644.

⁷³ Royal Institute of International Affairs, "Social Security in Canada," *Bulletin of International News* 21, no. 9 (1944): 344-345.

⁷⁴ Strong-Boag, "'Forgotten People of All the Forgotten,'" 43.

⁷⁵ "Only Indirect Aid for 'Drug' Babies," *Toronto Daily Star*, July 28, 1962.

announcement of indirect aid was followed by protests from various camps, including religious, welfare, and municipal offices, that demanded federal financial assistance. The executive director of the Catholic Children's Aid Society, Ward Markle, for example, stated: "These drugs came in under federal government control. If these controls were lax enough to allow such dangerous drugs, the government itself is responsible."⁷⁶ Of course, while financial assistance was needed, it was not easy on families to expose their financial needs. Paul and Peter's mother explained to a journalist: "I have never applied for welfare in my life. [...] But I do need help definitely. It's something I'll probably have to swallow my pride and do."⁷⁷ Margaret Little's work, which discusses the Canadian welfare state and its impact on poor single mothers' lives, indicates that becoming dependant on welfare was associated by women with a level of opening their lives to intrusive investigations and moral regulation.⁷⁸ The mothers of the thalidomide children were already negotiating the gaze of the medical profession and were now placed in a position where they exposed their families' financial needs. While it was lauded by the media that "[...] financial assistance will be available to all families with children deformed by thalidomide, each case being treated on its merits,"⁷⁹ the financial situation remained dire for many and government support was lacking. One young father said that "although he hasn't much money, he will spend all he has on his son's physical improvement."⁸⁰ His statement indicates the immense financial pressure experienced by parents. At the same time, media outlets both drew attention to the financial plight and celebrated the changes that Canada had gone through in the recent decades. One article stated that: "If the problem of thalidomide babies has a lesson, it

⁷⁶ "Only Indirect Aid for 'Drug' Babies," *Toronto Daily Star*, July 28, 1962.

⁷⁷ "Thalidomide Mother Needs Aid Under Robarts' Plan." (Newspaper clipping, date and source unknown.)

⁷⁸ Margaret Jane Little, *No Car, No Radio, No Liquor Permit: The Moral Regulation of Single Mothers in Ontario, 1920-1997* (Toronto: Oxford University Press, 1998).

⁷⁹ "Thalidomide Baby Parents Get \$50 a Month – Province." (Newspaper clipping, date and source unknown.)

⁸⁰ "Parents to spend 'Every Last Penny' on Deformed Baby." (Newspaper clipping, date and source unknown.)

is that in this age we are vitally related members of one social body. We are right to use the new instruments and services the new age has brought.”⁸¹ Yet, self-consciously the article continues: “But sometimes they fail. This is why public-mindedness is indispensable to our world.”⁸² Marie recalls that as she was growing up the primary burden of negotiating a tight budget remained her mother’s obligation: “We were very definitely a blue-collar family, so it was a financial burden on my family to go to Montreal so often. There was a small fund to help with the travel expenses that was set up by the hospital itself; it didn’t come from the government. Mom had to do a lot of sewing and adaptations of my clothes; she became a very good seamstress because we didn’t have much choice.”⁸³ It was not until the late 1980s that victims of the drug began an organized campaign for compensation with the assistance of War Amps, a long struggle that deserves its own research.⁸⁴

The stresses experienced by families led in many cases to an immense strain on the marriages of parents. Quoting the 1989 *Thalidomide Task Force Report* from the War Amputations of Canada, Strong-Boag has argued that “at the beginning of the twenty-first century, families with members who were disabled could still be capsized only too easily by poverty and other stresses.”⁸⁵ Marital break ups had gendered patterns, as has been described by Barbara Brookes in her study of disability in families in New Zealand: “Men, women and children were bound together in the endeavour to provide the necessities of life and, if possible, to progress beyond them. If the burden of support became too much, men could – and did – leave

⁸¹ “The Baby Belongs To All.” (Newspaper clipping, date and source unknown.)

⁸² “The Baby Belongs To All.” (Newspaper clipping, date and source unknown.)

⁸³ Reid Southwick, “Calgary Thalidomide Victim Issues Personal Appeal to Health Minister for Aid,” *Calgary Herald*, November 26, 2014. <https://calgaryherald.com/news/local-news/calgary-thalidomide-victim-issues-personal-appeal-to-health-minister-for-aid>.

⁸⁴ As stated in Chapter One, in 1991, 109 Canadians were able to demonstrate that they were harmed by thalidomide. They received lump-sum payments that ranged from \$52,000 to \$82,000.

⁸⁵ Strong-Boag, “‘Forgotten People of All the Forgotten,’” 38.

families. Women were much less likely to abandon their children, whose needs structured their lives.”⁸⁶ Indeed, one of the twins observed: “My dad stuck around. A lot of thalidomide fathers didn’t. My mum worked hard to keep the family together, and she did.”⁸⁷ Yet, placing the onus of keeping a family together on the mother and wife downplays the significance of social and economic forces that bore down on the thalidomide parents’ relationships.

Perhaps it is unsurprising, given the challenges parents faced, that to Mercédes it was they, not the children, who were the victims of the drug. She says: “I believe the parents are the victims and we are the survivors. [...] I don’t believe they received the proper assistance. [...] They were abandoned.”⁸⁸ She is referring to a lack of both financial and practical assistance provided to parents across all provinces. Despite her parents’ eventual divorce, her life was, as she describes it, one of privilege. Expecting social disablement and barriers, her parents worked together, when together and apart, to ensure a fulfilling childhood for their daughter. In interesting ways, the efforts of thalidomide parents show parallels to the adoptive parents of black or mixed race children, as discussed by historian Karen Dubinsky. In her study of white parents confrontation with racism faced by their children, Dubinsky notes that parents realised that “love is not enough.”⁸⁹ Parents needed to actively realize and confront the barriers experienced by their children. For much of her childhood Mercédes’ parents did just that. “If a social barrier was in front of us, my parents were there to overcome it. [...] I realized that my childhood made all the difference because it was important for my parents for me to be the most autonomous.”⁹⁰ The confidence they installed in Mercédes shaped the future she envisioned for

⁸⁶ Barbara Brookes, *A History of New Zealand Women* (Wellington, New Zealand: Bridget Williams Books, 2016), 73.

⁸⁷ Peter Settle, Personal Interview, January 14, 2017.

⁸⁸ Mercédes Benegbi, Personal Interview, October 13, 2017.

⁸⁹ Karen Dubinsky, *Babies Without Borders: Adoption and Migration Across the Americas* (Toronto: University of Toronto Press, 2010), 75.

⁹⁰ Mercédes Benegbi, Personal Interview, October 13, 2017.

herself and paved the way for her life to come. Yet, as successful as their parenting was, Mercedes nonetheless acknowledges that her parents accomplished this under strenuous circumstances that led to the end of their marriage.

Priya Lalvani and Lauren Polvere have pointed out how researchers fall into the trap of understanding such pressures experienced by families through the medical model: “Rather than examining whether parents of children with disabilities experience significant stress or chronic grief, medical-model based studies begin with assumptions of pathology and seek to evaluate the extent of psychological distress. Additionally, in research based in medical model perspectives, the source of the psychological distress experienced by parents is located in their children’s impairments.”⁹¹ Mercedes’ account of the pressures in her parents’ life, while related to her disability, were not located in her impaired body. Her parents did a great deal for their daughter, but this came at an emotional price as they were confronted with a lack of structural support. This provides an interesting contrast to the emotional and psychological burden that the medical profession and media expected when the thalidomide babies first entered the world. It was, at least for some, not the child and her disabilities, but the social structures in which they were required to raise the child that caused pressures and stresses on individuals and partnerships. Unbeknownst to her mother, Mercedes found a letter by her mother in the woman’s drawer. Addressed to a Canadian Minister, it was an emotional request for help from the government. Clearly taken by the words her mother had put down on paper, Mercedes never dared to bring the contents up with her. Addressing the burden her parents experienced on a very personal level directly was too emotionally taxing not only for Mercedes herself, but likely also for her mother. Unlike other thalidomide children who were confronted with their parents’ struggles, Mercedes’

⁹¹ Priya Lalvani, and Lauren Polvere, “Historical Perspectives on Studying Families of Children with Disabilities: A Case for Critical Research,” *Disability Studies Quarterly* 33, no. 3 (2013): Introduction

parents had done a wonderful job shielding their daughter from the challenges they faced. Overall, like in Mercedes' interview, despite the challenges faced by the parents and their children, many positive experiences surfaced during the various interviews. Mercedes herself expressed that her childhood and the ways her parents supported and treated her installed "great confidence" in herself.⁹²

While it is important to acknowledge the pressures parents faced, it is equally important to note that other family members also experienced challenges as a result of having a child with disabilities in the family. Thalidomiders and their parents or guardians were seldom alone in negotiating everyday life. As mentioned in the case of Susan, whose sibling had to assist her in using the bathroom, siblings played an important role in the thalidomide children's childhoods. Susan recalls that even though her family moved from Perth to Kemptville when she was three years old to allow her father to come home from work to help care for her, her siblings were involved in raising her as well. "Rather reluctantly," as Susan described it. Christine, Susan's sister, vividly remembers that she was the one often helping her younger sister in their daily routines. "I would help her get ready for school, we'd come home, sometimes we'd come home and we couldn't wake our mother up because she was so drugged, sometimes we had to call the ambulance because we really couldn't wake her up, get any response from her. Yeah, that was shitty."⁹³ In their family the burden of the older sibling was exacerbated by the difficult mental health situation of their mother. Yet, despite the added challenges of a drug-impaired parent, the responsibilities Christine faced mirrored those other siblings recall. Speaking with the twins' sisters, the ways in which thalidomide impacted the whole family becomes very apparent. While their father worked full-time and their mother juggled doctor's appointments and hospital visits,

⁹² Mercedes Benegbi, Personal Interview, October 13, 2017.

⁹³ Christine Orton, Personal Interview, February 9, 2017.

a lot of work fell on the shoulders of the siblings. Karen recalls how she took on household chores and caring for the needs of her younger siblings, including the task of ensuring her brother was wearing his leg prosthetic:

My mother had numerous doctor's appointments, and I mean when she had those boys I don't even think she had her driver's license then. So it was really difficult for her to get to appointments and the surgeries they had. [...] Now as far as in the house goes, I was the right hand then. [...] I mean I was the one that was responsible for putting braces on in the morning, and Peter's leg on, and help them get ready for school. [...] In the summertime it was also my job to get the boys ready for bed. You know, have them take their bath and get to bed.⁹⁴

Karen felt that she had significantly more responsibility to carry than any of her friends who did not have disabled siblings. Her sister Jackie remembers too that it was not solely responsibilities around the house, but also missing out on attention from their mother who was often preoccupied with their twin brothers. Speaking about their mother, she remembers: "She would reassure me she would be home that night or, if she stayed over-night, she'd be home the next day [...] I think as a young child I do remember that anxiety of her having to leave me and go to the hospital."⁹⁵ Siblings certainly shared in the experiences of being a member of a family impacted by thalidomide.

Besides practical assistance, siblings also functioned as environmental markers of normality. Instead of experiencing the physical ease with which siblings functioned as disabling when compared to their own embodied challenges, thalidomiders recount seeing their siblings' capabilities as milestone of growing up they too could accomplish. It was simply a matter of finding the appropriate accommodations. In her own oral-history-based research of individuals with disabilities, Mona Gleason has effectively summarized this point:

⁹⁴ Karen Foster, Phone Interview, February 28, 2017.

⁹⁵ Jackie Buckle, Phone Interview, February 2, 2017.

Their memories suggest that in terms of their embodied differences and their capabilities, social attitudes (centrally shaped by medical discourse) and familial attitudes could be informed by different priorities. On the one hand, physical disabilities could be experienced as constraining, painful, and shameful pathologies. On the other hand, and primarily in the context of the family and communities, physical disabilities were experienced as simply another dimension of growing up. The space between these two constellations of attitudes and expectations had to be deftly mediated and navigated.⁹⁶

Gleason's insight parallel thalidomiders' experiences. While social attitudes did impact the familial experiences of living with a child with disabilities, families and friends could also provide thalidomiders with a space where their bodily difference was not the primary signifier of ability. In Aline's words: "I saw my brother, sister, friends, they could do different things, and I was thinking I can do it. I can do it. I knew I was different, but I have a determination. When I have something in my head, I have something in my head."⁹⁷ Peter and Paul, who were surrounded by their siblings, experienced their lives with siblings similarly. It was not so much a question *if* they could do something, only in some instances *how* they would go about doing it, like the way Peter used accessibility tools when skiing. Indeed, this way of thinking could extend beyond the confines of the family, as the example of Mercedes playing on the schoolyard in Chapter Three suggests. More so, the image of Mercedes in her car, published by *The Gazette* in June 1983, shows how her vehicle was adapted with a long shift-stick and a knob on the steering wheel to allow her to reach them (Illustration 12). The text under the image stated: "Mercedes Benegbi: Just 'wants to do all the things that other people can do.'"⁹⁸ Clearly, Mercedes' achievement to drive a car challenged assumptions about her capabilities enough to make it newsworthy. Importantly here is that when she received her driver's license, Mercedes

⁹⁶ Gleason, *Small Matters*, 122.

⁹⁷ Aline Vachon, Personal Interview, October 13, 2017.

⁹⁸ Heather Hill, "How thalidomide babies have grown up," *The Gazette*, June 11, 1983. Photographed by Pierre Onendrauf.

immediately drove to visit her friend Myriam, another thalidomide girl, who was immensely curious to see the accommodations that made driving possible. Their mothers had decided years prior that their daughters ought to meet, as they would likely face similar challenging experiences in their futures and the women saw the potential for the girls to help each other through them. Initially meeting sometime between the time when they were ten to twelve years old, the girls indeed remained in contact with each other. Such networks of peer-support among young thalidomiders appear to have been rare, however, and most of my interviewees emphasized the role that siblings played in their lives. Wherever it took place, witnessing acts and achievements by those around them, both non-disabled siblings, as well as others with disabilities, could serve to, quite literally, open up new roads into their futures.



Illustration 12: Mercedes in her car, which she described as one of the first adapted vehicles. Cars were literally a vehicle for enabling greater independence for young thalidomiders. The caption of the image states: “Mercedes Benegbi: Just ‘wants to do all the things that other people can do.’” Source: Heather Hill, “How thalidomide babies have grown up,” *The Gazette*, June 11, 1983. Photographed by Pierre Onendrauf.

Yet, when siblings served as markers of normality it could also result in detrimental experiences of social disablement within the wider community, demonstrating that families existed in larger social networks that influenced everyday lived experiences. When seventeen-year-old Ramesh attended the traditional Hindu wedding of his older sibling in 1979, he was seated next to his younger brother, surrounded by family and friends. Although he was born in England in 1962 with reduction deformities of both his upper and lower limbs caused by thalidomide, his story might as well have transpired in Canada. In the midst of the wedding celebration that he was attending, someone turned to the two brothers, talking right past Ramesh, and declared to his younger brother: “Well, you’ll be next! [...] We’ll find you a nice girl. [...] You’re handsome looking.”⁹⁹ Since the older brother, whose wedding they were attending, was having an arranged marriage it was not unlikely that the extended family would be involved in creating and choosing a family for all the siblings. However, Ramesh had just started college and was still unmarried himself. Ramesh remembers how he sat there while his younger brother received compliments, and it never seemed to cross his relatives’ minds to be saying something similar to him. In our interview Ramesh shared: “I don’t think they ever thought I would be capable of being in a relationship.”¹⁰⁰ This was not the first time something like this happened to Ramesh, and even as a young boy it was not lost on him how his potential future was perceived differently than that of his siblings and cousins. Today, Ramesh is married. Allison Kafer’s considerations of ableist thinking that suggests a hierarchical value of those who are able-bodied (and able-minded) as inherently more valuable than those who live with disabilities introduced in her influential book *Feminist, Queer, Crip* is worthwhile considering here. Kafer notes that such assumptions are political decisions. She emphasises that ideas of normalcy and “ableist attitudes

⁹⁹ Ramesh Lad, Phone Interview, February 22, 2017.

¹⁰⁰ Ramesh Lad, Phone Interview, February 22, 2017.

and barriers” inform relationships between the non-disabled and those living with disabilities.¹⁰¹ Such assumptions of normalcy hide the inherently political nature of the ways disability functions in social interactions. It was, in Ramesh’s case, his family’s perceptions of his body that shaped their understanding of his potential future. Rosemarie Garland-Thomson observes in her study of freak shows how such cultural attitudes can appear as natural, instead of being cultural constructs. She states: “what we assume to be a freak of nature was instead a freak of culture.”¹⁰² Ideas of his unsuitableness for an arranged marriage did not stop Ramesh from pursuing relationships later on in life, yet it did serve to create an awareness of the different expectations he and his siblings faced within their community.

To summarize, the discussion above has demonstrated that discussing siblings is relevant to the study of the long-term consequences of the drug’s impact in Canada in two ways: Firstly, they played significant roles in the ways the thalidomide children were raised and how their lives were made accessible. This shaped both the thalidomiders’ childhood as well as those of the siblings. Thus, it is essential to reiterate here that the impact of the drug was not limited to the children whose bodies had been affected by the drug. Instead, parents’ and siblings’ lives were also shaped by the drug and the social context in which families raised the thalidomiders. Secondly, siblings presented markers of normality that could serve to alleviate or escalate social disablement faced from inside and outside of the family. Non-disabled siblings (and, as was shown in Chapter Three, classmates) served as a demonstration of what children would and could do when they were not confronted with social disablement, thus serving as examples of what any child might want to pursue in their everyday lives.

¹⁰¹ Alison Kafer, *Feminist, Queer, Crip* (Bloomington: Indiana University Press, 2013), 7-8.

¹⁰² Garland-Thomson, *Freakery*, 10.

It is certain that families were impacted by the long-term consequences of the thalidomide tragedy. It was not only thalidomiders themselves who became subject to the medical gaze, parents, too, were monitored and assisted by doctors and the wider public. Judges, reporters, doctors, and social workers were all involved in observing the families and private homes in which the thalidomide children lived. At times such involvement of the public was appreciated, at other times it disrupted family life. However, the examples of siblings and interactions with community members show that beyond the way homes were surveilled, private homes and relationships were political spaces that served to both impose and demarcate societal notions of “normalcy.” Mediation of what their disabilities meant for the thalidomide children when growing up did not occur in a social vacuum, but was shaped by the lived experiences of each individual. Whereas Chapter Two highlighted the drastic embodied management of children’s bodies through prosthetics, this chapter has outlined different aspects of the social management thalidomiders were exposed to during their childhood and adolescence, both imaginary and in terms of physical spaces. Thalidomiders and their families both conformed with societal expectations but also challenged them. This chapter has therefore shown that the lives of the thalidomide children remained political and public, even when they moved into domestic environments. The next chapter will continue the discussion of how seemingly private relationships and experiences are indeed political, by discussing abuse and intimate relationships.

Chapter 5: Sexuality, Intimacy, and Abuse

We know that severance of close relationships early in life sometimes has a reaction later in life when as an adult the patient finds it difficult to develop lasting relationships with other people.¹

Policed by social and cultural taboos, holding emotional and existential significance, sex is tied to hegemonic processes that make it a topic demanding careful discussion. As the previous chapters have demonstrated, experimentation, both personal and medical, shaped the ways that thalidomiders understood their bodies' capabilities. As children, thalidomiders learned to navigate between medical discourses, social environments, and embodied self-perception. The institutional and domestic settings in which thalidomiders grew up were significant in shaping the ways they would experiment with and engage in intimate encounters during adolescence and adulthood. The overlap of disability and sexuality with social, political, and medical ideas is widely acknowledged by disability studies scholars. Eunjung Kim, for example, writes: "disability depends on ideological, social, and medical categories that determine what constitutes an average body, ability, trait, and performance, and those categories often overlap with sexual realms."² The sexual experiences of individuals with disabilities therefore serve to expose the way that disabled bodies not only transgress the hypothesised boundary between public and private but that disability eliminated the possibility of separating, even theoretically, private aspects of disabled experiences.

Thalidomide bodies have been sites of sexual pleasure as well as sexual abuse, and analyzing their experiences contributes to our understanding of the lived experience of sexuality

¹ Ian Adams, "There is Hope – and Help – for Thalidomide Babies," *Weekend Magazine* (Newspaper clipping, date unknown.).

² Eunjung Kim, "Asexuality in Disability Narratives," *Sexualities* 14, no. 4 (August 1, 2011): 481.

among people with disabilities, a dimension that is frequently overlooked in the too-often theoretical scholarship examining the intersection of disability and sexuality. This point was emphasized in 2018 by Tom Shakespeare and Sarah Richardson who write that “studies reporting on the lived experience of disability and sexuality continue to be thin on the ground.”³ This chapter therefore continues the important scholarly work of integrating the lived experiences of people with disabilities in regards to their sexuality into disability scholarship. In addition, this chapter demonstrates that while the long-term consequences of the scandal certainly impacted thalidomiders’ lives with regards to sexuality, it did not do so homogenously. The diversity of lived experiences is therefore highlighted in the discussion below. This chapter argues that the embodiment of their disabilities created opportunities for thalidomiders to reflect on and form their sexual identities. At the same time, socially constructed discourses of normality and able-bodiedness, as well as heteronormativity and gender, shaped thalidomiders’ experiences. Thus, the thalidomide case once again provides insight into societal perceptions of physical disability in Canada.

This chapter is inspired by and contributes to the important scholarship that seeks the liberation of disabled individuals from their historically-ascribed sexual passivity within academic narratives.⁴ Perhaps the most notable effort to ensure the inclusion of sexuality in the study of disability was the creation of an academic journal in 1978 dedicated to the topic; the journal *Sexuality and Disability* publishes interdisciplinary studies that address the psychological

³ Tom Shakespeare and Sarah Richardson, “The Sexual Politics of Disability, Twenty Years On,” *Scandinavian Journal of Disability Research* 20, no. 1 (2018): 82.

⁴ My review of this literature is limited to academic works that are concerned with the discursive exclusion of disabled sex in Western and Western-influenced societies.

and medical aspects of sexuality in relation to rehabilitation and community settings.⁵ However, it has been noted that the journal “still tends to be dominated by papers about sexual dysfunction.”⁶ Nonetheless, this attention to the intersections of sexuality and disability is particularly important since the sexuality of people with disabilities has been ignored, rejected, mythologized, exotified, and denied in the past because their bodies are seen as abject. An important and heavily cited contribution to this literature is Tom Shakespeare, Kath Gillespie-Sells, and Dominic Davies’ *The Sexual Politics of Disability: Untold Desires* published in 1996. They state: “It would be fair to say that issues of sexuality, relationships, and personal identity have [...] been neglected within the disability studies perspective, and it is this absence which we aim to rectify. It is not just that ‘the personal is political’, but also that a key area of disabled people’s experience has been largely ignored.”⁷

This silence about sexual experiences in the scholarship is closely related to the denial of their sexuality that people with disabilities have historically experienced. Shildrick explains how the absence of discussions of sexualities must be construed as negative. She writes: “Any notable silence [...] must surely convey a negative meaning, implying in the case of disability that any

⁵ *Sexuality and Disability* 1 (1978), <https://link.springer.com/journal/11195>

Examples especially useful for this thesis are Shelley Tremain, “Queering Disabled Sexuality Studies,” *Sexuality and Disability* 18, no. 4 (December 1, 2000): 291-299; Eleanor Richards, Mitchell Tepper, Beverly Whipple, and Barry R. Komisaruk, “Women with Complete Spinal Cord Injury: A Phenomenological Study of Sexuality and Relationship Experiences,” *Sexuality and Disability* 15, no. 4 (December 1, 1997): 271–283; Michael Rembis, “Beyond the Binary: Rethinking the Social Model of Disabled Sexuality,” *Sexuality and Disability* 28, no. 1 (March 2010): 51–60; Cheryl-Ann Potgieter, and Gadija Khan, “Sexual Self-Esteem and Body Image of South African Spinal Cord Injured Adolescents,” *Sexuality and Disability* 23, no. 1 (March 1, 2005): 1-20; Ernesto Morales, Véronique Gauthier, Geoffrey Edwards, and Frédérique Courtois. “Women with Disabilities’ Perceptions of Sexuality, Sexual Abuse and Masturbation,” *Sexuality and Disability* 34, no. 3 (September 1, 2016): 303-14; Arno Karlen, “Positive Sexual Effects of Chronic Illness: Case Studies of Women with Lupus (SLE),” *Sexuality and Disability* 20, no. 3 (2002): 191–208; Anne Guldin, “Self-Claiming Sexuality: Mobility Impaired People and American Culture,” *Sexuality and Disability* 18, no. 4 (December 1, 2000): 233–38.

⁶ In addition to *Sexuality and Disability*, Tom Shakespeare and Sarah Richardson name four other journals as fostering literature on the intersection of disability and sexuality, namely the *Scandinavian Journal of Disability Research*, *Disability and Society*, *Alter*, and *Sexualities*; Tom Shakespeare and Sarah Richardson, “The Sexual Politics of Disability, Twenty Years On,” *Scandinavian Journal of Disability Research* 20, no. 1 (2018): 82.

⁷ Tom Shakespeare, Kath Gillespie-Sells, and Dominic Davies, *The Sexual Politics of Disability: Untold Desires* (Cassell, 1996), 5.

reference to a specific sexuality is missing because disabled people are being actively constructed as non-sexual.”⁸ Implicit in the missing discussion surrounding disability and sexuality is the denial of sexuality which is in itself a highly political act. In a study of asexuality, Eunjung Kim explains how assumptions about disability and sexuality are actively sustained: “This assumed asexuality is not a natural consequence of having a disability; rather, it is the result of a desexualizing process that is continuously applied and maintained.”⁹ Scholars have begun the important work of uncovering the social processes that impact the ways sexuality is understood in relationship to disability. As a result of abject understandings of disabled bodies, there are two main myths that scholars have identified as commonly being associated with people living with disabilities regarding sexuality: the idea of the disabled body as hypersexual, oftentimes even predatory, and the notion of the disabled body as nonsexual.¹⁰ Both myths have subsequently been vigorously criticized. Spurred by political activism, scholars are attempting to remedy narratives of the negative association between disability and sexuality. However, even among disability scholars there continue to be gaps in the literature, especially pertaining to disability and pleasure.¹¹ Further studies are needed that provide insight into the everyday lives of people with disabilities and their sexual experiences to help nuance understanding of sexuality and disability. The subsequent discussion enters the lived experiences of thalidomiders into this historiography.

It is important to separate sexual encounters that were coerced and those that were consensual in the discussion below. While sexual abuse is unquestionably an important topic, it

⁸ Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (New York: Palgrave Macmillan, 2009), 64.

⁹ Eunjung Kim, “Asexuality in Disability Narratives,” 483.

¹⁰ Cassandra Loeser, Barbara Pini, and Vicki Crowley, “Disability and Sexuality: Desires and Pleasures,” *Sexualities* 21, no. 3 (2018): 257.

¹¹ See Mitchell S. Tepper, “Sexuality and Disability: The Missing Discourse of Pleasure,” *Sexuality and Disability* 18, no. 4 (2000): 283-290.

is, for the most part, an aberration from the ways thalidomiders expressed and experienced their sexualities. Disability scholars Tom Shakespeare and Sarah Richardson emphasize this point when they write, with regards to sexual abuse, that it is “not central to the everyday expression of sexuality for most disabled people.”¹² This dissertation begins with a discussion of sexual abuse to clearly separate it from subsequent sexual experiences that were consensual. Discussing abuse and experiences of rape first will allow these negative experiences to stand apart from sexual encounters that were willingly entered into.¹³ While there are good reasons to classify sexual abuse as non-sexual encounters, sex as a topic sparks memories of pleasurable, experimental, uncomfortable, as well as harmful and abusive experiences; as such, combining these issues in one chapter symbolizes how sexual acts could enter thalidomiders’ lives in both positive and negative ways. Beginning the discussion with abuse not only allows for it to stand apart from the subsequent discussion of intimacy and sexuality, it is also chronologically consistent with when abuse was experienced, which was primarily during childhood.

Thalidomiders experienced the painful manipulation and intrusive surveillance of their bodies within the rehabilitation programs, but the transgression onto their bodies that were, or threatened to be, of a sexual nature, starkly document their vulnerability as a group. Aline says: “Vulnerability is going to follow me my whole life, I think, because it is as though I had been

¹² Shakespeare and Richardson, “The Sexual Politics of Disability, Twenty Years On,” 82.

¹³ I make use of the definition of child sexual abuse put forth by Martina Higgins and John Swain in their book *Disability and Child Sexual Abuse* that is based on the narratives of seven people with disabilities who were sexually abused as children: “Sexual abuse involves any sexual activity with a child where consent is not or cannot be given. This includes sexual contact that is accomplished by force or threat of force, regardless of the age of the participants, and all sexual contact between adult and child, regardless of whether there is deception, or the child understands the sexual nature of the activity. Sexual contact between an older and a younger child can also be abusive if there is a significant disparity in age, development, or size, rendering the younger child incapable of giving informed consent. The activities may involve physical contact, including penetrative or non-penetrative acts. They may include noncontact activities, such as involving children in looking at, or in the production of, pornographic material or watching sexual activities, or encouraging children to behave in sexually inappropriate ways.” *Disability and Child Sexual Abuse: Lessons from Survivors’ Narratives for Effective Protection, Prevention and Treatment* (Jessica Kingsley Publishers, 2009), 15.

marked by a branding iron.”¹⁴ As recently as 2019 sociologist Bill Hughes, in a discussion of the intersection of abjection and vulnerability, writes: “Represented as abject and monstrous, disability is *good to mistreat*.”¹⁵ The way mistreatment and abuse occurred can be discussed by first considering the particular vulnerability thalidomiders experienced because they often needed to expose their bodies to the hands of others. Not only could their physical impairments make it more difficult – and for some almost impossible – to defend themselves from intentional harm, other factors also increased risks of abuse for these individuals.¹⁶ Susan, for example, notes that while not abusive, the help of her father and brother in the bathroom left her feeling exposed in ways that she resented:

My dad had to deal with the period issue. I mean, it was horrible that it ever had to be that way and I started my period when I was eleven. [...] Very early. [...] When I think back to that, I just think that’s horrible, that I had to go through that. There wasn’t more assistance or somebody didn’t recognize that there was something wrong there. That’s not appropriate, you know. I don’t think that’s appropriate. And I don’t think that it’s appropriate that my fifteen-year-old brother had to help me. You know, with that sort of thing either. But that was reality in my life.¹⁷

Because her daily bodily functions placed Susan in a position of requiring help, the presence of male hands on her body was something she had to tolerate in order to get through her daily routine. This issue has attracted attention in the scholarship. One interpretation asserts that personal care is separated from sexuality because it positions the person with disabilities as a non-sexual being. Disability scholar Sarah Smith Rainey explains: “needing physical care for activities like using the bathroom, bathing, and eating is linked to dependency and is considered

¹⁴ Aline Vachon in *Right The Wrong*, TVAC, 2013.

¹⁵ Bill Hughes, “The Abject and the Vulnerable: The Twain Shall Meet: Reflections on Disability in the Moral Economy,” *The Sociological Review* 67, no. 4 (2019): 830.

¹⁶ See also Ernesto Morales, Véronique Gauthier, Geoffrey Edwards, and Frédérique Courtois, “Women with Disabilities’ Perceptions of Sexuality, Sexual Abuse and Masturbation,” *Sexuality and Disability* 34, no. 3 (2016): 303-314.

¹⁷ Susan Wagner-White, Personal Interview, December 13, 2016.

infantilizing. This is the type of care that mothers give to babies, and, in society, it is taboo to associate sexuality with this activity.”¹⁸ Instead of emphasizing problematic experiences of infantilization, however, for Susan there was a blurring of lines that caused her to express her unease with exposing herself, and especially her genitals, to the male family members that assisted her. As Smith Rainey asserts: “despite their constant attempts [of divorcing the invasion of disabled people’s personal parts from its sexual association], private parts that pee and poop and need to be cleaned and cared for are also sexual parts.”¹⁹ Indeed, such unease likely also contributed to her reluctance to use the bathroom facilities at school, as discussed in Chapter Three. Such forms of daily transgressions left thalidomiders like Susan feeling exposed to necessary access of others to their bodies’ most private areas.

While Susan’s story is an example of a transgression into her privacy, it can also be read as signifying transgressions into disabled lives more broadly. Privacy for people with disability is elusive, indeed, as Smith Rainey observes, “disabled people expose the reality of connection between public and private, and the way in which private is really a sphere for the nondisabled, the rich, the white, and the heterosexual.”²⁰ In fact, disability studies advocate Tobin Siebers has pointed out how the problematic lack of the private relates to the feminist discussion of the private/public divide: “disability studies supports the feminist argument that the private/public split is responsible for political oppression, while deepening the perception that privacy is abandoned at a terrible cost.”²¹ The story of Susan’s unease is a sharp reminder that the issue of personal care is a key aspect of larger issues surrounding disability and how disabled bodies fit

¹⁸ Sarah Smith Rainey, *Love, Sex, and Disability: The Pleasures of Care* (Boulder, Colorado: Lynne Rienner Publishers, 2011), 152.

¹⁹ Smith Rainey, *Love, Sex, and Disability*, 153.

²⁰ Smith Rainey, *Love, Sex, and Disability*, 153.

²¹ Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008), 144.

within society. In their book, *Intimate and Personal Care with People with Learning Disabilities*, Steven Carnaby and Paul Cambridge have acknowledged this as they argue that “Individual care interactions are undoubtedly political.”²² One of the most intimate experiences in a person’s life, the care for personal hygiene, is exposed to the public by drawing on the help of others, whether those be family members, partners, nursing staff, or support workers.²³

The discussion of personal care has highlighted the vulnerability to bodily transgressions thalidomiders experienced, but beyond challenging everyday interactions my interviews brought to light that some thalidomiders experienced violent physical abuse. In fact, Susan made sure I learned about the abuse she suffered, something I had been hesitant to address directly. Towards the end of our first interview I asked Susan “Do you feel like there is something that you would like to share [...] something that was particularly important for your life that I have not touched on?” Susan paused and then began speaking slowly:

I don’t think we talked about this before but sexual abuse. Statistics say that 90 percent of disabled children are sexually abused and that is a horrible statistic. When I think of all the children I knew at Crippled Children’s Center and I heard stories from every one of them and if it wasn’t a parent, if it wasn’t a cousin, if it wasn’t a health care professional, nurses... [silence] you know *that* is something that I think unfortunately a lot of us have been involved in. It happened to us. And it happened to me.²⁴

Susan began the above assertion by citing a statistic, which established for me that the issue of sexual abuse was widespread and that it deserved acknowledgment and attention. Then, as she recounted how many instances of abuse she was aware of, her voice became impassioned, incredulous at the prevalence of abuse among her peers. Then she disclosed that she too had been

²² Steven Carnaby and Paul Cambridge, *Intimate and Personal Care with People with Learning Disabilities* (London: Jessica Kingsley, 2006), 9.

²³ Accommodations, such as the use of Bidets have become available for some of the thalidomiders more recently, but they are oftentimes time-consuming to make use of and interrupt daily activities.

²⁴ Susan Wagner-White, Personal Interview, December 13, 2016.

abused. By this point we had established only a very brief, yet pleasant relationship, sitting in her living room; as Paul Thompson has asserted, “people may be much more willing to talk intimately in a sympathetic interview situation.”²⁵

Clearly it mattered to Susan that abuse not be overlooked when the long-term consequence of the drug’s impact on lives was being discussed. Based on Martina Higgins’ doctoral research about disability and child sexual abuse, she and John Swain have established that certain patterns emerge when individuals disclose their experiences of abuse. They write: “The limitations presented by many family networks often result in survivors initially seeking support and validation of their abuse narrative through discussion with partners and friends [...], then involvement in counselling, and perhaps later through their participation in research.”²⁶ This observation matched the way Susan has described the way she dealt with and disclosed her abuse story. Therefore, we may surmise that Susan may have been motivated by a variety of factors to entrust me with knowledge of this aspect of her past. What is certain is that abuse experiences, including sexual abuse, were prevalent among Canadian thalidomiders.

Susan was only eight-years-old when she was raped throughout an entire summer by a boy double her age. With a calm face she recalled her past: “I was molested by our neighbour and I think a lot of it has to do with the fact that I was helpless. I was seen as helpless. The situation I was in with my parents, I didn’t think I had anywhere to go or any recourse. I didn’t really know what to do. So I did nothing. [...] It lasted for most of a summer.”²⁷ The young girl was not only vulnerable due to her physical impairments but also because the poor mental health and substance abuse of her parents meant they were not present to supervise, protect or support

²⁵Paul Thompson, *The Voice of the Past: Oral History* (New York: Oxford University Press, 2017), 234.

²⁶Higgins and Swain, *Disability and Child Sexual Abuse*, 45.

²⁷Susan Wagner-White, Personal Interview, December 13, 2016.

their daughter. The sixteen-year-old boy that lived next door began to rape her in her family's attic under the guise of spending play time with her. What began with innocent games typically played by children eventually evolved into abuse during which the neighbours' son penetrated her anally. Though she recounts that she knew what was happening was wrong, this eight-year-old girl was too young to conceptualize what this act symbolized. Her vulnerability made her accessible and an object of violence. Susan's case exemplifies the difficulty of reaching out for help for children with disabilities. Given her challenging familial situation, Susan did not feel that she could turn to her family. This experience of being unable to reach out for help is one that has been identified as common by scholars analyzing the intersection of disability and childhood abuse.²⁸

Today, looking back at that horrific summer, Susan suggests that several factors likely contributed to the abuse: "His father was my father's boss. And I don't know if that played into anything about the power, I mean I am sure it did. I think he probably felt there was nothing I could do because if I said something my dad could lose his job. [...] He never had to say 'Don't say anything,' because I was probably very aware that it was wrong and I probably thought I would get in trouble. That would be another unspoken part of it."²⁹ This statement demonstrates that although her disability had, in her recounting of events, made her into a vulnerable target for the abuse as it had other thalidomide children, other power dynamics also played a role in the way the child experienced this tragic summer and its aftermath. (Note that the intersection of abuse and gender will receive attention below). It is important to emphasize that each story deserves individual attention, even while acknowledging that as a group thalidomiders were

²⁸ Higgins and Swain, *Disability and Child Sexual Abuse*, 45.

²⁹ Susan Wagner-White, Personal Interview, December 13, 2016.

vulnerable to such occurrences of abuse. For Susan, the abuse only ended when the boy's family moved away.

The accounts of sexual abuse and rape of other thalidomide women illuminate the ways vulnerability can become a site of abjection. In the TVAC-produced video *Right the Wrong: The Canadian Thalidomide Survivors Crisis*, Judith Pilote recounts: "From the age seventeen up to the age of twenty-five, he started putting his filthy thing in my vagina. It would go in and it hurt me."³⁰ Judith has no arms or legs due to thalidomide. Despite the name of the video, produced to elicit support in their fight for compensation payments, it is impossible for anything to "right the wrong" that Judith Pilote and others experienced at the hands of their abusers. Brigitte Courval reveals: "I was raped. [silence] I was beaten."³¹ Bernadette Bainbridge was abused by her foster father: "The foster father was coming down in the basement and I was crying 'I just want to get out.' And he kept me down, and I was crying."³² The vulnerability of children was, in the case of the thalidomiders, only magnified by their disabilities; their apparent helplessness due to the physical disabilities appears to have attracted predators.³³ Bernadette's story highlights not only the vulnerability of children with disabilities, but how such experiences of abuse can be viewed as sites of abjection. Wilson defines the abject as follows: "[B]eing abject is the condition of having been discarded, like excrement or a corpse, feeling this like venom in the veins, yet still

³⁰ Thalidomide Victims Association of Canada, *Right the Wrong*.

³¹ Brigitte Courval in *Right The Wrong*, TVAC, 2013.

³² Bernadette Bainbridge in *Right The Wrong*, TVAC, 2013.

³³ There is a plethora of scholarship discussing perpetration and perpetrators of sexual abuse. Within this literature various theories offer a range of understandings why perpetrators sexually abuse children. This chapter puts forth the argument that the physical disabilities made the thalidomiders who experienced abuse especially vulnerable based solely on the ways that the thalidomiders themselves explained these experiences. No interviews were conducted with abusers. For a detailed discussion of the literature and theoretical models discussing the question "Why perpetrators abuse" see Higgins and Swain, "Who Abuses and Why?" in *Disability and Child Sexual Abuse*, 127-146.

clinging to a sense of personal identity.”³⁴ In eerie resemblance to being discarded, the young Bernadette was thrown away from the perpetrator, down the basement stairs.

My interviews indicate that abuse and rape was suffered by additional thalidomiders who remain unnamed. The theory of abjection here is relevant, because Kristeva outlines in *Powers of Horror* that abjection is primarily a feeling of the person that is understanding themselves against that which they see as abject, something she describes as a kind of “narcissistic crisis.”³⁵

Kristeva later theorized that when confronted with disability the onlooker experiences fear of the limits of what it means to be human.³⁶ When disabled bodies are seen as abject, it makes them vulnerable to abuse, as Hughes points out: “Abjection opens up the moral order to the legitimation of violence against persons on the grounds of their repulsiveness: people categorised as monsters, scum, demons, animals, idiots, imbeciles, degenerates, sinners, lunatics, useless eaters ... etc., to list a few ‘western’ metonyms and metaphors for disability, are ‘matter out of place’ or ‘dirt’. These classificatory representations undermine claims to humanity”³⁷ Viewed this way, people with disabilities are at greater risk for violent rejection. As I consider such instances of abuse, it is the crimes of the “shameless rapist”, as Kristeva notes, that are, in fact, abject.³⁸

The forums in which experiences of abuse, including sexual abuse, were shared by thalidomiders emphasise the fact that such experiences remain highly political, as well as personally traumatic. Female thalidomiders disclosed experiences of sexual abuse in personal interviews as well as for the campaign video produced by TVAC cited above, *Right the Wrong*:

³⁴ Robert Wilson, *The Hydra's Tale: Imagining Disgust* (Edmonton, Canada: The University of Alberta Press, 2002), xxi.

³⁵ Julia Kristeva, *Powers of Horror: An Essay on Abjection* (New York: Columbia University Press, 1982), 14.

³⁶ Julia Kristeva, “A Tragedy and a Dream: Disability Revisited,” *Irish Theological Quarterly* 78, no. 3 (2013): 225.

³⁷ Hughes, “The Abject and the Vulnerable,” 840.

³⁸ Kristeva, *Powers of Horror*, 4.

The Canadian Thalidomide Survivors Crisis. Specifically, the video directed by videographer Shirley Ann Claydon was produced by the Thalidomide Survivors Task Force, introduced in Chapter Two, which was formed in 2013 to help build the case for long-term financial support from the Canadian government. Revealing instances of abuse was obviously difficult for the women. Emotions and tears are visible on their faces, there are silences when words fail them. The purpose of the video, shown to government officials and made available online to elicit support for their cause, was to buttress their demand that another injustice, the lack of financial support from the government, be corrected. The abuse was therefore positioned as a direct consequence of the government's negligence in an effort to sway Members of Parliament to support Canada's thalidomide survivors. Josée Lake states in the video: "If I could go on without any help, I would. [...] I cannot because my government did not take their responsibility like they should have. So I think what I am asking is just for justice."³⁹ These testimonies of abuse therefore occurred in an environment of support from other thalidomiders who suffered as they had, and as a result of the hardship they faced alone and as a community.

There were also less overt forms of sexual abuse experienced by thalidomiders. Mercedes recounts a story involving a man in a car attempting to entice her with candy. She was about eight or nine years old and walking home from school, wearing a cape that was swinging around her little body, covering her short arms. She heard a car driving behind her, which was not unusual, until the car stopped. Turning around, she noticed that the window was being lowered and a man stuck his head out. Mercedes' parents had had many conversations with her about safety, so she was alert and wary. A man beckoned: "Come here little girl, I have some candies for you." Mercedes ran home as fast as she could, knowing instinctively that her safety had been

³⁹ Josée Lake in *Right The Wrong*, TVAC, 2013.

compromised.⁴⁰ By noting that her short arms, the visible signifier of her disability, were hidden, Mercedes seemingly suggests that it was not her physical impairment that made her vulnerable to the potential male abuser. Instead, it seems likely that it was her gender or young age that made her a target of the unwanted attention.

Significantly, it is only the stories of young girls' sexual abuse that have been shared with me or in the TVAC video, indicating that perhaps gender, in addition to disability, made these women vulnerable. While the instances of being publicly examined while naked by medical professionals, which were recounted by male thalidomiders (see Chapter Two), could be included here as instances of transgressive and even abusive behaviour, explicit sexual abuse of male thalidomiders, if it occurred, remains hidden within this research. Therefore, we must consider that the intersection of gender and disability may be relevant to understanding the devastating occurrences of abuse. In their article "Vulnerabilities for Abuse Among Women with Disabilities," disability scholars Nosek, Foley, Hughes, and Howland note that the nature of the abuse of women with disabilities has been understood as a variation of the abuse experienced by women in general and that it "shares the same roots" as a patriarchal need to exert power and control over women.⁴¹ The women certainly experienced the reality of risk women with disability specifically have been exposed to historically. Education scholar Yvon Appleby expands on this observation when she wrote in 1993 that "Disabled women are particularly at risk of (hetero) sexual abuse and rape, while they are generally not considered to have any sexual feelings or functions (motherhood) and are therefore considered to be less than female."⁴²

⁴⁰ Mercedes Benegbi, Personal Interview, October 13, 2017.

⁴¹ Nosek, Foley, Hughes, and Howland, "Vulnerabilities for Abuse Among Women with Disabilities," *Sexuality and Disability* 19, No. 3 (2001): 180.

⁴² Yvon Appleby, "Disability and Compulsory Heterosexuality," in *Heterosexuality - A Feminism & Psychology Reader*, eds. Celia Kitzinger and Sue Wilkinson (London: Sage, 1993), 266. Cited in Tom Shakespeare, Kath Gillespie-Sells, and Dominic Davies, *The Sexual Politics of Disability: Untold Desires* (Cassell, 1996), 5.

Appleby's analysis was an important contribution to the understanding of "compulsory heterosexuality," as it challenged Adrienne Rich's influential formulation of the concept by pointing out that some women, those with disabilities, fall outside of societal expectations regarding their sexualities. The conflicting social scripts of disability and gender will receive further attention in Chapter Six. However, it is important to acknowledge here that the oral history interviews demonstrated that female thalidomiders recalled abuse in ways that suggest gendered contexts.

While sexual abuse and rape are important topics, it is also essential to provide discursive space for thalidomiders' experiences of pleasurable sex. Scholars have established that individuals with disabilities have frequently embraced identities as sexual beings.⁴³ Moreover, sexuality educator Mitchell Tepper has written that "when we do not include a discourse of pleasure we perpetuate our asexual and victimization status."⁴⁴ Therefore, while analyses of insecurities and abuse are important, it is equally necessary to take seriously thalidomiders' expressions of sexual confidence and assertions of sexual prowess. Sexual satisfaction and pride were part of the interviewees' narratives in much the same ways as abuse was. Thus far, historians have commonly marginalized acts of pleasurable sex.⁴⁵ And this is particularly true for individuals with disabilities.⁴⁶ Leading scholar on disability and sexuality Tom Shakespeare and his colleague Sarah Richardson point out that, regarding sex: "[...] there seems to be a

⁴³ See for example Anne Guldin, "Self-Claiming Sexuality: Mobility Impaired People and American Culture," *Sexuality and Disability* 18, no. 4 (2000): 233-238; and Cheryl-Ann Potgieter, and Gadija Khan, "Sexual Self-Esteem and Body Image of South African Spinal Cord Injured Adolescents," *Sexuality and Disability* 23, no. 1 (2005): 1-20.

⁴⁴ Mitchell S. Tepper, "Sexuality and Disability: The Missing Discourse of Pleasure," *Sexuality and Disability* 18, no. 4 (2000): 288.

⁴⁵ Victoria Harris, "Sex on the Margins: New Directions in the Historiography of Sexuality and Gender," *The Historical Journal* 53, no. 4 (December 2010): 1096.

⁴⁶ Tepper, "Sexuality and Disability," 283-290; Michelle Fine, "Sexuality, Schooling, and Adolescent Females: The Missing Discourse of Desire," *Harvard Educational Review* 58, no. 1 (1988): 29-53.

distinction between what disabled people do, and what other people think they do.”⁴⁷ The marginalization of pleasurable sex in scholarship is an oversight that needs correction, because rewarding and pleasurable experiences of sexuality are an important part of many disabled peoples’ lives, as was expressed by several thalidomiders in our interviews. Sex and sexuality were parts of the narratives offered by most of the thalidomiders’ whom I interviewed.

Before considering the lived experiences of thalidomiders as they pertain to pleasurable sex, it is necessary to acknowledge that sexual pleasure is a topic where disability, sexuality, and medicine intersect, because sexual pleasure itself was medicalized. Tepper explains: “In the late 18th century and early 19th century with the increased popularity and reliance on doctors and the medical profession, sexual pleasure was thought of or viewed as disease or sickness instead of sin, making it now a medical problem.”⁴⁸ Until the mid-twentieth century, when researchers such as Alfred Kinsey emerged, sexual pleasure associated with non-reproductive sex was typically perceived by professionals as a sign of sickness.⁴⁹ With the increasing focus of doctors on sexual pleasure and erotic encounters in the twentieth century, a new interest in sexual performances and orgasm emerged.⁵⁰ This has significant implications for people with disabilities. Sexual and reproductive health scholar, Tinashe Moira Dune, has noted that the postulation of mainstream assumptions regarding sexual performance, measured in the ability to achieve pleasure and ultimately orgasm, is key to evaluating an individual’s sexuality. These assumptions need to be carefully critiqued and taken to task. She writes that: “For some people with chronic illness the message seems to be that sex can be possible or better if one did not have a disability. As the field of medicine has historically been cure/goal-oriented and experimentally focused, separating

⁴⁷ Shakespeare and Richardson, “The Sexual Politics of Disability, Twenty Years On,” 83.

⁴⁸ Tepper, “Sexuality and Disability,” 286.

⁴⁹ Tepper, “Sexuality and Disability,” 286.

⁵⁰ Tepper, “Sexuality and Disability,” 286-7.

sexuality from the stereotypical performance model can be difficult to do.”⁵¹ The importance given to sexual performance is one that may have been internalized by some thalidomiders, an issue discussed below. While it is imperative to consider that a satisfied sex life was the experience of most of the participants of this study, the measure of what constituted satisfaction must be determined on an individual basis and not based on some abstract, fixed definition. This is made possible by pursuing bottom-up histories, which once again highlights the importance of utilizing oral history methodology.

Mercédes explains that she pursued pleasurable sex from a young age by means of masturbation, which translated into sexual confidence that helped her establish positive sexual relationships with partners. Mercédes explained: “Very young sexuality was important to me. I created tools to provide satisfaction. I have to reach over there, and it would provide me pleasure.”⁵² The act of self-pleasuring was also important later in her life. She states: “There was not going to be a universe with Mercédes not being satisfied [...] I was not dependant on others.”⁵³ Having such a clear understanding of her own needs, and her right to having those needs met, helped Mercédes develop a self-confident perception of her sexuality that greatly alleviated nervousness with sexual partners. Her experience demonstrates that at least some thalidomiders whose physical impairments had encouraged them to find individual ways of exploring their bodies also took charge in the ways their bodies could be explored by partners.⁵⁴ Feeling that it is important to “promote the diversity of beauty,” it has been Mercédes’ experience that her sexual partners would, in turn, be “sensitive to show desires” and considerate

⁵¹ Tinashe Moira Dune, “Sexuality and Physical Disability: Exploring the Barriers and the Solutions in Healthcare,” *Sexuality and Disability* 30, no 2 (2012): 248.

⁵² Mercédes Benegbi, Personal Interview, October 13, 2017.

⁵³ Mercédes Benegbi, Personal Interview, October 13, 2017.

⁵⁴ A particularly interesting discussion of the ways that body image and sexual confidence intersect can be found in George Taleporos and Marita P. McCabe, “Body Image and Physical Disability—Personal Perspectives,” *Social Science & Medicine* 54, no. 6 (2002): 971-980.

in accommodating hers.⁵⁵ Her positive sexual experiences and the ways her partners sensitively acknowledged her disabled body during intimate moments, draws attention to the argument that partners may embrace physical impairments and engage in more creative sexual practices, which can provide for an adventurous sexual experience.⁵⁶ This parallels the argument put forth by Arno Karlen that disabilities have spurred some to make them better lovers or partners.⁵⁷ Mercedes noted that the confidence with which she addressed her desires, and the way she demonstrated her authority over her body, was in fact appealing to partners. This was similarly emphasized by Alvin who also spoke about the appeal of sexual self-confidence: “My wife was attracted to me not because I had no arms [...] there was something about me that my wife was attracted to and a lot of it had to do with independence. You know? Confidence.”⁵⁸ Alvin had built confidence in himself and his sexuality throughout a life that had always required him to be self-assured and resist ableist notions of ability. Importantly, one of the life-lessons he acquired was that he needed to pursue relationships with people that valued him and to find fault in those who did not see beyond his disability, a lesson, he recalls, that shaped his life in positive ways.

Confidence and assertions of independence regarding sexuality served to counteract being viewed as abject. Margrit Shildrick argued in her book *Dangerous Discourses of Disability, Subjectivity and Sexuality* that “disabled people experience broad cultural alienation, not so much for their difference (which may of course be hidden) but because their form of

⁵⁵ Mercedes Benegbi, Personal Interview, October 13, 2017.

⁵⁶ Eleanor Richards, Mitchell Tepper, Beverly Whipple, and Barry R. Komisaruk, “Women with Complete Spinal Cord Injury: A Phenomenological Study of Sexuality and Relationship Experiences,” *Sexuality and Disability* 15, no. 4 (1997): 271-283.

⁵⁷ Arno Karlen, “Positive Sexual Effects of Chronic Illness: Case Studies of Women with Lupus (SLE),” *Sexuality and Disability* 20, no. 3 (2002): 191-208.

⁵⁸ Alvin Law, Phone Interview, February 14, 2017. His assurance that his wife was not attracted to him because he had no arms alludes to the fact that there are some who fetishize non-normative or impaired bodies. However, none of my interviews indicated that individuals who contributed to this research had experienced the fetishization of their bodies as a result of their disabilities, and this topic is therefore omitted from this dissertation.

living in the body lays bare the psycho-social imaginary that sustains modernist understanding of what it is to be a subject.”⁵⁹ Independence in all matters is one of the building blocks of such modern understandings of what it means to be respected in society. Disability, therefore, has the potential to threaten humanness and belonging. Shildrick elaborates: “Where physical and mental autonomy, the ability to think rationally and impartially, and interpersonal separation and distinction are the valued attributes of western subjectivity, then any compromise of control over one’s own body, any indication of interdependency and connectivity, or of corporeal instability, are the occasion – for the normative majority – of a deep-seated anxiety that devalued difference.”⁶⁰ Shildrick’s observation is relevant to understanding the lives of thalidomiders because by asserting confidence and control over their bodies, thalidomiders counteracted the fears and uncertainties their bodies caused potential sexual partners. Thalidomiders’ control over their bodies as well as their sexual desires asserted a level of humanness, as the demonstration of corporeal stability served to claim belonging within a socio-cultural context that valued such attributes as independence and control.

If masturbation could create sexual confidence and help foster positive sexual experiences, then the failure to engage in such sexual acts had the potential to destabilize a person’s identity. To understand what sexual identity entails, I make use here of Jeffrey Weeks’ definition:

Identity today is not something you assume or are born into or that has to remain fixed all your life. It is something that you make for yourself, as part of what has been called the ‘reflexive project of the self’. We can no longer assume, either a single identity from which all social action proceeds. We have multiple possible identities [...] each of which carries different, often contradictory, loyalties, claims and commitments. Identities are varied and changing. [...] This does not mean a dissolution for the self, but a recognition that the task of

⁵⁹ Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (Springer, 2009), 1-2.

⁶⁰ Shildrick, *Dangerous Discourses of Disability*, 2.

finding an anchor for the self, a narrative which gives meaning to all our disparate potential belongings, is a task of invention and of self-invention.⁶¹

Drawing on Weeks' definition, sexual identity in this chapter may be understood in two ways. First, it may be considered as belonging to a specific social group based on the sexual orientation of its members, for example gay, lesbian, or heterosexual persons. Second, sexual identity may be understood as "a general label for one's awareness of one's own sexual characteristics."⁶² As such, the experiences of self-confidence in sexual matters, the sense of sexual (dis)satisfaction, awareness of sexuality as an important aspect of one's life, and the self-perception of one's performance as a sexual partner, could all be part of a person's sexual identity just as much as someone's sexual orientation.

When sexuality intersected with physical impairments it could lead to moments of confusion regarding the person's sexual identity, an experience Alvin had long before meeting his wife. He recalls that as an adolescent, with upper limbs that fall just short of complete absence of the arm, he was not able to masturbate and explore his sexuality in this way. "You realize you can't do that, so you just don't."⁶³ Having a lot of female friends growing up, he still did not date. This is not to say that sexuality did not shape some of his thinking. Feeling no need to explore alternative means of sexual stimulation, he began questioning his sexual orientation, an integral part of his identity. He recalls: "I did start to question that. Am I gay?"⁶⁴ Not experiencing sexual desire, a supposed "drive" that was considered a normal aspect of virile masculine adolescence, led to a self-perception of his sexuality as queer. While Alvin did not

⁶¹ Jeffrey Weeks, "The Sexual Citizen," *Theory, Culture and Society* 15, no. 3-4 (1998): 45.

⁶² Victor Moin, Ilana Duvdevany, and Daniela Mazor, "Sexual Identity, Body Image and Life Satisfaction among Women With and Without Physical Disability," *Sexuality and Disability* 27, no. 2 (2009): 84.

⁶³ Interview conducted on February 14, 2017.

⁶⁴ Interview conducted on February 14, 2017.

explicitly draw on queer theory in understanding his sexuality, he realized that his experience did not reflect the heteronormative stereotype of a young male discovering his sexuality. Although he was not attracted to other boys or men, he questioned his heterosexual identity because he sensed his corporeal experience of pleasure-seeking differed from what was considered “normal.”

Identifying today as heterosexual, and being married to a woman, his relationship to his sexuality has clearly evolved since his teenage years. From initially feeling conflicted about pursuing sexual stimulation, he now has a partner that has made sexuality an active element in his everyday life. Tobin Siebers’s discussion of the ableist nature of typical understandings of sex life is relevant here: “Being able-bodied assumes the capacity to partition off sexuality as if it were a sector of private life: that an individual has sex or a sex life implies a form of private ownership based on the assumption that sexual activity occupies a particular and limited part of life determined by the measure of ability, control, or assertiveness exercised by that individual. People with disabilities do not always have this kind of sex life.”⁶⁵ To Alvin, sexual exploration is considered special in his relationship with his wife, as it is something accomplished together, a shared experience. We see here how his disability has resulted in him defining sexuality as something that is a shared practice, and while this occurs in his case within a relationship, it demonstrates how disability shifts ideas about private acts and achieving control over one’s body (or, in this case, pleasure). This development in Alvin’s personal understanding of his sexuality underlines what Tom Shakespeare suggests about people with disabilities being able to assert their own social benchmarks for what constitutes acceptable sexuality. He writes: “Rather than struggling to conform and to fit into stereotypes which developed on the basis of exclusivity and

⁶⁵ Siebers, *Disability Theory*, 138.

the body beautiful, and narrow, limited notions of how to behave and how to look, disabled people can challenge the obsession with fitness and youth and the body, and demonstrate that sexual activity and sexual attraction can be whatever you want it to be.”⁶⁶ With the help of his sexual partner(s) Alvin affirmed his masculinity and his sexual orientation.

The reference to Alvin’s masculinity in the previous paragraph indicates that it is important to also consider the intersection of sexuality and gender. Disability can be a useful lens through which underlying assumptions of gendered expressions and sexual expectations can be problematized.⁶⁷ While in the earlier discussion of masturbation Alvin noted how his body led him to temporarily question his sexual orientation, that same body later allowed him to portray his masculinity in a way that positively contrasted against the normative idea of the strong male that prioritizes career over family.

Alvin recalls that in some ways his masculinity was shaped by the lessons he learned from his disability:

My wife was married once before too. She was married to a RCMP officer [...] he was a typical policeman. He was very much a man who was more about his job and being a cop than about being a decent human being, and she didn’t know that when she married him either. I think that’s important in the conversation, because when she met me, there was a degree of comparison of this rather masculine man she was with to being now with a man who wasn’t as masculine when it came to his physical ability, but way more masculine when it came to his confidence and a comfort level. I just was comfortable in my own skin.⁶⁸

Indeed, having been confronted about their appearance throughout the years, both in their personal lives as well as in medical environments and the media, all the thalidomiders

⁶⁶ Tom Shakespeare, “Disabled Sexuality: Toward Rights and Recognition,” *Sexuality and Disability* 18, no. 3 (2000): 163.

⁶⁷ Shelley Tremain, “Queering Disabled Sexuality Studies,” *Sexuality and Disability* 18, no. 4 (December 1, 2000): 292.

⁶⁸ Alvin Law, Phone Interview, February 14, 2017.

interviewed asserted a level of comfort with their bodies. Regarding the external perception of disabled bodies, Anne Guldin found in her research on how people with mobility impairments self-interpret and self-claim their sexuality, that some disabled men assert that the disability has in a way been beneficial because they are no longer the “stereotypical guy.”⁶⁹ At least in Alvin’s case this seems to hold true. Karen Yoshida, who has considered the intimate and marital relationships of men with spinal cord injuries, suggests that for some potential partners “individuality was an important dimension in the social construction of ‘humanness’,”⁷⁰ focusing on values other than gendered representation when connecting with disabled partners. Furthermore, it is possible to consider the conclusions drawn by Smith Rainey in her study of the intersections of disability and gender, that disability “may destroy masculinity that is associated with superiority, physical strength, and potency, but it can also be a way for men to have other, perhaps better, ways of expressing masculinity.”⁷¹ Disability then intersects with expressions of gender, though it can do so in a variety, including positive, ways.

In these ways gendered expectations may actually be advantageously challenged through disability, whether directly or indirectly. Yet, the interviews also indicated the ways in which male thalidomiders did negotiate the notion, identified by disability scholars, that “disability is perceived to render a man less masculine.”⁷² When asked about physical intimacy, another thalidomider felt that his body was a key factor in negotiating the relationship between him and women. He assured me: “The women that I have slept with have said that I was the best man they ever had. And I was like ‘Really?’ [...] That part of us hadn’t been affected. So that made

⁶⁹ Anne Guldin, “Self-Claiming Sexuality: Mobility Impaired People and American Culture,” *Sexuality and Disability* 18, no. 4 (2000): 236.

⁷⁰ Karen K. Yoshida, “Intimate and Marital Relationships: An Insider’s Perspective,” *Sexuality and Disability* 12, no. 3 (1994): 183.

⁷¹ Smith Rainey, *Love, Sex, and Disability*, 80.

⁷² Smith Rainey, *Love, Sex, and Disability*, 78.

everything normal in that area. [...] The intimacy part is still ongoing good.”⁷³ In this statement he emphasises that he was just like any other man, even better, since his impairments did not include erectile dysfunction. His emphasis on being “normal” stands out. As Smith Rainey has pointed out before me, “[...] there is still a desire for average persons to claim normality, to hide the ways in which their sex lives may be different.”⁷⁴ The construction of disabled bodies as undesirable and “non-functioning” is also counteracted by Peter’s assertion of women’s exclamations of sexual satisfaction and his assurance of erectile capability. Yet beyond the importance of asserting normalcy, Peter’s statement also draws attention to the issue of health when discussing the absence of erectile dysfunction. The discourse of health and disability intersect when it comes to sexuality since, in our society, “at the most superficial level, a sex life is described almost always in the context of health. A sex life must be, first and foremost, a healthy sex life, and the more healthy a person is, the better the sex life is supposed to be.”⁷⁵ This signifies how ideas about ability impact perceptions about sexuality and outlines the ways that discourses of health, so prevalent for many thalidomiders who continuously move in and out of their role as patients, continue to blend into various aspects of their personal lives.

What is particularly interesting in Peter’s recollection is his question, “Really?” His sexual performance, as described, was one that clearly mattered to him. His masculinity, it may be argued, hinged on his sexual ability. It not only affirmed his ability to achieve intimacy with women, it also helped him suggest that his body was functioning in so far as it met the socially constructed expectation of male virility. In their discussion of sexual esteem and sexual satisfaction among people with physical disabilities, Marita McCabe and George Taleporos have

⁷³ Peter Settle, Personal Interview, January 14, 2017.

⁷⁴ Smith Rainey, *Love, Sex, and Disability*, 152.

⁷⁵ Siebers, *Disability Theory*, 141.

pointed out that “Some authors have argued that physical disability poses more difficulties for the sexual adjustment of men, highlighting how the loss of ability for a ‘normal’ sexual performance can have a devastating, emasculating effect because of the strong association between masculinity and sexual performance.”⁷⁶ This highlights the intrusion of public discourses on seemingly private perceptions of worth and belonging. As such, thalidomiders needed to negotiate their bodies’ capabilities, and societal expectation of what they ought to be capable of, even in their private lives as lovers. The ways in which individuals experience erotic pleasures and encounters helps us understand how they express themselves as human beings.

The ways in which disability and sexuality intersected in the identity formation of the thalidomiders are important for another reason. As Robert McRuer has put it: “disability, sexuality, and (most importantly) their conjunction are dangerous to existing, normative orders.”⁷⁷ This is important because it emphasizes, yet again, that disabled bodies inherently carry political significance. Sexual identities of people with disabilities challenge prevailing ideas about the perceived dichotomy between disabled individuals and sexual desire as well as between disabled bodies and sexual acts. Tobin Siebers has made this point explicit in his own work: “the sexual experiences of disabled people expose with great clarity both the fragile separation between the private and public spheres, as well as the role played by this separation in the history of regulating sex.”⁷⁸ Even if disability was not recognized by thalidomiders themselves, it may be useful to consider them, as Siebers suggests, a sexual minority to

⁷⁶ Marita P. McCabe and George Taleporos, “Sexual Esteem, Sexual Satisfaction, and Sexual Behavior Among People with Physical Disability,” *Archives of Sexual Behavior* 32, no. 4 (2003): 360.

⁷⁷ Robert McRuer, “Dangerous Discourses of Disability, Subjectivity and Sexuality by Margrit Shildrick (Review),” *Journal of Literary & Cultural Disability Studies* 8, no. 2 (2014): 236.

⁷⁸ Siebers, *Disability Theory*, 136.

emphasize that their status as “sexual citizens” has political importance.⁷⁹ Like Mercedes and Alvin, many thalidomiders have laid claim to sexuality as a basic part of human interaction.

When thalidomiders engaged in sexual (or other intimate) relationships with non-disabled partners, those partners shared experiences of disablement, whether it be socially produced or in relation to the physical implications. In some instances, that simply meant a learning curve in the beginning of the relationship. Susan’s wife, Rae, recalled their first date in our interview. After they met online, Rae rented a car so she could drive to meet Susan and they could go see a movie together. Sitting in the movie theater: “I wanted to hold her hand but I didn’t know how. It was like...you know...we figured it out now, but, I mean, at the time, it was like hmm...you know (laughs)...I felt like a teenage boy.”⁸⁰ A simple desire to make a gesture of interest and connection brought Rae back to being a teenager and trying to figure out for the first time how best to approach her love interest. When Rae shared her nervousness about the situation with Susan a few days later, they laughed about it together. Rae notes: “She is very relaxed about how things are. She is a very balanced person, really, and she doesn’t take offence at much really unless it’s in a mean spirit, and it wasn’t.”⁸¹ For Rae it was a matter of speaking with Susan and communicating her interest that allowed her to achieve the intimacy she had wanted to pursue. The physical gestures followed, as Susan reassured Rae. This example speaks to the issue of confidence, discussed previously, and the importance of communication in the relationships of thalidomiders. Indeed, beyond the initial stages of dating, communication in relationships between differently abled partners is essential. This has been demonstrated in Smith Rainey’s study of non-disable/disabled relationships; she states “managing physical impairment in an

⁷⁹ Siebers, *Disability Theory*, 136.

⁸⁰ Rae Wagner-White, Personal Interview, December 29, 2016.

⁸¹ Rae Wagner-White, Personal Interview, December 29, 2016.

intimate relationship requires conversations about alone time, duties and tasks, respect, and balance that often go silently assumed in nondisabled relationships.”⁸² In an analysis of the affective relationality between disabled individuals and their care providers, disability, women’s and gender scholar Akemi Nishida writes that “It takes the time and patience of both parties to build such a connection. Through this recursive collaborative dance of reconfiguration and adaptation, care partners begin moving their bodies to be in sync with other bodies in order to accomplish care tasks.”⁸³ The same can be said of the relationship between Susan and her wife. Thalidomiders collaborated with their partners in navigating the social and embodied barriers to intimacy. After the movies, the two women went to dinner, where Rae recalls that she did not catch on to a lot of the innuendoes Susan was making. Susan was the experienced partner in the relationship when it came to lesbian romance and sex, thus in many ways she took the lead in negotiating where their relationship might go on an intimate level. Theirs was a whirlwind romance: within a week of their first date they were living together, not willing to continue their lives separately.⁸⁴

As relationships grew and partners became integrated into day-to-day living, the various implications disabilities had on a shared life became apparent to some spouses. Partners experienced first hand how disability ensured their lives came under public scrutiny. The perceived burdens and stresses were carefully balanced with assurances of love and the expressed realizations that it was petty to utter complaints. For life-partners, one way in which the disability impacted their personal relationships was the presence of care-takers in the private

⁸² Smith Rainey, *Love, Sex, and Disability*, 137.

⁸³ Nishida, Akemi. “Relating through Differences: Disability, Affective Relationality, and the U.S. Public Healthcare Assemblage,” *Subjectivity* 10, no. 1 (2017): 95.

⁸⁴ Rae Wagner-White, Personal Interview, December 29, 2016.

home; a third party that can enter the private sphere and infringe, inadvertently, on the personal moments shared between partners. Julie Lad, wife of Ramesh, explains how her life is impacted:

He has someone who comes in the morning who helps him shower and get ready and someone who helps him when he goes to the gym to exercise and someone helps when he is shopping [...] so we are super fortunate from that point of view. Most of those needs are taken care of. It just means there is always ... that's one of the challenges I think ... there is always more people around. Like you can never – except for Sunday mornings – never get up in our house and there isn't somebody else in the house in the mornings.

Christine: So it impacts your privacy to some extent?

Julie: Oh totally! It does, yeah. And we are super lucky, we have awesome people, but some days... ⁸⁵

When Ramesh goes on vacation to see his mother in England, Julie confessed being exited to having no support workers in her space for a while. About admitting this, she told me guiltily: “That sounds so bad..” ⁸⁶ Her account demonstrates that care providers access private homes in a way that impacts family life. This is a continuation of the reach, discussed in Chapters Two and Four, that medical professionals had into the homes of thalidomiders during their childhoods.

In other situations, the thalidomider might prefer the help of their partner, which they are comfortable with, over the use of technological or mechanical means that, while useful and appreciated, might take more time for completing tasks.⁸⁷ When Susan requests help to meet certain needs that she would be able to accomplish herself, only with more effort and time, Rae said that “Most days, my head is on straight and it doesn't bother me at all.”⁸⁸ But as with any relationship, stress factors do emerge. In these ways the presence of disabilities has produced challenges to intimacy.

⁸⁵ Julie Lad, Phone Interview, March 1, 2017.

⁸⁶ Julie Lad, Phone Interview, March 1, 2017.

⁸⁷ Rae Wagner-White, Personal Interview, December 29, 2016.

⁸⁸ Rae Wagner-White, Personal Interview, December 29, 2016.

Because of the pressure disabilities can place on a relationship, some thalidomiders found advantages in pursuing relationships with other individuals with physical impairments or health complications. Mercedes felt that when she began dating her husband, his disability had an impact on how she felt in the relationship. Mercedes noted that “because he had a disability, I did not feel like I was a burden.”⁸⁹ By dating someone who had needs specific to a disability, the relationship seemed equal. In the same way, a male thalidomider, too, believes that his disability shaped not only the way he felt in his relationships, but how he chose his partners, two of which had significant health problems. After growing up with the burden of his parents’ guilt, one male thalidomider felt hesitant to burden a healthy partner with his disability. Instead, he took on the role of care-giver for chronically sick partners. With a sad chuckle, he shares “I am probably a sucker for punishment.”⁹⁰ In fact, he also pursued friendships with people with physical disabilities, because he found it easier to connect and relate with them. “If you are told, like me, in a tacit way, you really won’t fit in, you really can’t fit into this world, [...] that’s why, when I was psychologically open to a relationship, it was somewhat too late already. To live all the other stuff. So there is also a mourning of not having children.”⁹¹ He draws a clear connection between his upbringing and the long time it took him to feel that his disability did not define whom he could be with. The choice to seek out partners with disabilities or health problems may be viewed as a form of resistance to ableist barriers to relationships with non-disabled partners. The matter of how reproductive choices were impacted by experiences of disablement will be discussed in Chapter Six.

⁸⁹ Mercedes Benegbi, Personal Interview, October 13, 2017.

⁹⁰ Anonymous, Phone Interview, February 19, 2018.

⁹¹ Anonymous, Phone Interview, February 19, 2018.

On another level, the care offered to non-disabled partners is something that was raised by both Susan and Aline. Susan noted that when her wife Rae was on crutches they had to negotiate the perception of need by outsiders who offered to step in and help, as both women were physically impaired, albeit temporarily. Susan emphasized the ways that she was able to help Rae, as she had significant experience in negotiating physical barriers and had developed a creative mind in terms of problem resolution when it came to physical tasks. In her work Smith Rainey discovered several instances of such reciprocity: “Reciprocity helped them maintain that delicate balance between self and other that fuels intersubjectivity, allowing couples to forge a shared practical perspective about their lives, hopes, and dreams.”⁹² Indeed, by emphasizing her acquired skill of problem solving when it came to physical barriers which she utilized to help her wife in a time of need, Susan outlines one way in which she was able to reciprocate. Similarly, taking on the role of the caring wife when her husband fell ill was one particularly cherished by Aline. While this time in her life was immensely difficult, she noted her relief to have been physically able, at the time, to relieve his burden by caring for him. She described it in these words: “I took care of him for two years before he passed away, but for me taking care of him was a gift, because I was able to do it. Take care of the man that I love.” Both of these women feel that their appreciation for the physical abilities they retained and the mental skills they gained because of their disabilities allowed them moments of joy in their relationships, even during trying times. Here we see again how the ideas about self and ability thalidomiders developed in response to physical and social environments they encountered allowed them to negotiate their every-day lives.

⁹² Smith Rainey, *Love, Sex, and Disability*, 137.

The stories of every-day inter-personal interactions, such as caring for partners, contribute to the conversation about the relevance of medical histories and disability histories to this dissertation. This chapter is located more firmly within the field of disability history. As stated in the Introduction, while medical historians have included patient histories and have thus provided access to previously marginalized voices, they generally do not share the aim of broader disability historians that focus on the everyday life experiences of people with disabilities. Karen Hirsch laments "...while medical historians have occasionally conceived their studies to include the relevant intellectual, political, and economic history, they have rarely given space to the voices of the patients, the clients, the recipients of services. While these areas of historical inquiry are beginning to benefit from adding the perspectives of disabled individuals in the roles of clients, students, patients, or consumers, their primary focus remains the history of medicine or of the professions – not a broader disability history focused on the everyday life experiences of people with disabilities."⁹³ This may be where the differences between the fields are fruitful, as each field encourages scholars to pursue new outlooks in their analysis. It is useful to allow sections of an analysis, as exemplified by this chapter, to be primarily shaped by one field of literature to provide room for perspectives that might otherwise go overlooked.

Sexuality in the lives of thalidomiders has many different facets. Sexual abuse and violence, masturbation, as well as consensual sex and intimacy were recalled by different thalidomiders in the private interviews. Thalidomiders devised strategies in their sex lives to manage the bodily realities of impairment and intimate encounters on their own and with the help of others. Sexual acts in these lives can be viewed as challenging individuals' identities as impairments, lack of information, and social attitudes have caused moments of confusion and

⁹³ Karen Hirsch, "Culture and Disability: The Role of Oral History," *The Oral History Review* 22, no. 1 (1995): 5.

(re-)orientation in thalidomiders' understanding of their sexual identities. Simultaneously, sexuality did not manifest in a limited set of specific instances, instead it was a basic component of individuals' every-day lives, not least because sexuality – and, as the next chapter will demonstrate, reproduction – tends to serve culturally to define the value of an individual's roles in society and even help to establish their humanness. By analysing the experiences of thalidomiders' own understandings of sexuality and intimacy, scholars can gain a better understanding of the social dimensions of sexuality for those whose sexualities have been marginalized. Like sexuality, reproductive choices, including fertility control, bearing children, and raising or not raising children, indicate the ways that embodied experiences and social perceptions worked together to help thalidomiders form and articulate their choices. As such, embodied experiences of sex, and bearing and rearing children, which will be discussed in the following chapter, were shaped by and negotiated against social discourses and perceptions of ability. The sexual choices thalidomiders made throughout their lives continuously provoked a confrontation of social perceptions through embodied experiences.

Chapter 6: Reproduction

If I had a baby, how would I be able to carry it around?¹

The parenting and reproductive choices of thalidomiders had an impact on the ways they evaluate their lives today. While I discussed the intricate lived experience regarding sexuality, desire, intimacy, and sexual violence in the previous chapter, posing questions about reproduction and birth control can add to our understanding of thalidomiders' ideas about, and perceptions of, sex. This chapter focuses on the reproductive experiences of people with disabilities and outlines how thalidomiders navigated social perceptions and discrimination with regards to their reproductive choices. Thalidomiders' reproductive capabilities had the potential to threaten the social order and were perceived through competing discourses of disability and gender. The experiences recalled in interviews emphasize the ways that each thalidomider had distinct experiences, while simultaneously highlighting how individuals with disabilities nonetheless faced universalized values that inform mainstream attitudes towards disability and reproduction. Some thalidomide bodies were able to bear or father children, others were not. Some chose to have children, some unintentionally became parents, some came to terms with infertility, and some others decided not to have children. Thus a case study of thalidomiders allows insight into an incredible array of parenting and reproductive choices of people with physical disabilities. Here the embodied capabilities and social circumstances both demonstrate that whereas thalidomide had an immense impact on the reproductive experiences of women

¹ Mercedes cited by Bill Trent in "If I had a baby, how would I be able to carry it around?" *Weekend Magazine*, February 15, 1969, 2.

who took the drug, the long-term consequences of thalidomide also shaped the reproductive experiences of the next generation.

The theme of reproduction will be explored in terms of fertility and fertility control, as well as thalidomiders' choices surrounding becoming a parent and raising children. The question of birth control will be addressed first. This is a choice that contains a particular political bias. Addressing themes of conception and fertility control before childbearing and rearing parallels dominant cultural assumptions regarding the timeline within which reproductive choices should be made. Beginning this chapter with analysis of thalidomiders' efforts to control their fertility does not signify my endorsement of common assumptions about a supposedly ideal time for conception prevention and pregnancy, it simply mirrors thalidomiders' experiences related to fertility and parenting.

Contraceptive technologies enabling women to assert their sexual agency are a double-edged sword for people with disabilities when making reproductive choices. Historian Sarah Hodges has aptly written about the importance of contraceptive technology, popularly called birth control, for women, stating it was “revolutionary because it allowed women to prevent pregnancy while existing as sexual agents. The use of contraception thereby offered the potential for women to obliterate motherhood as central to their experiences or identities.”² Disability and reproductive control, however, have tense and difficult historical ties, located in the intersections of disability and eugenic thinking.³ In Canada, cases like the wrongful sterilization of Leilani

² Sarah Hodges, *Contraception, Colonialism and Commerce: Birth Control in South India, 1920-1940* (Aldershot, England: Ashgate, 2008), 85.

³ See Dagmar Herzog, *Unlearning Eugenics: Sexuality, Reproduction, and Disability in Post-Nazi Europe* (Madison, Wisconsin: The University of Wisconsin Press, 2018), 5. In addition, Erica Dyck's article on Reproductive Rights in the Eugenics Archive provides a brief synopsis. accessed August 18, 2018, <http://eugenicsarchive.ca/discover/connections/535e0dec7095aa0000000253>.

Muir, deemed by an Alberta eugenics board in the late 1950s to be of inferior intelligence, serve as reminders of the problematic ways in which perceptions of ability clash not only with individuals' rights but also with the values ascribed to disabled people's reproductive choices.⁴ In the late 1990s, North American disability scholars addressed the growing concern that advances in new reproductive technologies to screen for genetic irregularities in a foetus furthered eugenic thinking, at times in subtler but still intrusive ways.⁵ As Dan Goodley explains, "The human worth of disabled people is rendered highly questionable through the growing use of reproductive technologies."⁶ Genetic testing and other procedures women undergo during pregnancy are often conducted with the primary assumption that disabled children would be unwanted, an issue that has caused significant ethical debate.⁷ However, for disabled women, as for non-disabled women, fertility control is often a central concern when negotiating their sexuality. Thus, a discussion might well focus on where moments of liberation can be located. Of course, as historians Kate Fisher argues, sometimes "both men and women were involved in

⁴ Muir filed the first successful lawsuit against the Alberta government for wrongful sterilization under the Sexual Sterilization Act of Alberta. In the process she raised awareness of eugenics and human rights for individuals with disabilities. Erica Fagen, "Leilani Muir: Eugenics on Trial in Canada." *Peace and Conflict: Journal of Peace Psychology* 19, no. 4 (2013): 358.

⁵ This matter has been addressed most succinctly by Tom Shakespeare. Tom Shakespeare "Choices and Rights: Eugenics, Genetics and Disability Equality," *Disability & Society* 13, no. 5 (1998): 665-681. The distinction between old and new reproductive technologies has been usefully outlined by Renate Duelli Klein, "What's 'New' About the 'New' Reproductive Technologies," in *Man-Made Women*, ed. Gena Corea (London: Hutchinson and Co. Publishers Ltd., 1985), 64.

⁶ Dan Goodley, *Disability Studies: An Interdisciplinary Introduction* (Thousand Oaks, California: Sage Publications, 2010), 6.

⁷ Judith Mosoff, "Reproductive Technology and Disability: Searching for the Rights and Wrongs in Explanation," *Dalhousie Law Journal* 16, no. 1 (1993): 99.

Worthwhile to note here is that the births of the thalidomide babies encouraged policy makers internationally to include eugenics abortion clauses when legalizing abortions. Clare Parker, "From Immorality to Public Health: Thalidomide and the Debate for Legal Abortion in Australia," *Social History of Medicine* 25, 4 (2012); Susanne Klausen and Julie Parle, "'Are We Going to Stand By And Let These Children Come Into the World?': The Impact of the 'Thalidomide Disaster' in South Africa, 1960-1977," *Journal of Southern Africa Studies* 41, no.4 (2015): 735-752; Susanne Klausen, "'There is a Row about Foetal Abnormality Underway': The Debate about Inclusion of a Eugenics Clause in the Contraception, Sterilisation, and Abortion Act, 1977-1978," *New Zealand Journal of History* 51, No. 2 (October 2017): 80-103; Herzog, *Unlearning Eugenics*, 29. Canada was a noteworthy exception. See my article: Christine Chisholm, "The Curious Case of Thalidomide and the Absent Eugenic Clause in Canada's Amended Abortion Law of 1969," *Canadian Bulletin of Medical History* 33, no. 2 (January 2, 2017): 493-516.

discussions surrounding contraception.”⁸ She further suggests that men’s role in private deliberations surrounding birth control ought to be incorporated into discussions.⁹ It ought to be noted that Fisher has been criticised for painting a picture in which the women included in her research “actively maintained ignorance about sex and birth.”¹⁰ While this seems a valid concern, future research might still pursue an in-depth consideration of the ways that disabled men have approached deliberations regarding their disabilities when it comes to discussing reproductive choices with their partners.

Given that it was a drug that caused the disabilities of the participants, it was not unsurprising to learn that several participants, such as Mercedes, Peter, and Paul, operated with a great deal of caution towards pharmaceuticals throughout their lives. This had implications for choice of birth control methods. While Mercedes is firm in asserting that she believes in the importance of medicine to help people, she also acknowledges that her fear of drugs motivated her to educate herself in homeopathy. When it came to contraception, she began charting her temperature to keep track of her ovulation and fertile window to avoid pregnancy. While she later did decide to go on the birth control pill to help alleviate menstrual cramps, her disability, caused as it was by a poorly-tested medication, made her conscious of the often dismissed side-effects of pharmaceuticals.¹¹ In this way thalidomide not only impacted the pregnant women who took it, the failure of the pharmaceutical industry in that instance also translated into longstanding distrust in medical products, a concern that could have direct implications for family planning strategies.

⁸⁸ Kate Fisher, *Birth Control, Sex and Marriage in Britain, 1918-1960* (Oxford University Press, 2006), 65.

⁹ Fisher, *Birth Control, Sex, and Marriage*, 65.

¹⁰ Susanne Klausen, “Rethinking Reproduction: New Approaches to the History of Sexuality, Gender, the Family, and Reproductive Control,” *Journal of Contemporary History* 44, no. 1 (2009): 119.

¹¹ Mercedes Benegbi, Personal Interview, October 13, 2017.

Contraception also meant that some thalidomiders needed to negotiate, once again, the authority medical professionals sought to exercise over their bodies. As a young woman, Susan too was concerned about side effects of the birth control pill, such as blood clots. At a time before she was out to her parents as gay, her father did consider that she may be or become sexually active in the foreseeable future and wanted her to be protected from unwanted pregnancy.¹² Susan stated: “He didn’t say that was why, but I knew it was.”¹³ Later on, being gay, she did not require contraception as a means to control her fertility. However, birth control methods would become important in her life for another reason and her story elicited one of only a few references to the ways that the control over bodies exerted by medical professionals continued into thalidomiders’ adulthood. In addition to the uncomfortable issue of requiring help in the bathroom, Susan experienced issues with painful menstrual cramps, to the extent that at twenty-three years of age, she decided to address the problem and asked her doctor for a hysterectomy. The doctor, however, refused to perform the requested procedure on the grounds that Susan might later want children. He did not present her with a medical reason to reject the procedure that could have eased her physical, psychological, and embodied discomfort, instead imposing an idea about the centrality of motherhood onto Susan’s imagined future. To him it seemed too risky to take away her chance of becoming a mother. She told him confidently “I will never want children”, nevertheless he did not comply with her request.¹⁴ In this story gender and disability intersect. Scholars, drawing on Foucault, have argued that “medicine does more than identify and help us understand the sources of normal and abnormal function and capacity. Instead it has been productive in shaping the types of bodies drawn into the protection of being

¹² Having two older siblings Susan is certain that his intent to provide her with access to birth control was unrelated to her disability.

¹³ Susan Wagner-White, Personal Interview, December 13, 2016.

¹⁴ Susan Wagner-White, Personal Interview, December 13, 2016.

defined as ‘normal’ and those positioned as abnormal and in need of treatment.”¹⁵ While Susan had experienced her body being perceived as in need of treatment due to her disability as a child, she was now denied treatment because such treatment would enable her to reject the (potentially) fertile body that was perceived as normal and desirable for a woman.

The irony to Susan was that she still could have become a mother if she had wanted to. Susan points out that as a lesbian, her partner could have carried a child to term for them, had she felt the slightest bit of desire to be a mother. This instance of a refused procedure that would have alleviated physical pain and discomfort is extremely important. While the medical expert did not promote the problematic idea that disabled women should not reproduce, something other disabled women were confronted with, the doctor nonetheless refused to allow Susan the authority over what ought to be done with her body.¹⁶ Despite this conflict with her doctor, Susan pursued the issue further and, although about a decade went by, she did eventually find a doctor who at least prescribed oral contraception for menstrual suppression. This incident taps into a broader discussion of women’s rights to control their reproductive sexuality as well as spurs consideration of the ways disabled women’s bodies have been controlled by the medical profession.

Scholars have drawn insightful comparisons between disabled women’s reproductive rights and the feminist fight to legalize abortions. Legal scholar Vanessa Volz has argued that the feminist movement, led by able bodied women, advocated for women’s reproductive rights by foregrounding the issue of abortion, and that disabled women share in feminist concerns but also

¹⁵ Janice McLaughlin and Edmund Coleman-Fountain, “The Unfinished Body: The Medical and Social Reshaping of Disabled Young Bodies,” *Social Science & Medicine* 120 (2014): 77.

¹⁶ For examples of how other disabled women were confronted with doctors’ eagerness to provide abortions, indicating the belief that disabled women were not suitable for motherhood, see Herzog, *Unlearning Eugenics*, 136. Herzog is drawing on a collection of narratives provided by women with disabilities in Silke Boll et al., *Geschlecht: Behindert, Besonderes Merkmal: Frau – Ein Buch von Behinderten Frauen* (Munich: AG SPAK, 1985).

have distinct concerns based on the barriers they face based on their disabilities.¹⁷ Reproductive justice advocate Loretta Ross and historian Rickie Solinger rightfully point to the intersection of disability rights claims and reproductive justice concerns when they emphasize that people with disabilities face reproductive discrimination at the hands of physicians.¹⁸ Volz points out that “if all women have the right to choose not to bear a child, then all women must also have the right to bear children.”¹⁹ Primarily women with disabilities have had to fight for the right to be recognized as capable of motherhood, therefore the patronizing way in which a disabled woman’s right to reject motherhood was denied is significant as it highlights that social scripts of both gender and disability impacted thalidomiders. Importantly, while disabled women have had to fight for their rights to be mothers, it is equally important to recognize that “Not all disabled women are interested in marriage or mothering; some may be more interested in sexual freedom and access to contraception; some may be lesbians; some choose not to have children.”²⁰ Susan’s experience brings to scholars’ attention the ways in which the intersection of gender and disability raises important questions regarding reproductive rights.

The control of disabled individuals’ bodies and sexuality by parents, care takers, and medical professionals continues to deserve scholarly attention. As early as 1992, in *The Women’s Foundation Newsletter*, K. Simpson described disabled women’s reproductive choices, particularly when they did choose to have a child, “as daring as the choice to have an abortion

¹⁷ Vanessa Volz, “A Matter of Choice: Women with Disabilities, Sterilization, and Reproductive Autonomy in the Twenty-First Century,” *Women’s Rights Law Reporter* 27, no. 3 (2006): 211.

¹⁸ Loretta Ross and Rickie Solinger, *Reproductive Justice: An Introduction* (University of California Press, 2017), 144.

¹⁹ Volz, “A Matter of Choice,” 211. This statement reflects the political theory of the African-American group SisterSong, who took the leading role in developing the shift from reproductive rights to reproductive justice in the 1990s. See SisterSong, “What is Reproductive Justice?” accessed July 25, 2019, <https://www.sistersong.net/reproductive-justice>.

²⁰ Virginia Kallianes and Phyllis Rubinfeld, “Disabled Women and Reproductive Rights,” *Disability & Society* 12, no. 2 (1997): 205.

was 50 or 60 years ago.”²¹ People with disabilities who choose to become parents are subject to public scrutiny and women’s bodies, already deeply political, receive further surveillance if they are marked by doctors as disabled bodies. The intersection of feminist ideas with issues of disability, in discussions about the control of bodies and sexuality, is further outlined by disability scholar Monika Parchomiuk who studies the social context of disabled parenting, when she writes: “If an individual with disability wants to start a family, they are subject to close scrutiny by the specialists who will often quote medical discussions on threats related to procreation, such as hereditary disorders, or fetal damage caused by parents’ medicalization. Although this type of discourse also concerns many ablebodied women who have contact with health institutions during procreation, women whose bodies are ‘abnormal’ are especially prone to experience stronger monitoring related to it.”²² There is a level of infantilism at play that seemingly encourages medical professionals to assert their expertise over disabled women’s choices.

It is important to emphasise that the experiences of thalidomiders in regards to reproductive choices were not homogenous. Aline did not experience problems accessing the type of birth control she wanted. She specifically chose to go on the birth control pill when she was first dating her future husband.²³ For her, birth control was about being able to explore her sexuality and intimacy with her partner. In her case, the story of birth control can be told as one of increased emancipation and control over her own body. This emphasizes that contraception and reproductive technologies, sometimes used as part of eugenic measures, can in other contexts be liberating. Historian Johanna Schoen emphasises, “reproductive technologies, like

²¹ K. Simpson, “Disabled Women & Health Care: The Meaning of Accessible,” *The Women’s Foundation Newsletter* (1992), 8. Cited in Kallianes and Rubinfeld. “Disabled Women and Reproductive Rights,” 210.

²² Monika Parchomiuk, “Social Context of Disabled Parenting,” *Sexuality and Disability* 32, no. 2 (2014): 236.

²³ Aline Vachon, Personal Interview, October 13, 2017.

other medical technologies, are never value free, but gain their meaning from the larger cultural and political context in which they emerge, the circumstances under which women encounter them, and the intentions with which health professionals grant women access to them.”²⁴ Like Susan, Aline aimed to take charge of her reproductive sexuality. Agency in regard to birth control demonstrates the different ways in which scepticism towards pharmaceuticals, medical involvement in reproductive choices, and emancipatory fertility regulation manifested in the lives of thalidomiders. However, it is clear that analyzing their experiences related to fertility control has helped uncover the ways in which thalidomiders, especially women, were extremely self-aware regarding their contraceptive choices.

Given the normalcy of sexuality in many thalidomiders’ lives, it is important to address not only contraception but also fertility. While for many, there was some initial concern (perpetuated by the media) about second generation birth defects, these concerns were soon dispelled. Still, Peter remembers how at first concerns about second generation effects of thalidomide were worrisome for the thalidomiders who wanted to have biological children. Turning to doctors did not help alleviate worries, as the medical experts remained uncertain, at first, about the potential that thalidomiders may pass on their physical disabilities to their children. “Professionals said, ‘we don’t know. We don’t know if you will have normal children.’”²⁵ Nonetheless, the question of second-generation defects was eventually answered. In 1998, Dick Smithells, at the Department of Paediatrics and Child Health in Leeds, England, seemingly frustrated by the perpetuation of the suggestion that thalidomide may cause second generation birth defects in newspapers, reviewed a series of medical studies and stated

²⁴ Johanna Schoen, *Choice and Coercion: Birth Control, Sterilization, and Abortion in Public Health and Welfare* (Chapel Hill: University of North Carolina Press, 2005), lxxviii.

²⁵ Peter Settle, Personal Interview, January 14, 2017.

emphatically: “the answer to the question, ‘Can thalidomide cause second generation defects?’ is a very definite ‘No.’”²⁶ His article was made available to Canadian thalidomiders on the TVAC website. Yet even when second-generation birth defects had been ruled out, thalidomiders faced limitations on their reproductive rights, before and after they had children. Paul recalls: “My in-laws said you’re going to have babies born freaks if you have any kids with her and we want nothing to do with you. They look at me as a midget. And they thought I’d just have circus babies. And that was insulting.”²⁷ He already knew that his disabilities and health problems caused by thalidomide could not be passed on to his children and resented the discriminatory antipathy directed at him. The resistance towards thalidomiders potentially reproducing demonstrates the fear such disabilities caused others. Disability itself is perceived as dangerous to the subjectivity of the able-bodied onlooker, but when individuals with disabilities demonstrate that they too are sexual beings and/or are potentially reproducing, the threat of reproducing disability might lead to violent rejections based on the vulnerability of the “normative”/non-disabled self.²⁸ Tobin Siebers, in his book *Disability Theory*, links such resistance to the discussion of sexuality outlined in the previous chapter: “Sex is the action by which most people believe that ability is reproduced, by which humanity supposedly asserts its future, and ability remains the category by which sexual reproduction as such is evaluated. [...] It is reproduction then that marks sexuality as a privileged index of human ability.”²⁹ It is then a matter of who belongs to society, measured on ability, and who has a stake in its future; people

²⁶ Dick Smithells, “Does Thalidomide Cause Second Generation Birth Defects?” *Drug Safety* 19, no. 5 (1998): 341.

²⁷ Paul Settle, Personal Interview, January 14, 2017.

²⁸ Margrit Shildrick, *Dangerous Discourses of Disability, Subjectivity and Sexuality* (New York: Palgrave Macmillan, 2009), 28.

²⁹ Tobin Siebers, *Disability Theory* (Ann Arbor: University of Michigan Press, 2008), 140.

with disability are marked as a problematic existence whose reproductive potential threatens social stability.

Despite normative ideas asserting the incompatibility of disability and reproduction that many thalidomiders encountered, and which can be seen in several of the following anecdotes shared by participants, many were fertile and wanted to have children. The twin brothers Peter and Paul, who grew up in a large Catholic family, were encouraged by their family to explore everything their peers might explore, including building families. From musical instruments to sports, their family provided an environment in which social opportunities seemed endless. In fact, they often worked hard to ensure that their image as capable of anything their peers could do would not falter, by, for example, engaging in physical fights at school to demonstrate their normative masculinity and physical prowess on the school yard. Thus, when later in life one of the brothers announced his wife's pregnancy, one of his sisters recalls that she viewed her brothers' parenting as something that would occur within a supportive family unit in which, similar to their familial environment growing up, accommodations and shared responsibilities would ensure that he could successfully parent. She remembers: "It was exciting! It was a happy time."³⁰ And even though the other twin's first child was unplanned, she recalls it was also a happy event. Of course, this did not mean that their siblings did not also worry. Another sister recalls the twins taking on fatherhood: "I was worried that it would be too much for them [instead] I was impressed."³¹ While neither twin's marriage lasted, one man became a single father who has subsequently raised two children, and the other found a new partner with whom to share parenting responsibilities.³² According to the brothers, neither experienced fatherhood as

³⁰ Interview conducted on February 2, 2017.

³¹ Interview conducted on February 28, 2017.

³² Interview conducted on January 14, 2017.

a more difficult challenge than the one every new parent faces, instead it was a cherished aspect of their lives. Clearly, fatherhood was and remains an extremely meaningful role that is central to their life story. Such experiences are important to consider because parenthood is often perceived as being elusive, even contradictory, for people with disabilities.³³ Neither the twins, nor Aline, felt that their disability was an obstacle in parenting.

To argue that reproduction is something that can be achieved by disabled and non-disabled people alike undermines, to an extent, both the social and physical discomfort or difficulties some thalidomiders experienced due to their disability when trying to become a parent. Aline's story highlights the difference between the ease with which some thalidomiders were able to become biological parents and the difficulties others faced. Her reproductive choices were drastically impacted by the physical limitations her body placed on her. It was her embodied impairments that presented a challenge to bearing children, rather than the social barriers she experienced as a result of her non-supportive family. When her adopted sister had a baby boy, before Aline herself was pregnant, her family did not trust that Aline would be able to even hold the child. She remembers that they repeatedly warned her "Oh don't drop her!" They requested she, an adult at the time, should sit down and only then would they give her the baby, the scenario eerily similar to the ways a small child may be instructed when first holding a new sibling. Aline resented the lack of trust. "I didn't like that. Not at all. Because [I thought] you raise me and tell me that? You don't know me and you don't trust me."³⁴ In fact, later on in the interview she described her adopted family's behaviour as policing. The assumption thalidomiders would require help caring for babies had been raised by medical professionals as

³³ Roni Rothler, "Disability Rights, Reproductive Technology, and Parenthood: Unrealised Opportunities," *Reproductive Health Matters* 2, no. 50 (2017): 110.

³⁴ Aline Vachon, Personal Interview, October 13, 2017.

early as when the thalidomiders were teenagers. Dr. Maurice Mongeau of the Montreal Rehabilitation Institute stated that “The children are all doing very well [...] when they have children of their own they need help.”³⁵ Such concerns about the problems thalidomiders may face, however well-meaning they may have been intended, were proven unnecessary by the participants of this research. Aline herself had confidence in her abilities to mother. This confidence was unaffected by her difficult relationship with her adoptive family. “My decision to have children was: *I wanted children.*”³⁶ Even though her adoptive parents had raised her since she was three years old, they could not look beyond her disability to see the potential of her raising a child. Rosemarie Garland-Thomson has written, importantly, that “Women with disabilities often must struggle to have their sexuality and rights to bear children recognized. Disability thus both intensifies and attenuates the cultural scripts of femininity.”³⁷ Previous chapters have demonstrated that thalidomiders negotiated social expectations in their everyday lives, and performances of gender – including related ideas about reproduction – can be included as further examples of such negotiations.

Societal ideas (and fears) about disability, could, at times, threaten to de-gender individuals with disabilities. Scholar-activist Samantha Walsh has pointed out that, although not interested in becoming a mother, her disability almost provided an incentive to become a mother to counter social perceptions. Walsh wrote in *Disability and Mothering*, that “I find myself caught between the demands of my culture and my interpretation of those demands. It seems as though I must perform the intersectionality between my gender and disability; for example, I feel

³⁵ “No Tears from Denis After 25 Operations – The Thalidomide Children Today.” (Newspaper clipping, date and source unknown.)

³⁶ Aline Vachon, Personal Interview, October 13, 2017.

³⁷ Rosemarie Garland-Thomson, “Integrating Disability, Transforming Feminist Theory,” *NWSA Journal* 14, no. 3 (January 17, 2003): 17.

compelled to have children to prove my capacity and capability as a mother.”³⁸ A similar sentiment was echoed in another academic discussion about disabled women’s reproductive choices. Disability scholars Virginia Kallianes and Phyllis Rubenfeld write: “Given society’s insistence that disabled women are asexual and ‘unfit’ mothers, perhaps a disabled woman may wish to bear a child to disprove the stereotype of asexuality, to prove that she is indeed like other women, or to regain some semblance of an ordinary life.”³⁹ Walsh’s conscious decision to not have children, provides insight into a different pressure placed on disabled parents. Here disability and gender are interlinked in an interesting way. Not only would motherhood re-affirm gendered perceptions, it would also serve to counteract a negative social assumption about disabled women’s capabilities. Thus reproductive choices have the potential to function as a resistance strategy to counteract doubts and discrimination levelled at disabled individuals. Private reproductive choices and embodied experiences of bearing a child are therefore highly political, whether intentionally or not, when they are made or experienced by a person with disabilities.

Disabled women are placed in a social position that forces them to negotiate conflicting social scripts and pressures. Indeed, “Women with disabilities have claimed that the denial of their mothering rights through forced sterilization or general discouragement by doctors, professionals, and family members not to have children, is an experience of oppression.”⁴⁰ Thus while feminists fought for the rights of women not to bear children, disabled women have had to additionally fight against assumptions of their inability to mother and for the right to have

³⁸ Samantha Walsh, “‘What Does It Matter’ A Meditation on the Social Positioning of Disability and Motherhood,” in *Disability and Mothering: Liminal Spaces of Embodied Knowledge*, eds. Cynthia Lewiecki-Wilson (Syracuse University Press, 2011), 82.

³⁹ Kallianes and Rubenfeld. “Disabled Women and Reproductive Rights,” 211.

⁴⁰ Volz, “A Matter of Choice,” 212.

children. This echoes the claims of reproductive justice movement, which was formed and led by American women of colour.⁴¹ If we place this double-burden into the context of sexual citizenship, a concept understood here as “signifying access to rights granted or denied to different social groups on the basis of sexuality,”⁴² it can be recognized that “where discourses promote the sexual citizenship of disabled people what they actually refer to is the sexual rights of male heterosexuals, whilst the sexual rights of women and other sexualities are marginalized.”⁴³ Thalidomide women were no exception, and in their identity as both women and disabled individuals had to negotiate both types of oppression as can be seen in the examples of Susan and Aline. Despite her family’s attitude, Aline did not waver in her certainty. She attributes her determination to have children to her knowledge about her own body and capabilities, derived from her embodied experiences and desires that remained unaffected by doubts and barriers. She knew she could raise a child, even before she had her daughter. When Aline eventually became pregnant at the age of twenty-four, she was ready for motherhood. It was a good time to have her child, as she recalls the timing of her pregnancy today, because her body had more ability, more strength, when younger, making many of the tasks of a new mother easier.

However, when it comes to reproductive choices, the embodiment of an impaired body can determine and limit choices. Despite her positive experience getting pregnant, Aline could not have a second child. As she recalls:

When I gave birth, it was so painful because my body is not made to have babies, to give birth. I am lucky that I have a daughter, but [...]

⁴¹ Luz Rodriguez, Loretta J. Ross, Dazon Dixon Diallo, Latina Roundtable, and Sarah L. Brownlee, “The ‘SisterSong Collective’: Women of Color, Reproductive Health and Human Rights. (SisterSong Women of Color Reproductive Health Project),” *American Journal of Health Studies* 17, no. 2 (2001): 79-88.

⁴² Diane Richardson, “Rethinking Sexual Citizenship,” *Sociology* 51, no. 2 (2017): 211. Richardson’s article provides an in-depth discussion of the various ways sexual citizenship can be and has been theorized by scholars.

⁴³ Andre Dupras, “Disability and Sexuality: Solutions for Sexual Misery?” *European Journal of Disability Research* 6, no. 1 (2012): 441.

after close to twenty-four hours of pain they put me to sleep and they went to take her through the natural way. But they put me to sleep. To go take her they broke my coccyx. [...] So it was very painful and it was about two years to recover from the birth of my daughter. But having the opportunity to give birth for me was such a gift, such a blessing. I wanted to have two but it was a trauma to my body to give birth, so I stopped there.⁴⁴

Her body, rather than social circumstances, determined her decision to not have any more children after her daughter was born. A caesarean section was not medically advisable for her. Due to her particular body, Aline's birthing was medicalized: she became a patient undergoing a medical intervention when giving birth. This recollection emphasises the potential of oral history for medical historians pursuing patient histories. As Geoffrey Reaume notes regarding oral history: "This approach to uncovering the voices of marginalized people [...] provides an invaluable example of the importance and fruitfulness of hearing the patient's views free from the constraints of 'official' medical interpretations. Through their own commentary, drawings, and photographs, episodes from the lives of these former patients are briefly recounted with a directness which is far more powerful about understanding their condition than any diagnosis could indicate."⁴⁵ In other words, while there are ways in which the sexuality of thalidomiders may have been studied by employing a top-down medical history lens that could foreground the clinical assessment of Aline's body and potential risks of future pregnancies, allowing Aline to recall this event in her own words shifts the emphasis away from the pathologization of her body towards an understanding of this time in her life as one that was defined by embodied experiences of pain and healing, but also one informed by emotions of gratitude about what her body was able to accomplish. Providing room for the stories of thalidomiders themselves

⁴⁴ Aline Vachon, Personal Interview, October 13, 2017.

⁴⁵ Geoffrey Reaume "Keep Your Labels Off My Mind! Or 'Now I Am Going to Pretend I Am Crazy but Done be a Bit Alarmed': Psychiatric History from the Patients' Perspectives," *Canadian Bulletin of Medical History* 11, no. 2 (1994): 400.

highlights a key methodological goal of this dissertation: to give the last word to what the individuals have to say about their experiences, since, in the words of Reaume, “that, after all, is what this research is all about.”⁴⁶

Other female thalidomiders carried pregnancies to term as well. Some even multiple times. In 1999, a study of forty-five Canadian thalidomiders, of which twenty-seven were women, revealed that twelve had been pregnant; “3 with 1 pregnancy, 6 with 2 pregnancies each, and 3 with 3 pregnancies.”⁴⁷ The results demonstrate the diversity of experiences of motherhood. Indeed, one woman interviewed for this study acknowledged that her disability only became an issue for her when she was pregnant. This acknowledges “that one’s disability is subject to change, and thus can appear or and disappear, dependent on time, setting, and relationships.”⁴⁸ In other words, women (and men) may have changing perceptions and desires when it comes to their own ability to parent and choice to have children, at times impacted by their embodied experiences of disability.

This diversity of experiences is even further demonstrated by others who did not have the option of bearing biological children. Judith Pilote says: “I don’t even have a trunk to bear a child!”⁴⁹ Nor were they necessarily in a position to adopt or foster a child. One man had learned in his mid-twenties that he was infertile as a result of his thalidomide-induced disabilities. Yet, he explained that instead it was the timing of finding his life partner that was the main reason for not becoming a father. He had simply met her too late to start the process of looking into adoption. Today he only regrets that he met his wife when they both were already in their late

⁴⁶ Reaume “Keep Your Labels Off My Mind!” 417.

⁴⁷ Steven M. Edworthy, Shawna Edworthy, Gregor Wolbring, “Thalidomide Survivors: A Questionnaire Survey on Musculoskeletal Abnormalities, General Health Status and Quality of Life,” 1999 <http://www.thalidomide.ca/thalidomide-survivors-survey/>

⁴⁸ Roni Rothler, “Disability Rights, Reproductive Technology, and Parenthood: Unrealised Opportunities,” *Reproductive Health Matters* 2, no. 50 (2017): 106.

⁴⁹ Thalidomide Victims Association of Canada, *Right the Wrong*.

forties and had already come to terms with the fact that they had passed the time for having a child. He does believe, however, that his disability would have made adoption difficult had they pursued it. Thus, it is apparent that a great variety of factors determined whether thalidomiders became parents, some unrelated to medical issues of fertility.⁵⁰

Despite the doubts of some family members, thalidomiders raised children. Aline remembers: “I was never afraid to do things with my baby.”⁵¹ When asked about access to information regarding parenting, Aline said she did not seek any. While Shakespeare, Gillespie-Sells, and Davies identified that disabled parents often experience a lack of information and role models, Aline had no trouble simply envisioning her future as a mother and felt no need for further support in her preparations.⁵² To pick up her daughter, she would grab the baby’s pyjama with her mouth to pull up her daughter Melody slightly and then scoop her arms, which are short, under the girl’s back and cradle her as any mother might do. To change her daughter’s clothes, Aline placed her on the bed, secured her with one leg and then used her arms to change the outfit. In the end, Aline felt it was easy for her to raise and help her daughter; her disability did not hinder her abilities as a mother.

However, Aline did not raise her daughter alone. “It was normal, I knew my strength and I knew my limits. When it was too hard, [Aline would tell her husband Daniel] ‘okay, help me please.’”⁵³ In their everyday life, caring for her daughter was by no means an insurmountable challenge, but Aline decided to share the responsibilities with her husband, which allowed her to balance the upbringing of their daughter between herself and her partner. The sharing of

⁵⁰ Ramesh Lad, Phone Interview, February 22, 2017.

⁵¹ Aline Vachon, Personal Interview, October 13, 2017.

⁵² Tom Shakespeare, Kath Gillespie-Sells, and Dominic Davies, *The Sexual Politics of Disability: Untold Desires* (Cassell, 1996), 111.

⁵³ Aline Vachon, Personal Interview, October 13, 2017.

responsibility has been identified as a key issue in disabled/non-disabled relationships when Smith Rainey writes that “disabled/nondisabled intimate relationships are characterized by mutual support.”⁵⁴ As such, intimate and familial relationships were involved in the ways that thalidomiders viewed their reproductive options and how they engaged in rearing their children, if they became parents. Until their child was twelve years old, Aline’s husband helped raise his daughter, then illness took him from the family, leaving Aline (thirty-six years old at the time) and daughter behind to adjust after the loss. Neither pair of the grandparents, on Aline’s or Daniel’s side, were involved in the raising of their granddaughter. When it was just Aline and her daughter, they adapted and as Melody grew older, Aline believes that the way her disability necessitated Melody’s involvement in every-day tasks such as changing lightbulbs, made her daughter a more independent person. Aline’s story is one of resistance against social ideas of the limitations of disabled motherhood. She defied the expectations of her family, did not rely on educational material about (disabled) parenting, and pursued being a mother without giving credence to outside influences. Aline’s example demonstrates that reproductive and child-rearing experiences forced a confrontation of social perceptions through embodied experiences of bearing and caring for children.

In *The Impossibility of Motherhood*, Patrice DiQuinzio discussed the analytical problems of focusing on individual accounts of motherhood. She notes how it can lead to essentialising the experience, thereby overlooking and marginalizing difference. On the other hand, individualising motherhood runs, in turn, the risk of weakening the power of the collective that fights the stigma of disabled parents as being incapable. Instead, by focusing on “specific instances of mothering

⁵⁴ Smith Rainey, *Love, Sex, and Disability*, 160.

in specific contexts,” one might carefully navigate these methodological challenges.⁵⁵ As such, the case studies, such as Aline’s, presented here, need to be read with this in mind, assuming both their individuality and their importance for understanding disability and parenting in general. Particularly interesting was the revelation that all of the men whom I interviewed and who had children ended up raising their children after they divorced. Literature on fathers with disability and their experiences is sadly scarce. Majella Kilkey and Harriet Clarke explain:

To understand the marginalisation of disabled fathers from relevant research agendas, it is important to appreciate the ways in which disability and parenting have been constructed. We have already highlighted that disabled parents have often been invisible. Where disabled parents have been recognised as the focus of research, until recently this almost exclusively involved a focus on deficits or problems in parenting and in outcomes for children. Such work has been impairment specific (and so fragmented), rather than exploring the ways in which different elements of (social) disability can impact on parents and family life.⁵⁶

Thus it is important to include stories of fathers’ parenting, not to essentialise their specific experience nor to necessarily make a distinct argument about social stigma, but to simply bridge this existing gap in knowledge about how disabled fathers’ experiences are shaped by a variety of social barriers.

For the children, being raised by a disabled parent also resulted, sadly, in experiences of social stigma. Challenges to obtain custody as a disabled parent are not uncommon, thus the retaining of custody of these men is an important issue to note. While two of the men found new partners, one raised his children as a single parent. For the children, having a thalidomide parent was “just our version of normal.”⁵⁷ Still, when sitting with Paul and his two children, daughter

⁵⁵ Patrice DiQuinzio, *The Impossibility of Motherhood: Feminism, Individualism and the Problem of Mothering* (London and New York: Routledge, 1999), 28.

⁵⁶ Majella Kilkey and Harriet Clarke, “Disabled Men and Fathering: Opportunities and Constraints,” *Community, Work & Family* 13, no. 2 (2010): 132-133.

⁵⁷ Cassandra Settle, Personal Interview, January 14, 2017.

Cassandra and son Paul Charles, Paul, who was a single-parent, recalls: “When we would go to shopping malls or grocery shopping, how awkward, sometimes, you would feel.” His daughter jumps in to elaborate: “There was always little kids pointing and staring. [...] It used to bother me when I was a little kid. [...] I was so bitter about it, but then I got older and I got to a point in high school when I was actually more angry at their parents than I was at the kids [...]”⁵⁸ It was, therefore, the social perceptions that were a challenge during Cassandra’s childhood, rather than the physical disability of her father.

Cassandra, alongside her father, experienced the ways that people with disability are seen as abject. Staring is used as a way to establish distance. Smith Rainey explains: “Staring is another way in which the nondisabled segregate the disabled.”⁵⁹ Rosemarie Garland-Thomson has described this phenomenon as follows: “staring registers the perception of difference and gives meaning to impairment by marking it as aberrant.”⁶⁰ The long-term consequences of thalidomide thus also encapsulate the ways in which families were confronted with discriminatory situations. Paul tried to help shape the way his daughter would feel about people staring. He would tell her that “I am like a celebrity. People will remember me. I stand out.”⁶¹ He emphasised the positive aspects of his disability and how social stigma and innocent curiosity might work in his favour. While generally a positive person, parenting required an active re-formulation of social interactions for the benefit of teaching his children important lessons. As one study about disabled parenting found, “parenting plays a normalizing and rehabilitative role in the life of individuals with disability. It is a source of profound positive experiences which

⁵⁸ Cassandra Settle, Personal Interview, January 14, 2017.

⁵⁹ Smith Rainey, *Love, Sex, and Disability*, 85.

⁶⁰ *Extraordinary Bodies: Figuring Physical Disability in American Culture and Literature* (New York: Columbia University Press, 1997), 217.

⁶¹ Paul Settle, Personal Interview, January 14, 2017.

form bonds between family members (especially between the spouses) and satisfaction from overcoming one's limitations."⁶² In this way we may consider parenting another part of thalidomiders' lives that allowed them to re-contextualize the social ideals directed at their bodies they were confronted with in their every-day lives.

In addition to the thalidomiders themselves, the disability of their father permitted thalidomiders' children access to coping strategies and a community that relates to each other through what has been termed "crip humor."⁶³ While the staring of strangers can be perceived as negative, thalidomiders and their families may intentionally draw attention to aspects of the thalidomide-induced disabilities in humorous ways in an effort of community building and to bridge the relationship between the disabled and non-disabled experiences within the families.⁶⁴

Gary Albrecht has discussed the significance of such humor:

But on reflection, disability humor can be emancipating. In some instances, laughing at one's self or with others redefines the experience. Disability humor may convey group solidarity, articulate inherent value structures, put experiences in context and ease the difficulties experienced in everyday life. Indeed, disability humor is an example of everyday experiences that tell us so much about social and cultural life. In sum, disability humor is important because it points at the boundaries between cultural groups and communities and at the social glue that holds them together.⁶⁵

The words of Paul's daughter highlight how ideas about normalcy that often serve to exclude certain groups of people are entirely socially constructed. She said to me: "It was just our version of normal."⁶⁶ Yet, it is worthwhile remembering that most people with visually apparent

⁶² Parchomiuk, "Social Context of Disabled Parenting," 237.

⁶³ There have been several notable volumes that discuss the intersections of disability and humor: a 1999 issue of *Body and Society*, a 2003 symposium of the *Disabilities Studies Quarterly*, and a 2013 issue of the *Journal of Literary & Cultural Disability Studies*.

⁶⁴ I am drawing especially on the interviews with Cassandra and one anonymous interview where such humor was discussed to have occurred in social and private settings.

⁶⁵ Gary L. Albrecht, "Disability Humor: What's in a Joke?" *Body & Society* 5, no. 4 (1999): 67.

⁶⁶ Cassandra Settle, Personal Interview, January 14, 2017.

impairments have experienced being laughed at (rather than with), as was noted in previous chapters. As has been pointed out by Tom Shakespeare, “There is an ambiguity about cultural responses to impairment [...] Disability jokes flourish at the margins of civilized society: among children in the playground most obviously, where words such as ‘spakker’ and ‘cripple’ and ‘Thalidomide’ are relished as much as words like ‘poof’ and ‘bender’ and ‘queer’.”⁶⁷ Humour reverberated throughout thalidomiders’ lives, at times in challenging ways and, at other times, in ways that helped open up spaces for them and their families to create a meaningful community based on and shaped by the long-term consequences of the drug.

As noted above, when individuals with disabilities become parents, they might experience a different type of scrutiny regarding their parenting abilities. In their interviews, Shakespeare, Gillespie-Sells, and Davies, noted that “there is a perception that disabled people are not capable parents, and that their children are consequently in danger.”⁶⁸ The thalidomide parents all emphasized that raising a child was well within their capabilities. Paul’s daughter, however, noted in our interview her opinion that the disability did have an impact on her father’s parenting style. “He works really, really hard at everything. I think he tries too hard because of his disability. All through life he probably had to listen to so many people tell him you can’t do this and you can’t do that, so it’s all about proving people wrong. So he was twice as hard to deal with when we were going through rebellious stages because it was going to be his way or no way, and that’s it.”⁶⁹ Cassandra also discussed how the social realities of her father’s disability shaped his parenting style. He was less likely to compromise since he had learned throughout his life that he needed to be assertive and determined in anything he approached to counteract

⁶⁷ Tom Shakespeare, “Joking a Part,” *Body & Society* 5, no. 4 (1999): 48.

⁶⁸ Shakespeare, et al., *The Sexual Politics of Disability*, 111.

⁶⁹ Cassandra Settle, Personal Interview, January 14, 2017.

negative perceptions of disability. Having children and using effective parenting as a way to counter social perceptions of disability is an issue that deserves more attention in the scholarship on disability.

Exploring further stories, it became apparent that several thalidomiders chose not to parent. Throughout our interviews, Susan identified numerous issues in her life as having helped inform her decision to never become a mother. The primary two reasons were her parental home, which had not been very nurturing, and her disability, which had made it difficult at times to provide for herself, let alone a child. “I couldn’t really see how I could physically manage having a child. Part of my mind just couldn’t really wrap my head around changing a diaper, picking a child up, doing all the things that needed doing.”⁷⁰ When asked if she ever received advice regarding her choice to have children she says that the only advice she ever got was to be independent. For her, focusing on her own independence took precedence throughout her life. Although Susan knew some women’s reproductive organs were affected by thalidomide, she never found out whether she herself was biologically able to bear children, it simply did not matter. “I’ve never felt that clock ticking. Never, ever. I don’t know why. Maybe it is a combination of both the disability and my own upbringing.”⁷¹ In addition, Susan’s sexual orientation may have made the option to have a child more challenging as well. As Shakespeare, Gillespie-Sells, and Davies have noted “Society may be hostile or ambivalent to disabled people becoming parents, but perhaps not even aware that disabled lesbians and gays rear children too.”⁷² As one man explained in a different study: “I have competently ‘parented’ kids and enjoyed them. They all turned out ‘normal’, not that gay disabled men are meant to be capable of

⁷⁰ Susan Wagner-White, Personal Interview, December 13, 2016.

⁷¹ Susan Wagner-White, Personal Interview, December 13, 2016.

⁷² Shakespeare, et al., *The Sexual Politics of Disability*, 110.

such parenting!”⁷³ While the quote also hints at the additional gendered notion of male parenting, it expresses the social distrust towards the parenting capabilities of those who do not fit the image of heteronormative, able-bodied parents.

Other barriers to parenting existed as well. Some thalidomiders were open to parenting but did not have the opportunity to become parents. Mercedes, for example, considered becoming a mother. In her case she did not have the right partner at the time she felt she was at the right age to have a child. She had begun a relationship with a man when she was in her early twenties that lasted for seven years. She says: “I remember him asking me two or three times whether we should have children.”⁷⁴ But, she did not feel that they were in a suitable place to have a child together. While she entered into a marriage later on in life, she had, at that point, already focused on pursuing a career that allowed her to care for others in a way that filled her life in a rewarding way. As a social worker she felt that her “maternal need was fulfilled by [her] care for others.”⁷⁵ In fact, she has pursued an impressive career that has culminated, one might say, in her role as the president of TVAC and as a public face for the fight for compensation in Canada. However, while not a mother, Mercedes states that: “I went through the experience of caring for a baby.”⁷⁶ She was twenty years old when her brother was born. Since she lived in the apartment below her father and his wife, she was there when her brother was little. One memory stood out to her: “When he was a little boy, he would stretch his little hand to hold hands. Stretching high.”⁷⁷ The child naturally took charge and grasped his sister’s hand. Recalling Rae’s story of dating Susan, shared in the previous chapter, holding hands was a gesture that could

⁷³ Shakespeare, et al., *The Sexual Politics of Disability*, 110.

⁷⁴ Mercedes Benegbi, Personal Interview, October 13, 2017.

⁷⁵ Mercedes Benegbi, Personal Interview, October 13, 2017.

⁷⁶ Mercedes Benegbi, Personal Interview, October 13, 2017.

⁷⁷ Mercedes Benegbi, Personal Interview, October 13, 2017.

seem like a challenge to overcome for those partners who entered the lives of thalidomiders' after they had already acquired perceptions of how such gestures looked like.

Importantly, the thalidomide-induced disabilities were not the only or central factor in determining thalidomiders' reproductive lives. Marie did not foreground choice when asked about her reproductive past. When interviewed about dating she shared: "Did I date? Yes. Frequently? No. Am I bummed about it? A bit. But, do I know the real reason why I didn't? No, because it could be my personality or it could be the disability or it could be a combination of the two or neither, or just that me and the right guy never met."⁷⁸ Her disability does not exist in a vacuum that is judged by others separate from who she is as a person. She is a successful person and pursued an impressive career, with her political engagements taking center stage in her recollection of personal achievements. What was clear to Marie was that she would not lower her personal standards "just to have a boyfriend."⁷⁹ Not having the right partner, as was the case with Mercedes, played a role in her reproductive experiences. These instances serve as an important reminder that while disability featured centrally in the interviews, it was not necessarily central to all aspects of thalidomiders' lives, even if it cannot be separated entirely from the various life experiences of these individuals.

The initial scandal in the early 1960s witnessed a great deal of attention to the experience of pregnancy and birthing of the women who ingested the drug. Since the teratogenic effects of the drug were discovered, the wombs of pregnant women have been turned into ticking bombs in the public imagination. Given this fascination with pregnancy and thalidomide, it was necessary to consider whether the long-term consequences of the thalidomide scandal also had implications

⁷⁸ Marie Olney, Phone Interview, November 13, 2017.

⁷⁹ Marie Olney, Phone Interview, November 13, 2017.

for this aspect of thalidomiders' lives. As noted in the introduction, I set out to explore whether the disabilities resulting from the ingestion of thalidomide by mothers shaped the lived experiences of the thalidomiders to the extent that it was a significant factor in determining their reproductive (and parenting) futures. The anecdotes and varying experiences demonstrate the complexity of sexual politics that is key to understanding the intersection of sexuality and disability. Thalidomiders, by asserting their rights to determine their reproductive choices as well as parenting in a way that counteracted abject understanding of disability, demonstrated that their reproductive and (non-) parenting choices were highly political; their actions laid claim to a level of humanness and belonging challenged in discriminatory confrontations.

This chapter has outlined how both embodied and social circumstances shaped thalidomiders' experiences of parenting in both positive and challenging ways. Thus, it can be argued that the aftermath of the thalidomide scandal did impact thalidomiders' reproductive lives. However, it would be problematic to assume that the thalidomide-induced disabilities were the only or central factor in determining the experiences of fertility control, birthing, or (non-) parenting. Nonetheless, for some, the physical impairments determined their reproductive options, while others experienced fear and social stigma directed at their reproductive choices and parenting capabilities. In sum, it can be established that while thalidomide did not cause second generation defects as some had feared, the drug's long-term consequences still shaped the reproductive experiences of the next generation.

Conclusion

Allowed onto the Canadian market under problematic circumstances, the drug thalidomide had a significant impact on Canadian lives. In Canada the drug was licensed for use by prescription on April 1, 1961 and remained on the market until the spring of 1962, despite knowledge of the possible connection between the medication and birth defects in newborns. In the aftermath of the scandal, caused by the births of the thalidomide babies and knowledge of the government's negligence, families, provincial and federal governments, medical professionals, communities, and thalidomiders themselves were forced to negotiate the long-term consequences of the disabilities the treacherous drug – and the subsequent scandal – had caused. This dissertation focused on life *after* the scandal and added, for the first time, the voices and experiences of Canadian thalidomiders themselves into scholarly analysis of the tragedy.

This study has shown that private and public environments and discourses were constantly re-evaluated and moderated by thalidomiders as they attempted to make sense of every-day life in the scandal's aftermath. The thalidomide tragedy therefore provides insights into the ways a nation and its citizens responded to bodies that did not meet normative expectations of embodiment. In the immediate aftermath of the crisis, families with thalidomide-affected babies aimed to achieve “normalcy,” and benevolent, yet paternalistic, health professionals sought to assist them in overcoming difficulties posed by the disabilities. In subsequent years, the Canadian public used the thalidomide crisis when negotiating ways in which normal and acceptable behaviour and bodies should be defined.

The dissertation made use of Julia Kristeva's (1982) concept of the abject to help illuminate the political nature of disabled bodies. The abject is “what disturbs identity, system,

order,” that which “does not respect borders, positions, rules.”¹ When disabled bodies have the potential to disrupt socially constructed notions of ‘normality’ and ‘humanness,’ the attempts to regulate thalidomiders’ bodies can be explained as reactions to the anxieties their bodies so obviously caused in public consciousness. As this dissertation has shown, feelings of anxiety and repulsion towards disabled bodies can occur at the individual level and be engrained in culture and social relations. Understanding disability as abject therefore enabled theorization of political acts of exclusion, rejection, and attempts at assimilation and integration. As abject bodies, the thalidomide babies disrupted social order at birth and continued to do so throughout their lives. Thalidomiders’ lives were political as they, both inadvertently and intentionally, confronted notions of normality and engendered the limits of socially-prescribed norms.

Chapter One provided the historical context of the initial scandal and pointed to the delayed reaction of the Canadian government regarding withdrawal of the drug from the market. The chapter demonstrated that, curiously, the Canadian public turned to the government, not the companies responsible, for a solution to the “deformed” babies that had been born. This became essential in spurring federal funding for the emergence of the four Canadian Prosthetic Research and Training Units in the early 1960s, a topic addressed in Chapter Two. Chapter Two showed that the federal Canadian government simultaneously tried to limit its liability and create a response to the demands for government action that would be consistent with the national discussion underway regarding a broadening of health care access in Canada. Both Chapters Two and Three highlighted how the social and political effects of the thalidomide tragedy were contingent on the historical context of Canada in the 1960s and 1970s.² The chapters pointed out

¹ Julia Kristeva, *Powers of Horror: An Essay on Abjection* (New York: Columbia University Press, 1982), 4.

² For a similar argument see the discussion of German measles by Leslie Reagan. Leslie Reagan, *Dangerous Pregnancies: Mothers, Disabilities, and Abortion in Modern America* (Berkeley: University of California Press, 2010), 240.

that the social services provided through rehabilitation and education, sometimes forced upon thalidomiders and at other times developed in a collaborative effort, were contingent on political developments already underway in Canada at the time, such as the changing nature of Canada's welfare state and changing attitudes towards individuals with disabilities.

Chapter Two contrasted the rhetoric employed by doctors to promote the potential benefits of prosthetics with the experiences of the children in the rehabilitation programs. What emerged as part of this discussion is the disturbing realization that the young children had to endure significant hardships within the Prosthetic Research and Training Units. Drawing on medical discourses, newspaper coverage, and oral interviews, the chapter demonstrated that prosthetics, the primary solution offered for the "thalidomide problem," seemed to serve the purpose of making the *social environment* more comfortable with the disabled children in their midst rather than improving the lives of the thalidomiders.

While the role of medical professionals in the rehabilitation institutes comes as no surprise, Chapters Three and Four demonstrated that the ways in which the medical profession was recruited in solving the perceived problems associated with the thalidomide bodies had consequences that reached far beyond the medical institutions in which the bodies of the young children were trained. Indeed, doctors claimed an active role for themselves not only in the management of thalidomiders' health and rehabilitation care, but also in their schools and family lives. Doctors positioned themselves as mediators between the thalidomide bodies and the social environments in which the children grew up. We see in the ways that appropriate behaviour and embodiment was discussed, practiced, and resisted in various environments, that disabled bodies retained political significance even in seemingly private environments.

The discussion of thalidomiders' schooling in "normal" schools, put forth in Chapter Three, considered the ways the thalidomide children understood their belonging to society in contrast to those around them, including their non-disabled friends and foes in the schoolyard, as well as in comparison to those with intellectual and mental impairments. The chapter observed that thalidomiders themselves experienced abject encounters when faced with differently disabled children. At the same time, their own embodiments forced moments of self-reflection, for examples in instances when a bathroom break required thalidomiders to leave school and return home. This Chapter therefore provided insight into the continuous efforts of thalidomiders to position their own worth within social interactions and when confronted with social barriers, such as inaccessible environments.

At the end of Part One of the dissertation it was already apparent that the most private aspects of thalidomiders' lives, their bodies, and the ways they understood themselves, were shaped and understood through their experiences in the public sphere. Part Two of the dissertation shifted focus to what may be thought of as private settings, only to immediately problematize, once again, the distinction between public and private. Chapter Four began by demonstrating that, like with thalidomiders' entry into schools, doctors monitored thalidomiders' integration into family and domestic environments. They continuously instructed and monitored parents' engagement with their children in the home. However, once the children were embedded in a family unit, many families provided a forum in which both collaboration with and resistance to social norms, expectations, and practices occurred. In some families, unfortunately, adult failure and abuse also occurred in domestic settings. This chapter demonstrated that not only thalidomiders, but also their entire families, were impacted by the challenges the

thalidomide-induced disabilities presented, thereby challenging the notion of home and domestic life as a private setting sealed off from the public.

Chapter Five began with a consideration of sexual abuse suffered by thalidomiders, highlighting the vulnerability of the group to abuse. By considering the intersection of disability and gender, also addressed in Chapter Six, the chapter illuminated how various, sometimes competing, discourses determined the ways thalidomiders were perceived by those around them. The chapter furthermore demonstrated that thalidomide bodies have been sites of sexual pleasure, a dimension that is too often overlooked in the scholarship examining the intersection of disability and sexuality. By combining a discussion of moments of confusion with stories of sexual confidence, the chapter showed that disability held a variety of meanings for thalidomiders' sexual experiences. While sex and sexuality were not central to or even part of all thalidomiders' lives, it was a basic component of every-day life for many.

The final chapter, Chapter Six, built upon the affirmation that sex was part of thalidomiders' lives and considered, in turn, their reproductive choices. The chapter determined that socially-shaped perceptions of humanness were an integral part of reactions faced by thalidomiders in response to their reproductive choices and parenting lives. Whereas Chapter Two discussed how thalidomiders were displayed and photographed in the rehabilitation institutes, this chapter highlighted that they, and their children, were stared at in every-day outings as well. In understanding abjection as a fundamentally political experience, this dissertation outlined how photographing and staring were processes in which identity boundaries, both individual and social, were drawn in a way that constructed the thalidomide bodies as the threatening other. By including this chapter on the effects thalidomide had on second-generation reproductive choices, the dissertation came full circle by emphasizing that

disability shaped not only the reproductive lives of the women to took the drug, but also those of the thalidomiders themselves.

Importantly, as is outlined throughout the dissertation, engaging with social discourses did not occur without simultaneously addressing questions of embodiment. Nirmala Erevelles reflected in 2015 on the development of disability studies and mused about the material constraints on the social. She notes that some tensions, or rather “complicated impasses,” exist in disability studies that provide further impetus to reflection on questions of the transgressive possibilities of disability scholarship.³ Regarding this important observation, Chapters Two, Five, and Six offered interesting case studies. Many thalidomiders had to learn early on to negotiate medical concerns and socio-cultural disablement with their own embodiment and perceptions. This continued later on in their lives when they were confronted with questions of intimacy, sexuality, and reproduction.

The structure of this dissertation was superimposed on the life stories shared with me during my interviews with thalidomiders and members of their families. As stated in the Introduction, the dissertation does not provide a linear narrative about the lives of Canadian thalidomiders. Nor does it provide a chronological discussion of the intersections of medical science and government policies since the 1960s. Instead, the thesis provides examples of attempts to control, transform, and manage thalidomide bodies, and even efforts to ‘civilize’ the qualities of health, appearance, and personality, while simultaneously contrasting such narratives with experiences of forms of self-expression, resistance, and perseverance within various environments. This has served the purpose of illuminating the impossibility of separating public institutions and private lives.

³ Nirmala Erevelles, “Thinking with Disability Studies,” *Disability Studies Quarterly* 34, no. 2 (2014): Intersectionality/Impasse.

As I am concluding this dissertation, I wish to return to my positioning of this dissertation at the Borderland of medical history and disability history. Especially Chapter Two has shown that medical approaches to the thalidomide bodies, which regarded them as bodies in need of treatment and alteration, have had devastating effects on many thalidomers. The impetus of disability historians to move past medicalized understandings of disability and provide analyses that highlight the lives of individuals with disabilities outside of medical settings has served to produce important scholarship that offers a methodological framework for understanding how (dis)ability, power, and social discourses are related.⁴ Disability scholar Catherine Kudlick writes that we, as scholars, “must understand the complex factors that shape how a society deals with such an important part of the human condition, medicine being only one piece of the puzzle.”⁵ Of course, what this quote highlights is that although, when studying disability, it is important to look beyond medical aspects, medicine is indeed a relevant, and often important, aspect of the lives of people with disabilities. By drawing on medical histories, this dissertation was able, at times, to theorize thalidomiders’ experiences as parallel to issues discussed in disease and patient histories, such as the experiences of Canadian polio survivors leaving rehabilitation hospitals or reactions to German measles outbreaks in the United States. Most importantly, this dissertation has proven that patient histories can be expanded to include analyses of every-day lived experiences that uncover the applicability of disability as an analytical tool. This dissertation therefore adds to both historiographies by providing insights about thalidomiders’ patient histories and beyond.

⁴ These developments in the history of medicine have in many cases sadly remained separate from the literature disability scholars engage with. See also Kudlick’s discussion of this separation in Catherine Kudlick, “Comment: At the Borderland of Medical and Disability History,” *Bulletin of the History of Medicine* 87, no. 4 (Winter 2013):” 548.

⁵ Kudlick, “Comment,” 545.

Of the seventeen individuals interviewed for this dissertation, ten were thalidomiders. While this is a small number of interviewees, and each of these individuals has a distinct story and individual experiences, the themes identified in the chapters nonetheless permitted some conclusions to be drawn regarding Canadian thalidomiders as a group. Furthermore, a discussion of their experiences spurred insights into individual lives as well as larger socio-political issues. Overall, this analysis of thalidomiders' lives continuously demonstrated the ways in which the private and public lives of individuals intersected in ways that reveal the inherently political nature of disabled bodies.

The dissertation thus argued that in Canada, thalidomiders' experiences in the aftermath of the tragedy demonstrate that their disabled bodies remained political and public bodies in all aspects of their lives. Overall, I believe that oral history methodology has served the study of the long-term consequences of the thalidomide scandal well. Nevertheless, there are many significant issues that this dissertation has not examined that deserve further study. One issue stands out as a glaring example: the compensation fight and the fascinating history of thalidomiders' activist history. This issues deserve consideration in its own right and will help further complicate and deepen the conversation about the long-term consequences of the effects of thalidomide in Canada. In addition, too little is known about the social experience of aging among thalidomiders. Similar to the way thalidomiders' stories were shared by parents to incite public sympathy and help them lobby for assistance when they were babies, thalidomiders have revealed to the Canadian public their worsening health conditions as they age as a tactic in their successful campaign to receive funding from the Canadian government in recent years. Surely, this requires scholarly attention.

Throughout this dissertation the voices of Canadian thalidomiders were heard and I wish to end with one last quote. Alvin works today as a motivational speaker and states: “The best thing that ever happened to me is being born without arms. It brought me to circumstances never thought possible.”⁶

⁶ Alvin Law, “Change The Label,” accessed July 28, 2019, <https://alvinlaw.com/about/>.

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APPENDIX A: Ethics Clearance Forms

2016



Carleton University
Research Ethics Office
Research Ethics Board
511 Tory, 1125 Colonel By Drive
Ottawa, ON K1S 5B6 Canada
Tel: 613-520-2517, ethics@carleton.ca

Ethics Clearance Form – New Clearance

This is to certify that the Carleton University Research Ethics Board has examined the application for ethical clearance. The REB found the research project to meet appropriate ethical standards as outlined in the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Human, 2nd edition*, and the *Carleton University Policies and Procedures for the Ethical Conduct of Research*.

Date of Clearance: March 18, 2016

Researcher: Dr. Susanne Maria Klausen (Primary Investigator)

Christine Chisholm (Student Research: Ph.D. Student)

Department: Faculty of Arts and Social Sciences/History (Department of)

University: Carleton University

Research Supervisor (if applicable): Prof. Dr. Susanne Maria Klausen

Project Number: 104150

Project Title: Life after the Scandal: Canadian Thalidomiders [Christine Chisholm]

Funder (if applicable): SSHRC

Clearance Expires: May 31, 2016

All researchers are governed by the following conditions:

Annual Status Report: You are required to submit an Annual Status Report to either renew clearance or close the file. Failure to submit the Annual Status Report will result in the immediate suspension of the project. Funded projects will have accounts suspended until the report is submitted and approved.

Changes to the project: Any changes to the project must be submitted to the Carleton University Research Ethics Board for approval. All changes must be approved prior to the continuance of the research.

Adverse events: Should a participant suffer adversely from their participation in the project you are required to report the matter to the Carleton University Research Ethics Board. You must submit a written record of the event and indicate what steps you have taken to resolve the situation.

Suspension or termination of clearance: Failure to conduct the research in accordance with the principles of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans, 2nd edition* and the *Carleton University Policies and Procedures for the Ethical Conduct of Research* may result in the suspension or termination of the research project.



Louise Heslop

Chair, Carleton University Research Ethics Board



Andy Adler

Vice-Chair, Carleton University Research Ethics Board

2017

Research Compliance Office
511 Tory |1125 Colonel By Drive
Ottawa, Ontario K1S 5B6
613-520-2600 Ext: 4085
ethics@carleton.ca

CERTIFICATION OF INSTITUTIONAL ETHICS CLEARANCE

The Carleton University Research Ethics Board-B (CUREB-B) at Carleton University has renewed ethics clearance for the research project detailed below. CUREB-B is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2).

Title: Life after the Scandal: Canadian Thalidomiders [Christine Chisholm]

Protocol #: 104150

Principal Investigator: Dr. Susanne Maria Klausen

Department and Institution: Faculty of Arts and Social Sciences\History (Department of), Carleton University

Project Team (and Roles): Dr. Susanne Maria Klausen (Primary Investigator)
Christine Chisholm (Student Research: Ph.D. Student)

Funding Source (If applicable):

Awards File No	Title	Status	
104034	The “Thalidomide Disaster,” the British Abortion Act (1967), and the Passage of Eugenic Abortion Laws in the Commonwealth, 1961-1977	Completed	CURO Awards

Effective: **May 02, 2017**

Expires: **May 31, 2018.**

Restrictions:

This certification is subject to the following conditions:

1. Clearance is granted only for the research and purposes described in the application.
2. Any modification to the approved research must be submitted to CUREB-B. All changes must be approved prior to the continuance of the research.

3. An Annual Application for the renewal of ethics clearance must be submitted and cleared by the above date. Failure to submit the Annual Status Report will result in the closure of the file. If funding is associated, funds will be frozen.
4. A closure request must be sent to CUREB-B when the research is complete or terminated.
5. Should any participant suffer adversely from their participation in the project you are required to report the matter to CUREB-B.

Failure to conduct the research in accordance with the principles of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2nd edition* and the *Carleton University Policies and Procedures for the Ethical Conduct of Research* may result in the suspension or termination of the research project.

Please email the Research Compliance Coordinators at ethics@carleton.ca if you have any questions or if you require a clearance certificate with a signature.

CLEARED BY:

Date: May 02, 2017

Andy Adler, PhD, Chair, CUREB-B

Shelley Brown, PhD, Vice-Chair, CUREB-B

2018

Office of Research Ethics
5110 Human Computer Interaction Bldg | 1125 Colonel By Drive
Ottawa, Ontario K1S 5B6
613-520-2600 Ext: 2517
ethics@carleton.ca

CERTIFICATION OF INSTITUTIONAL ETHICS CLEARANCE

The Carleton University Research Ethics Board-A (CUREB-A) at Carleton University has renewed ethics approval for the research project detailed below. CUREB-A is constituted and operates in compliance with the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans* (TCPS2).

Title: Life after the Scandal: Canadian Thalidomiders [Christine Chisholm]

Protocol #: 104150

Project Team Members: **Dr. Susanne Maria Klausen (Primary Investigator)**
Christine Chisholm (Student Research: Ph.D. Student)

Department and Institution: Faculty of Arts and Social Sciences\History (Department of), Carleton University

Funding Source (If applicable):

Awards File No	Title	Status	
104034	The “Thalidomide Disaster,” the British Abortion Act (1967), and the Passage of Eugenic Abortion Laws in the Commonwealth, 1961-1977	Completed	CORIS Awards

Effective: **May 10, 2018**

Expires: **May 31, 2019.**

Please ensure the study clearance number is prominently placed in all recruitment and consent materials: CUREB-A Clearance # 104150.

Restrictions:

This certification is subject to the following conditions:

1. Clearance is granted only for the research and purposes described in the application.
2. Any modification to the approved research must be submitted to CUREB-A. All changes must be approved prior to the continuance of the research.

3. An Annual Application for the renewal of ethics clearance must be submitted and cleared by the above date. Failure to submit the Annual Status Report will result in the closure of the file. If funding is associated, funds will be frozen.
4. A closure request must be sent to CUREB-A when the research is complete or terminated.
5. Should any participant suffer adversely from their participation in the project you are required to report the matter to CUREB-A.
6. It is the responsibility of the student to notify their supervisor of any adverse events, changes to their application, or requests to renew/close the protocol.
7. Failure to conduct the research in accordance with the principles of the *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans 2nd edition* and the *Carleton University Policies and Procedures for the Ethical Conduct of Research* may result in the suspension or termination of the research project.

Upon reasonable request, it is the policy of CUREB, for cleared protocols, to release the name of the PI, the title of the project, and the date of clearance and any renewal(s).

Please email the Research Compliance Coordinators at ethics@carleton.ca if you have any questions.

CLEARED BY:

Date: May 10, 2018

Andy Adler, PhD, Chair, CUREB-A
Bernadette Campbell, PhD, Vice-Chair, CUREB-A

APPENDIX B: Letter of Information

Page 1 of 2



Letter of Information for Participants

Researcher:
Christine Chisholm
Ph.D. Candidate
Department of History
Carleton University
1125 Colonel By Drive,
Ottawa, ON K1S 5B6
Email: christine.chisholm@carleton.ca

Ph.D. Supervisor:
Dr. Susanne Klausen
Department of History
Carleton University
1125 Colonel By Drive,
Ottawa, ON K1S 5B6
Phone: 613-520-2600 x 2827
E-mail: susanne.klausen@carleton.ca

Dear Sir or Madam,

The intention of this letter is to provide you with my background, the nature of the research that I would like to conduct, and the details on how the information that you choose to share with me will be treated during and after the research.

I am a Ph.D. Candidate in the Department of History at Carleton University. My current academic research investigates 1) the lived experiences of thalidomiders in Canada and their perspectives on those experiences, and 2) the impact thalidomide had on families and family planning.

I would like to invite you to participate in this project. Your participation will take place through a one-on-one interview for which the location, time and place will be chosen by you and me. The interviews would take no more than two hours and will be recorded (or, if you choose not to have the interview recorded I will take notes). I will be the only person present at the interviews, unless you would like to include another person(s). Participation in the research is at your discretion and can be terminated either during the interview or any time within one month afterwards. If you convey to me by e-mail or mail (for which I will provide you with the necessary contact details) that you wish to withdraw your participation I will immediately destroy any information that resulted from your participation. Please note that if a thalidomider withdraws from the study, their family members and professionals associated with that person are still welcome to participate. To ensure confidentiality these participants will be anonymized in the study and only information about their personal experiences will be included. No personal information communicated about a thalidomider will become part of the study.

If at any point during the interview you feel anxious, upset or stressed to the point where you feel too uncomfortable to continue, you have the right to stop the interview. You can take a break,

reschedule the interview, or else withdraw from the interview process altogether: whichever option you choose is completely valid and acceptable. You can also stop the interview as many times as you wish. If you decide to end the interview process I will delete any recording taken thus far in your presence.

If you wish your identity to be anonymous in research I publish, I guarantee that everything you tell me during the interview will be confidential. After the interview I will make a copy of the audio-recording available to you (for example, by e-mail or else regular mail to a location of your choosing). If, after listening to the interview, you wish to modify your answer to any of the questions you can do so by contacting and telling me what aspect of the transcript you wish changed in order that it is accurate.

I will be the sole researcher for this project. In addition to recording the interview I will take notes to record information that you share with me. Measures will be taken to secure the information and data resulted from the research. The information will be accessible only to me. This research may be included in my academic work including research papers, journal articles, book(s), conferences, and classroom presentations.

This project has been reviewed and received clearance by the Carleton University Research Ethics Board. Should you have any concerns or questions about your involvement in the study, you are invited to contact:

Carleton University Research Ethics Board
Office of Research Services, Carleton University
Tel: 613-520-2517
E-mail: ethics@carleton.ca

Chair: Dr. Louise Heslop
Tel: 613-520-2600 x2378
E-mail: louise_heslop@carleton.ca

Vice-Chair: Dr. Andy Adler
Tel: (613) 520-2600 ext. 8785
E-mail: adler@sce.carleton.ca

Thank you for your interest in the research.

Sincerely,

A black rectangular box redacting the signature of Christine Chisholm.

Christine Chisholm

APPENDIX C: Informed Consent

Page 1 of 2



Researcher:
Christine Chisholm
Ph.D. Candidate
Department of History
Carleton University
1125 Colonel By Drive,
Ottawa, ON K1S 5B6
Email: christine.chisholm@carleton.ca

Ph.D. Supervisor:
Dr. Susanne Klausen
Department of History
Carleton University
1125 Colonel By Drive,
Ottawa, ON K1S 5B6
Phone: 613-520-2600 x 2827
E-mail: susanne.klausen@carleton.ca

Informed Consent

I, _____, agree to participate in the research project conducted by Christine Chisholm, a Ph.D. Candidate at Carleton University, Ottawa.

I have read the Letter of Information for Participants, which explains the intent and purpose of this research and the interview process. Christine Chisholm and I will engage in an interview of two hours or less. The interviews will include discussions on thalidomide in Canada, on my personal background, experiences related to thalidomide and thalidomiders, as well as perspectives on those experiences. Christine Chisholm asks me to give permission for her to audio record the interview (see below); if I choose not to have the interview recorded she will take notes.

From Christine Chisholm and the Letter of Information, I understand that the research aims to explore 1) the lived experiences of thalidomiders in Canada and their perspectives on those experiences, and 2) the impact thalidomide had on families and family planning.

Christine Chisholm has assured me that our one-on-one interview will be stopped at any point if I so wish. If I become anxious or upset by any of the questions I know that I can stop the interview to take a break, reschedule the interview or withdraw from the interview process altogether. I understand that Christine Chisholm will keep my participation confidential if I wish. At my request, I will be given access to the audio recording of our interview. I understand that I can withdraw from this project for up to one month after the interview (Date: _____) and that, if I do so, all transcribed interview data, audio recordings and information gathered from me will be destroyed. Please note that if a thalidomider withdraws from the study, their family members and professionals associated with that person are still welcome to participate. To ensure confidentiality these participants will be anonymized in the study and only information about their personal experiences will be included. No personal information communicated about the thalidomider will become part of the study.

I understand that Christine Chisholm will be the sole researcher for this project and that note-taking will be used to record information. Christine Chisholm has confirmed that measures will be taken to secure the information and data resulting from the research. The information will only be accessible to Christine Chisholm. This research may be included in Christine Chisholm's academic work including research papers, journal articles, book(s), conferences, and classroom presentations.

1. I give my permission to the researcher to use my name in publications
 I wish to remain anonymous in publications
2. I agree to have the interview audio recorded
 I do not agree to have the interview audio recorded
3. I will be given cop(ies) of the Audio recording
4. I agree to have my photograph [digital image] taken
 - for researcher's file only
 - to appear in the final Ph.D. dissertation and resulting publications
 I do not agree to have my photograph taken
5. I acknowledge that upon the withdrawal of my participation in this research project, my information will be destroyed
6. I am aware that the researcher Christine Chisholm may break confidentiality and disclose personal information if she encounters thoughts of imminent intent to self-harm on the part of an interviewee
7. I am aware that the researcher Christine Chisholm may break confidentiality and disclose personal information if she becomes aware of offences listed under the Criminal Code of Canada

I, _____ (Name) _____ (Signature) _____ (Date)

Agree to participate in the research project identified above.

 _____ (Date)
 Christine Chisholm

This project has been reviewed and received clearance by the Carleton University Research Ethics Board. Should you have any concerns or questions about your involvement in the study, you are invited to contact:

Carleton University Research Ethics Board
 Office of Research Services,
 Carleton University
 Tel: 613-520-2517
 E-mail: ethics@carleton.ca

Chair: Dr. Louise Heslop
 Tel: 613-520-2600 x2378
 E-mail: louise_heslop@carleton.ca

Vice-Chair: Dr. Andy Adler
 Tel: (613) 520-2600 ext. 8785
 E-mail: adler@sce.carleton.ca

APPENDIX D: Archive Documentation – Landesarchiv Nordrhein-Westfalen

Landesarchiv
Nordrhein-Westfalen



Christine Chisholm

10 Mai 2016

(Ort, Datum)

(Name und Anschrift der Antragstellerin/des Antragstellers)

An das
Landesarchiv NRW
Abteilung Rheinland
Mauerstr. 55
40476 Düsseldorf

Benutzung von Archivgut, das Benutzungsbeschränkungen unterliegt

Hiermit bitte ich um Genehmigung zur Benutzung der im folgenden aufgeführten Akten zu wissenschaftlichen Zwecken für meine Dissertation¹ über Contergan

Im einzelnen handelt es sich um folgende Akten bzw. Aktengruppen
(Bestand - Signatur - Titel ggf. summarische Bezeichnung - Laufzeit)²:
Findbuch 223.01.02 Staatsanwaltschaft Aachen
Gerichte Rep. 139 Nr. 1-369

Justizministerium
NW 377 Nr. 5869
Ermittlungsverfahren gegen Personen der Chemie Grünenthal GmbH
1962-1972

NW 875 Nr. 14101
Ermittlungsverfahren gegen Chemie Grünenthal GmbH Stolberg; Contergan-
Verfahren
1967-1971

Ministerium für Arbeit, Gesundheit und Soziales
NW 1180
„Contergan-Prozess“ – enthält 6 Akten unterschiedlicher Provenienz (z. T.
Innenministerium)
1961-1971

Die Bearbeitung des Themas erfolgt im Auftrag von:
Carleton University, Ottawa, Canada (Supervisor: Susanne Klausen, Department of
History)

Eine Befürwortung meines Antrags durch
Dominique Marshall, Carleton University, Department of History Chair

ist beigefügt.

Mir ist bekannt, dass die Genehmigung unter Auflagen erteilt wird, und ich verpflichte
mich, diese einzuhalten.



(Unterschrift der Antragstellerin/des Antragstellers)

Hinweis:

Dieser Antrag ist vollständig ausgefüllt und im Original (nicht per Fax) an das
Landesarchiv NRW Abteilung Rheinland zu senden.

Ein zweites Exemplar ist für die Unterlagen der Antragstellerin/des Antragstellers
bestimmt.

7.03.011/2009



Benutzungsantrag
(gemäß §§ 6 – 7 und 12 Archivgesetz NRW)

Persönliche Daten

17.05.2016

> Frau Christine Chisholm



EU

Kanada
(Nationalität)

(Telefon)

ctinechisholm@gmail.com

(Fax)

(E-Mail)

Nutzung im Auftrag:

Anderes

Dissertation, Carleton Universität,

Thema der Benutzung/Forschung:

Contergan in Kanada, Dissertation

Ich willige ein, dass Name und Anschrift an Dritte weitergegeben werden,
wenn die Kenntnis meines Nutzungsvorhabens für diese von Belang ist:

Ja

Duisburg, den 17.05.2016

(Datum)

(Unterschrift*)

(Nicht von Nutzer/in auszufüllen)

Tagebuchnummer: Tgb.-Nr. 1469/2016

Kundennummer:

NEUKUNDE

Benutzerkarte: 500009412L

Antrag genehmigt
(Datum, Paraphe): 17.05.2016, LA

Ableitung Rheintand
Dienstgebäude und
Lieferanschrift:
Schifferstr. 30
47059 Duisburg
Telefon: (0203) 99721-0
Telefax: (0203) 99721-111
E-Mail: rheintand@lav.nrw.de
Internet: http://www.lav.nrw.de

Öffnungszeiten des
Lesesaals: Mo.-Di. 8.30-19.00
Uhr, Mi.-Do. 8.30-16.00 Uhr,
Fr. 8.30-13.00 Uhr.

Öffentliche Verkehrsmittel:
Vom HBF: U-Bahn 901 bis
Haltestelle Schifferstr.,
Parkplätze: Schifferstr., z.T.
Parkscheibe.

Sitz des Landesarchivs
Nordrhein-Westfalen:
Duisburg



Landesarchiv
Nordrhein-Westfalen



Landesarchiv NRW, Schifferstraße 30, 47059 Duisburg

23.05.2016

Frau
Christine Chisholm

Aktenzeichen R 1-5.2.0-3735/16
bei Antwort bitte angeben

Bearbeiter/in Frau Hönerlage
Telefon 0203 98721-227
Telefax 0203 98721-111
regina.hoenerlage@lav.nrw.de

**Nutzung von Archivgut des Landesarchivs NRW, das
Nutzungsbeschränkungen gemäß § 7 Absatz 1 ArchivG NRW
unterliegt**

Ihr Antrag vom 10.5.2016 hier am 17.5.2016 eingegangen

Sehr geehrte Frau Chisholm,

Hiermit genehmige ich Ihnen unter den Bedingungen des § 7 Abs. 6 (Nr.
3 oder 4) ArchivG NRW zum Thema/mit dem Titel

Dissertation über "Contergan"

die Einsichtnahme in die im Folgenden aufgeführten Archivbestände des
Landesarchivs NRW:

NW 377 Nr. 5869

NW 875 Nr. 14101

NW 1180

Gerichte Rep. 0139 und das Findbuch 223.01.02

Die Genehmigung wird unter folgenden Bedingungen erteilt:

1. Die Nutzung darf ausschließlich den in Ihrem Antrag angegebenen Zwecken dienen.
2. Die aus dem benutzten Archivgut gewonnenen Kenntnisse dürfen nur zu dem von Ihnen benannten Zweck verbreitet werden. Dabei sind die Rechte Dritter, die sich aus dem Artikel 1, 2 und 5 Abs. 2

Abteilung Rheinland
Dienstgebäude und
Lieferanschrift:
Schifferstraße 30
Besuchereingang:
Schifferstraße 30a
(Hafenseite)
47059 Duisburg
Telefon 0203 98721-0
Telefax 0203 98721-111
rheinland@lav.nrw.de
www.lav.nrw.de
Lesesaalöffnungszeiten:
Mo. + Di. 8.30 - 19.00 Uhr,
Mi. + Do. 8.30 - 16.00 Uhr
und Fr. 8.30 - 12.30 Uhr
Öffentliche Verkehrsmittel:
Straßenbahnlinie 901
Haltestelle „Landesarchiv
NRW“
Fußweg vom Hauptbahnhof:
ca. 20 Minuten
Kostenlose Parkplätze für
Besucher des Landesarchivs
im Parkhaus Schifferstraße 52

Sitz des Landesarchivs
Nordrhein-Westfalen:
Duisburg

des Grundgesetzes der Bundesrepublik Deutschland gewährleisteten allgemeinen Persönlichkeitsrecht, dem Grundrecht auf Datenschutz (Artikel 4 Abs. 2 Landesverfassung NRW) sowie dem Urheberrecht und den Rechtsvorschriften über die Geheimhaltung (wie z. B. Steuergeheimnis, Betriebs- und Geschäftsgeheimnis, Bank- und Kreditgeheimnis) ergeben, zu beachten. Verletzungen solcher Rechte müssen Sie dem Berechtigten gegenüber selbst vertreten.

3. Namen von Personen, deren Einverständnis mit der Veröffentlichung des Namens (bzw. das ihrer Rechtsnachfolger) nicht vorausgesetzt werden kann, dürfen nicht wiedergegeben werden. Eine Erwähnung in verschlüsselter Form darf nur dann erfolgen, wenn eine Identifizierung der betroffenen Person anhand der übrigen Angaben nicht möglich ist. Die Wiedergabe von Namen noch lebender Personen in der Publikation ist nur zulässig, wenn die Betroffenen vorher schriftlich eingewilligt haben.
4. Sie sind verpflichtet, der zuständigen Abteilungsleitung des Landesarchivs NRW (s. Briefkopf) eine schriftliche Erklärung zu übergeben, dass Sie die unter Nr. 1 – 3 genannten Bedingungen einhalten werden.
5. Diese Genehmigung schließt grundsätzlich nicht das Recht zur Herstellung von Kopien aus dem benutzten Archivgut ein.

Mit freundlichen Grüßen
Im Auftrag



Dr. Brachtendorf



Landesarchiv
Nordrhein-Westfalen



Landesarchiv NRW, Schifferstraße 30, 47059 Duisburg

23.05.2016

Frau
Christine Chisholm



Aktenzeichen R 1-5.2.0-3735/16
bei Antwort bitte angeben

Bearbeiter/in Frau Hönerlage
Telefon 0203 98721-227
Telefax 0203 98721-111
regina.hoenerlage@lav.nrw.de

Sondergenehmigung zur Benutzung von Archivgut der staatlichen Archive Nordrhein-Westfalens, das Benutzungsbeschränkungen gemäß § 7 Absatz 1 ArchivG NW unterliegt

Ihr Antrag vom 10. 5.2016 hier am 17.5.2016 eingegangen

Sehr geehrte Frau Chisholm,

beiliegend übersende ich Ihnen die Sondergenehmigung zur Benutzung von Archivgut der staatlichen Archive Nordrhein-Westfalens, das Benutzungsbeschränkungen gemäß § 7 Absatz 1 ArchivG NW unterliegt, sowie ein Formular in zweifacher Ausfertigung, mit dem Sie sich zur Einhaltung der mit dieser Genehmigung verbundenen Benutzungsaufgaben verpflichten. Ich bitte Sie, uns ein Exemplar dieser **Verpflichtungserklärung** ausgefüllt und unterschrieben auf dem Postweg mindestens 7 Tage vor Ihrem Besuch zurückzusenden.

Ab Eingangsdatum der unterschriebenen Verpflichtungserklärung ist diese Genehmigung 5 Jahre gültig.

Vorbestellungen von Archivgut können Sie gerne unter Nennung Ihres Besuchstermins und des obigen Aktenzeichens an rheinland.lesesaal@lav.nrw.de richten.

Bei Ihrem Besuch im Lesesaal legen Sie die Sondergenehmigung bitte der Aufsicht vor.

Mit freundlichen Grüßen

Im Auftrag



Hönerlage

Abteilung Rheinland
Dienstgebäude und
Lieferanschrift:
Schifferstraße 30
Besuchereingang:
Schifferstraße 30a
(Hafenseite)
47059 Duisburg
Telefon 0203 98721-0
Telefax 0203 98721-111
rheinland@lav.nrw.de
www.lav.nrw.de
Lesesaalöffnungszeiten:
Mo. + Di. 8.30 - 19.00 Uhr,
Mi. + Do. 8.30 - 16.00 Uhr
und Fr. 8.30 - 12.30 Uhr
Öffentliche Verkehrsmittel:
Straßenbahnlinie 901
Haltestelle „Landesarchiv
NRW“
Fußweg vom Hauptbahnhof:
ca. 20 Minuten
Kostenlose Parkplätze für
Besucher des Landesarchivs
im Parkhaus Schifferstraße 52

**Sitz des Landesarchivs
Nordrhein-Westfalen:
Duisburg**

07.01-10/03/14



An das
Landesarchiv NRW
Abteilung Rheinland
Schifferstr. 30
47059 Duisburg

AZ: R 1-5.2.0-3735/16

Verpflichtungserklärung
für die Nutzung gesperrten Archivguts

Hiermit erkläre ich,

Chisholm, Christine

(Name, Vorname)



(Straße, Hausnr., Postleitzahl, Ort)

die mir in der Benutzungsgenehmigung vom 23.5.2016/R1-5.2.0-3735/16 erteilten Auflagen bei der Nutzung von Archivgut des Landesarchivs NRW, das Nutzungsbeschränkungen gemäß § 7 Absatz 1 ArchivG NRW unterliegt, zu beachten.

Ich verpflichte mich ausdrücklich, die aus dem benutzten Archivgut gewonnenen Kenntnisse nur im Rahmen der geplanten wissenschaftlichen Arbeit zu verbreiten, die Rechte Dritter, die sich aus dem durch Artikel 1, 2 und 5 Abs. 2 des Grundgesetzes der Bundesrepublik Deutschland gewährleisteten allgemeinen Persönlichkeitsrecht, dem Grundrecht auf Datenschutz (Artikel 4 Abs. 2 Landesverfassung NRW) sowie dem Urheberrecht und den Rechtsvorschriften über die Geheimhaltung (wie z.B. Steuergeheimnis, Betriebs- und Geschäftsgeheimnis, Bank- und Kreditgeheimnis) ergeben, zu beachten und Verletzungen solcher Rechte dem Berechtigten gegenüber selbst zu vertreten.

Duisburg am 24 Mai 2016

(Ort, Datum)



(Unterschrift)