Canadian Thalidomiders Ask the Government of Canada to Fulfill Its Promise.

Alexandra Niblock, MA, (Poli Sci)

Virtually everyone knows that pregnant women are advised not to take drugs - whether prescription or non-prescription, but few are aware of the events that led to this recommendation. These events are the start of our story. We are Canadian thalidomide survivors, and we, along with thalidomide survivors the world over, are the embodiment of what can happen when pregnant women take improperly tested drugs.

Thalidomide is the infamous sedative advertised as so safe that even pregnant women could take it. It was prescribed to pregnant women in the late 50s and early 60s, to treat morning sickness. The result was tens of thousands of babies around the globe born with severe birth defects, including missing limbs, missing organs, blindness, deafness, and cognitive deficiencies. Many thousands of these babies died at or near birth because of the severity of their deformities. Approved for sale in spring 1961, thalidomide was on the market in Canada for less than a year. Despite its short run on the Canadian pharmaceutical market, hundreds of thalidomide births are believed to have resulted. Approximately 110 thalidomide babies survived to adulthood in Canada. Unfortunately, the deformities suffered by Canadian thalidomiders could have been avoided had a government office properly fulfilled its responsibilities.

Canadian thalidomiders live each day with the catastrophic consequences of a decision taken by officials in the Health Protection Branch - which was responsible for approving pharmaceuticals marketed in Canada - allowing thalidomide on the Canadian market regardless of growing concern around the world about its safety. In other words, Canadian thalidomiders were injured **because** of this decision by the Health Protection Branch, **not in spite** of it. The Canadian government's Health Protection Branch failed in its responsibility of due diligence in ascertaining the safety of thalidomide.

That the 'thalidomide tragedy' occurred needlessly in Canada is evident by the fact that it did not occur in the United States, despite applications to market thalidomide made by the same licensee in both countries at the same time. Thalidomide was never formally approved for sale in the US because of concerns being raised in Europe about its safety and whether sufficient testing of it had been done by Chemie Grunenthal - the company that developed thalidomide - and the drug's licensees.

¹ Harris, Gardiner. 13 Sept. 2010. 'The Public's Quiet Savior From Harmful Medicines.' NYTimes.com http://www.nytimes.com/2010/09/14/health/14kelsey.html?r=5& accessed 06/15/2014. Copyright New York Times Company.

^{&#}x27;Francis Oldham Kelsey: Medical reviewer famous for averting a public health tragedy.' Copyright US. Food and Drug Administration. http://www.fda.gov/aboutfda/whatwedo/history/ucm345094.htm. last updated 03/25/2013; accessed 06/15/2014.

Rouhi, Maureen. 'Thalidomide.' <u>Chemical and Engineering News.</u> Date unknown. <u>http://pubs.acs.org/cen/coverstory/83/8325/8325thalidomide.html</u>. Accessed 06/14/2014.

² See above noted sources.

The Honourable J. Waldo Montieth, Minister of Health and Welfare, on January 29th, 1963, made a promise to the Canadians regarding the Canadian thalidomide babies:

It is our job to ensure that those thalidomide victims are cared for in the best possible manner, that their needs are met to the fullest extent we can devise, and to ensure, as much as possible, that a similar tragedy will never occur again.³

It is true that in response to the thalidomide tragedy, the Canadian federal government revamped the protocol for bringing new pharmaceuticals to the market, developing a comprehensive and multi-tiered system of testing before a new drug would be approved for sale. However, while the Canadian government acted, as promised, to "as much as possible" prevent a similar tragedy occurring in Canada, promises made by the government to help Canadian thalidomiders and their families, went largely unfulfilled.

Around the world in the late 60s and early 70s, thalidomiders and their families, largely through class action suits⁴, sought and obtained compensation from their governments and from the relevant pharmaceutical firms responsible for the sale of thalidomide. Such was not the case in Canada, where no class action legislation even existed until the early 1990s.⁵ This meant that our families, already struggling with the trauma of having a thalidomide child, were 'on their own' in their efforts to obtain some form of compensation for their thalidomide-affected children. Unable to bring a class action suit against the North American licensees⁶, and usually subject to 'gag' provisions in any agreed upon settlement, each family and their legal representatives essentially had to 'reinvent the wheel' when dealing with the pharmaceutical companies. As a result, settlements in Canada were very uneven. For example, one Canadian thalidomider with no arms could have received an annuity that paid approximately \$700.00 per month for his/her lifetime, while another thalidomider with all four limbs affected and confined to a wheelchair for life might have got a total lifetime settlement of only \$10,000.00.⁷ There was no way for families to work together and no help from any government body in dealing with the pharmaceutical companies.

³ Montieth, The Honourable Minister for Health Welfare. 01/29/1963. From Thalidomide Victims Association of Canada. 'About Us: the promise.' Copyright TVAC, 2014.

⁴ Numerous documents are available to verify this statement. For a generous selection of them see: 'Thalidomide: What the Papers Said - Media Archive on Thalidomide from 1962 Onwards. www.thalidomide50blogspot.co.uk. Sue Kent - archive manager. Last updated 05/15/2014.

⁵ Health Insurance Reciprocal of Canada (HIROC). 'White Paper: Class Action Proceedings.' 2005. Copyright HIROC, 2005. https://www.hiroc/getattachment/ 27334657-4662-4c05-8dcd-5oe7508clc5d/Class-Action-Proceedingsasp.x. Accessed 06/14/2014.

⁶ William S. Merrell of Ontario, subsidiary of Richardson-Merrell of Cincinnati, Ohio, and Frank W. Horner of Montreal, Quebec.

⁷ These examples are just two of the settlements of the many of which I am personally aware and have been obtained through personal conversations with numerous Canadian thalidomiders.

As thalidomiders, we are known for our determination and drive for independence, no matter how severely we were affected by the drug; however, with our increasing age, we are forced by significant physical deterioration to accept help in even the most mundane of daily tasks. While we greatly value our independence, it is gradually being stolen from us, just as our limbs were stolen. Our rapid physical deterioration in the last decade is universal amongst thalidomiders.8 More than 50 years of using and abusing our bodies in ways that they were not meant to be used has had a serious and detrimental impact on them. In Germany, where the greatest concentration of thalidomiders is found, one comprehensive study found that the skeletons of thalidomiders are, on average, 20-30 years older than our chronological age9 and that this finding is related to the ways we have used our thalidomide-affected bodies to achieve and maintain our independence. Extreme joint deterioration and muscular pain are commonplace, as are extensive dental issues after years of using our mouths like a hand to lift and carry things. In other jurisdictions, thalidomiders have launched successful campaigns and court cases¹⁰ for additional compensation from both the relevant governments and pharmaceutical companies to meet the increasing cost of maintaining independence in the face of deteriorating bodies.

Canadian thalidomiders, with the critical assistance of the War Amputees of Canada, received from the federal government a 'compassionate grant' of approximately \$75,000.00 in the early 90s. We greatly appreciated these funds, but they were barely a drop in the bucket compared to the expense of living with our thalidomide-damaged bodies - bodies damaged because our government failed to perform due diligence when considering the application to market thalidomide in Canada. The continuing and increasing cost of adapting and maintaining cars, installing accessible kitchens and bathrooms, of purchasing suitable wheelchairs, of repairing our teeth with crowns, dental implants, and bridges etc., far exceeds the dollars we received twenty years ago.

⁸ For a wide selection of reports and studies documenting this statement, please see The Thalidomide Trust website at www.thalidomidetrust.org.

See also Thalidomide: Enquiries to be carried out repeatedly with regard to problems, specific needs and support deficits of thalidomide victims. Kruse, Dr. H.C. Andreas, et al., 05/31/2012. (also known as The Heidelberg Study). Institute of Gerontology, University of Heidelberg. Copyright University of Heidelberg. English translation: original in German.

⁹ Thalidomide: Enquiries to be carried out repeatedly with regard to problems, specific needs and support deficits of thalidomide victims. Kruse, Dr. H.C. Andreas, et al., 05/31/2012. (also known as The Heidelberg Study). Institute of Gerontology, University of Heidelberg. Copyright University of Heidelberg. English translation: original in German. page 29.

¹⁰ See, for example:

^{&#}x27;Australian thalidomide victims get \$89 million in compensation from the drug's distributor after settling class action.' new.com.au. 12/02/2013. www.news.com.au/national/Australian-thalidomide-victims-get-89-million-in-compensation-from-the-drugs-distributor-after-settling-class-action/story-fncynjr2-1226773226746. Copyright news.com.au. 2014. Sydney, Aus. Accessed 06/15/2014.

^{&#}x27;Thalidomide Victims could benefit from German fund.' Rté News. 07/15/2013. www.rte.ie/news/2013/0714/462399-thalidomide/. Copyright Rté News 2014, Dublin, Ireland. Accessed 06/15/2014.

Canadian thalidomiders are asking the Government of Canada to follow the lead of the Great Britain, German, and other national governments in accepting their responsibility for thalidomide births in their jurisdictions. We are asking our government to show Canadian thalidomiders the respect we are due by acknowledging its role in the thalidomide debacle in Canada and to fulfill its promise of more than 50 years ago by ensuring our "... needs are met to the fullest extent [the Government of Canada] can devise"

11 We are asking the Government of Canada to provide the financial wherewithal sufficient to allow us to live the remainder of our lives with dignity and independence. We are asking our fellow Canadians to support us in our efforts to right this wrong.

¹¹ Montieth, The Honourable Minister for Health Welfare. 01/29/1963. From Thalidomide Victims Association of Canada. 'About Us: the promise.' Copyright TVAC, 2014.