

THE GLOBE AND MAIL

Cursed by 'miracle drug,' thalidomide victims wait for Canada's apology



The untested medication was supposed to cure nausea in pregnant women, but it led to severe birth deformities in their children instead

<http://www.theglobeandmail.com/news/national/cursed-by-miracle-drug-thalidomide-victims-wait-for-canadas-apology/article1458417/>

Ingrid Peritz

From Saturday's Globe and Mail Published on Friday, Feb. 05, 2010 11:02PM EST Last updated on Tuesday, Feb. 09, 2010 4:05AM EST

The day Mercedes Benegbi was born, the priest came into her hospital room and administered the last rites. The little baby with no arms and a stunted shape was not supposed to live.

Mercedes was a thalidomide baby - one of about 125 born with profound deformities in Canada after their mothers were given the "miracle" drug during pregnancy.

The priest's bleak prognosis in a Montreal hospital proved premature: Forty-seven years later, Mercedes Benegbi is still alive. And she and other survivors of thalidomide want Canada to apologize for the nation's most notorious drug disaster.

The Thalidomide Victims Association of Canada, which Ms. Benegbi heads, is calling on Ottawa to follow the lead of Britain, whose government last month offered its "sincere regret and deep sympathy" to that country's more than 460 thalidomide victims.

In Canada, the shock over the thalidomide catastrophe has faded, but the pain for its victims has not. Canada's so-called thalidomide babies are now in late middle age. Their bodies are deteriorating and some rely on the care of aging parents. Their association wants the Canadian government to make amends.

"It's time for Canada to apologize for this tragedy and say sorry for their monumental mistake," Ms. Benegbi says. "The apology is for us and it's for our parents, who felt massacred when they saw their mutilated children enter the world."

The little blond baby given up for dead at Sacré Coeur hospital sits on her living-room couch next to her father, Marco, who lives upstairs. Her mother, Colette, lives in the same triplex. From the day their daughter was born, Marco and Colette cared for and protected their daughter. Marco designed a hockey-type visor to prevent her from harming her face as an infant - without arms, she couldn't break her fall. He carried her in his arms on her first day of school. Colette still peels the potatoes to make her shepherd's pie. They both help her lift heavy grocery bags.



But as Mr. Benegbi ages - he is 85 - both he and his daughter know they face an uncertain future. "You'll be sad when I go," he says, reaching across the couch to tenderly touch his daughter's shoulder, where a hand with misshapen fingers begins.

"We suffered a lot at first," Mr. Benegbi says. "The pain of having a little child without arms was enormous. I felt rage over that cursed medication. But the Canadian government washed its hands, like Pontius Pilate."

Thalidomide, used to fight nausea and insomnia in pregnant women, became available in Canada in late 1959 without testing by Canadian health officials. It was licensed for prescription use on April 1, 1961. By December that year, thalidomide was pulled off the market in West Germany and Britain as alarms were sounded over severe birth defects: babies born without arms or legs, some with no ears, some with internal organ damage.

Yet thalidomide remained available in Canada for three more months. The United States, meanwhile, never approved the drug at all. Ironically, it was a Canadian-born medical officer, Frances Kelsey, who withstood drug-company pressure to approve it.

Today, some of Canada's "thalidomiders," as they call themselves, live fulfilling lives, with jobs, spouses and children. Most, however, are struggling, according to the victims' group. Ms. Benegbi, who speaks to survivors across Canada, hears heart-rending stories of poverty and isolation. Some children were shunned by their own parents. Four have died in the past six years due to complications from their handicap, leaving 96 Canadian-born survivors.

Their parents, meanwhile, also live with the drug's legacy. Anne Marie Bainbridge, 70, was given thalidomide by her family doctor in Quebec in 1961 when she became nauseous while pregnant with her fourth child.

"Here's something new," the doctor told her. Mrs. Bainbridge took nine pills.

When her daughter was born, the doctor kept Mrs. Bainbridge sedated in hospital for days and refused to let her see the baby. Once she emerged from her fog, they told her not to bother bonding because the child wouldn't live. The baby, named Bernadette, was placed in a care facility for six months, until Mrs. Bainbridge went to get her.

That daughter, now a 47-year-old known as Bernie, lives with Mrs. Bainbridge and her husband, Chuck, in Whitby, Ont. Mrs. Bainbridge has to perform daily tasks like combing her daughter's hair and cleansing her wounds from medical interventions. Her husband drives her to doctors' appointments and shopping.

Bernie, who was born with seal-like hands, no right ear and partial facial paralysis, has become an accomplished watercolour artist, but remains utterly dependent on her parents.

Mrs. Bainbridge has suffered a series of strokes. Neither she nor her daughter wants to contemplate the future.

"Both of us pray every night to please take us now. I don't want to leave her behind and she doesn't want me to die before her. She cannot fathom the idea of still living when we're not here," Mrs. Bainbridge says.

Canada compensated thalidomide victims in 1991; the lump sums of \$80,000 on average were ex gratia, meaning Ottawa recognized no legal liability. At the time, no one knew how long the thalidomide survivors would live, let alone what kind of health problems they would face.

Mrs. Bainbridge says she felt powerless to challenge Ottawa's package. She also felt strong-armed into signing an earlier settlement with the drug's Canadian distributor; families at the time were forced to sign confidentiality agreements to keep the terms secret.

"I felt that if I didn't sign, I was going to get nothing," she said. "But if I had known really and truly the extent Bernie would be suffering for the rest of her life, I would never have signed. It seemed like a lot of money at the time, but it was really a pittance."

Basics like physiotherapy are too expensive for some. Louis Gaudry of Winnipeg says he would like to alleviate the back and neck pain that result from his handicap, but he can't afford the fees. The 47-year-old, who has tried unsuccessfully to land jobs throughout his adult life, also looked into buying a raised computer-keyboard tray to let him pursue his interest in Web design. At about \$300, "it's out of my ballpark," he said.

Survivors have spent their lifetime paying for someone else's error. Some have learned to brush their teeth with their feet, or rely on outside help for something as basic as washing their hair because their hands can't reach. Their bodies are degenerating quickly. For Ms.

Benegbi, the simple task of pulling on her socks is an excruciating daily challenge, requiring her to double over to reach her feet. She is exhausted by the time she has finished getting dressed in the morning.

To the War Amps, which led the campaign for federal government compensation for the thalidomide victims, Canadian authorities cannot walk away from their responsibility in the tragedy.

"The consequences of this particular government mistake were just so disastrous," says Ottawa lawyer Brian Forbes, legal counsel for the War Amps. "When you think of the problems [the victims] have had with employment, housing, transportation, just their enjoyment of life - it goes on and on. I'm not sure the government should ever feel, 'Well, we've closed the book.' I think the government really has an ongoing obligation.

"Victims feel that the government surely could at least put forward some kind of apology for their gross negligence."

Roger Vadeboncoeur, a doctor at a Montreal rehabilitation clinic that treats many thalidomide patients, says he has been struck by the survivors' resiliency. Still, they are aging prematurely, he says, and a 2002 study of 26 thalidomide victims found that many faced health problems.

"These people have touched me. They complain very little and many have succeeded despite their handicaps," said Dr. Vadeboncoeur, a physician at the Institut de réadaptation Gingras-Lindsay. "But the more the years go by, the harder it will be to cope because of the pain. They may have been all right at 25 or 30, but it's getting more and more difficult dealing with the stress of day-to-day activities."

The thalidomiders' group has retained an Ottawa law firm to collect up-to-date data on their living conditions, with an eye to seeking financial help so they can live out their remaining years decently.

But in many ways, the apology means even more.

"If someone has wronged you, it's only human to say I'm sorry," Anne Marie Bainbridge says. "Someone should stand up and say, 'I was responsible for this.' No one ever has."

TIMELINE OF A TRAGEDY

Wrongly hailed as a wonder drug, thalidomide was available in Canada for a few brief years but caused life-long harm to 125 babies.

Thalidomide is a teratogenic drug, causing malformations in the fetus. The extent of damage depended on when the drug was taken during gestation. The most common birth

defect associated with the drug was phocomelia, from the Greek words phoke meaning "seal" and melos meaning "limb." Hands, feet, or both, started immediately from the shoulder or hip.

1957 Thalidomide is marketed in West Germany. It is hailed as a wonder drug providing a "safe, sound sleep" and a treatment for nausea in pregnant women.

1959 The William S. Merrell Company of Cincinnati, Ohio, starts developing thalidomide under brand name Kevadon. Thalidomide becomes available in sample form in Canada.

April, 1961 Thalidomide is licensed for prescription use in Canada.

November-December, 1961 Thalidomide is taken off the market in West Germany and Britain as evidence links it to congenital malformations.

March, 1962 Thalidomide is withdrawn from the market in Canada. About 125 babies are already born with malformations.

1998 U.S. Food and Drug Administration approves the drug for treating complications related to leprosy. The FDA promises to make it one of the most tightly restricted medications ever marketed.

2006 Thalidomide is authorized in the U.S. to treat multiple myeloma, a form of blood cancer, under strictly controlled distribution.