

## Thalidomide survivors face uphill battle for further compensation.

By Jessica Murphy, THE CANADIAN PRESS

MONTREAL - It's been almost 50 years since thalidomide was pulled from the market and 20 years since thalidomide survivors in Canada began fighting for compensation.

Canadian thalidomide survivor, in Montreal over the weekend to honour the man who championed their cause when no one else would, also committed to seeking further compensation from Grunenthal - the drug's original German manufacturer.

"They'd lost faith in the government before I was on the scene," said Cliff Chadderton, CEO for the War Amputations of Canada and the first to assist Canadian thalidomide survivors in their battle for compensation.

"If we didn't do it, who would?" he asked. "They didn't have an organization. To be honest, they were being treated as medical curiosities."

Mercedes Benegbi, the executive director for the Thalidomide Victims Association of Canada, said Chadderton's help proved invaluable.

"The Canadian government never took responsibility for the thalidomide tragedy," she said.

"With Chadderton and his team, we were able to lobby the Canadian government for moral compensation."

Fifteen years ago, the Canadian government offered the survivors a compassionate grant that Benegbi said totalled about \$80,000 per victim.

"That's for someone with no arms, no legs, and with deformities of internal organs, visual impairment," she said, adding the money was often spent within a year on modifying houses to accommodate the special needs of victims.

Thalidomide was first marketed in Germany in 1957 and became widely prescribed as a sleep aid and to pregnant women suffering from morning sickness.

But when taken during the first trimester, it compromised the development of the fetus, causing birth defects that ranged from missing or shortened limbs to visual impairment, cleft palates and poorly developed internal organs.

It's estimated that between 6,000 and 10,000 thalidomide babies were born worldwide by the time the drug was finally pulled from the market in 1962.

About 125 "thalidomiders" - a name they've chosen-were born in Canada between 1961 and 1962.

Thalidomide remained available in Canada three months after it was withdrawn from the market in the U.K. and West Germany. It wasn't approved for use in the United States until the federal Food and Drug Administration OK'd it in 1998 to treat cancer HIV, leprosy, Crohn's disease and a host of other illnesses.

Today, Canadian thalidomiders are facing increasing physical difficulties and are part of an international lobby seeking further compensation payments from Grunenthal.

"We're suffering from a physical degeneration, caused by efforts to overcome our limitations," Benegbi said.

"I have no arms, so the effort of doing daily tasks has really destroyed my spine."

Her association joined an international alliance to pressure Grunenthal for compensation to offset the costs related to living with the physical effects of thalidomide.

"There were some (survivors) who used to be able to work," Benegbi said.

"They're no longer able to. Also, some of us are no longer able to live independently. There's all sorts of new limitations that have cropped up over time."

In 1970, a case was settled for US\$31 million with Grunenthal along with an estimated US\$13.5 million to US\$27 million from the German government for German thalidomide survivors.

Chadderton said while many of the survivors are smart and independent, they still have to live with the consequences of thalidomide.

"It's a sobering experience to sit among them and see how they've coped but realize how dreadful it is to have to live with the effects of this drug," he said.