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The amazing resilience of Canada's thalidomide survivors

By ANDRÉ PICARD

At a gala to celebrate the first anniversary of their settlement with Ottawa, there was not the slightest hint of anger or bitterness

There is nothing quite like a dance floor overflowing with people with missing arms and legs, on crutches, in wheelchairs, tripping the light fantastic with their parents, their children, their friends, even their lobbyists and lawyers.

Yet, the surreal scene, which unfolded Saturday night at a Gatineau, Que., hotel, came as no surprise because there is nothing quite like Canada's thalidomiders.

The victims – nay, survivors – of one of the country's worst medical disasters have always shown unbelievable resilience and grace in their 50-year fight for justice and, on Saturday night, it was in full display as they celebrated.

Thalidomide, a drug that was marketed as a treatment for morning sickness and insomnia, was available in Canada from 1959 to 1962 under the brand names Kevadon and Talimol. The drug, which was never properly tested, caused horrific limb deformities, damage to vital organs and miscarriages; in Canada, it remained on the shelves even after these dangers became clear.

Yet, despite egregious failings of the manufacturer and regulator, victims and their families never received anything but token amounts of compensation. They were essentially relegated to society's scrap heap, burdened by stigma, physical woes and often crushing poverty.

A few years back, aging survivors, of which there were fewer than 100, decided to make one last push for recognition and reparations. Against all odds, they won that battle – in both the court of public opinion and in Parliament – and received a \$180-million settlement.

In the past year, the members of the Thalidomide Victims Association of Canada have received their first payments – a \$125,000 lump sum, which will be followed by annual compensation of between \$25,000 and \$100,000. The money has been¹ liberating and transformative, especially when you consider that, before the payouts, the average income of surviving thalidomiders was \$14,000 a year.

Individuals have purchased everything from homes to home care with their money; one survivor splurged modestly on a new mattress to help relieve his life-long back pain. But they also wanted to celebrate as a group, so they organized a gala.

Mércedes Benegbi, the irrepressible leader of TVAC, opened the event in her inimitable fashion, with a piercing *cri de joie*. When she was born in Montreal 54 years ago, stunted and with flipper-like arms, a priest performed last rites, assuming she would soon die. But Ms. Benegbi's parents nurtured her instead of abandoning her, as other

babies were, and she became the public face of thalidomide in Canada and a tireless advocate for justice.

It was Ms. Benegbi who, in 2013, approached U.S. lawyer Stephen Raynes – whose father had sued and won settlements for some thalidomide victims in the 1970s – to help. He embraced the cause, and enlisted Canadian allies, including lawyer Joe Fiorante and well-known political lobbyist Barry Campbell. Together, they fashioned one of the most effective lobbying efforts in Canadian history, and did it all pro bono, and with little public credit. (From the outset, they agreed that only thalidomide survivors would speak publicly.)

On Saturday night, the survivors honoured all these backroom players for their roles, along with Globe and Mail reporter Ingrid Peritz, who wrote a series of forceful stories² that pushed the struggle into the public spotlight, on Nov. 21, 2014, and resulted in a unanimous Parliamentary vote³ on compensation nine days later, on Dec. 1. What they really should have celebrated was their own courage – the decision to, after years of being stared at, mocked and dismissed, to risk putting themselves out there and tell their stories in a bid to put a human face on a public policy failing.

The most remarkable aspect of the gala was its celebratory tone; there was not the slightest hint of anger or bitterness, despite the decades of neglect thalidomide sufferers endured. "Nothing can totally correct the wrong inflicted on thalidomide victims. But we today we have a balm on our wounds," Ms. Benegbi said.

There was virtually no talk of money. Rather, the survivors spoke emotionally of how their fellow citizens no longer look upon them in horror, but with compassion.

The victims of thalidomide were liberated not so much by money as by the acknowledgment of their self-worth – the formal recognition that they were wronged and that Canadian society had a duty to right that wrong. "What we have, after all these years, is our dignity," Ms. Benegbi said.

That and the new-found confidence to let their hair down and dance with abandon. And dance they did.

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