



U.S. thalidomide victim Tony Melendez at age 4. He now lives in Dallas, and is one of thousands of Americans with deformities from the drug.

REUTERS/STR NEW

Fifty years since the notorious drug thalidomide was banned in the United Kingdom, the company who produced the drug have yet to apologize for causing birth defects around the world. Campaigners are taking the fight to a German pharmaceutical giant in their pursuit for justice.

'We will get justice ... nothing will stop us'

BY ADAM FORREST
STREET NEWS SERVICE

Liz Buckle lives on the north side of Lismore, a small island a few miles off the west coast of Scotland. A lively woman of 51, Liz knows every inch of the Argyll countryside, having spent many years driving around to work on rural development projects for the Scottish government. Sadly, poor health forced her to give up the job six years ago. "It was lovely work but my body just couldn't take it anymore," she explains. "I used to come home and collapse and spend the evening flat out on the floor."

Liz is a survivor of the notorious drug thalidomide. Marketed at the end of the 1950s as a "wonder drug" for pregnant women suffering from morning sickness, the substance was withdrawn from the shelves of British chemists in 1961 after it was found to cause debilitating birth defects. The UK government only apologized for its part in the scandal last year when it finally set aside compensation money for the victims. Thanks to this new health grant, Liz is making some changes. She expects her kitchen to be retro-fitted soon with low-hanging boiled water taps, a custom-made oven and cabinet drawers which can be opened by foot. Until then, Liz's stunted arms mean simple tasks like making a cup of tea remain fraught and exhausting.

"You see I have to lean the kettle against my chest to sort of pour it into the mug, so I seem to forever be covered in singes and burns," she laughs and sighs. "I make the most of the day because by the evening I do feel incredibly tired and achy. Most of our group are like that. It's like we've become old very early. Our doctors say it's like we're sort of 80-years-old, in body. Not old in mind of course, because there's still a lot to do."

Here in the United States, thalidomide was never licensed for general use. The Food and Drug Administration blocked it from being marketed for sale. However, that didn't stop physicians from giving out millions of samples to a reported 20,000

patients in a clinical trial. It has also been reported that many Americans received the drug from overseas sources.

New Jersey-based Celgene Corp. won FDA approval to use the drug against a painful side-effect of leprosy known as erythema nodosum leprosum.

Of the 2,000 babies born with deformities in the U.K. between 1958 and 1961, less than 500 are alive today. Half a century on, the survivors have entered middle age still battling the disabilities the drug caused, and many find their health deteriorating. As well as living with shortened limbs, some have also endured malformations of the eyes and ears, heart, genitals, kidneys and the digestive tract. Since original compensation deals made with British distributors in the 1970s are no longer enough to pay medical bills, the survivors are now fighting to ensure the major player in the thalidomide story – German pharmaceutical giant Grunenthal – finally makes an apology and fitting recompense.

Sitting behind the gates of the huge Stolberg headquarters in the heart of Germany, Grunenthal's bosses have good reason to fear an impressively determined bunch of British campaigners. London jeweller Nick Dobrik, Yorkshire businessman Guy Tweedy and single mom Mikey Argy are adamant that the original sin is addressed. The drug was developed by Grunenthal in 1953, and brought onto the German market in 1957, then internationally the following year. By the end of 1959, the first clear reports of nerve damages reached the company, but it wasn't until an independent Australian doctor, William McBride, did his own research about the connection between mothers taking thalidomide and a marked increase in birth deformities that the drug began to be withdrawn in late 1961.

Mikey, who does Pilates with specialist equipment to keep back pain at bay, explains why so many retain their outrage. Although Grunenthal was pressured to establish a trust fund for German victims in 1970, the company has never acknowledged

any error, or established any compensation for those affected in 46 other countries.

"Grunenthal looks at us as disabled people, not people who have been injured by their mistake," she says. "We feel treated with contempt because they've continued to ignore their mistake for fifty years. It's hurtful, but you need to put your head down and get on with campaigning. Even the best natured of us are angry. We will get justice. Nothing will stop us."

Distillers, the British distributor of the drug, did set up a compensation fund back

In the United States, thalidomide was never licensed for general use. The Food and Drug Administration blocked it from being marketed for sale. However, that didn't stop physicians from giving out millions of samples to a reported 20,000 patients in a clinical trial. It has also been reported that many Americans received the drug from overseas sources.

in 1968. The company, now part of Diageo, paid £2.8 million (\$4.4 million) a year to the Thalidomide Trust and earmarked an extra £150 million (\$237 million) to be given to survivors in 2005. Campaigners also received a huge boost in January 2010 when the UK government expressed its "sincere regret" for failing to protect consumers and set up a health fund so survivors could adapt their homes. "We piled on the political pressure," Nick explains of the meeting with Members of Parliament and the Fostering of Commons debates. "We lived it 24 hours a day, seven days a week. A parliamentary campaign might seem dry, but it was very, very important to a just cause."

Nick calculates that he and Guy have

See THALIDOMIDE, page 9