

SUBMISSION – Senate Inquiry – Support for Australia's Thalidomide survivors.

By: [REDACTED] (husband)

Chemie Grunenthal GmbH was primarily a German soap and perfume company that expanded into pharmaceuticals with the aid of Nazi research scientists soon after the second world war. Thalidomide had been developed in the concentration camps of Europe and Chemie Grunenthal was to turn this product into the greatest medical catastrophe ever known. The murder that had been developed so effectively under the Nazis was to continue throughout the world.

Distillers were a British company that bought the licence to produce Thalidomide in 1957 and began to supply the Australian market in 1960. Early concerns were being raised about the safety of Thalidomide, and reports of nerve damage were coming from doctors who had prescribed it to their patients. In December 1960 Doctor Leslie Florence (in Scotland) had written in the Lancet medical journal of the concerns for the safety of Thalidomide. Meanwhile, in America Dr Francis Kelsey of the F.D.A. was deeply concerned of the reports she was hearing on safety of Thalidomide and of the standard of data that was being supplied to enforce the safety of Thalidomide. This resulted in her refusal to allow the release of Thalidomide onto the American market.

Australia had at this time, the National Health and Research Council (NHMRC). Its goal was to establish a uniform national approach to labelling and standards, and it emphasized the need for independent laboratory testing of pharmaceuticals released onto the Australian market. The NHMRC was active from 1939-1961. The Federal Government had also moved to enact legislation that pharmaceuticals were of a high standard and of good quality. The Australian Government should have (and would have) heard the concerns that others were having over the safety of Thalidomide. They had laboratories, the personnel, and the laws to prevent the murder and the mutilation of unborn children ... BUT, even though they had the warning signs, they did not act.

Distillers released 5 tablets onto the Australian market in 1958. Distaval, Valgraine, Valgis, Tensivale, and Asmaval, all contained enough Thalidomide to kill or mutilate an unborn child. Distaval was the main drug prescribed for women with morning sickness, while the others were given for anything from asthma to migraine, toothache to bronchitis, gout to hay-

fever. Thalidomide was a “cure-all” and was the world’s most popular drug after Aspirin ... it was everywhere,

Distillers took the tablets off the market on the 1 December 1961 although the sale of Thalidomide containing tablets remained until the 9 August 1962. At the time that the Australian Government prohibited the sales of Thalidomide, there remained over 8 million tablets and 30 thousand vials in storage in Sydney. This was equivalent to 6 months of supply to Australian citizens. How could there be a nine-month lag between distillers acknowledging the murder and mutilation that was taking place, and the Australian Government doing something to protect its citizens?

The Australian Government’s response was for the [then] Health Minister, Senator Wade, to issue a couple of press releases on the dangers of Thalidomide and for pregnant women not to take Distaval. Even the Health Department at the time said it did not seem that warnings were getting out to the public. The leader of the opposition and the public were writing letters and raising concerns on the inadequate response the Government was giving to the crisis. Private individuals were printing booklets warning women to the dangers of Thalidomide.

Senator Wade was asked in December 1962 if he knew that 4 additional tablets (Tensivale, Valgris, Asmaval, and Valgraine), contained Thalidomide. He said he would have to look into it! Wade had no idea to what drugs were in the public containing Thalidomide ... and he was the Federal Minister for Health. All he had to do was ask Distillers, they had truck loads of stuff, a simple letter or phone call, but no ... *“he would have to look’ in it”*. Wade should have “looked into” it 12 months earlier. At this point in time, these tablets were still out in the community, they were in wide circulation, and they could kill or mutilate the unborn child. Harry Wade did nothing!

Meanwhile in the United States of America where Thalidomide had never been allowed to go on sale because of safety concerns for its citizens and the welfare of the unborn child; President John F. Kennedy personally went on the T.V. and radio to warn of the dangers, he had newspaper advertisements published, he held weekly press meetings warning the public to the dangers of Thalidomide. John F Kennedy also authorised 200 inspectors to search the

country with the authority to enter any warehouse, doctor's surgery, chemist, hospital, or home, to find and destroy any stocks of Thalidomide.

New Zealand also authorised inspectors to search and destroy any stocks of Thalidomide on sight. Australia did nothing. The Australian Government had the ability; to notify the public, to organise the personnel, to give the authorisation, to search, to find and destroy. To give adequate warnings. Other countries had done so. Our government did nothing. They left Thalidomide in circulation in the public, to go on and kill, mutilate and maim children ... **THEY DID NOTHING!!!**

MY WIFE:

■ is my wife and the youngest survivor of Thalidomide. I am lucky to have been married to her for nearly 32 years. We met in a small country town in Victoria. She had just moved in across the road and as happens in these towns everyone got to know her very quickly. Her home and my house were 5 houses apart only on the opposite side of the main street and she went on to spend a lot of her time over at our house with my large family.

As she was growing up I think that ■ would be game to have a go at most things. She used to ride a bike, learnt to ride a horse, swam, and tried to do all the things that kids in small towns do ... although her mother was extremely protective of ■ and wanted to know where she was at any given minute. ■ finished her education in town and then moved to Melbourne to do further studies. It was at this stage we began dating and I moved to Melbourne to be with her and to find employment. Her zest for life was fantastic, she was into dance and photography, she even had a dark room in the kitchen of the flat that we shared. She loved going out with mates from the country and having a good time. ■ got a job at the Health Department and then at the Royal Women's Hospital as a ward clerk, and she loved it. We got married and soon had a son, ■. ■ loved parenthood despite the challenges of raising a child when she had a disability. But she was a determined young woman and seemed to find a way through the difficulties she faced. I remember when ■ was "denied" for a disabled parking sticker, she refused to try and appeal her case. So instead, she had to lug the groceries and the baby capsule back and forth to the car ... unbelievable!

■ had enrolled at Monash University and was hugely excited to be going back to school and bettering herself, when she found out that she was pregnant with our second child ■. She stayed at University and ended up getting her Master's degree. The university wanted her to complete her Doctorate, but she declined. All this with major disabilities and a young family, she is an amazingly talented and determined woman. ■ then worked at the State Coroner's Office as a Grief Counsellor. Leaving the court's, she started teaching. ■ worked as a lecturer/tutor until she was forced to retire due to her declining health issues relating to Thalidomide. She was extremely well liked by her peers, and her students absolutely loved her. Her forced retirement meant that Thalidomide had done even more damage as it had robbed the education system of an extremely respected teacher and robbed ■ of a sense of self-worth. She misses the class room dreadfully

Today ■ is not the woman I married, she has gotten older, well ahead of her time. The constant posturing and movements that her body goes through to complete everyday tasks has taken its toll and the nerve pain that thalidomide has given her is unbearable at times. It starts in her face and moves down her neck, then radiates through her shoulders and then her back and finally to her legs. It may grab her at any time and anywhere; walking to the shops, sitting at a chair, laying on her bed ... she can only remain immobile till it passes. ■ has also got nerve damage where there are areas of numbness and these are spreading and growing larger.

■ has longevity in her genetics, but her body has already been compared to that of a 78-year-old and the reality is, she may well die much sooner than she should. The fun-loving young woman with a zest for life is broken both in a physical and emotional sense. The constant stares and questions have finally taken its toll, the simple fact of not being able to pick cloths of the rack, of not being able to hug her husband or kids have taken its toll. At 55 she is just worn out, and we can thank Thalidomide and the Australian Government for that. She can no longer do photography, ride a horse, work, cook, garden or shop by herself. Her feet cause her so much pain that at times, she can hardly walk. Unbelievably she used to use them almost as hands, but no longer as they have seized up and they cause too much pain.

We have gone from a dual income family to relying on the pension. I now do most of the chores around the house. I really don't know what we are going to do when one of us (or both of us) needs to go into an old age home ...however could we afford that?

What this Thalidomide group is now asking for, is no more than what other governments worldwide have been giving their victims of Thalidomide. How much are your arms worth or your legs, having a family, your hearing or your sight, to be able to toilet yourself? Everyday things that were robbed from the victims of Thalidomide. Susan Ley, when she was the Minister for Health in 2016, commissioned Maddocks Lawyers to investigate and report on the Australian Government and their role of Thalidomide. Recommendations were given in that report. Neither Susan Ley or Greg Hunt have allowed us to view the recommendations through F.O.I. and it is my understanding that they have refused the oppositions requests for viewing.

Germany, Canada, England, Ireland to name a few have been giving targeted support to their victim for years, and some for decades. They have acknowledged their part in the tragedy and developed packages that would support their survivors. The Australian victims are only asking for parity with other victims worldwide.

The Australian Government have shown far more support for their partners Chemie Gruenthal in the greatest medical tragedy to have happened in medical history. Gruenthal have been allowed to continue to trade here on Australian shores, unencumbered or without sanction. Even without a worthwhile apology to their victims. Gruenthal boasted a 1.4-billion-euro revenue in 2016. This is a company making money and huge profits, forming partnerships with Australian companies and the Australian Government without any payment to their victims. How is it that a company that murdered and mutilated so many victims worldwide can operate here in Australia, with the blessing of the Australian Government. Why would the Australian government support these murderer's? This is sickening.

The more you investigate, the more that you read on the responses to the tragedy that unfolded by the Government and the tragedy that is still unfolding, the contempt that they have shown is just unfathomable. To read Harry Wades letters to Distillers he was more concerned for them than the victims that together they had created.

█ could have, should have been saved from Thalidomide. Harry Wade did nothing. He was told and yet he did nothing, and the Australian Government are STILL doing nothing. In fact, █ was conceived during the time that Harry Wade did nothing. While he sat on his contemptuous hands and said "No action is necessary" ... █ was conceived to unsuspecting parents.

It is disgraceful that my wife is today taking so much of her time and energy to fight the Australian government for the support that should have been offered years ago. █ is leading the charge and has done so for well over 4 years now. It is absolutely exhausting for her and for us as a family. There is no doubt that the Australian government have a duty of care to the victims they helped create. Why should █ and all the other survivors be fighting for their lives in a battle that should and could have been avoided?

HOW IS THIS FAIR???