

SENATE INQUIRY – SUPPORT FOR AUSTRALIAN THALIDOMIDE SURVIVORS

By: [REDACTED] (Survivor)

The Expectation:

My name is [REDACTED] ... and I am a Thalidomide survivor. In fact, I am the youngest of our Australian survivors. I was conceived at a time when the Australian government knew about the dangers of Thalidomide but, did nothing. I was born in a small outback Queensland town, where my father was a doctor, and while my life was just beginning, my parent's lives had been thrown into a spiral of shock, disbelief, and guilt. It wasn't supposed to be like this for them ... they were expecting a healthy baby that would complete their new family, and that would go on to lead a normal and happy life. And it wasn't supposed to be like this for me ... I should have had a whole life of opportunities ahead. But already from within the womb, my doors of opportunities had slammed shut. On [REDACTED], 1963, my mother delivered a tiny baby girl, with severely deformed arms as a result of Thalidomide. Sadly, this should never have happened ... and heartbreakingly, it could have been avoided, especially for me.

The Reality:

So here I am at age 55, and the question of how much Thalidomide affected my life is simple. It affects me completely. Every single step of my journey has been governed, decided upon, influenced, or impeded, because of Thalidomide. I can't escape it as it lives with me every day. Sometimes it sits quietly in the background, with little to say but making sure its presence is noted. Sometimes it raises its ugly head and challenges my ability to move forward. And sometimes it simply overpowers me and crudely says "No".

The effect of Thalidomide accompanies me where ever I go. There is no escaping it, or even temporarily avoiding it, and no pretending it doesn't exist. It is extremely visible and for the most part, it is ugly. It has often entered the room before I have ... and can linger long after I have gone. It disables my ability to function without pain, and too often leaves me feeling embarrassed, scared or angry. These days, it always leaves me exhausted, and sometimes wondering 'how can I end it?'

It was through the determination of my parents that I live as normal a life as possible, and that I learned the value of 'fight' and 'independence'. But Thalidomide was a cruel and callous thief. It stole from me so many of the simple childhood opportunities that should have been mine, such as playing ball, skipping rope, playing marbles, even going to the bathroom by myself. In my teenage years, it stole my self-esteem, my ability to date, to play sport, to blend with my peers. As a young woman, Thalidomide continued to steal. I was unable to do simple house chores, apply for most jobs, study most degrees, travel freely, or dress and carry my babies.

I am now 55 years old, and Thalidomide has decreed me an old woman. Years of struggle and compensating for my disability has further crippled my body. I have been forced into early retirement, I need continual care, and my body aches with pain. Along with my physiological exhaustion, my psychological well-being is depleted. My sense of contribution, independence, worth, and dignity has been stolen. Unlike most thieves that come [and leave] in the shadow of darkness, Thalidomide came to my life and "robbed" ... in the bright light of day, under the watchful eye of the world, AND of the Australian government.

The Blame:

So how did such a tragedy happen? The drug Thalidomide was developed by scientists at Chemie Grünenthal, in Germany and first entered the German market in 1957 as an over-the-counter sedative and sleeping tablet based on the maker's safety claims. It was advertised as "*completely safe*" for everyone, including mother and child, "*even during pregnancy*", as its developers "*could not find a dose high enough to kill a rat*". Researchers also discovered that Thalidomide was a useful anti-nausea drug and was prescribed to pregnant women experiencing morning sickness.

Originally in Australia the drug, marketed as Distaval, could be obtained over the counter at a chemist without a prescription (although, later a prescription was required). Initially, patients taking thalidomide as a sedative had minimal side effects and although there were reports of nerve irritation if taken in large doses, it was considered an effective sleeping tablet and anti-nausea tablet. Medico's reasoned that the "pros" outweighed the "con's" ... and continued prescribing. If, however, a pregnant woman took Distaval during the critical time

of foetal development (between eight to fourteen weeks gestation), it undoubtedly led to her baby's death, or varying degrees of birth defects.

It was marketed as a 'wonder drug', but Thalidomide turned out to be a monster that showed no mercy. The world has never seen such a medical disaster as it saw with Thalidomide and it is estimated approximately 40% of babies damaged by the effects of Thalidomide died in their first year of life. Without evidence-based research and believing in the words of a salesman, the Australian Liberal Government allowed Thalidomide to enter our country. The results were devastating.

Fuelled by greed and glory, Chemie Grünenthal promoted Thalidomide throughout the world. By 1960, it was marketed in 46 countries with sales almost matching Aspirin. It really was "the wonder drug!" But the warning signs were already there, heralding the disaster that unfolded. As early as 1956 the first Thalidomide-affected baby was born in West Germany to a Chemie Grünenthal employee. Armed with this information, and knowledge nerve damage, and of additional babies born with deformities, Chemie Grünenthal pushed forward with their sales.

Enter, the Australian government. In June of 1960, Thalidomide was marketed in Australia. Untested and without question, the government welcomed a murderer to its shores. Alarmingly, in October of 1961, the Australian government were so relaxed with Thalidomide, that sale over the counter without prescription was approved in Victoria. Eighteen months after its introduction to Australia, amidst the increasing reports and evidence of the dangers, Chemie Grünenthal withdrew Thalidomide from the British and Australian markets. Within weeks, the Australian distributor Distillers withdrew from sale all Thalidomide related products. The warning bells had sounded.

So why then, did it take a further 9 months for the Australian government to finally ban the sale of Thalidomide? The bells had rung, the world was on notice. But Thalidomide was still on sale in Australia for that additional 9 months. And even when the ban on the sale of Thalidomide was announced ... little notice was given to the public. Medicine cabinets around Australia still contained this killer, and in several different disguises. Senators were

asking questions, Members of Parliament were asking, the Director-General was asking, the Leader of the Opposition (the Hon Arthur Caldwell) was asking, educated Midwives were asking, ... why wasn't the Government screaming to its citizens about the dangers of Thalidomide. More specifically, why wasn't Senator Harry Wade (Minister for Health) showing appropriate concern and acting responsibly to ensure the safety of its citizens?

Despite the many questions and plea's for Senator Wade to deliver an acceptable action to the Thalidomide tragedy, his response was simplistic and abhorrently inadequate. He enforced "no action" was necessary on the drug Thalidomide in Australia, because "the manufacturer had withdrawn it from the market" (The Age, August 9, 1962). He ignored the lengths that other countries (such as the U.S.A. and New Zealand) had implemented in warning their citizens and deploying a 'search and destroy' approach to eradicate Thalidomide stock. Senator Wade was culpable, and his ignorance and arrogance ensued a failure of process. He ignored the warning bells, and showed himself to be profoundly incapable, and his procedural failings allowed the ongoing maiming, mutilation, and murder of Australian babies. In simplistic terms, had Senator Wade fulfilled his obligation as Minister of Health ... I would have been saved from the Thalidomide tragedy.

The Responsibility:

Ask me how I feel? I tremble with the hatred and bitterness I feel for Chemie Grünenthal who designed Thalidomide ... and remain free of accountability. I abhor hearing how much money they make each year as they continue their successful business ... yet have never paid me compensation for stealing so much of my life.

The fact that Thalidomide made its way into my mother's hands over 55 years ago is repugnant and inexcusable. I am disgusted at the lack of support from my own government as they have allowed me to be unsupported all these years. It is nothing less than shameful that I am here now fighting my Government for security for my "todays" and "tomorrow's". And I am repulsed by our Government in allowing Gruenthal to still practice their business here in Australia, unencumbered and without penalties. And I am embarrassed for our Government in not recognising their moral obligation to the Thalidomide cohort they helped

create. Governments worldwide have developed and implemented support packages for their victims ... we are simply asking the same.

The Difference:

My future is bleak. As my body continues to age at an accelerated rate, so will my arthritis, immobility, pain, fear, and my needs increase. The difference a suitable support package would make to my life is immense. It would allow me to once again find purpose and direction. It would allow me to pursue medical procedures needed to enhance my health. It would enable me to plan for a future in Aged Care, whilst allowing me to stay at home longer. It would enable me to buy equipment to support my old lifestyle that I dream to rekindle. It would take a huge financial pressure from our shoulders as my needs become more complex. It would allow me to change my home to best suit my needs, giving me a sense of contribution and usefulness. And it would allow me some dignity, independence, and security, to move forward with my life.

Make this difference for me. Make this difference for us all.

In the words of A. E. Housman ... *I've yet to live a little while, before I die forever!*