

SENATE ENQUIRY INTO THALIDOMIDE USE IN AUSTRALIA.

Submission by [REDACTED] (Thalidomide victim) for:

- **Financial support and redress by the Australian Government to the victims of Thalidomide use.**
- **To assure that such financial support reaches Parity with the compensation given to thalidomide victims of other countries.**
- **Public Acknowledgement by the Australian Government of hardship both financial and emotional caused upon the families and survivors of Thalidomide use.**

Terms of Reference of Senate Enquiry:

- a) Adequacy of compensation and support
- b) Responsibility for providing support
- c) Provision of financial compensation
- d) The role of the Australian Government in compensation and support
- e) Any related matters

I am a victim of Thalidomide. All my family are also the victims of what this drug has done to me. Mum lives with so much guilt for taking that 1 tablet, the guilt has eaten her away she will have that guilt till the last breath she takes. Only then will she have peace from what thalidomide did to her, her family, and to me. Countries worldwide have recognised their victims of Thalidomide and implemented support packages ... but not Australia. How can the Australian government possibly believe they are beyond any guilt, when historical documents show that they let the untested drug into my country, and did nothing to stop the distribution of thalidomide even when they knew it was causing birth deformities?

"I want to mention the tranquilizing drug, thalidomide , and the frightful results that flowed from its use. A number of babies who have been born in this country and in other parts of the world are the victims of the use of this drug which had not been properly tested by the pharmaceutical laboratories that produced it. The Commonwealth, through its Department of Health, bears a great deal of responsibility for the babies that have been born with frightful deformities. **We in this Parliament must bear some of the responsibility for that**".

Hansards—1963

Background

- Mum was given Distaval for treatment of vomiting endlessly for days on end from bouts of migraines she suffered from.
- Mum took 1 tablet of Distaval for her migraines, she was unaware she was pregnant with me.
- That 1 tablet sealed my fate, destroyed my body then and still destroys my health to this day.
- The Doctor who gave Mum the sample bottle of thalidomide destroyed Mum's medical records, once the news of what this drug did to unborn babies, he denied that Mum had ever been a patient of the clinic.
- It was over three days before the Drs allowed Mum to see and hold me after my birth, the Doctors thought 'I was too grossly deformed for her to love me'.
- Mum was finally allowed to take me home from the hospital, the doctors uttered these words to her. "Take [REDACTED] home, and the kindest thing you can do for her is to smother her while she is sleeping". All because of what thalidomide did to my body.
- Thalidomide mutilated my body, inside and skeletally:
- I have no arms, virtually all I have is 3 fingers coming out of each of my deformed shoulders.
- - Tetralogy of Fallot- four abnormalities that occur together – heart condition: the abnormalities are
 1. Hole in the heart (ventricular septal defect- VSD)
 2. Large aorta which overrides the VSD
 3. Pulmonary outflow obstruction with small narrowed pulmonary valve, muscular narrowing and often small branch pulmonary arteries (your left PA was very small)
 4. Right ventricular hypertrophy (thickening up to cope with the load) I also had an ASD or atrial septal defect – a hole between the atria. All of this means that I have had many open-heart surgeries & still more to come.

Responsibility for providing support

We live with Thalidomide 24/7 there is no escaping from it, it has tortured us physically and mentally our whole life, why can't the Australian government who allowed thalidomide to be dispensed (over the counter at the chemist or by Doctor's prescription and his samples) in my country do the right thing by its affected victims? So, we can live out the rest of our lives with dignity and enable us to buy equipment to make our lives easier. We aren't asking so that we can be wealthy, we are asking so that we can be comfortable for the rest of our lives, we are asking for parity to what other governments around the world have done for their thalidomide survivors. We are the innocent victims of the governments failure to protect mothers and the babies they were carrying. The government eventually banned the drug thalidomide, but it did not stop the sale/dispensing of all the tablets (8million) that were already here in Australia. The Australian Government failed in their duty of care.

The role of the Australian Government in compensation and support

- You only have to read The Hansards of the day or go delving into the national archive Australia records, type in thalidomide and you will be kept busy for days/weeks/months reading information all the while shaking your head and as my 91 year old mum said to me after reading some of these articles to her "How can they get away with what they did to us?" In my eyes the government played their part in the thalidomide disaster they even set up the TGA so nothing like this would happen again. Below are just some events from the Australian Government departments and how they have treated me, because I live in a confronting body image caused by their inaction and lax safeguards regarding thalidomide because of that, I have stories to tell, all because of my body and what thalidomide did to it.

- Dad took me down to Centrelink, after I had finished grade 12, so I could apply to get the unemployment benefits. As I wasn't working, it seemed only logical, that's what everyone else did when they had no job. However, the government department in their infinite wisdom said that "I couldn't get the dole, I had to prove to them that I was capable of working first, cause, people like me didn't work". The government decided that I had to go and do four months 'work' at a sheltered workshop for the mentally challenged. I sat beside people who had mental challenges. They could barely put more than three words together, I was the only one there with a physical disability. Our sole job in that workshop was to stuff plastic cutlery into little bags for an airline & I wasn't getting paid to do it. Exactly 4 months to the day I left the sheltered workshop & went back to Centrelink to get my benefits, but they still wouldn't give it to me & they then told me, "that was where I belonged in society." Even though I was humiliated to say the least by the governments treatment of me I am happy to say that I did indeed find my own employment and worked for over 14 years. Ironically 10 of those years was in a govt department. My working career was short and job promotions were non-existent, as such there was no chance of building up a nice nest egg of superannuation to live off, all because of my body and what thalidomide did to it.

- Learning to drive a car was a bit like the above story. I was told by the Department of Transport and the police that they couldn't give me a learner's permit or a license until I could prove that I could drive 'cause people like me didn't drive'. How on earth could I prove to them that I could drive if I couldn't get a permit to learn how? This made no sense to my family, and I simply learned to be a passenger. My freedom that you have when you get a license was taken off me by government agencies, all because of my body and what thalidomide did to it.

- In 2003 my husband passed away, I was left to raise our 9-year-old daughter on my own, I asked the government for help. Disability services said 'they couldn't help me cause my daughter wasn't disabled and they didn't fund thalidomide survivors'. So, I turned to Centrelink they said, 'I was too young to get a widow's pension, but I should apply for the disability pension'. Getting the disability pension was quite an ordeal, not that I expected that it would go smoothly for me after all my other dealings with the Government. I applied and got knocked back, they told me to fill out the forms and try again. I think I did this about four or five times until they finally asked me to come in for a 'face to face' interview with one of their 'expert staff' so they could determine what was happening. So, I sat down with the Centrelink officer who filled out the forms with me, going through all the paperwork and medical reports I had, answering all the questions on their forms. I left feeling good, but a week or so later I got a letter saying I'd been knocked back again. I couldn't believe it, I took that letter down to Centrelink, "How much more disabled do I need to get for the disability pension?" I asked. A very nice Centrelink officer said, "Let me go and get your file and I'll sort it out for you" He went through the latest form that the previous officer had filled out and said, "I see the problem". Even though I had been sitting right there in front of her, she had failed to notice my arms or lack thereof my arms, how did she not notice that I

signed stuff with the pen she gave me - with my foot?! Nowhere had she written that I had a physical disability, they had only been going on my heart condition for assessment. I mean, every single person, young or old, stares at me. How on earth did I get the only person in the world who didn't notice them? I wasn't granted any back pay, either, as (according to Centrelink) it was my fault for not noticing that she hadn't noticed my arms or lack of them – really? – my body is just so confronting. I had to go through all this stress because there is no square on their forms for thalidomide and all because of my body and what thalidomide did to it.

- NDIS - I would love a dollar for every time a politician has told me that they won't help us because the NDIS will 'save us'. NDIS looks terrific on paper, though, in real life, it doesn't work, apart from the very few lucky participants who are better off with it, many I know are worse off once they are under NDIS. It is not in my area yet and won't be here till mid next year. But I've been told already that they won't modify my bathroom as I want or need it done, they won't buy me a new mobility scooter, It is doubtful whether they will give me all new doors so that I can have keyless entry into every door in my house, imagine opening your door by putting the key in your mouth and placing the key in the lock then turning it with your mouth. Now NDIS is terrific for those that get some benefit out of it, but the Australian government forget that we thalidomide survivors are purely disabled because they allowed the untested drug thalidomide into our country and didn't stop the havoc this drug was causing, we wouldn't have to be relying on NDIS if the government hadn't failed in their duty of care of protecting pregnant women and their families. To get anything from the NDIS you have to jump through all these hoops then rely on OT's – Occupational Therapist, who have no idea on thalidomide, or what we need and usually have to wait months and months for equipment to come through, if the government funded us like other governments around the world do, then we could buy what we need tomorrow without having to go through all the hassle of jumping through hoops. For example OT's, in my case the first one I encountered was in high school, when I was given an electric typewriter to help me with my schoolwork, this OT wanted me to wear a big helmet on my head that had a stick coming out of the front of it so I could hit the keyboard with this stick, so that I could sit up and look normal, instead of having to put typewriter on the floor so I could type with my toes. How was wearing a big helmet with a stick thingy on my head going to make me look normal? The second OT I had to deal with, told me, "that I was lazy because I didn't hang my own washing on the clothesline". The fact that my arms can't even reach up and touch my ears had no bearing on this OT, she purely said I was lazy. The last OT was far worse, I have a tiny little mobility scooter that I drive with my feet. I get so tired from pain and my heart condition that it is hard to walk long distances. I had to buy this on my own because I had no government funding for it. I paid someone to modified it myself. I had no government funding of any kind till I turned 53 (2015), that was only after I had done lots of campaigning to the federal and state governments about Thalidomide and why can't the Australia government support survivors like other governments around the world have done? The Prime Minister of the day told me 'thalidomide was not a federal problem, it was a state issue'. The PM's letter told me to contact Qld govt for funding, he provided me with a phone number to ring (which was disconnected) then added that maybe I should engage a social worker. After lots of letters to every state Qld MP, I was finally offered a small amount of funding. I asked if it could go towards renovating my bathroom which I thought would be fantastic, finally I will get a bathroom that will be easier for me, but no, the first thing the Queensland government offered me to modify my bathroom was a set of 'handrails'. This would have been very helpful, if I had of had arms and fully functioning hands to use handrails, unfortunately little tiny arms with three fingers on each arm are quite useless when it comes to using handrails. So, when I got this little bit of funding from disability services 2015 I asked if I could get a better scooter because it is only good for very flat surfaces. They said they would send out an OT, the OT was supposedly the best of the best OT's, she came out and told me I didn't need a scooter, I needed a wheelchair. I knew I didn't need an electric wheelchair (a) because it wouldn't fit in my car (b) because a wheelchair is tight fitting around the body as such, I wouldn't have been able to lift my leg to do anything for myself, such as get stuff out of my purse or just to use my mobile. This OT went ahead and ordered an electric wheelchair which cost the government \$25,000, nine months later, (yes nine months, that is how long people relying on government funding through NDIS/disability services must wait for equipment), the wheelchair arrives and guess what? I couldn't use it and it wouldn't fit in the car, but hey that OT was an expert, she didn't listen to me, she didn't understand my disability, hence the wheelchair was totally useless, she wasted government money that could have been better spent on what I asked for at a fraction of that \$25,000. Therefore, NDIS is not enough to 'save us' we need financial assistance to get what we need when we need because there was no one more qualified that know about thalidomide and what it did to our bodies then us. I am the expert when it comes to what equipment or aides I need - what will and will not work for me, all because of my body and what thalidomide did to it.

What Thalidomide robbed me of, the simple things of life, such as, but there are many more things not listed here.

- Arms – missing digits - 2 thumbs plus 2 fingers – fully functioning hands
- A heart that works properly which equalled many major heart surgeries
- The freedom of being a child
- Never being able to run, skip, or jump, or do any sports of any kind – to play in the playground
- Never being able to tie shoelaces, or wear socks or shoes on my feet as my feet are my hands (only wear thongs, even in winter)
- Never being able to wear the latest fashion as I can't do up buttons or zips. Never buying clothes that fit me off the shelf, every piece of clothing must be modified
- Not being able to dress or toilet myself till I was 18 – the ability to do these daily tasks for myself has now gone
- Going to any school I wanted to, there was only 1 school in all of Brisbane that allowed me to be a pupil
- Never being able to go to the toilet at home or school when I needed to go, had to wait till someone could take me. My mum came up to my school every day at lunch time to toilet me, no one else would assist me, which meant she gave up her lunch hour from her job and every student there at school, saw my mum taking me to the toilet
- Never being allowed to go and play or stay over at friends' houses, because I was so sick and couldn't toilet/dress myself
- Not being able to walk till I was nearly 7, even then after a few steps I would have to be carried, right up till I was 12 because of my heart condition and lack of balance, continually falling over and landing flat on my face
- Never being in the school band or being a leading star in the school plays nor a school leader
- Never getting a driver's license and that freedom of hopping in a car to go out
- The ability to carry my daughter in my arms when she had fallen over and was hurt
- The ability to hug people
- The ability of going out in public and not being bullied every day of my life because of my confronting body
- The ability of living in a body that is not in pain 24/7
- Being unable to have simple blood tests – I must go into hospital to have blood taken from my groin – femoral stab
- Reaching my full potential, whether it was at school, at work, never getting promotions to climb the corporate ladder, never getting that high paying job and being financially secure.
- Not being able to wipe my own bottom and be able to use a bathroom outside my own home unassisted
- Eating in a restaurant, café or at home without having to put my feet up on the table to use cutlery to eat
- It robbed me of the ability to use an ATM. Reach a bank teller, counters in shops to purchase items
- Thalidomide robbed me of my independence - having to relying on someone to do everything for me these days
- Never being able to walk hand in hand with anyone I loved. My Mum, my Dad, my daughter, my husband

My thoughts on who is responsible for ongoing support, the first is of course the drug company Grunenthal, but that seems very unlikely as thalidomide survivors around the world are still pursuing them for compensation for the disaster they created, but they seem untouchable. The Australian government certainly played their part in the thalidomide disaster in Australia, you just have to have a look back through newspapers, The Hansards of the day to prove that they certainly didn't do much to stop this disaster of babies with mutilated bodies being born and certainly not forgetting all of those who did not survive. There is evidence that after the Australian Government approved and allowed thalidomide to come into our country, and after the warnings went out about what thalidomide did to babies in the womb, the Health Minister of the day Senator Wade (Liberal) eventually banned the drug but he did not stop the sale of all the thalidomide pills that were already here in Australia. Because of his 'lack of any action' regarding the drug Thalidomide in Australia, it was still possible to walk into a Chemist shop and purchase 100 tablets over the counter without a script, 7.5 months after 'the manufacturer had withdrawn it from the market'. It is now time that the Australian Government stepped up and do the right and moral thing by us. **No one has ever said 'sorry' to my parents and I, for what this drug, thalidomide, did to us, we are the innocent people in this, the greatest pharmaceutical disaster.**

How do you put a price on my constant poor health, the no escaping of what thalidomide did to me even for a second? It has been with me ever since mum swallowed that tablet, it will be with me till my last breath. How do you put a price on what it did to my body, my family? How do you put a price on the constant and horrific bullying, the mental abuse, the physical abuse I have been subjected to all my life and still to this day, all because of my body and what thalidomide did to it? I'm not saying my disability is worse than any other person with a disability, but my disability was purely created by a drug maker & the Australian Government the blame lies purely with both parties. **We deserve so much more than just a 'sorry' for what we have been through and as my 91-year-old mum said, "How can they get away with what they did to us?"** If this had of happened to you and your family wouldn't you seek justice?

References: <https://www.thalidomidegroupaustralia.com> https://www.aph.gov.au/Parliamentary_Business/Hansard
<http://www.naa.gov.au> <https://www.thalidomidesociety.org/> My medical reports