

Thalidomide Group Australia

“Looking for Justice”



www.thalidomidegroupaustralia.com

Table of Contents:

Table of Contents.....	2
Proposal to Government	3
Looking for Justice.....	4
Introduction.....	6
A Brief History.....	7
Thalidomide in Australia Timeline.....	8
Chasing the Australian Government.....	16
Worldwide Governments.....	24
One Story.....	31
A Mothers Story.....	35
Thalidomide Articles.....	37
Supportive Documentation.....	38

* Images accessed via Creative Commons and Lisa McManus *

Thalidomide Group Australia

Submission for Compensation from the Australian Government.

The Australian Survivors of Thalidomide are in dire need of recognition and support from their Government. It has been 50+ years since the onslaught of Thalidomide, which maimed, mutilated and devastated the lives of Australian Children and their families. Governments around the world have supported their survivors for decades. To this date, the Australian government has offered the barest minimum of assistance.

Below is a submission outlining what the Australian Thalidomide Survivors desperately need to ensure security into the future. The supporting documentation evidences the responsibility the Australian Government owes to its victims and survivors.

Our needs are as follows:

1. A one-time upfront payment of up to \$500,000.00 (scaled) to each Thalidomide survivor. This payment would be considered partial **compensation** for the 50+ years of pain and suffering each survivor has been subjected to, partially due to the negligence of the Australian Federal government for allowing the sale, and then ongoing circulation of Thalidomide (after notification had been given of the atrocities this drug was causing).
2. **Annual payment** of \$2,190,260.00 (Tax and DHS exempt) paid to The Thalidomide Australia Fixed Trust, administered by Adrian Dean Kelly and Paul Jozef Bakker as trustees who will distribute to the beneficiaries as per current support programs from Diageo PLC on the 1st of October each year until survivor becomes deceased. This figure is subject to CPI.
3. A **Gold Card** (similar to the Gold Card - DVA Health Card). This card would assist with health care needs and all health related conditions.
4. An "**Extraordinary Assistance Fund**" of \$500,000 to allow survivors to adapt their homes, environment, and vehicles to accommodate their disabilities.
5. A **formal Apology** to Australian survivors and their parents for the Australian Federal Governments negligence relating to Thalidomide.
6. A **plaque** in recognition of Australian Thalidomide Survivors and their parents to be mounted in a place of significance (to be decided on).

As the Australian Survivor of Thalidomide ages, so does their need of support increase. A monetary value could never fully be equated to compensate for the disabilities needlessly inflicted through this tragedy. Our submission to you however, would allow survivors to move forward with some quality and assurance into the future. We are asking for an Australian-made solution, to an Australian-made problem.

Our needs are real. Our needs are urgent. And our needs are immediate.

"Looking for Justice"

1962 bought to light the devastating tragedy of Thalidomide. Marketed as a wonder drug, Thalidomide turned out to be a monster that rendered thousands of babies with life threatening and life altering deformities. 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.

It's now 2018 and the adults that are living with the effects of thalidomide are simply existing in bodies that are worn out, painful, and unbelievably disabling. The future is bleak and understandably, survivors are scared. For the most part, Thalidomide survivors in Australia have been fiercely independent. Along with their families and loved ones, they have struggled and suffered ... but they lived quietly. Today however, their disabilities and general health is being severely impeded upon as they age. After more than 50 years, Thalidomide survivors are looking to the Australian Government to recognize, own, and deliver on its responsibilities.

Attempts to contact our government to discuss the plight of Thalidomide survivors commenced in earnest in 2014. Hundreds of phone calls have been made and letters sent to political Ministers, Members, and media throughout Australia requesting governmental support. Unfortunately replies have been few and generally offered words of sympathy towards our situation ... but little else.

In February 2016 (as requested by her office), a proposal was sent to the [then] Minister of Health, Sussan Ley, that would enable Thalidomide survivors in Australia the security needed to move into the future. The proposal was extremely unpretentious when taking into consideration the pain and suffering of those effected by Thalidomide. Responsible governments throughout the world have set up processes to compensate for the past, and financially support their survivors into the future ... yet the Australian government has offered nothing. In fact, the evidence of abysmal neglect by the [Liberal] government (55+ years ago) to protect its citizens against Thalidomide is shameful. The further evidence of that government's abhorrent involvement to allow the drug to stay on the Australian market (even after they knew of its catastrophic effects), is unpardonable. And further to their total disregard of the Thalidomide disaster, is the fact that the German company responsible for

manufacturing Thalidomide is [to this day] still allowed to operate here in Australia unencumbered by sanctions or penalties.

In December of 2014, the first of hundreds of contacts seeking support from our Government was initiated ... and still the neglect and contempt continues.

The Health Minister (in 2016) offered us assurances that her department was working towards recognising our needs and guaranteed she wanted to see a resolution to our plight ... but still, nothing.

The current Minister of Health (The Hon Greg Hunt MP), met with us in June 2017 and appeared concerned and compassionate to our plight. In the following September, he forwarded a letter to Thalidomide Group Australia that was dismissive, disrespectful, and contemptuous to our needs.

World-wide, governments have heard the cries of their native Thalidomiders and are responding accordingly. They have recognised, designed, implemented, and reviewed packages that will support their Survivors, and enable them to move forward into the future with financial security and a sense of respect.

We are simply asking the same of our government ... to afford us parity.



Introduction:

1962. Prime Minister Robert Menzies led the Liberal Party, we witnessed the foundation of the Australian Ballet, Rod Laver dominated the tennis courts, and Even Stevens was known as “a sure thing” on the race track. Australian’s “twisted” with Chubby Checker, and then tuned into Elvis Presley as they motored in their EJ Holden’s. Jacqueline Kennedy was inspirational to our women’s fashion, and there was an increased awareness of the dangers of smoking by our Health Department.

1962 was also the year that finally saw the withdrawal of the drug Thalidomide. Marketed as a wonder drug, Thalidomide turned out to be a monster that rendered thousands of babies with life threatening and life altering deformities. 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 and be distributed accordingly. The results were devastating.

It’s now 2018. Time has passed, the surviving Thalidomide babies have grown and adapted to living with their disabilities as best as possible. Throughout the years our country has witnessed the coming-and-going of Liberal governments, and seen the many faces of our changing Prime Ministers. Unfortunately, what we haven't seen, is the recognition from our government that the Thalidomide disaster even occurred, and, that it occurred here in Australia under the ‘protection’ of a Liberal government. Support offered [financial or medical] has been at its barest minimum and sadly for the survivors and their families, there hasn’t even been an apology. It would be easy to believe that from a governmental perspective, Australian survivors of Thalidomide don’t even exist.



A Brief History:

The drug Thalidomide was developed by scientists at Chemie Grünenthal, in Germany. Thalidomide first entered the German market in 1957 as an over-the-counter sedative and sleeping tablet based on the maker's safety claims. Thalidomide 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. Although there were reports of nerve irritation if taken in large doses, it was an effective sleeping tablet and anti-nausea tablet. If pregnant women took Distaval during the critical time of foetal development (between eight to fourteen weeks gestation), it would undoubtedly lead to death, or varying degrees of birth defects.

By 1960, thalidomide was marketed in 46 countries around the world, with sales almost matching those of Aspirin.

The main abnormalities noted in babies of Thalidomide were:

- Defects of the muscles of the eye and of the face.
- Absence of the auricles with deafness.
- Absence or hypoplasia of arms, preferentially affecting the radius and the thumb.
- Thumbs with three joints or no fingers at all.
- Defects of the femur and of the tibia.
- Malformations of the heart, the bowel, the uterus, the digestive tract and the gallbladder.
- Defects of the spine



Thalidomide in Australia *Timeline*

Timeline – Thalidomide in Australia

- 1953:** Thalidomide was created in Germany by the Grünenthal Group.
Primarily prescribed as a sedative thalidomide also claimed to cure anxiety, insomnia, gastritis, and tension.
Later, it was used against nausea and to alleviate morning sickness in pregnant women.
- 1956/Dec 25:** The first Thalidomide-affected baby was born in West Germany to a Grünenthal employee.
- 1958/April:** Thalidomide was first licenced for use in the United Kingdom under the brand name Distaval.
- June 1960:** Thalidomide was marketed in Australia.
- 1961/March:** Distaval is declared a potent drug in Victoria, Australia. This restricted its sales to Chemists.
- 1961/April:** Australian Dr. William McBride, notified Chemie Grünenthal's Australian distributor Distillers about his suspicions of the link between Distaval (Thalidomide) and malformations.
Distillers claim they never received the written report.
Yet sales promotion of the drug was stepped up and a quarter of a million leaflets distributed saying Thalidomide is "*Harmless even over a long period of use*" and "*completely harmless even for infants*".

- 1961/May 4:** Dr. William McBride reported further malformations due to Thalidomide and succeeded in convincing his superiors at Crown Street Women's Hospital, Sydney, that the drug must be withdrawn from use in the hospital.
- In October and November Dr. McBride reported further malformed babies.
- 1961/Oct:** Approved for sale over the counter without a prescription in Victoria, Australia.
- 1961/Nov:** Thalidomide was withdrawn from the British and the Australian markets by the manufacturer, Chemie Grünenthal.
- 1961/Dec 2:** Australian distributor Distillers withdrew from sale, Distaval, Asmaval, Tensivale, Valgis, and Valgraine.
- All (5) of these medications contained Thalidomide.
- Whilst Distaval was most commonly associated with morning sickness and baby abnormalities, the other medications were prescribed for symptoms of headache, toothache, hay fever, bronchitis, migraine, fibrositis, asthma, neuralgia, arthritis.
- The reality was, that any of these tablets (or syrup) could be given to an unsuspecting woman, her child be mutilated or murdered, and the connection between Thalidomide and Thalidomide babes, not be made.
- Whilst Thalidomide (under the collection of trade names listed above) was withdrawn by Distillers, the Australian Government did nothing to alert the public and/or search and destroy remaining stock.

- 1961/Dec 16:** Dr McBride's observations were published in the *Lancet* highlighting the connections between Thalidomide and birth defects.
His observations were also published in the Australian Medical Journal on December 23.
- 1962/Jan 6 and Feb 3:** Prof. Widijung Lenz who had warned against Thalidomide in Germany published evidence of deformities in the *Lancet*.
Chemie Grünenthal continued making and distributing Thalidomide, stepping up its advertising and intensive marketing despite criticism of doctors
- 1962/March 4:** Thalidomide was removed from the shelves in Germany because of public opinion and against the wishes of Chemie Grünenthal.
News of the dangers of Thalidomide was played down by the media.
In many cases, malformed births occurred after the drug was withdrawn as many households were in possession of the drug.
Pregnant mothers took it never realizing the risks involved.
- 1962/April:** Classified as a drug to be sold only on doctors' prescriptions in Victoria, Australia.
- 1962/July:** FDA inspector Frances Kelsey, prevented the drug's approval within the United States despite pressure from the pharmaceutical company and FDA supervisors.
Kelsey felt the application for thalidomide contained incomplete and insufficient data on its safety and effectiveness.
Kelsey was also concerned that there were not yet any results available from U.S. clinical trials of the drug.

1962/Aug 1: President John F. Kennedy immediately responded to the recommendations of Frances Kelsey, by;

- * Alerting the people of America to the dangers of Thalidomide. He personally made appearances on television warning of the dangers.
- * Had warnings flashed on the television screens and over the radio at regular intervals throughout the day and night for weeks.
- * Called for a nationwide search of every home and medicine cabinet in the country.
- * Ordered for the destruction of every Thalidomide tablet found.
- * Allocating a team of 200 men to track down every doctor who May have obtained supplies from outside sources, giving orders that any Thalidomide found to be destroyed on sight.

1962/July 27: New Zealand Department of Health issued a directive to seize Thalidomide From Chemists and hospital shelves, under the Section 12 of the Food and Drug Act.

1962/Aug: New Zealand Government prohibited the importation, manufacture, sale, and use of Thalidomide in New Zealand.

1962/Aug 9: **The Australian Government FINALLY bans the sale of Thalidomide.** (at the time of this ban, stocks of Thalidomide and related products were being held in storage at Artarmon, N.S.W., totalling over 8 million tablets).

1962/Aug 9: Minister for Health (Senator Wade) said no action was necessary on the drug Thalidomide in Australia, because “the manufacturer had withdrawn it from the market.” (The Age, August 9, 1962)

- * Because of this “no action”, it was still possible to walk into a Chemist shop and purchase 100 tablets 7.5 months after “the manufacturer had withdrawn it from the market”.
- * Because of this “no action” it was also possible for the

manufacturer to make supplies available to hospitals at any time

1962: The following citations from the Federal Parliament Hansard suggest a delay occurring between when the Australian Health Department became aware of the effects of Thalidomide, and the banning of the drug.

August 22: *"Why was not the ban on Distaval imposed then, instead of four months afterwards, when a question was asked in this House?"*
Senator Turnbull (Tas), 22 August 1962;

August 30: *"The reason why I raise this matter, Mr. Deputy President, is that I have a disquieting feeling that our Department of Health is not sufficiently aware of what is happening."*
Senator Turnbull (Tas), 30 August, 1962;

October 17: *"I think that not only every honourable member but everybody in the country was shocked by the tragedy of babies born deformed as a result of the use by their mothers during pregnancy of the drug thalidomide. Australia's Minister for Health does not seem to have been shocked sufficiently to do much about it",*
Mr. Webb (Stirling), 17 October, 1962.

Dec 13, 1962: Letter from J.F. Cairns (Member of House of Representatives) writes to Senator Wade (Federal Health Minister) to inquire as to the possibility of Thalidomide being contained in Tensival, Valgis, and Valgraine.
These medications were on sale for common complaints.

Dec 17, 1962: Federal Health Minister Wade replies to J.F Cairns responding, "he would have to investigate this matter".

Jan 3, 1963: As written by the Director General to Minister Wade;
"On the 10th December, The Melbourne Herald published your warning to householders to destroy supplies of Thalidomide preparations in

their possession, but so far as can be ascertained, your statement did not appear in Interstate newspapers.

Jan 9, 1963: Minister Wade responds:

"I am of the opinion that a further press statement on Thalidomide would serve no useful purpose at present time"

May 14, 1963: Senator McClelland, addresses the Australian Federal Parliament;

"The fact is, as I have said, that very little, if anything at all, is being done to assist these 23 malformed Australians. Perhaps it is that society, consciously or unconsciously, wants to forget about them. Perhaps it is that a collective family group of 23 cannot be regarded as a pressure group. In any event, very little, if anything at all, is being done in Australia to alleviate the problems of the parents of these children or to assist the afflicted children themselves."

The Senate Appropriation Bill (No.2) 1962-63. May 14, 1963.

(Note: only 23 babies were identified as Thalidomide at this stage)

Mid to late 1960's: The Australian Government made available the facilities of Veterans Affairs to provide the fitting of artificial limbs for those children missing either upper or lower limbs.

1968: Chemie Grünenthal is brought to trial in Germany charged with intent to commit bodily harm and involuntary manslaughter.

1970: The trial against Grünenthal is brought to a premature end by the German government stating that the trial "was not in the public interest".

1974: The Australian government made a one-off payment of \$150,000 to the Thalidomide Foundation to offset Taxes incurred through the Trust.

2010: United Kingdom Health Minister (Mike O'Brien) makes a formal apology to their Thalidomide Victims, expressing "sincere regret and deep sympathy" on behalf of the government.

2012: The inventor of Thalidomide (the Grünenthal Group) releases a statement saying it regrets the consequences of the drug.

"We ask that you regard our long silence as a sign of the silent shock that your fate has caused us!"

Company Chief Executive, Harold Stock

Currently: Following any settlements in 1974 (Distillers), 2010 (Diageo), and 2014 (Diageo), the Australian Federal Government passed legislation ensuring that the lump sum and ex-gratia payments were not considered income and therefore not liable for payment of income tax.

Currently: The Grünenthal Group have never recognised and/or compensated its Australian victims.
In 2016, The Grünenthal Group boasts a revenue of 1.39 billion euro.
The Grünenthal Group are present in 32 countries with products sold worldwide in 155 countries.

Currently: Chemie Grünenthal is STILL operating here in Australia unencumbered by sanctions or penalties.

Currently: The Australian Federal Government is still ignoring its Thalidomide survivors.

Currently: The ALP and The Greens are supporting Australian survivors of Thalidomide with the ALP establishing on a Senate Inquiry.



CHASING the Australian Government

Timeline - Australian Government

Please note that the following is a brief timeline summarizing some of the efforts to communicate with Politicians over the past 3 years.

Hundreds of letters, emails, and phone calls have been made and we are still waiting to be heard.

- 2014/Dec:** Letters sent in email and hard-copy to relevant Ministers of Parliament requesting a meeting to discuss the needs of the Australian Thalidomide survivors.
- 2015/Jan:** Phone calls with both the Department of Social Services and the department of Health led to each pointing the finger of responsibility to the other ... saying Thalidomide issues fall under the umbrella of someone else.
- 2015/Jan:** Contacts and meetings were made with local members and Ministers to enlighten them to our needs.
- 2015/Feb:** Letters of appreciation forwarded to any member responding to our initial contacts.
- 2015/March:** Letter received from Prime Minister Abbott's office stating he was too busy to meet with our representatives.
The letter suggested we contact Minister Sussan Ley, Health Minister.
- 2015/May:** Contacts began with the Media requesting meetings to discuss our plight.

2015/July: Discussions surrounding a rally in Canberra of Thalidomide survivors.

2015/Dec: Meeting with Minister Sussan Ley in her Sydney office.
Minister Ley afforded us 20 minutes in which she listened, empathised, promised to “go in to bat for us”, and asked her attending assistant to look at how NDIS will support our needs.

2016/Jan: Contact with Minister Ley asking for direction and reminding her of her promise.

2016/Feb 24: Phone call from (E) in Minister Leys office stating that Minister Ley was sincerely concerned and wanted to follow us through to a resolution.
(E) was a senior staff member that had been directed by Minister Ley to contact us.
(E) asked how was it that we hoped the government would offer support?
That same afternoon, a proposal was presented to Minister Ley.

2016/March: (E) advises [by phone] that the apology asked for on our proposal would not be forthcoming as the government felt no responsibility towards the Thalidomide disaster in Australia.

2016/April 26: Phone call from new contact at Minister Leys office.
(L) was a senior advisor to Ley.
(L) advised Minister Ley was preparing a report to be then presented to the Department of Finance.

2016/May: (L) phones to report that [due to the complexity of Thalidomide in Australia]

Minister Ley was commissioning an investigation from legal representation to look at the history of Thalidomide in our country and its relationship to/with the government.

2016/May 17: (L) phones and asks [to help their research] if there are any supporting articles and/or documentation that outlines the projected health and aging concerns of a Thalidomide survivor?

An extensive research was undertaken, and a list of references was sent to (L) within the week.

2016/July 2: FEDERAL ELECTIONS

2016/July: Invitations sent to Minister Ley, (E), and (L) to attend the 2016 TAI Bi-Annual Conference in Adelaide.

2016/Aug: After requesting feedback from Leys office re: update of our proposal, we were advised Minister Ley had her investigative report on her desk (complete with recommendations) but had not yet read it.

We were advised to allow 4 weeks for the Minister to familiarise herself with the investigation.

2016/Sept: After five weeks we made enquiries to Leys office, and were informed the Minister still hadn't gotten around to the paperwork.

2016/Nov 28: Met with (E) at her Canberra office.

She was apologetic to be unable to shed further light on our situation with the Minister.

2017/Jan 12: Sussan Ley resigns her position as Minister of Health, Aged Care, and Sport.

2017/Jan 17: Letters sent in email and hard-copy to relevant Ministers and members of Parliament requesting a meeting to discuss the needs of the Australian Thalidomide survivors.

Any responses from Ministers and members (Liberal, Shadow, and Independent), echoed the same message that unfortunately they are too busy to meet with us!

2017/Feb 7: A response from the new Minister of Health (Greg Hunt) states our request to meet has been forwarded to the Minister's advisor for follow-up, and to the Minister's diary manager.

2017/Mar 7: Still waiting to hear from Minister Hunt's staff.

2017/April 21: Appointment to see Shadow Minister of Health, Catherine King, (in her Ballarat office) to discuss our cause.
Shadow Minister King promised to "look into" and "ask around" ... and get back to us within a few weeks.

2017/June 20: Meeting in Canberra with Federal Minister of Health, Greg Hunt MP (at the Ministers Invitation) to discuss the proposal presented by Thalidomide Group Australia.
Also met with a representative from Hon Bill Shorten's office. We have been continually informed that Mr Shorten's schedule was too busy to accommodate a meeting with us.

2017/Sept 27: Letter received from Health Minister Hunt to Thalidomide Group Australia

outlining the governments intent of support.

This letter informs us of the Ministers;

1. intention to write to the Managing Director of Diageo Australia requesting urgent consideration for further support, and
2. offers a “formal and lasting recognition of what occurred in the tragic case of Thalidomide” [which we believe is a memorial plaque as this was discussed in our meeting with the Minister].

2017/Oct 6: A response letter was sent to Health Minister Hunt from Thalidomide Group Australia expressing our disbelief and disappointment in the Ministers Offering. This letter was also “cc’d” to other relevant contacts.

2017/Nov 30: Mailout to ALL Federal members and ALL members in the Senate to notify them of our communications with Minister Hunt, update them of our ‘fight’, and ask for their support.
Total of 222 letters were posted.

2017/Dec 14: Contact made from Shadow Health Minister, Catherine King (8 months after meeting with her at her Ballarat Office).
King’s office stated the shadow Minister was intending to contact Minister Hunt to present a bipartisan option.
(as of 21.06.2018, we are still waiting to hear back from King’s office and they have ignored our contacts).

2018/Jan 3: Reply email from Minister Hunt saying he was “keen to meet”. Despite many attempts to secure an appointment, the Minister has ignored our calls.

2018/Jan 17: Meeting with Senator Richard Di Natale’s office (Leader of the Australia Greens and Senator for Victoria).

Assurances were given by the Senators office that the Senator would raise our issues with Minister Hunt, that he would also raise our issues in the Senate Estimates, and to also source specific documentation vital to our cause.

2018/Feb 8: Senator Jordan Steele-John's office makes contact with us, (Senator for Western Australia). Assurances given that the Senator was extremely interested in our plight and was keen to follow-through with support.

2018/Mar 7: Meeting with [2] representatives from Minister Greg Hunt's office to discuss a permanent memorial in recognition of Thalidomide in Australia.

NOTE: This was a meeting to establish what the Minister was offering, NOT an acceptance of his offer.

2018/April 12: Interview with ABC News.

2018/May 3: Meeting with Senator Chris Ketter (Senator for Queensland) to discuss the plight of the Australian Thalidomide victim, and any possible supports offered.

2018/Jun 24: ABC News screening of report on Thalidomide Group Australia's "Looking for Justice!"

2018/June 26: In Canberra ... meeting with Senator Jordan Steele-John (Australian Greens).

2018/June 27: In Canberra ... meeting with Shadow Health Minister, Hon Catherine King. Shadow Minister King offered a Senate Inquiry, which TGA accepted

2018/June 28: In Canberra ... meeting with Federal Health Minister, Hon Greg Hunt MP.

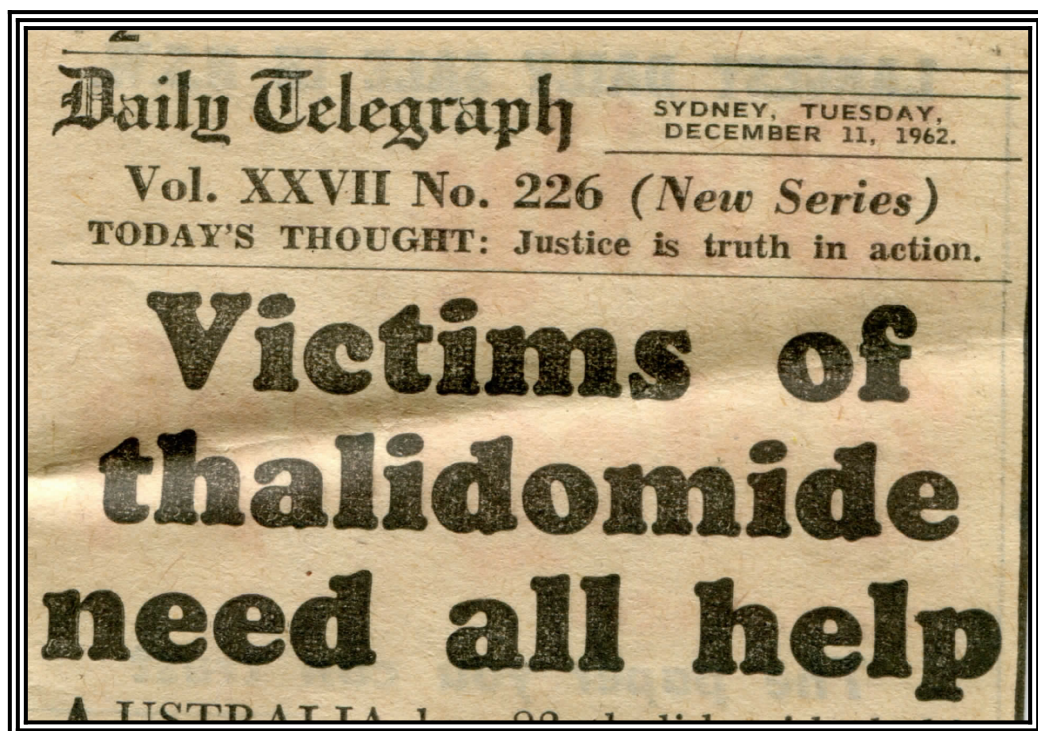
2018/June 28: In Canberra ... meeting with Senior Health Advisor to Prime Minister.

2018/July 18: Channel 10 broadcast on The Project, reporting on Thalidomide Group Australia's fight for justice.

2018/Aug 20: MEDIA RELEASE – ALP moves for Senate Inquiry into support for Australian Thalidomide survivors.

**** Please note:** This timeline is current as of August 21, 2018.

Further updates may be accessed via the website, www.thalidomidegroupaustralia.com





Worldwide Governments

What some governments have done for their survivors...

UK National Government

- 1973:** The Thalidomide Trust was set up to administer payments made by Distillers, who had distributed the Thalidomide drug in the UK.
- 1973:** Distillers (now Diageo), agreed to pay £20 million sterling in compensation.
- 1974:** The British government donated £5 million sterling to the Thalidomide Trust, which was an offset of tax on the original £20 million paid in by Distillers.
- 1996:** The British government, without offering any particular reason, donated a further £7 million.
- 2004:** The UK Government introduced new legislation (Statutory Instrument 2004 1819) so that the Annual Grants received by beneficiaries were treated as damages for personal injury and were therefore exempt from Tax.
- 2005:** Distillers agreed a complex new multi-year financial settlement estimated to cost in the order of £153 million as additional compensation for Thalidomide survivors. The additional funding provided for covenant payments to be increased and for the payments to be extended from 2022 to 2037. This was calculated based on the money required to double beneficiary annual payments from 2004 levels by 2022.
- 2010/Jan 14:** British Health Minister, Mike O'Brien, confirmed a new £20 million support package, which had been announced during the month of December '09. This was for three years funding (initially on a pilot basis) to meet the increased health needs of beneficiaries. The £20 million will be administered through the Thalidomide Trust. If the £20 million was to be divided equally across all surviving Thalidomide survivors in the UK, each survivor would receive in the order of £43,000 sterling (dependent on their level of Thalidomide damage).

2010: United Kingdom Health Minister (Mike O'Brien) makes a formal apology to their Thalidomide survivors, expressing "sincere regret and deep sympathy" on behalf of the government.

2012/Dec 20: British government paid £80-million sterling into the Thalidomide Trust.

2017: The UK Government introduces a "benefits disregard" so that the funding received by the UK Thalidomide survivors from the Thalidomide Trust is disregarded when they are assessed for eligibility to receive state-funded benefits.





Canadian Government

1980: Thalidomide victims settled with William S Merrell (Canadian distributors).

1991: Federal Government gave survivors of Thalidomide a one-time payout of \$8.5 million.
(between \$52,000 - \$82,000 a person depending on level of disability)

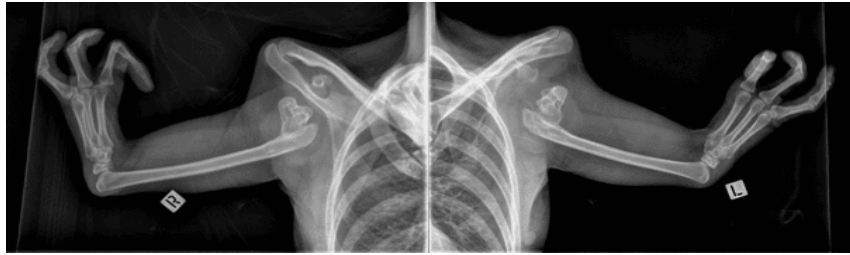
2015/Early: Federal Government offered a second lump-sum payment of \$125,000 to survivors.

The Government also promised \$168-million availability as annual compensation,
(although did not explain how survivors would access that fund).

2015/May: Details provided on the \$168-million included victims of Thalidomide receiving annual payments of up to \$100,000, depending on level of disability.

2015: Federal Government to create an annual Extraordinary Medical Assistance Fund of \$500,000 to assist survivors with medical, living, and transport expenses.

2015: Health Canada to allocate an administrator to manage the EMA Fund and compensation re-assessments levels.



National Government of Ireland

1970: the German government set up a compensation scheme from which Irish Thalidomiders received financial support.

In detail Thalidomiders received the following;

- 1) A lump sum ranging between DM7,500 (IR£1,250 approximately) and DM25,000 (IR£4,200 approx), and
- 2) A monthly allowance for life ranging between DM100 (IR£17 approx) and DM450 (IR£75 approx).

1973: The Irish government as a matter of principal decided to significantly increase the German compensation scheme.

In addition to the German scheme the Irish government provided the following;

- 1) A lump sum ranging between IR£6,600 and IR£21,300, and
- 2) A monthly allowance for life ranging between IR£31.75 and IR£95.00.

The allowances, German and Irish, are tax-free, are not reckonable for State benefits and each of the Thalidomide survivors are the holders of medical cards.

In addition, a Thalidomide survivor can also claim disability allowance of approximately €849 per month or €10,192 per annum (2010 figures).

If disability allowance is added (€849 per month – 2010 figures) the total tax-free sum claimable by a Thalidomide survivor is €1,773 (least severe) or €3,381 (most severe) monthly i.e. €21,280 or €40,568 annually (2010 figures).

Updated figures are still being researched by this website.



German Federal Government

Grünenthal, the German manufacturer of the drug, set up a €50m (£41m) fund for 3,000 thalidomide victims on the Continent, mostly in Germany, and unveiled a memorial last September when, for the first time, it expressed its “sincere regrets” and “deep sympathy” for those affected. But it has never compensated the British victims.

2012: The inventor of Thalidomide (the Grünenthal Group) releases a statement saying it regrets the consequences of the drug.

“We ask that you regard our long silence as a sign of the silent shock that your fate has caused us!”

Company Chief Executive, Harold Stock

On average, German survivors of Thalidomide receive the equivalent of £10,000 sterling a year from a foundation funded by Chemie Grünenthal and the government.

Updated figures are still being researched by this writer.

Federal Government of Australia

Mid to late 1960's: The Australian Government made available the facilities of Veterans Affairs to provide the fitting of artificial limbs for those children missing either upper or lower limbs.

1974: The Australian government made a one-off payment of \$150,000 to the Thalidomide Foundation to offset taxes incurred through the Trust.

Following any settlements in 1974 (Distillers), 2010 (Diageo), and 2014 (Diageo), the Federal Government passed legislation ensuring that the lump sum and ex-gratia payments were not considered income and therefore not liable for payment of income tax.



Carolyn

Joanne Bernadette

Vaughan Andrew

Greg Mark

Suanne

Lisa Lee

Lance Agata

Jeffrey Suzanne

Nola Mary

One Story

Barbara-Ann Helena

Patricia Deidre

Brett Mandy

John Craig

Peter Sharon

Rochelle Richard

Andrew

Tony Janelle

Craig Ricky

Vicki Laura

Lisa ~ my thoughts

Many times, I have been asked “how has Thalidomide affected my life?” The answer, in all its complexity, is simple. It has affected me completely. Its impact to my life fills my waking hours, and often seeps into my sleeping ones. It 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, it is ugly, and many times it has made others recoil in distaste. It has often entered the room before I have, and can linger long after I have gone. Like a weighted cloak, I wear it and it constricts my life. It disables my ability to function without pain, embarrassment, fear or anger. It leaves me exhausted. It has broken my heart. It has even left me wondering ‘why bother?’

Thalidomide entered my life in my mother's first trimester of pregnancy. In fact, news of the Thalidomide disaster came to my parent's just months before I was born. The anguish this newly married couple must have experienced waiting for my birth is unfathomable. The pain and sorrow they carried with them ever since has been immeasurable. It was through their determination that I live as normal a life as possible, that I learned the value of ‘fight’ and ‘independence’. In my younger years, these qualities gave me the strength to survive and although my parent's dreams were for me to be able to achieve anything I desired, the harsh reality was that so many of the doors to my opportunities in life, had already slammed shut.

From a small child trying to hide behind my mother's skirts to avoid the uncomfortable stares of others, through to a 54-year-old woman today, (who is still exposed to unwanted stares and unwarranted comments), the journey has been difficult. Thalidomide started stealing from me in early childhood. Like a thief, it stole my ability to climb a tree, to catch a ball, to dress and toilet myself, to play a musical instrument, to skip rope, to swim, and to ride a bike. As I grew older it stole my ability to play sport, to follow my passion of ballet, to attend school camps, to hold hands with boys, to keep up with class notes, to shave my legs, or to even brush my hair. Every month I was house bound with my menstruation, and no one wanted

to “date the chick with the short arms”. Thalidomide dictated what I could do, and what I wasn’t able to do.

As a young married woman, I was unable to cook, clean house, hang out washing, carry my baby, hold my husband, follow a career in medicine, grocery shop, volunteer at the school canteen, sew or knit. Thalidomide severely limited any courses I could study, and continued stealing from me by taking away most employment opportunities. Whether I wanted to follow medicine or be a sandwich maker, or a Police Officer, or a Coles cashier ... Thalidomide disabled me.

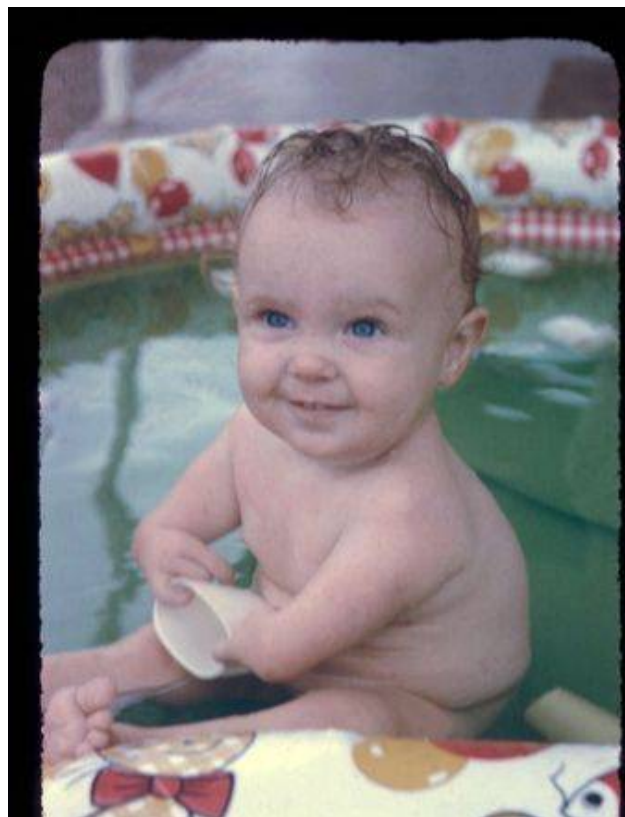
Today, at aged 54, Thalidomide has rendered me an old woman. The simplest of tasks such as; washing dishes, getting dressed, cutting my roses, writing a letter, walking through the garden, picking up a dropped pencil, are all almost out of my reach now. My back, neck, shoulder, arm, hand, hip, leg, foot, finger and toe pain, and headaches are constant. My psychological well-being is exhausted. My body has almost worn out, and my mind is being dragged into the downward spiral. I am tired of the battle. Thalidomide has stolen my body and is chasing my mind. It has continually robbed me, hurt me, and hurt my loved ones. It came into my life as an uninvited guest, and it has stayed a lifetime. It is continually with me and it dictated much of how I am today. It has severely limited the options of my life and has already decided my future.

Ask me if I am angry? In honesty ... I wasn’t! But I am now. I tremble with the hatred and bitterness I feel for those that designed this drug, and also for those that allowed it to be marketed in our country. I seethe at the lack of responsibility surrounding Thalidomide, and the fact that it made its way into my mother’s hands over 54 years ago is abhorrent and inexcusable. I loathe hearing of how much money Gruenthal makes each year as it continues in its successful business, yet has never paid me compensation for stealing so much of my life. I am disgusted at the lack of support from my own government as they have allowed me to be unsupported all these years, and I am equally repulsed by them in allowing Gruenthal to still practice their business here in Australia.

So when I am asked, “how has Thalidomide affected me?” I maintain my perspective that despite its complexity, the answer is simple. It has affected me completely! The reality is however, that even though I am at the epicentre of my experience, Thalidomide has also

touched and affected anyone close to me. My mother and father, my husband, my son and my daughter have also felt the devastation of Thalidomide. How could they not? They are an extension of me, as I am an extension of them. Like the very worst of horror movies, Thalidomide causes pain and heartache and continually haunts the lives it has entered. My future is bleak. As my body continues to age, so will my arthritis, immobility, pain, fear, and my needs increase. The fight and independence I was once so respectfully known for, are gone. Gone but not forgotten.

How dare Thalidomide come into my life and affect me like this!



A Mothers Story



Beryl ~ A Mother's Love



“Not a day goes by where I don’t feel the guilt and the pain of what happened to our daughter.

After her birth, with each bad or sad thing that happened to me in my life ...

I wondered if I was being punished for taking those tablets?

I am 91 years old now ... and I still wonder!

I’ve loved her from the moment I saw her, and I’m so very, very proud of who she is today.

X

Thalidomide Articles – relevant to current and projected health of survivors

- *Securing Our Future - The disability and health costs of UK Thalidomide affected people.* (2012). National Advisory Council to the Thalidomide Trust. UK.
http://www.fiftyyearfight.org/images/SOF_Final_Nov_2012_.pdf

- *Pain News. The British Pain Society - Thalidomide Embryopathy.* (June 2013). Vol 13. Issue 2. A publication of the British Pain Society.
https://www.britishpainsociety.org/static/uploads/resources/files/PAN_13_2_web_Vol_13_issue_2_June_2015_1.pdf
page 89 onwards
- *Looking to the Future: Evaluation of the Health Grant to Thalidomide-Impaired People.* (2012). Firefly Illuminating Research. UK.
http://www.fiftyyearfight.org/images/Health_Grant_Evaluation_Year_3_Final_Report_July_2013_.pdf
- *Thalidomide: Enquiries to be carried out repeatedly with regard to problems, specific needs and support deficits of thalidomide victims.* (2012). University of Heidelberg. Germany.
(from pages 54)
http://www.thalidomide.ca/filesNVIAdmin/File/Heidelberg%20study_ENGLISH.pdf
- *REPORT: Study on the current living conditions of Canadian Thalidomide Survivors and their projections for their future.* (2013). Thalidomide Victims Association of Canada. Canada.
<http://www.thalidomide.ca/filesNVIAdmin/File/TVACs%20Study.pdf>
- *EU Thalidomide Survivors' Campaign: Press Pack*
EPP, S&D, ECR Joint Press Conference: 11am: Wed 27th May
http://www.fiftyyearfight.org/images/Thalidomide_Press_Pack_English.pdf
- *Q & A on Thalidomide-Impaired People.* (2014). National Study on the Health and Living Situation of Thalidomide-Impaired People. Japan.
- *Damage to Health, Psychosocial Disorders and Care Requirements of Thalidomide Survivors in North Rhine Westphalia from a Long-Term Perspective.* (2015). Expert Opinion
Commissioned by LZG.NRW. Germany.
<http://www.thalidomidetrust.org/wp-content/uploads/2016/04/The-Cologne-Report.pdf>

