

The Senate

Community Affairs
References Committee

Support for Australia's thalidomide
survivors

Final report

March 2019

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Terms of Reference

Support for Australia's thalidomide survivors, with particular reference to:

- (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; and
- (e) any related matters.

Abbreviations

CEO	Chief Executive Officer
committee	Senate Community Affairs References Committee
CRA	Compensation Reduction Amount
DHS	Department of Human Services
Diageo	Diageo Australia
Distillers	Distillers Company
FDA	Food and Drug Administration
Grünenthal	Grünenthal GmbH
Interim report	Senate Community Affairs References Committee, <i>Inquiry into support for Australia's thalidomide survivors – interim report</i> , February 2019
NDIA	National Disability Insurance Agency
NDIS	National Disability Insurance Scheme
NDIS Act	<i>National Disability Insurance Act 2013 (Cth)</i>
NHMRC	National Health and Medical Research Council
PGPA Act	<i>Public Governance, Performance and Accountability Act 2013 (Cth)</i>
Rules	National Disability Insurance Scheme (Supports for Participants—Accounting for Compensation) Rules 2013
US	United States

List of Recommendations

Recommendation 1

- 4.12 The committee recommends that the Australian Government apologise to Australian thalidomide survivors and their families.**

Recommendation 2

- 4.22 The committee recommends that the Australian Government provide all Australian thalidomide survivors who have been recognised by Diageo with a lump sum payment on a scale according to their level of disability that is exempt from income tax and the social security income test.**

Recommendation 3

- 4.23 The committee recommends that the Australian Government provide any person who has not yet received financial compensation with a lump sum payment as soon as they are recognised as a thalidomide survivor on an equivalent basis with those thalidomide survivors already recognised with a similar level of impairment.**

Recommendation 4

- 4.29 The committee recommends that the Australian Government provide all Australian thalidomide survivors with an ongoing annual payment to provide them with flexibility to purchase the services they need. The committee considers that this annual payment should be increased over time to reflect thalidomide survivors' increasing health needs.**

Recommendation 5

- 4.34 The committee considers that the Australian Government should establish a centre to disseminate information and coordinate services for thalidomide survivors and currently unrecognised survivors.**

Recommendation 6

- 4.38 The committee considers that the National Disability Insurance Agency should implement a policy to refer matters relating to compensation payments and reduction amounts involving thalidomide survivors to the Chief Executive Officer, or their delegate, for consideration.**

Recommendation 7

- 4.41** The committee recommends that the Australian Government establish an Extraordinary Assistance Fund to aid thalidomide survivors to meet major expenses such as home and vehicle modifications.

Recommendation 8

- 4.44** The committee recommends that the Department of Social Services and the Department of Health consider developing a health care card that could provide access to a broader range of health services than are available under the Pensioner Concession Card that could be provided to people in circumstances where they require a higher level of care or in special circumstances.

Recommendation 9

- 4.47** The committee recommends that Diageo expedite the examination of its archives to determine if it retains copies of assessments of thalidomide survivors' disabilities and, if it finds relevant documents, offer to make copies of those documents available to the thalidomide survivors to whom they pertain at no cost.

Recommendation 10

- 4.50** The committee recommends that the Australian Government publish the Maddocks Lawyers' advice.

Recommendation 11

- 4.52** The committee recommends that the Australian Government consider options to recover money from Grünenthal GmbH to support Australia's thalidomide survivors.

Chapter 1

Introduction

For almost 60 years thalidomide has been the cataclysmic benchmark that health disasters all over the world are measured against. There has never been a health disaster like it.¹

- 1.1 Thalidomide was the active ingredient in a sleep-inducing and sedative drug that was distributed for sale in Australia between 1 August 1960 and 29 November 1961.² Marketed as a safe drug, it was provided to pregnant women to ease the symptoms of morning sickness. As these unsuspecting pregnant women later discovered, taking even one tablet had the capacity to cause malformation of limbs, facial features and internal organs in their unborn children.
- 1.2 The Senate Community Affairs Reference Committee's (committee) interim report focused on the effect that thalidomide has had on the lives of survivors and their families and the support that has been provided to date.³ The committee noted that thalidomide has affected every part of their life, including their ability to work, to dress and toilet themselves and to provide physical affection to their loved ones.⁴
- 1.3 In addition to their severely debilitating congenital injuries, thalidomide survivors are experiencing 'wear and tear' injuries that they have developed through contorting their bodies to adapt to a world that was not built to accommodate their disabilities, including their shortened limbs. Thalidomide survivors are now also experiencing nerve pain and the symptoms of early onset ageing.⁵ The combination of symptoms has meant that thalidomide survivors' bodies are rapidly deteriorating and most live with chronic pain.
- 1.4 The committee also noted that the lives of survivors' family members have been greatly affected. Parents, spouses and children have surrendered both career and life opportunities to provide care for their loved one.⁶ The

¹ Brett, *Committee Hansard*, 31 January 2019, p. 46.

² Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 21.

³ Senate Community Affairs References Committee (committee), *Inquiry into support for Australia's thalidomide survivors—interim report*, February 2019, https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/ThalidomideSurvivors/Interim_Report (Interim report).

⁴ See: Interim report, Chapter 2.

⁵ Ms Michelle French, Director, Michelle French and Associates, *Committee Hansard*, 31 January 2019, p. 36.

⁶ See, for example: Name withheld, *Submission 21*, p. 2.

committee found that as survivors' family members age they are less able to provide the increased level of support that many survivors need, meaning that survivors will soon need to rely on additional external assistance and support.

- 1.5 In its interim report, the committee concluded that the current supports that have been made available to thalidomide survivors are inadequate. Thalidomide survivors told the committee that the existing payments that they receive from Diageo are inadequate to purchase the necessary supports and the existing government supports from the health and disability sector, including the National Disability Insurance Scheme (NDIS), do not meet their needs. Unlike other governments around the world, the Australian Government is yet to provide substantial financial assistance to support thalidomide survivors.
- 1.6 The committee recognised in the interim report that Australia's thalidomide survivors require additional assistance, both financial and non-financial. Thalidomide Group Australia, who represents the group of thalidomide survivors who were identified in the early 1970s, urged the committee to support six requests for support:
- a one-off upfront payment of up to \$500 000 to each thalidomide survivor;
 - an annual payment of \$2 190 260.00 to the Thalidomide Australia Fixed Trust to be distributed to beneficiaries on a tax and social security exempt basis;
 - a 'Gold Card' similar to a Department of Veterans' Affairs health card;
 - an 'Extraordinary Assistance Fund' of \$500 000 to allow survivors to adapt their homes, environment and vehicles;
 - a formal apology to thalidomide survivors and their parents; and
 - a plaque in recognition of Australian thalidomide survivors and their parents to be mounted in a place of significance.⁷

Scope of final report

- 1.7 This final report considers the role of the manufacturer, the distributor and Australian governments in providing support to Australia's thalidomide survivors. It also considers some of difficulties thalidomide survivors have experienced with the NDIS and how the requests made by the Thalidomide Group Australia, together with better coordination of services, could assist Australia's thalidomide survivors. The report contains the committee's final recommendations and conclusions regarding additional supports for thalidomide survivors.

⁷ Thalidomide Group Australia, *Submission 1*, p. 3.

Conduct of the inquiry

- 1.8 As noted in the interim report, on 21 August 2018 the Senate referred the support for Australia's thalidomide survivors to the committee for inquiry and report by 28 November 2018.⁸ On 28 November 2018, the Senate agreed to extend the reporting date to the last sitting Wednesday in February 2019 to allow the committee time to hold a second public hearing for the inquiry.⁹
- 1.9 After receiving important evidence at its public hearing in Sydney on 31 January 2019, the committee sought a further extension of time to 22 March 2019 to allow the committee time to complete its final report.¹⁰

Submissions

- 1.10 The committee advertised the inquiry on its website and issued 38 invitations to organisations the committee considered may have had relevant knowledge. The committee requested that submissions be lodged by 21 September 2018, but the committee continued to accept submissions after that date. The committee also issued three media releases to advertise the inquiry and provided copies of these media releases to stakeholders and submitters.
- 1.11 The committee received 71 submissions. A list of the submissions received by the committee can be found at Appendix 1 and copies of the submissions are available on the committee's webpage.¹¹

Hearings

- 1.12 The committee held two hearings for the inquiry: one in Melbourne on 2 November 2018 and one in Sydney on 31 January 2019. A list of the witnesses who appeared at the hearings can be found at Appendix 2 and copies of the transcripts are available on the committee's webpage.¹²

Acknowledgement

- 1.13 The committee thanks all of those who contributed to the inquiry. In particular, the committee would like to thank thalidomide survivors and their families who shared their personal experience with the inquiry.

⁸ *Journals of the Senate*, No. 111, 21 August 2018, pp. 3555–3556. A copy of the terms of reference for the inquiry can be found at the front of this report.

⁹ *Journals of the Senate*, No. 132, 28 November 2018, p. 4292.

¹⁰ *Journals of the Senate*, No. 140, 14 February 2019, p. 4685.

¹¹ Committee, *Completed inquiries and reports* (2016-present), https://www.aph.gov.au/Parliamentary_Business/Committees/Senate/Community_Affairs/Completed_inquiries

¹² Committee, *Completed inquiries and reports* (2016-present).

Note on references

1.14 In this report, references to *Committee Hansard* are to proof transcripts. Page numbers may vary between proof and official transcripts.

Chapter 2

Responsibility for providing supports

They are brave and strong beyond belief and deserve to live out their lives with support and dignity, compensation and with an increased level of ongoing financial support because what they have received to date has been manifestly inadequate.¹

- 2.1 In its interim report, the committee concluded that Australia's thalidomide survivors require additional support to help alleviate the physical strain that their thalidomide injuries are placing on their bodies. However, it is unclear where this support will come from. The manufacturer, the distributor and the Australian and state governments all contributed to the thalidomide tragedy and have taken different steps to offer support to thalidomide survivors.
- 2.2 This chapter examines the role of each of these entities in responding to the needs of thalidomide survivors and considers who should be responsible for providing the support Australia's thalidomide survivors need to live out their lives with dignity.

Grünenthal's responsibility

- 2.3 Thalidomide was developed and manufactured by German pharmaceutical company Chemie Grünenthal, now Grünenthal GmbH (Grünenthal).² Grünenthal licensed thalidomide for sale globally, including to the distributor of the drug in Australia, Distillers Company (Distillers) (now Diageo).³
- 2.4 Since the damaging effects of thalidomide became known, Grünenthal has been subject to significant and ongoing criticism for its role in the thalidomide disaster. The committee heard that thalidomide survivors around the world are united by a 'profound sense of injustice over the lack of accountability of Chemie Grunenthal'.⁴

Release of thalidomide

- 2.5 Grünenthal released thalidomide in West Germany in 1957 and marketed the drug as a 'sleep-inducing agent and sedative under the brand name

¹ Name withheld, *Submission 17*, [p. 2].

² Department of Health, *Submission 2*, p. 3.

³ Mr Peter Gordon, *Submission 66*, [p. 11].

⁴ Mr Gordon, *Submission 66*, [p. 11].

Contergan'.⁵ The first known thalidomide-affected baby was born in West Germany to the spouse of a Grünenthal employee on 25 December 1956.⁶

- 2.6 Mr Michael Magazanik, a lawyer who worked on behalf of Australian thalidomide survivors, noted that Grünenthal extensively marketed thalidomide during the late 1950s:

During 1958 alone, Grünenthal placed fifty advertisements for thalidomide in medical journals and sent more than 200,000 letters to doctors, plus further mail-outs to 50,000 doctors and pharmacists. Sales started slowly but Contergan would soon become the success story Grünenthal had been hoping for: by early 1960 it was the bestselling sleeping pill in Germany.⁷

- 2.7 Grünenthal submitted to the inquiry that it had 'never marketed its thalidomide products for the treatment of morning sickness in pregnancy'.⁸
- 2.8 The committee is aware of accounts which indicate Grünenthal did promote the use of thalidomide by women who were pregnant, and gave safety assurances to doctors to that effect.⁹

Testing

- 2.9 Grünenthal has maintained that when it developed thalidomide, it tested the drug using the standards of that time.¹⁰ However, the appropriateness of the testing of thalidomide by Grünenthal has been contested.¹¹
- 2.10 The committee notes that when the United States (US) Food and Drug Administration (FDA) assessed whether thalidomide should be approved for sale in that country, it questioned the drug safety information presented by the US licensee, particularly following reports the drug had been associated with potential nerve damage overseas.¹² The FDA's assessor, Dr Frances Kelsey, requested information from the licensee as to whether thalidomide was safe

⁵ Grünenthal GmbH (Grünenthal), *Submission 65*, [p. 3].

⁶ Thalidomide Group Australia, *Submission 1*, p. 9.

⁷ Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 63.

⁸ Grünenthal, *Submission 65*, [p. 3].

⁹ See, for example, Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 69.

¹⁰ Neil Vargesson, *Thalidomide Induced Teratogenesis: History and Mechanisms, Birth Defects Research (Part C)*, vol. 105, 2015, [p. 140].

¹¹ Neil Vargesson, *Thalidomide Induced Teratogenesis: History and Mechanisms, Birth Defects Research (Part C)*, vol. 105, 2015, [p. 140]; Mr Michael Magazanik, Partner, Rightside Legal, *Committee Hansard*, 31 January 2019, p. 30.

¹² See, for example, Thalidomide Group Australia, *Submission 1*, p. 11; Name withheld, *Submission 10*, p. 1; Irish State Claims Agency, *Compensation for Thalidomide Survivors*, April 2010, p. 4; Neil Vargesson, *Thalidomide Induced Teratogenesis: History and Mechanisms, Birth Defects Research (Part C)*, vol. 105, 2015, [p. 140].

for foetuses when used by pregnant women.¹³ By the end of November 1961, the FDA received information that thalidomide was possibly associated with cases of a birth defect that caused malformation of the upper limbs, known as phocomelia, in Germany and the US licensee's thalidomide application became inactive.¹⁴ As a result, thalidomide was never commercially sold within the US and was only available through clinical trials.

Response to the thalidomide disaster

- 2.11 As the manufacturer, Grünenthal received early reports that thalidomide was causing nerve damage to the patients to whom it was prescribed. Mr Peter Gordon, Senior Partner, Gordon Legal, a personal injury lawyer who has been highly involved with thalidomide, argued that Grünenthal was aware of, and was in a unique position to recognise, the harmful effects of thalidomide when the drug was being distributed in Australia:

Within weeks of thalidomide's first distribution of thalidomide in Australia, Grünenthal, and Grünenthal alone, knew of many hundreds of reports of side effects including many cases of peripheral neuritis associated with thalidomide and of several reports of birth defects. Grünenthal's knowledge was unique because it received and dealt with (often suppressing) complaints from all over the world. It uniquely knew of its lack of research. It uniquely knew of its false claims of safety. It uniquely knew of both Governments' and international pharmaceutical companies' pushing back on Grünenthal about shoddy and inadequate research. It knew that it had heaved and threatened its licensees (including Distillers,) in various parts of the world, including Europe and North America, not to disclose its shoddy research, its reported side effects or adverse reactions relating to thalidomide (especially peripheral neuritis.)¹⁵

- 2.12 Mr Magazanik told the committee that Grünenthal's and Distillers' first response to the thalidomide disaster was to avoid accountability:

Their chief tactic was to pour all of their considerable resources and efforts into ensuring that the disaster was seen as regrettable and sad and tragic and shocking, and an act of God and utterly unavoidable. That was the key: they wanted it to be seen as something that was completely unavoidable. The argument went that nothing—the best science in the world, the best testing, the smartest researchers, the most conscientious companies—could have stopped it, and that the companies were blameless.¹⁶

¹³ Mr Magazanik, Rightside Legal, *Committee Hansard*, 31 January 2019, p. 30.

¹⁴ Frances Kelsey, 'Problems raised for the FDA by the occurrence of thalidomide embryopathy in Germany, 1960-1961', *American Journal of Public Health*, vol. 55, no. 5, May 1965, p. 704.

¹⁵ Mr Gordon, *Submission 66*, [p. 11].

¹⁶ Mr Magazanik, Rightside Legal, *Committee Hansard*, 31 January 2019, pp. 29–30.

- 2.13 Mr Magazanik told the committee that the perception that the thalidomide disaster was unforeseeable, rather than the product of inadequate testing, 'completely shaped' the view of the thalidomide disaster. Mr Magazanik considered that this has had an adverse impact for survivors in obtaining compensation and addressing the failings associated with the tragedy.¹⁷

Grünenthal's assistance to survivors

- 2.14 Grünenthal has provided some assistance in countries where it directly marketed thalidomide, in particular, Germany.¹⁸ Following the conclusion of the German trial against Grünenthal in the early 1970s, the German Government announced the establishment of the Contergan Foundation to provide support for Germany's thalidomide survivors. The German Government and Grünenthal equally funded the Contergan Foundation and in 2009 Grünenthal made a further voluntary contribution to the foundation.¹⁹
- 2.15 Separate to the Contergan Foundation, Grünenthal operates the Grünenthal Foundation which provides non-cash benefits and project financing to support thalidomide-affected people.²⁰ Grünenthal provided examples of the supports available through the foundation, which include: financial support of up to €25 000 for car modifications; financial support of up to €15 000 for home modifications; support for hospitals to develop expertise in treating those affected by thalidomide; and support for the use of voice controlled technology.²¹
- 2.16 Grünenthal told the committee that thalidomide survivors' access to the Grünenthal Foundation is subject to eligibility criteria and 'is subject to further discussion with representatives of those affected in Australia'.²²
- 2.17 Grünenthal Foundation notes that to access support survivors need to have already been recognised and be able to demonstrate why they require support and that it could not have been funded by other means.²³
- 2.18 The committee did not receive evidence that any Australian thalidomide survivor has received support through the Grünenthal Foundation.

¹⁷ Mr Magazanik, Rightside Legal, *Committee Hansard*, 31 January 2019, p. 30.

¹⁸ Interim report, p. 72.

¹⁹ Grünenthal, *Submission 65*, [p. 3].

²⁰ Grünenthal, *Submission 65*, [p. 3].

²¹ Grünenthal, *Submission 65*, [p. 7].

²² Grünenthal, *Submission 65*, [p. 7].

²³ Grünenthal Foundation, *Individual support in cases of hardship*, https://www.thalidomide.grunenthal.info/thalidomid/Home_/Stiftung/Unterstützung/en_EN/355300023.jsp (accessed 18 March 2019).

- 2.19 The Thalidomide Group Australia submitted that Grünenthal has not recognised or paid compensation to any Australian thalidomide survivor.²⁴ Submitters told the committee that, in their view, Grünenthal has a responsibility to provide ongoing assistance for thalidomide survivors.²⁵
- 2.20 At the conclusion of the 2014 class action brought against Grünenthal and Diageo, Grünenthal had the opportunity to provide support to Australia's thalidomide survivors by contributing to the settlement. However, the case was settled by Diageo, without any contribution being made by Grünenthal.²⁶
- 2.21 Mr Magazanik told the committee that despite being central to the thalidomide disaster, Grünenthal has not compensated Australian thalidomide survivors:
- ...Grünenthal is the key wrongdoer in all of this, and yet it's never paid a single cent to any Australian woman or survivor damaged by the drug. In relation to Australia, Grünenthal is really the culpable driver who absconds from the scene.²⁷
- 2.22 Mr Gordon suggested that Grünenthal could be compelled to pay if the Australian Government commenced and won cost recovery litigation against Grünenthal.²⁸ Mr Gordon commented that there was international precedent that suggested that the Australian Government could establish legislation to support cost recovery litigation.²⁹

Committee view

- 2.23 Grünenthal developed, manufactured and licensed thalidomide, the drug that was consumed by the mothers of Australia's thalidomide survivors and caused their children to be born with severe malformations. It is clear to the committee that Grünenthal's actions are central to the harm thalidomide has caused countless survivors and their families across the world. From the evidence before the committee, Grünenthal appears to have done nothing to assist Australia's thalidomide survivors.

²⁴ Thalidomide Group Australia, *Submission 1*, p. 15.

²⁵ Name withheld, *Submission 16*, p. 2; Mr Gordon, *Submission 66*, [p. 7].

²⁶ See, Slater and Gordon, *Thalidomide Class Action*, <https://www.slatergordon.com.au/class-actions/past-class-actions/thalidomide> (accessed 3 March 2019); Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, pp. 304, 312.

²⁷ Mr Magazanik, Rightside Legal, *Committee Hansard*, 31 January 2019, p. 31.

²⁸ Mr Gordon, *Submission 66*, [p. 11].

²⁹ Mr Gordon, *Submission 66*, [p. 12].

- 2.24 The committee notes Grünenthal appears to be operating as a highly profitable company. According to its corporate publications, in 2017 Grünenthal achieved global revenues of approximately €1.3 billion.³⁰
- 2.25 The committee considers that there is a wide scope for Grünenthal to support Australia's thalidomide survivors and the committee encourages Grünenthal to engage with survivors and the Australian Government in this regard.

Diageo's support for thalidomide survivors

- 2.26 Compared to other entities involved in the thalidomide tragedy, Diageo has acted constructively to provide financial assistance to thalidomide survivors both in Australia and in the United Kingdom, though it had no legal obligation to do so.
- 2.27 In the interim report, it was noted that the Distillers was responsible for distributing products containing thalidomide in Australia.³¹ Distillers made products containing thalidomide available for sale in Australia from 1 August 1960 and it withdrew the drug from sale on 29 November 1961.³² In 1997 Diageo purchased the Distillers and inherited its thalidomide legacy.³³
- 2.28 There are two differently compensated groups of thalidomide survivors in Australia: the group recognised in the 1970s and the group recognised through the class action that concluded in 2014.
- 2.29 In the 1970s, Distillers reached a settlement with the parents of the 40 Australian and nine New Zealand survivors whom Distillers recognised as having been injured by thalidomide.³⁴ The compensation that these survivors received from Distillers is detailed in the interim report. However, as part of this process, the survivors' parents signed an agreement that precluded these survivors from taking any further legal action against Distillers, Grünenthal or its successors.³⁵ This meant that Diageo owed no legal obligation to assist the Australian thalidomide survivors who were recognised in the 1970s.
- 2.30 In October 2008, Mr Ken Youdale, a retired senior executive whose daughter died from her thalidomide injuries, approached Diageo to request that it

³⁰ Grünenthal, *Corporate Publications*, <https://www.grunenthal.com/press-room/corporate-publications> (accessed 28 February 2019).

³¹ See Interim report, p. 3.

³² Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 21.

³³ Ms Lisa McManus, Director, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 4; Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 28.

³⁴ Mrs Lesley Fletcher, Founder and Former Secretary, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42.

³⁵ Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 28.

provide the Australian thalidomide survivors who had been recognised by Distillers in the 1970s with additional compensation.³⁶

2.31 Mr Youdale's request was highly unorthodox. Mr Gordon told the committee that he had 'never heard of anyone reopening and getting more compensation for anyone'.³⁷

2.32 In particular, Mr Gordon thought that the prospect of Diageo providing additional compensation was unlikely because of the legal circumstances surrounding the cases, namely:

...because further legal claims against Distillers were legally barred by the 1970s settlement deeds and accompanying court orders, and the claims had also been statute-barred for decades.³⁸

2.33 However, in August 2009 Diageo agreed to pay an ex gratia payment of \$50 million to fund payments to the survivors who had entered into settlements with Distillers.³⁹ The ex gratia scheme was structured to pay amounts out to survivors for at least 18 years from 1 April 2010.⁴⁰

2010 assessment process

2.34 All of the thalidomide survivors who were recognised in the 1970s were assessed at Diageo's expense before the ex gratia payments commenced.⁴¹ As noted in the interim report, the assessment process took place over a three week period in January 2010.⁴²

2.35 The assessment process was undertaken by a panel of three experts, Professor Janet McCredie, Professor Earl Owen and Mr Peter Semmler QC. Members of the 2010 assessment team apparently arrived at their conclusions by different methods. How the members of the panel arrived at their decisions may be important if other currently unrecognised survivors need to be assessed at a point in the future and integrated into the group of thalidomide survivors. Professor McCredie arrived at her conclusions by converting every disability into a number of points that added up to a numerical score, while Mr Semmler advised that he took a more holistic approach.⁴³

³⁶ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 41.

³⁷ Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 28.

³⁸ Mr Gordon, *Submission 66*, [p. 10].

³⁹ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42; Diageo Australia (Diageo), *Submission 70*, [p. 1].

⁴⁰ Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42.

⁴¹ Professor Janet McCredie, *Submission 67*, p. 5.

⁴² Mrs Fletcher, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 42.

⁴³ Professor McCredie, *Submission 67*, p. 6; Mr Peter Semmler QC, answers to questions on notice, Question 2, p. 1, (received 27 February 2019).

- 2.36 Professor McCredie explained that she used maps of the 'peripheral sensory nerve supply' and provided a score of one to three depending upon whether the nerve damage was mild, moderate or severe.⁴⁴ Professor McCredie also used this method for cranial nerves (for which a score of between one and six was provided) and additional damage, such as internal injuries such as a missing gallbladder (one point) or a heart defect (six points).⁴⁵ Professor McCredie submitted that a similar scoring system was used two years later by the North-Rhine Westphalen group and that this method was objective and 'fair to all parties'.⁴⁶
- 2.37 Mr Semmler advised the committee that he took a very different approach. Mr Semmler advised the committee that he expressed concern about the categorisation of survivors based solely on nerve damage.⁴⁷ Instead, he advised the committee that he took a more holistic approach to the assessment of survivors' disabilities. Mr Semmler explained that as a barrister specialising in the assessment of damages in personal injury cases, he approached the task in the same way as he would the assessment of any other personal injury matter:

My assessment of the entitlement to compensation... was based purely upon the disability of each person, in the same way in which a common law assessment of the ongoing consequences of injuries, whatever their cause, is customarily undertaken.⁴⁸

- 2.38 The third member of the panel, Professor Owen, has since passed away. However, Mr Semmler advised that his recollection of their conversations was that Professor Owen appeared to adopt a broader approach to considering survivors' injuries.⁴⁹ Mr Semmler advised that the scale of payments was based on an overall assessment of thalidomide survivors' disabilities.⁵⁰

Records from 2010 assessment process

- 2.39 Ultimately, survivors were not informed as to how the panel arrived at their decision and they were not provided with a copy of the assessment about their disabilities. As a result, the thalidomide survivors who were assessed do not

⁴⁴ Professor McCredie, *Submission 67*, p. 6.

⁴⁵ Professor McCredie, *Submission 67*, p. 6.

⁴⁶ Professor McCredie, *Submission 67*, pp. 6–7.

⁴⁷ Mr Semmler, answers to questions on notice, Question 2, p. 1, (received 27 February 2019); Mr Semmler, additional information, (received 27 February 2019).

⁴⁸ Mr Semmler, additional information, p. 2 (received 27 February 2019).

⁴⁹ Mr Semmler, additional information, p. 2 (received 27 February 2019).

⁵⁰ Mr Semmler, additional information, p. 2 (received 27 February 2019).

have any of the documentation that explains what their level of functionality was at that time.⁵¹

- 2.40 That information is important because survivors' bodies are deteriorating and their function is being limited by their thalidomide injuries. It would be helpful for survivors to have access to those documents as a form of baseline assessment.
- 2.41 Copies of the assessments still exist. Mr Semmler confirmed that he retained copies of:
- a copy of the 'Thalidomide Case Gradings';
 - a copy of the classification of survivors listed according to the severity of their disability;
 - a copy of the classification of survivors according to damage by neurological segments; and
 - documents 'summarising the problems encountered by 43 of the beneficiaries and recording my assessment of the degree of disability of each'.⁵²
- 2.42 Mr Semmler described the content of these documents as 'exquisitely personal' to survivors and raised significant privacy concerns about making the documents available.⁵³
- 2.43 Diageo advised that it was prepared to investigate whether it held copies of the assessments and whether it may be able to provide access to the assessments, if it was considered necessary.⁵⁴

Class actions

- 2.44 As noted above and in the interim report, Diageo made two substantial settlements to thalidomide survivors who participated in a class action that was approved by the Victorian Supreme Court in 2014: one to Ms Lynette Rowe, the lead plaintiff, for an undisclosed multi-million dollar sum and \$89 million to another group of 106 survivors (94 Australians and 12 survivors from New Zealand) who had not previously been compensated.⁵⁵ In total the matter was settled for just over \$100 million.⁵⁶

⁵¹ Mrs Fletcher, *Thalidomide Australia Incorporated, Committee Hansard*, 31 January 2019, p. 43.

⁵² Mr Semmler, answers to questions on notice, Question 2, pp. 1–2, (received 27 February 2019).

⁵³ Mr Semmler, answers to questions on notice, Question 2, p. 2 (received 27 February 2019).

⁵⁴ Diageo, answers to questions on notice, Question 5, [p. 2] (received 1 March 2019).

⁵⁵ Mr Gordon, *Submission 66*, [p. 4]; Michael Magazanik, *Silent Shock*, Text Publishing, Melbourne, 2015, p. 310.

⁵⁶ Mr Gordon, *Submission 66*, [p. 1].

Diageo's possible future support

2.45 Early in the committee's inquiry the Department of Health advised the committee that the Minister for Health, the Hon. Greg Hunt MP, had written to Diageo on two occasions urging Diageo to consider further compensation for Australia's thalidomide survivors.⁵⁷ In October 2017, the Minister for Health wrote to Diageo in the following terms:

The Government is considering options to formally recognise those affected by thalidomide. I request that in conjunction with this action by the Government, Diageo urgently consider the case for further compensation to be paid to thalidomide survivors to enhance their quality of life in the coming years.⁵⁸

2.46 Diageo responded to the letter from the Minister for Health advising of the support it had already provided to Australia's thalidomide survivors.⁵⁹

2.47 In April 2018, the Minister for Health wrote to Diageo again to ask the company to consider further compensation and requested a meeting to discuss such a 'complex and sensitive' matter.⁶⁰

2.48 Diageo Australia's Managing Director, Mr David Smith, advised the committee that he met with the Minister for Health on 15 August 2018 to discuss the contributions Diageo had made to the Thalidomide Australia Fixed Trust and the possible future supports for Australia's thalidomide survivors that might be provided by either the Australian Government or Diageo.⁶¹

2.49 Diageo advised the committee that it is prepared to consider what further support it can provide Australia's thalidomide survivors. However, Diageo noted that any future contribution was likely to be smaller than the contributions that have been provided to date.⁶²

2.50 Diageo noted that the Australian Government is yet to provide financial support to its thalidomide survivors:

Diageo has taken its responsibilities in relation to the distribution of thalidomide extremely seriously and has given substantial financial support to the thalidomide survivors...It is worth noting that in other

⁵⁷ Ms Elizabeth Flynn, Assistant Secretary, Preventative Health Branch, Department of Health, *Committee Hansard*, 2 November 2018, p. 33.

⁵⁸ Department of Health, answers to questions on notice, 2 November 2018, Question 8, [p. 10] (received 27 November 2018).

⁵⁹ Department of Health, answers to questions on notice, 2 November 2018, Question 9, [pp. 13–14] (received 27 November 2018).

⁶⁰ Department of Health, answers to questions on notice, 2 November 2018, Question 8, [p. 11] (received 27 November 2018).

⁶¹ Diageo, answers to questions on notice, Question 2, [pp. 1–2] (received 1 March 2019).

⁶² Diageo, answers to questions on notice, Question 1, [p. 1] (received 1 March 2019).

countries, governments have also made significant financial contributions to thalidomide survivors.⁶³

- 2.51 Diageo also clarified that it would only consider providing additional support after it understood what the Australian Government was proposing:

Any further contribution by Diageo would be considered after we understood the government's plan.⁶⁴

- 2.52 Any further contribution Diageo may provide would come on top of the substantial contribution it has already made. In his submission, Mr Gordon calculated that Diageo has already provided over \$150 million to Australian thalidomide survivors:

As stated, the principal outcomes of our work in Australia and New Zealand, were to assist Mr Ken Youdale in the 2010 ex gratia scheme, (for a total capped value of \$50,000,000;) and the settlements of class actions for 105 newly recognized [Australian and New Zealand] thalidomiders for total damages of just over \$100,000,000. The combined financial outcomes for the two groups therefore amounted to just over \$150,000,000.⁶⁵

Committee view

- 2.53 The committee understands that Diageo had no legal obligation to provide the ex gratia scheme to the group of thalidomide survivors who were recognised in the 1970s and has acted as a very good corporate citizen in providing the additional payments out to 2028.
- 2.54 The committee notes that Diageo has already provided a substantial contribution to Australia's thalidomide survivors. The committee welcomes Diageo's offer to consider providing a further contribution and notes that governments in other places Diageo operates have provided some financial support to their thalidomide survivors.
- 2.55 The committee notes that Diageo has offered to make enquiries about whether it holds copies of the individual assessments and whether it could make copies available if they were required to assist survivors. The committee thanks Diageo for its offer and notes that copies of the assessments could greatly assist survivors.

Responsibility of Australian governments

- 2.56 Many of the submitters to the inquiry consider that Australian governments have a moral obligation to provide further direct support, including financial

⁶³ Diageo, answers to questions on notice, [p. 1] (received 1 March 2019).

⁶⁴ Diageo, answers to questions on notice, Question 1, [p. 1] (received 1 March 2019).

⁶⁵ Mr Gordon, *Submission 66*, [p. 2].

compensation to thalidomide survivors.⁶⁶ They consider that Australian governments have a moral obligation because they allowed thalidomide products to be sold in Australia without proper testing and because when Australian governments were informed about the risks of thalidomide they did not do enough to ensure that the products were removed and destroyed.

Importation, testing and sale

2.57 In the early 1960s, the importation and sale of therapeutic drugs was regulated at different levels. Importation was regulated at the national level while distribution and sale was regulated at the state and territory level.⁶⁷

2.58 At the national level, therapeutic substances were regulated under the *Therapeutic Substances Act 1953* (Cth) as amended by the *Therapeutic Substances Act 1959* (Cth).⁶⁸ This legislation was largely concerned with labelling and ensuring that the drugs were manufactured to an appropriate standard of purity and consistency.⁶⁹ However, the drugs were not tested to see whether they would affect human health.⁷⁰

2.59 Thalidomide survivors suggested that allowing a product to be imported for sale without testing whether it was harmful to human health was a significant failing.⁷¹ For some survivors, the failure to test thalidomide prior to its distribution was unforgivable:

The fact that Thalidomide made its way into my mother's hands over 55 years ago is repugnant and inexcusable.⁷²

2.60 Some survivors noted that the Australian Drug Evaluation Committee was established in 1963 in direct response to the thalidomide tragedy.⁷³ Brett, one

⁶⁶ See, for example: Name withheld, *Submission 11*, p. 1; Name withheld, *Submission 13*, [p. 3]; Name withheld, *Submission 14*, [p. 4]; Name withheld, *Submission 16*, [p. 2]; Name withheld, *Submission 20*, [p. 2]; Name withheld, *Submission 39*, [p. 1].

⁶⁷ Tasmanian Government, answers to questions on notice (received 5 February 2019).

⁶⁸ Department of Health, *Submission 2*, p. 2; Tasmanian Government, answers to questions on notice (received 5 February 2019).

⁶⁹ Department of Health, *Submission 2*, p. 2; Tasmanian Government, answers to questions on notice (received 5 February 2019). The standard used relied on the British Pharmacopoeia and the British Pharmaceutical Codex. See: *Therapeutic Substances Act 1953* (Cth), s. 4; *Therapeutic Substances Regulation* (Cth), r. 10.

⁷⁰ Department of Health, *Submission 2*, p. 2; Tasmanian Government, answers to questions on notice (received 5 February 2019).

⁷¹ Name withheld, *Submission 6*, p. 4; Name withheld, *Submission 9*, [p. 2]; Name withheld, *Submission 11*, p. 1; Name withheld, *Submission 14*, p. 1.

⁷² Name withheld, *Submission 6*, p. 4.

⁷³ See for example, Name withheld, *Submission 11*, p. 1; Brett, *Committee Hansard*, 31 January 2019, p. 46.

of the thalidomide survivors, told the committee that the establishment of this committee in the aftermath of the tragedy demonstrated that there was a deficiency in the system at the time thalidomide was available:

[Thalidomide] resulted in the establishment of the Therapeutic Goods Administration, and it highlighted a major deficiency in the Australian government's duty of care. Our mothers took thalidomide because they had trust, complete faith, in the medical system that operated under the protective guidelines of the Australian government.⁷⁴

- 2.61 Brett provided the committee with excerpts of Dr John McEwen's *A History of Therapeutic Goods Regulation in Australia* to demonstrate that the Australian Government had been advised as early as 1907 by the Royal Commission on Secret Drugs and Cures that it was important to know the nature and composition of drugs that entered Australia:

As it is of national importance to prevent the introduction into Australia of epidemic diseases of men and animals, so it is of higher importance to prevent the introduction of deleterious, demoralising, and homicidal drugs, when the nature and composition are not fully known... it is of urgent necessity to provide a Bureau of chemistry, which would be of inestimable service in the preservation of health and life from frauds and mistakes...⁷⁵

- 2.62 The document further noted that other countries had already taken more proactive steps to protect public health than Australia had. In May 1949, a researcher addressed the National Health and Medical Research Council (NHMRC) following a research trip. Commenting on Australia's policy on regulating medicines he told the NHMRC:

One receives the impression...that as long as...the manufacturer does not overstep the bounds the policy is "we shall let be." That is in marked contrast to the positive policy in Canada and in the (United) States that no stone must be left unturned to protect the public...my visit overseas has convinced me more than ever that we in Australia have insufficient control over our own manufactures and over imported products, especially those from the Continent about whose origin and testing we know nothing whatever.⁷⁶

- 2.63 The Department of Health advised the committee that the implementation of such recommendations was hampered by a lack of clarity about whether the

⁷⁴ Committee Hansard, 31 January 2019, p. 46.

⁷⁵ Brett, *Historical recommendations by Governments, Royal Commissions and National Health & Medical Research Councils to prevent toxic and damaging pharmaceutical drugs entering Australia*, [p. 1] (tabled 31 January 2019); John McEwen, *A History of Therapeutic Goods Regulation in Australia*, September 2007, p. 2.

⁷⁶ Brett, *Historical recommendations by Governments, Royal Commissions and National Health & Medical Research Councils to prevent toxic and damaging pharmaceutical drugs entering Australia*, [p. 1] (tabled 31 January 2019); John McEwen, *A History of Therapeutic Goods Regulation in Australia*, September 2007, p. 17.

Australian Government had the constitutional authority to implement such regulation and by a view of federalism that reserved the power to regulate the sale and distribution of drugs to the states.⁷⁷

- 2.64 The committee wrote to the states and territories to obtain further information about how the sale and distribution of therapeutic drugs were regulated during this period. The states advised the committee that therapeutic substances were generally regulated under the jurisdiction's poisons controls.⁷⁸ The committee understands that thalidomide required prescriptions in Queensland⁷⁹ and, potentially, in Western Australia,⁸⁰ but thalidomide does not appear to have been legally restricted until at least 1962.

Recall and prohibition of sale

- 2.65 Submitters to the inquiry were particularly critical of Australian governments' responses to recalling and destroying products containing thalidomide that were still in Australia.
- 2.66 Thalidomide survivors were critical of Australian governments' responses because if governments had acted more quickly they potentially could have made a significant difference. Mr Peter Gordon estimated that approximately 20 per cent of thalidomide survivors would not be disabled if Australian governments had taken appropriate steps to recall and destroy the thalidomide products that were still in Australia at the time:

Our estimate is that 20 per cent of the entire thalidomide cohort as is known in Australia today had their mums be exposed to thalidomide after the government actually knew about the 'Dear doctor' letter, after they knew there were concerns about the adequacy of the recall project.⁸¹

⁷⁷ Dr John McEwen, Medical Adviser, Therapeutic Goods Administration, Department of Health, *Committee Hansard*, 31 January 2019, pp. 54–55.

⁷⁸ Note that the territories did not exercise self-government at that time. See Northern Territory Government, answers to questions on notice, Question 1 [p. 1] (received 30 January 2019); ACT Government, answers to questions on notice, Question 2, [p. 2] (received 15 February 2019) (regulated under the Poisons Ordinance 1933); New South Wales Government, answers to questions on notice, Question 2, [p. 1] (received 21 February 2019) (regulated under the *Poisons Act 1952*); Queensland Government, answers to questions on notice, Question 2, [p. 1] (received 1 February 2019) (regulated under the *Health Act 1937* and The Poisons Regulations of 1958); Western Australian Government, answers to questions on notice, Question 2, p. 1 (received 26 February 2019) (regulated under the *Pharmacy and Poisons Act Compilation Act 1910*).

⁷⁹ Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 21.

⁸⁰ The Western Australian Government notes that thalidomide was not controlled by law, but the Western Australian Government provided anecdotal evidence from pharmacists who were in practice at the time that thalidomide was dispensed with prescription rather than 'over the counter' in the early 1960s. Western Australian Government, answers to questions on notice, Question 2, pp. 1–2 (received 26 February 2019).

⁸¹ Mr Gordon, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 31.

- 2.67 The 'Dear doctor' letter was distributed by Distillers to announce that it would withdraw the products containing thalidomide from sale. Mr Gordon provided the committee with a copy of the letter from the National Archives of Australia that was stamped by the Department of Health to indicate that it received the letter on 4 December 1961.⁸²
- 2.68 Thalidomide survivors and their family members who submitted to the inquiry were upset by the response of Australian governments because it was both slow and lacklustre by comparison to other countries. These submitters asked the committee to consider the difference between the responses in Australia, the United States and New Zealand. In the United States, President John F Kennedy made a televised address and sent 200 public servants out to ensure that thalidomide tablets were collected and destroyed.⁸³ According to the Thalidomide Group Australia, warnings about the dangers of thalidomide were flashed on television screens and were broadcast over the radio encouraging citizens to search their medicine cabinets and to dispose of the drug.⁸⁴
- 2.69 In New Zealand, a directive was issued to seize thalidomide from chemists and hospital shelves.⁸⁵ In Australia, neither the Australian Government nor the state governments took immediate action.⁸⁶
- 2.70 On 9 August 1962 Australia declared thalidomide to be a prohibited import.⁸⁷ On that same day, the Australian Government's Minister for Health, Senator the Hon. Harrie Wade, told the media that no further action was necessary because the drug had been withdrawn from sale.⁸⁸ However, Senator Wade noted that the states had not formally prohibited the remaining supplies of the drug from being sold again at a later time.⁸⁹
- 2.71 State governments advised the committee that the following actions were taken to withdraw thalidomide from sale:
- Tasmania listed thalidomide as a poison in July 1962;⁹⁰

⁸² Mr Gordon, Gordon Legal, answers to questions on notice (received 1 March 2019).

⁸³ Thalidomide Group Australia, *Submission 1*, p. 10.

⁸⁴ Thalidomide Group Australia, *Submission 1*, p. 10.

⁸⁵ Thalidomide Group Australia, *Submission 1*, p. 12.

⁸⁶ Thalidomide Group Australia, *Submission 1*, p. 10; Mr Gordon, *Submission 66*, [pp. 6–7].

⁸⁷ Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 21.

⁸⁸ Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 38.

⁸⁹ At that time, Distillers had stockpiled more than 8 million tablets in a warehouse in Sydney, which was valued at over A£74 000. National Archives of Australia, [Series A1851, 1970/3655](#), p. 140; Thalidomide Group Australia, *Submission 1 – Attachment 1*, p. 2.

⁹⁰ Statutory Rules 1962, No. 126 was made 3 July 1962 and notified in the Gazette on 11 July 1962. Tasmanian Government, answers to questions on notice (received 5 February 2019).

- the New South Wales Government advised the committee that thalidomide was restricted to require a prescription in August 1962 and further legislative amendments were contemplated to strengthen the *Poisons Act 1952*;⁹¹
- the sale of thalidomide was prohibited in the Australian Capital Territory and Western Australia October 1962;⁹² and
- in Queensland, additional legislation was required which led to thalidomide being prohibited from being sold or supplied on 24 August 1967.⁹³

2.72 No State was able to inform the committee whether any action was taken to remove thalidomide products from the shelves of medical practices or pharmacies.⁹⁴

Support provided

2.73 As noted in the interim report, Australian governments have done relatively little to directly assist Australia's thalidomide survivors.

2.74 The Australian Government has primarily provided support to thalidomide survivors in the form of an exemption of compensation payments from the social security income test and income tax exemptions. As noted above, Australia has two differently compensated groups of thalidomide survivors, but they have received similar treatment from the Australian Government.

2.75 Thalidomide survivors who were recognised in the 1970s receive payments through the Thalidomide Australia Fixed Trust. Payments from The Thalidomide Australia Fixed Trust are exempt from income tax and the social security income tests.⁹⁵ In 2014, the class action payments were exempt from the social security income test and income tax on the payment.⁹⁶

⁹¹ The New South Wales Government advised that a Bill that was brought to Cabinet to strengthen the *Poisons Act 1952*, but it could not say whether the Bill was ever introduced to Parliament. New South Wales Government, answers to questions on notice, Question 3, [p. 1] (received 21 February 2019).

⁹² ACT Government, answers to questions on notice, Question 2, [p. 2] (received 15 February 2019); Western Australian Government, answers to questions on notice, Question 3, p. 2 (received 26 February 2019).

⁹³ Queensland Government, answers to questions on notice, Question 3, [pp. 1–2] (received 1 February 2019).

⁹⁴ See, for example: Western Australian Government, answers to questions on notice, Question 3, p. 2 (received 26 February 2019).

⁹⁵ Department of Social Services, *Submission 3*, [p. 1]; *Income Tax Assessment Act 1997*, ss. 11–5, 51–30; *Social Security Act 1991*, s. 8(8)(vc).

⁹⁶ Department of Health, *Submission 2*, p. 3; Department of Social Services, *Submission 3*, [p. 1]; Social Security (Exempt Lump Sum) (Thalidomide Class Action Payment) Determination 2014; Veterans' Entitlements Income (Exempt Lump Sum – Thalidomide Class Action Payment) Determination No. R19 of 2014.

- 2.76 As noted in the interim report, the Australian Government also offers to all Australians the benefits of income support, the health system (including Medicare and the Pharmaceutical Benefits Scheme) and, most recently, the National Disability Insurance Scheme (NDIS).⁹⁷
- 2.77 The Australian Government provided some support for thalidomide-affected children by facilitating the fitment of prosthetic limbs. In 1964, the Hon. Reginald Swartz told the House of Representatives that the then Repatriation Department was responsible for administering a scheme for thalidomide-affected children with malformed limbs to be fitted with, and receive early training in the use of, prosthetic limbs.⁹⁸ The Australian Government paid half of the cost of the scheme, with the other half paid by state governments.⁹⁹ The Department of Veterans' Affairs told the committee its facilities were used for the fitment of prosthetic limbs and that it actively participated in the Australian Government's programme to assist thalidomide-affected children.¹⁰⁰
- 2.78 State and territory governments advised the committee that they have some disability supports available that can be accessed by thalidomide survivors. In some jurisdictions, the NDIS was considered to be the major component of their disability service provision.¹⁰¹ For example, the Western Australian Government advised the committee that the NDIS constituted the core of its disability support, though individuals could be supported by the Department of Communities until they receive an NDIS plan.¹⁰²
- 2.79 New South Wales and Queensland noted that they provide comprehensive disability support services. The Queensland Government explained that thalidomide survivors who live in Queensland may be eligible for 'Accommodation Support, Community Access Support, Case Management, Life Skills Development, Goods and Equipment, Multidisciplinary Services, Early Childhood Intervention Services, and/or Respite Services'.¹⁰³

⁹⁷ Department of Health, *Submission 2*, p. 4.

⁹⁸ Minister for Repatriation, *House of Representatives Hansard*, 5 March 1964, p. 287.

⁹⁹ The Hon. Reginald William Colin Swartz, M.B.E, E.D., Minister for Repatriation, *House of Representatives Hansard*, 5 March 1964, p. 287.

¹⁰⁰ Department of Veterans' Affairs, answers to questions on notice, [p. 1] (received 8 March 2019).

¹⁰¹ See ACT Government, answers to questions on notice, Question 4, [p. 2–3] (received 15 February 2019); Western Australian Government, answers to questions on notice, Question 4, pp. 3–4 (received 26 February 2019).

¹⁰² The NDIS is scheduled to complete rollout in Western Australia in 2020. Western Australian Government, answers to questions on notice, Question 4, pp. 3–4 (received 26 February 2019).

¹⁰³ Queensland Government, answers to questions on notice, Question 4, [p. 2] (received 1 February 2019).

- 2.80 The New South Wales Government reported that thalidomide survivors may be eligible for supports under its Prosthetic Limb Program and/or the Aids and Education Program. If a thalidomide survivor was considered to be ineligible for the NDIS, the New South Wales Government said that its Safe and Supported At Home program could help provide non-clinical support services. However, the New South Wales Government noted that the Safe and Supported At Home program is time-limited.¹⁰⁴
- 2.81 However, thalidomide survivors who live in these states have advised the committee that they have experienced significant difficulties in accessing these programs.¹⁰⁵
- 2.82 The committee has received evidence that State governments consider that it is the Australian Government's responsibility to assist thalidomide survivors. The committee received a letter from the Queensland Government to advise that it does not consider this matter to be a 'State responsibility' and that it is the Australian Government's responsibility to provide compensation or any financial support.¹⁰⁶ The committee also received a copy of a letter from the Premier of Queensland, the Hon. Anastacia Palaszczuk MP, addressed to the former Prime Minister, the Hon. Tony Abbott MP, advising of the same and requesting that the Australian Government provide support for Australia's thalidomide survivors.¹⁰⁷

Australian Government as the 'funder of last resort'

- 2.83 In its submission, the Department of Health noted that the Australian Government would be the 'funder of last resort', but it considered that the manufacturer and the distributor should consider providing additional compensation.¹⁰⁸
- 2.84 The Department of Finance advised that the Australian Government would step in as the 'funder of last resort' in circumstances where all other possible avenues for providing financial support have been exhausted.
- 2.85 In its submission, Grünenthal was clear that it had contributed to the Contergan Foundation which supports thalidomide survivors in the 37 countries where Grünenthal directly marketed thalidomide products or where

¹⁰⁴ New South Wales Government, answers to questions on notice, Question 4, [pp. 2–3] (received 21 February 2019). Participants must be aged 64 or under. The program may be varied depending on the available budget.

¹⁰⁵ See Name withheld, *Submission 14*, p. 3.

¹⁰⁶ The Hon. Mark Ryan MP, Acting Minister for Disability Services and Seniors, Queensland Government, correspondence received 22 January 2019, [p. 1].

¹⁰⁷ The Hon. Mark Ryan MP, Acting Minister for Disability Services and Seniors, Queensland Government, correspondence received 22 January 2019, [p. 2].

¹⁰⁸ Department of Health, *Submission 2*, p. 3.

Grünenthal products were 'marketed through an independent company operating as Grünenthal's direct distributor'.¹⁰⁹ Grünenthal submitted that when Distillers had entered into an exclusive distribution arrangement to distribute products, it became exclusively responsible for the distribution and marketing of thalidomide products. According to Grünenthal, Diageo, as the legal successor to Distillers, is therefore responsible for providing any support to Australian thalidomide survivors.¹¹⁰

- 2.86 Submitters in this inquiry have noted that, between the two groups of recognised Australian thalidomide survivors, Diageo has provided just over \$150 million in compensation.¹¹¹ Diageo also notes that it provides a similar level of support to thalidomide survivors in the United Kingdom and it expects that the Australian Government should provide a level of financial support before asking it to contribute additional compensation.¹¹²

Legal advice regarding Australia's obligations

- 2.87 Early in the inquiry the committee was advised that the former Minister for Health, the Hon. Sussan Ley MP, commissioned advice from Maddocks Lawyers about Australia's obligations to its thalidomide survivors.¹¹³

- 2.88 On 19 June 2018, the Senate agreed that a copy of the document should be provided to the Senate by 20 June 2018.¹¹⁴ On 16 August 2018, Senator the Hon. Bridget McKenzie, representing the Minister for Health in the Senate, made a public interest immunity claim over the document.¹¹⁵ Senator McKenzie's public interest immunity claim was based on the fact that the document was legal advice to government:

It has been the long-standing practice of successive Australian Governments to not disclose privileged legal advice, including advice that canvasses possible constitutional issues.¹¹⁶

¹⁰⁹ Grünenthal, *Submission 65*, [p. 4].

¹¹⁰ Grünenthal, *Submission 65*, [p. 4].

¹¹¹ Mr Gordon, *Submission 66*, [p. 2].

¹¹² Diageo, *Submission 70*, [p. 3]; Diageo, answers to questions on notice, [p. 1] (received 1 March 2019).

¹¹³ See, for example: Ms McManus, *Thalidomide Group Australia, Committee Hansard*, 2 November 2018, pp. 2–7; Name withheld, *Submission 10*, p. 5.

¹¹⁴ *Journals of the Senate*, No. 99, 19 June 2018, pp. 3175–3176.

¹¹⁵ *Journals of the Senate*, No. 109, 16 August 2018, p. 3511.

¹¹⁶ Senator the Hon Bridget McKenzie, Minister for Rural Health, [correspondence to Senator the Hon. Scott Ryan, President of the Senate](#), 15 August 2018, [p. 1].

- 2.89 In the interim report the committee requested that a copy of the advice be made available to the committee to help it to understand the options available to the Australian Government.¹¹⁷
- 2.90 The Maddocks Lawyers' advice was not made available to the committee and the committee was unable to verify or consider the contents of the advice. This is important as the advice could have provided the committee with a better understanding of the legal context in which the Australian Government is being asked to respond to the Thalidomide Group Australia's requests. The advice could have also provided the committee with important information regarding the current options available to the Australian Government for supporting thalidomide survivors.
- 2.91 Instead, the only evidence the committee has about the advice comes to it indirectly. The committee received some evidence that a ministerial adviser revealed some of the content of that advice to the Director of the Thalidomide Group Australia, Ms Lisa McManus.¹¹⁸ According to Ms McManus, the adviser provided her with the following information about the advice:
- the advice is 23 pages long;
 - it provided five possible options;
 - one of the options was to 'do nothing'; and
 - it concluded that the Australian Government had no legal obligation, but that the Australian Government has a 'moral responsibility' to assist thalidomide survivors.¹¹⁹

Committee view

- 2.92 The committee considers that Australian governments have a moral obligation to Australia's thalidomide survivors. The committee notes that both the Australian Government and the state governments failed to monitor drug safety at a time when other governments around the world did so. Documents provided to the committee demonstrate that the Australian Government was aware that more could be done to safeguard public health from dangerous drugs. The committee notes that the formation of the Therapeutic Goods Administration was a direct result of the thalidomide disaster and notes evidence to the inquiry that suggests such a body could have been, and should have been, established earlier.
- 2.93 When it was revealed that thalidomide was toxic, Australian governments did not immediately react. Evidence provided to the committee indicates that neither state governments nor the Australian Government took any steps to

¹¹⁷ See Interim report, pp. 96–97.

¹¹⁸ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 7.

¹¹⁹ Ms McManus, Thalidomide Group Australia, *Committee Hansard*, 2 November 2018, p. 7.

immediately remove thalidomide from sale in Australia. The committee finds it deeply concerning to consider that the number of Australians affected by thalidomide could have been 20 per cent smaller if more had been done to recall and destroy the drug in a timely manner.

- 2.94 The committee notes that the Australian Government has offered to act as the 'funder of last resort'. However, the committee considers that thalidomide survivors have waited long enough and the Australian Government needs to take a more active role. The committee notes that Grünenthal does not consider that providing support is its responsibility and that Diageo has already provided a very substantial sum of compensation to Australia's thalidomide survivors and has indicated a willingness to consider some further compensation after the government's plans to support survivors are made clear.
- 2.95 The committee notes that other governments around the world have provided significant financial support to their thalidomide survivors and the committee considers that the Australian Government should provide some form of assistance. Further consideration about the forms of assistance that could be provided will be considered in the next chapter.
- 2.96 The committee considers that it would have been in a better position to make recommendations regarding the Australian Government's response to providing support to thalidomide survivors, and to the Thalidomide Group Australia's requests, if the committee had been permitted to review the Maddocks Lawyers' advice.
- 2.97 The committee notes the Minister's public interest immunity claim in relation to the advice and questions whether this claim satisfies the process the Senate has prescribed for such claims.¹²⁰ In particular, the committee notes that the fact that information consists of advice to government does not establish a basis for a public interest immunity claim. The Senate's expectation is that the Minister should establish the harm to the public interest that would result from disclosure on this occasion, particularly as legal advice to government has been disclosed by governments on numerous occasions.¹²¹

¹²⁰ The Senate, *Standing Orders and other orders of the Senate*, August 2018, Procedural Order 10(c).

¹²¹ Rosemary Laing, ed, *Odgers' Australian Senate Practice – as revised by Harry Evans*, 14th edition, Department of the Senate, 2016, pp. 668–669.

Chapter 3

Making supports work for thalidomide survivors

In terms of Government expenditure it would involve a relatively trifling cost to take over the care of these victims and give them every assistance that modern medical science can devise... Australia has already been criticized overseas for being slow in helping thalidomide victims. To be fair, both Federal and State Governments have indicated their willingness to help. But we should give nothing less than the fullest possible assistance - not just in answer to criticism but in the name of common humanity.¹

- 3.1 In its interim report, the committee concluded that the current supports that are available to Australia's thalidomide survivors are not sufficient and do not serve survivors well. The evidence received by the committee indicated that survivors experience difficulty in receiving appropriate levels of support from the National Disability Insurance Scheme (NDIS), forms of income support and accessing adequate mobility supports.
- 3.2 As noted in earlier chapters and in the interim report, the needs of thalidomide survivors are increasing. The committee received evidence that the deterioration of survivors' health is being caused by the worsening and newly emergent complications of survivors' thalidomide injuries, and also from the 'wear and tear' caused by the way survivors have been forced to contort their bodies to perform daily tasks.²
- 3.3 In its interim report, the committee noted its intention to conclude its consideration of a number of issues relating to the way supports can be developed to assist thalidomide survivors. This chapter builds on the committee's considerations in its interim report to ensure that the framework that is established to support survivors learns from the survivors' experiences.
- 3.4 The chapter first considers issues with the supports available through the NDIS and some of the other supports that have been made available to survivors before considering how the requests made by the Thalidomide Group Australia together with better coordination of services may be able to assist all Australian thalidomide survivors.

¹ Senator Douglas McClelland, *Senate Hansard*, 14 May 1963, p. 423 quoting from the Daily Telegraph newspaper of Tuesday, 11 December 1962.

² Senate Community Affairs References Committee, *Inquiry into support for Australia's thalidomide survivors—Interim report* (Interim report), February 2019, p. 35.

National Disability Insurance Scheme

3.5 The committee's interim report considered concerns that the NDIS is not adequately addressing the needs of thalidomide survivors.³ The committee also noted concerns regarding the adequacy of support packages available under the NDIS to meet the specific needs of individual thalidomide survivors and the extent to which earlier compensation payments have reduced the support available to thalidomide survivors under the NDIS.

Barriers to access

3.6 The committee noted a number of barriers encountered by thalidomide survivors seeking to access support through the NDIS. Principal among these is the complexity of the application and assessment process coupled with a lack of understanding of thalidomide injuries.

3.7 The NDIS is designed to provide individualised supports to people with disability based on their needs.⁴ However, the committee has heard evidence from individual thalidomide survivors that demonstrates both a lack of understanding of their needs and an inability to deliver necessary supports within an appropriate timeframe.⁵

3.8 The National Disability Insurance Agency (NDIA) told the committee that if an applicant for the NDIS has a diagnosis that is well recognised, it can be easier to understand the effect of that disability and identify the services and supports required.⁶

3.9 However, the committee's interim report noted that Australian thalidomide survivors have a wide array of injuries. Some Australian thalidomide survivors have serious physical malformations and disabilities, including missing or malformed limbs.⁷ Other thalidomide survivors are deaf or have significant hearing loss, vision impairment, issues with continence and other internal injuries, in addition to significant nerve pain.⁸ The committee also noted the evolving nature of thalidomide injuries and the propensity for a thalidomide survivor's needs to change dramatically in a short period of time.⁹

3.10 Many thalidomide survivors told the committee that their interactions with the NDIA and the NDIS have been a source of considerable frustration. The

³ Interim report, pp. 56–57.

⁴ Department of Social Services, *Submission 3*, [p. 3].

⁵ Interim report, p. 57.

⁶ Interim report, p. 57.

⁷ Interim report, p. 13.

⁸ Interim report, pp. 13–14.

⁹ Interim report, p. 58.

committee recommended that the NDIA take steps to better assist thalidomide survivors in their interactions with the NDIS, including the establishment of a central point of contact and the development of a guide to assessing and planning appropriate supports for thalidomide survivors.

Adequacy of packages

- 3.11 In its interim report, the committee also noted evidence that the amount of money that was being provided in NDIS participants' packages was insufficient to purchase the range of supports necessary to meet the needs of thalidomide survivors.¹⁰
- 3.12 The committee received confidential evidence of a thalidomide survivor's experience of seeking assistance to modify their home to accommodate their changing needs. They were advised by their NDIS service coordinator there were insufficient funds in the package to obtain quotes for the home modifications, let alone complete the modifications themselves.¹¹
- 3.13 The committee notes that this is consistent with the findings of the Joint Standing Committee on the National Disability Insurance Scheme about the NDIS scheme more broadly.¹²

NDIS and compensation payments

- 3.14 In its interim report, the committee noted it was concerned by evidence indicating the supports thalidomide survivors may receive under the NDIS could be limited by compensation provisions of the *National Disability Insurance Scheme Act 2013* (Cth) (NDIS Act).¹³
- 3.15 Professor Richard Madden, Centre for Disability Research and Policy, University of Sydney, submitted to the inquiry that NDIS entitlement is 'not straightforward, or not available at all' for people whose disabilities arise from injuries that allow for compensation to be obtained outside of the NDIS.¹⁴
- 3.16 Ms Vicki Rundle, Deputy Chief Executive Officer (CEO) of the NDIA, confirmed that the NDIS Act requires the NDIA to take compensation payments into account when determining the level of support a participant is eligible for:

The NDIS Act requires that we consider all compensation to participants in determining what level of support the NDIS will provide, and it has two

¹⁰ Interim report, p. 57.

¹¹ Confidential, *Submission 14.1*, [p. 1].

¹² See for example: Joint Standing Committee on the National Disability Insurance Scheme, *Market readiness for provision of services under the NDIS*, September 2018, p. 12.

¹³ Interim report, p. 100.

¹⁴ Professor Richard Madden, *Submission 5*, [p. 5].

components: a past component, in terms of recovery—that's if a person receives compensation ...and then we are required to take into account the support that they've received through the compensation system in determining what would be provided by the NDIS.¹⁵

Compensation payments under the NDIS Act

- 3.17 Chapter 5 of the NDIS Act contains provisions for the CEO of the NDIA to require an NDIS participant, or a prospective participant, to take action to seek compensation for a personal injury if the CEO considers that this is reasonable.¹⁶ Sections 106 and 107 of the NDIS Act provide power to the NDIA CEO to recover costs of NDIS supports provided to a participant if that participant is awarded compensation for their injuries.¹⁷
- 3.18 Section 116 of the NDIS enables the CEO of the NDIA to make discretionary decisions to disregard certain payments for the purposes of Chapter 5 of the NDIS Act. Section 116 has been applied by the NDIA on 12 occasions to 'treat a participant's payments as not having been fixed, in whole or part'.¹⁸
- 3.19 The NDIA told the committee that the purpose of the compensation provisions of the NDIA Act is to '...avoid duplicate funding where compensation includes damages for past and future supports of a kind provided by the [NDIS]'.¹⁹

Thalidomide survivors' settlements and ex-gratia payments

- 3.20 Thalidomide survivors have previously received settlement or ex-gratia payments associated with their thalidomide injuries.²⁰ The NDIA has requested details of thalidomide survivors past payments as part of their NDIS eligibility assessment.²¹
- 3.21 The NDIA told the committee that Chapter 5 of the NDIS Act is not applicable to settlements and ex-gratia payments that thalidomide survivors' received prior to entering the NDIS.²² However, the NDIA considers the payments received by thalidomide survivors to '...determine if a Compensation

¹⁵ *Committee Hansard*, 31 January 2019, p. 55.

¹⁶ *National Disability Insurance Scheme Act 2013*, s. 104.

¹⁷ See, *National Disability Insurance Scheme Act 2013*, s. 106, s. 107.

¹⁸ National Disability Insurance Agency (NDIA), answers to questions on notice (SQ19-000035), [p. 3] (received 7 March 2019).

¹⁹ NDIA, answers to questions on notice (SQ19-000031), [p. 1] (received 7 February 2019).

²⁰ Interim report, pp. 72–76.

²¹ Andrew, *Committee Hansard*, 31 January 2019, pp. 18–19; Mark, *Committee Hansard*, 31 January 2019, p. 25–26.

²² NDIA, answers to questions on notice (SQ19-000034), [p. 2] (received 7 March 2019).

Reduction Amount (CRA) is applicable to ensure there is no duplication in funding or supports'.²³

- 3.22 The NDIA is required to consider applying CRAs for thalidomide survivors who have identified as receiving a compensation amount under the provisions of the National Disability Insurance Scheme (Supports for Participants—Accounting for Compensation) Rules 2013 (Rules).²⁴ Rule 3.10 empowers the CEO of the NDIA to make a decision to ignore a CRA which would ordinarily arise if it is appropriate to do so in special circumstances.²⁵
- 3.23 Applying a CRA to the previous payments made to thalidomide survivors appears to be inconsistent with the previous treatment of those payments. In the previous chapter, it was noted that the payments made by the Thalidomide Australia Fixed Trust were exempt from income tax and the social security income test. These exemptions were provided to ensure that the other supports that they receive were not reduced because thalidomide survivors received the additional financial support. It is somewhat inconsistent for some parts of the Australian Government to ensure that the benefits thalidomide survivors are able to access are not being reduced, but for the compensation payment to be taken into account to reduce the level of support they are able to access under the NDIS.
- 3.24 As the committee noted in its interim report, the payments received by thalidomide survivors to date have not been calculated on the basis of their level of disability and are not commensurate with the cost of supports that thalidomide survivors need.²⁶ The committee noted that as such payments are not indexed for inflation, they will become increasingly inadequate to meet the evolving needs of thalidomide survivors as they age.²⁷
- 3.25 The NDIA was unable to provide details about the number of thalidomide survivors who had been asked for details about their settlement or ex-gratia payments, or have been deemed ineligible for the NDIS on the basis of receipt of those payments.²⁸ It is therefore not clear if thalidomide survivors have had the amount of support that they may be eligible for under the NDIS reduced.
- 3.26 Professor Madden noted that the compensation provisions of the NDIS Act were introduced so that the measures that supported state and territory based injury compensation schemes, including for road and workplace accidents,

²³ NDIA, answers to questions on notice (SQ19-000034), [p. 2] (received 7 March 2019).

²⁴ NDIA, answers to questions on notice (SQ19-000032), [p. 3] (received 7 February 2019).

²⁵ National Disability Insurance Scheme (Supports for Participants—Accounting for Compensation) Rules 2013, r. 3.10.

²⁶ Interim report, pp. 76, 78.

²⁷ Interim report, p. 75.

²⁸ NDIA, answers to questions on notice (SQ19-000032), [p. 3] (received 7 February 2019).

would continue.²⁹ Thalidomide survivors are not covered by those schemes. Professor Madden considered it was important that '...all necessary actions be taken to ensure that the compensation provisions of the NDIS Act do not block or limit [thalidomide survivors'] access to the full range of NDIS supports'.³⁰

Committee view

- 3.27 The committee believes that the NDIS must be accessible to those that would meet the eligibility criteria and should be able to effectively deliver supports to all NDIS participants, including those with specialised and complex needs, such as thalidomide survivors. Evidence provided to the committee makes clear that the NDIS has not always provided thalidomide survivors with support to appropriately meet their specialised requirements. The committee understands that some of the issues experienced by thalidomide survivors in accessing NDIS supports are consistent with the experiences of other NDIS participants.
- 3.28 The committee considers that the NDIA should develop a formal understanding of the specialised support requirements of thalidomide survivors. The committee considers that thalidomide survivors' NDIS access requests and NDIS plans should be assessed by NDIA staff with specialist knowledge of thalidomide injuries.
- 3.29 The committee recognises that supports provided under the NDIS are not intended to duplicate other funding or supports. However, the committee is concerned that provisions of NDIS Act and the Rules could result in thalidomide survivors receiving less NDIS support than they otherwise would if they had not received past settlement and ex-gratia payments.

Thalidomide Group Australia's requests

3.30 As noted in Chapter 1 and in the interim report, the Thalidomide Group Australia has sought the committee's support for six requests from the Australian Government. The six requests that the Thalidomide Group Australia has made are:

- a one-time upfront payment of up to \$500 000 (scaled) to each thalidomide survivor;
- an annual payment of \$2 190 260 to the Thalidomide Australia Fixed Trust which would be tax exempt and exempt from the social security income tests when distributed to beneficiaries;
- a Gold Card similar to the Department of Veterans' Affairs health card;
- an 'Extraordinary Assistance Fund' of \$500 000 to allow survivors to adapt their homes, environment and vehicles;

²⁹ Submission 5, p. 1.

³⁰ Submission 5, p. 1.

- a formal apology; and
- a plaque in recognition of Australia's thalidomide survivors and their parents to be mounted in a place of significance.³¹

3.31 Each of these requests has been made by Thalidomide Group Australia because they believe it is what they need in order to live the rest of their lives with adequate support.³²

Recognition

3.32 In its interim report, the committee noted that thalidomide survivors want a form of recognition from the Australian Government. Survivors want the Australian Government to recognise the role it played in their lives and want the government to apologise for the hurt and hardship that thalidomide has caused survivors and their families.³³

3.33 The Thalidomide Group Australia advised that one form of recognition could be to mount a plaque in a place of significance to honour thalidomide survivors and their families.³⁴ As one survivor told the committee:

I acknowledge the pain and suffering endured by our parents, grandparents and siblings throughout the previously uncharted waters of our thalidomide journey. It is my hope that a lasting memorial will be erected in their honour.³⁵

3.34 In November 2018, the Department of Health told the committee that the Minister for Health, the Hon Greg Hunt MP, had met with the Thalidomide Group Australia and 'indicated an interest in responding to one of those requests around a memorial'.³⁶ Dr Studdert told the committee that the Department of Health had recommended to government that the memorial be established and that the department had contacted the Thalidomide Group Australia to discuss the establishment of a memorial.³⁷ Dr Studdert described the nature of the potential memorial as follows:

...consistent with the request, it would be a publicly accessible place where there was some recording and testimony as to what had occurred. As I understood the request, and from our meeting, that the survivors, like all

³¹ Thalidomide Group Australia, *Submission 1*, p. 3.

³² Thalidomide Group Australia, *Submission 1*, p. 3.

³³ See Interim report, pp. 91–92; Mary, *Committee Hansard*, 2 November 2018, p. 22; Nola, *Committee Hansard*, 2 November 2018, p. 21.

³⁴ Thalidomide Group Australia, *Submission 1*, p. 3.

³⁵ Mary, *Committee Hansard*, 2 November 2018, p. 16.

³⁶ Dr Lisa Studdert, Deputy Secretary, Department of Health, *Committee Hansard*, 2 November 2018, p. 25.

³⁷ *Committee Hansard*, 2 November 2018, p. 27.

of us, were keen to ensure that this was never forgotten and that we were never in a situation where something like this happened again.³⁸

- 3.35 The Department of Health advised the committee that this was the only one of the Thalidomide Group Australia's requests currently being progressed by the Department of Health.³⁹
- 3.36 On 11 March 2019, in response to a program on the television program *Australian Story*, the Minister for Health announced that he had approved the development of a memorial garden at the National Arboretum in Canberra to recognise thalidomide survivors and their families.⁴⁰
- 3.37 The establishment of a memorial for thalidomide survivors in Australia is consistent with memorials established in other countries. For example, in 2016, a memorial was established in Cardiff, Wales for all persons affected by the thalidomide tragedy.⁴¹ On the memorial in Cardiff is a poem entitled 'To Remember is To Care'.⁴²
- 3.38 However, thalidomide survivors deserve and expect something more substantial from the Australian Government. In the United Kingdom, a memorial was not provided in isolation. As noted in the interim report, in 2010 the Government of the United Kingdom apologised to its thalidomide survivors and substantial financial support had already been provided.⁴³
- 3.39 In its interim report the committee noted that thalidomide survivors expressed a very strong desire to see the Australian Government apologise for its role in the thalidomide tragedy. Thalidomide survivors consider that they are owed an apology for the absence of support and the government's failure to acknowledge its involvement. Thalidomide survivors also want an apology for their mothers who often lived with terrible guilt about taking thalidomide.

³⁸ *Committee Hansard*, 2 November 2018, p. 27.

³⁹ Dr Studdert, Department of Health, *Committee Hansard*, 2 November 2018, p. 27.

⁴⁰ Australian Story, *Statement from Minister Greg Hunt*, 11 March 2019, <https://www.abc.net.au/austory/statement-from-minister-greg-hunt/10876174> (accessed 12 March 2019).

⁴¹ Thalidomide Society, *To remember is to care – Thalidomide memorial*, <https://www.thalidomidesociety.org/remember-care-thalidomide-memorial/> (accessed 6 March 2018).

⁴² Thalidomide Society, *To Remember is to Care – Thalidomide Memorial*, 1 July 2016, <https://www.thalidomidesociety.org/remember-care-thalidomide-memorial/> (accessed 6 March 2019).

⁴³ Interim report, p. 91.

- 3.40 The Department of Health advised the committee that it has not provided advice around an apology because the Minister for Health prefers to decide in what circumstances an apology is appropriate.⁴⁴

Lump sum payment

- 3.41 While thalidomide survivors may welcome a memorial and an apology, those requests will not provide the same tangible and direct support for Australia's thalidomide survivors as direct financial assistance.
- 3.42 The Thalidomide Group Australia has requested that a one-time upfront payment be made to each thalidomide survivor depending upon their level of disability. The Thalidomide Group Australia clarified that the current payments its members receive are arranged in five categories according to the severity of their injuries. It suggested that the payments could be structured so that payments could vary between \$100 000 and \$500 000 depending on the severity of their injury.⁴⁵
- 3.43 The Thalidomide Group Australia explained in its submission that the lump sum payment could be considered as partial compensation for the pain and suffering that survivors have endured:

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).⁴⁶

- 3.44 In its interim report, the committee noted that many governments have provided one-off lump sums to thalidomide survivors as a form of compensation. Countries that have paid thalidomide survivors a lump sum include Ireland, Germany, Spain, Canada and Sweden.⁴⁷ Belgium has also recently announced that it will provide a lump sum to thalidomide survivors and their parents.⁴⁸

⁴⁴ Ms Elizabeth Flynn, Assistant Secretary, Preventative Health Branch, Department of Health, *Committee Hansard*, 31 January 2019, p. 61.

⁴⁵ Thalidomide Group Australia, correspondence received 20 November 2018.

⁴⁶ Thalidomide Group Australia, *Submission 1*, p. 3.

⁴⁷ Interim report, p. 79.

⁴⁸ Thalidomide Group Australia, Additional information, 'Maggie De Block keeps her word: sixty years later, 5 million euros for the victims of Softenon' (received 14 February 2019). See also Sarah Delafortrie and Christophe Springael, 'Indemnisation des victimes des conséquences liées à la prise de médicaments contenant de la thalidomide durant la grossesse', *PressCenter.Org*, 15 February 2019, <https://www.presscenter.org/fr/pressrelease/20190215/indemnisation-des-victimes-des-consequences-liees-a-la-prise-de-medicaments-co> (accessed 1 March 2019).

- 3.45 In each case, the rationale for providing the payment has been slightly different. In its recent announcement the Belgian Government was clear that the sum was to compensate thalidomide survivors and their parents. Under the Belgian scheme, a single lump sum of €125 000 will be provided to thalidomide survivors or €30 000 will be paid to each parent who is still alive if their child died of their thalidomide injuries.⁴⁹
- 3.46 In Germany, thalidomide survivors are provided with a lump sum that is described as a 'capital payment' that will be provided in addition to the newly recognised survivor's first pension payment.⁵⁰ In Germany and in the other countries where the Contergan Foundation provides support, newly recognised thalidomide survivors are provided with a one-off payment of between €1278 and €12 782 depending on the survivor's level of assessed disability when they first join the scheme.⁵¹
- 3.47 In Canada, a lump sum is paid to newly recognised survivors when they are confirmed in the program.⁵² Unlike the German model, Canadian thalidomide survivors receive \$125 000 CAD regardless of their level of assessed disability.⁵³ In January 2019 the Minister for Health announced that a new program, to be known as the Canadian Thalidomide Survivors Support Program, will increase the lump sum payment to \$250 000 CAD to newly recognised thalidomide survivors and will provide an additional \$125 000 CAD to survivors who have already been recognised.⁵⁴ Providing additional funds to recognised survivors is intended to ensure that there is no

⁴⁹ Thalidomide Group Australia, Additional information, 'Maggie De Block keeps her word: sixty years later, 5 million euros for the victims of Softenon' (received 14 February 2019). See also Sarah Delafortrie and Christophe Springael, 'Indemnisation des victimes des conséquences liées à la prise de médicaments contenant de la thalidomide durant la grossesse', *PressCenter.Org*, 15 February 2019, <https://www.presscenter.org/fr/pressrelease/20190215/indemnisation-des-victimes-des-consequences-liees-a-la-prise-de-medicaments-co> (accessed 1 March 2019).

⁵⁰ Contergan Infoportal, *Conterganstiftungsgesetz* (trans: Thalidomide Foundation Act) (accessed 27 February 2019).

⁵¹ The Law on the Contergan Foundation for Disabled People as amended by the Fourth Amendment 2017, §12(2). An English translation of the law is available on the Contergan Foundation's website: Contergan Infoportal, *Conterganstiftungsgesetz* (trans: Thalidomide Foundation Act), https://www.contergan-infoportal.de/finanzen_recht/rechtsgrundlagen/conterganstiftungsgesetz/ (accessed 27 February 2019).

⁵² Health Canada, answers to questions on notice, Question 2, [p. 2] (received 28 February 2019).

⁵³ Health Canada, answers to questions on notice, Question 2, [p. 2] (received 28 February 2019).

⁵⁴ Health Canada, *Minister of Health announces new financial support program for eligible Canadian thalidomide survivors*, 9 January 2019, <https://www.canada.ca/en/health-canada/news/2019/01/minister-of-health-announces-new-financial-support-program-for-eligible-canadian-thalidomide-survivors.html> (accessed 28 February 2019).

difference between the lump sums thalidomide survivors receive based on when they were recognised.⁵⁵

- 3.48 The Canadian Government has stated that it considers that the lump sum payment will be used to pay for 'urgent health care needs'.⁵⁶
- 3.49 In the United Kingdom, thalidomide survivors are provided with a lump sum each year that can be used to support their health needs as they see fit.⁵⁷ As noted in the interim report, the health grant in the United Kingdom can be applied to a wide range of supports—from social activities to medical treatments costs—and it allows thalidomide survivors the flexibility to invest in the supports that they need.⁵⁸
- 3.50 Miss Michaelina Argy, the Deputy Chair of the National Advisory Council to the Thalidomide Trust in the United Kingdom told the committee that Australian thalidomide survivors are likely to require a substantial lump sum payment to help them invest in adaptations that they have otherwise been unable to make:
- What I can advise from the UK situation is that Australian thalidomiders will need a substantial lump sum to enable them to pay for major adaptations and changes they need to make now, a catch-up for a previous inability to invest properly in their needs.⁵⁹
- 3.51 The Thalidomide Group Australia expressed the view that its members would prefer the lump sum payment to be scaled to take account of the different levels of disability within its membership.⁶⁰
- 3.52 If a lump sum is to be paid by the Australian Government, one of the questions that needs to be resolved is how a lump sum payment could be made to thalidomide survivors.
- 3.53 The Department of Finance advised the committee that ex gratia payments, which have previously been provided to groups of people, are no longer

⁵⁵ Health Canada, answers to questions on notice, Question 2, [p. 2] (received 28 February 2019).

⁵⁶ Health Canada, *Minister of Health announces new financial support program for eligible Canadian thalidomide survivors*, 9 January 2019, (accessed 28 February 2019); Crawford Class Action Services, *Thalidomide Survivors Contribution Program*, <http://www.tscp-pcst.ca/homeeng.html> (accessed 28 February 2019).

⁵⁷ Miss Michaelina Argy, Deputy Chair, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, pp. 11–12.

⁵⁸ See, Interim report, p. 82. See also: Firefly, *Health, Quality of Life and Employment amongst Thalidomide-affected People – Evidence from the UK*, January 2015, pp. 26–28.

⁵⁹ Miss Argy, National Advisory Council to the Thalidomide Trust, *Committee Hansard*, 2 November 2018, p. 9.

⁶⁰ Thalidomide Group Australia, correspondence received 20 November 2018, [p. 1].

available.⁶¹ Instead, the Department of Finance advised that it was possible to make 'act of grace' payments under section 65 of the *Public Governance, Performance and Accountability Act 2013* (Cth) (PGPA Act).

- 3.54 Under section 65 of the PGPA Act, the Finance Minister is empowered to make act of grace payments to a person in special circumstances if they consider that it is appropriate to do so.⁶² The Department of Finance noted that neither 'special circumstances' nor 'appropriate' are defined in the PGPA Act.⁶³ However, the Department of Finance noted that act of grace payments may be able to be made to a non-natural person, such as a trust.⁶⁴
- 3.55 The Department of Health currently administers a number of special accounts,⁶⁵ including one special account which has been set up to provide one-off payments and to provide counselling and medical care, in certain circumstances, to people who were treated with human pituitary-derived hormones.⁶⁶ A special account may be able to be established to provide financial support to Australia's thalidomide survivors or to pay for certain other supports that may be required.
- 3.56 Another possible option may be to provide for a payment in legislation. The Department of Finance advised the committee that 'payments to groups of people are usually paid pursuant to legislation, or through a compensation scheme'.⁶⁷ The *Social Security Act 1991* currently contains a range of payments, including one-off payments to aged and older Australians,⁶⁸ carers,⁶⁹ for energy assistance payments⁷⁰ and for Australian Victims of Overseas Terrorism.⁷¹ Amendments to the *Social Security Act 1991* may allow for either a

⁶¹ Department of Finance, answers to questions on notice, Question 1, p. 1 (received 6 March 2019).

⁶² *Public Governance, Performance and Accountability Act 2013*, s. 65 (PGPA Act).

⁶³ Department of Finance, answers to questions on notice, Question 1, p. 1 (received 6 March 2019).

⁶⁴ Department of Finance, answers to questions on notice, Question 3, p. 3 (received 6 March 2019).

⁶⁵ A 'special account' is a form of special appropriation that is established either by determination of the Finance Minister (PGPA Act, s. 78) or through an Act (PGPA Act, s. 80). The establishing Act or determination provides the legal authority to debit Commonwealth money. See Department of Finance, *Special appropriations: special accounts*, <https://www.finance.gov.au/resource-management/appropriations/rmg-100-guide-to-appropriations/special-appropriations-special-accounts/> (accessed 12 March 2019).

⁶⁶ See PGPA Act (Human Pituitary Hormones Special Account 2015—Establishment) Determination 2015/09. For more information on the Creutzfeldt-Jakob disease settlement see: Senate Community Affairs Committee, *Report on The CJD Settlement Offer*, October 1997, [2.1]–[2.13].

⁶⁷ Department of Finance, answers to questions on notice, Question 5, p. 5 (received 6 March 2019).

⁶⁸ *Social Security Act 1991*, Part 2.2B (One-off payments to the aged and older Australians).

⁶⁹ *Social Security Act 1991*, Part 2.5A (One-off payments to carers eligible for carer payment).

⁷⁰ *Social Security Act 1991*, Part 2.6 (One-off energy assistance payment).

⁷¹ *Social Security Act 1991*, Part 2.24AA (Australian Victim of Terrorism Overseas Payment).

one-off payment or for ongoing payments to be made to thalidomide survivors.

Ongoing payments

- 3.57 The Thalidomide Group Australia has requested that, in addition to a lump sum payment, the Australian Government provide an additional \$2 190 260 into the Thalidomide Australia Fixed Trust to be shared among the currently recognised thalidomide survivors as annual disbursements.⁷² The committee notes that this would supplement the amount that is currently provided by Diageo through the Thalidomide Australia Fixed Trust.⁷³
- 3.58 In its interim report the committee noted that either annual or monthly pensions are provided to thalidomide survivors in a number of other countries including Germany, Canada, Ireland, the United Kingdom, Japan, Italy and Austria.⁷⁴
- 3.59 In Germany, thalidomide survivors receive the capital lump sum when they are recognised, a monthly pension, an annual lump sum and an annual 'special payment' which is provided on a scale according to the survivor's level of disability provided the survivor's level of disability is above a certain threshold.⁷⁵
- 3.60 In Canada, thalidomide survivors are provided with annual payments in accordance with their assessed level of disability. If a survivor feels that their condition has deteriorated and they are in need of more support, the survivor is able to ask to be reassessed and have their level of financial support increased.⁷⁶
- 3.61 Australian thalidomide survivors have advised the committee that ongoing payments provide financial certainty to allow them to plan and live the rest of their lives with dignity.⁷⁷
- 3.62 In the United Kingdom the health grant provides thalidomide survivors with a continuous stream of funding to support their health needs. Ms Elizabeth Newbronner, a researcher at the University of York, told the committee that money provided thalidomide survivors with the ability to choose how they maintain their independence and function:

⁷² Thalidomide Group Australia, *Submission 1*, p. 3.

⁷³ See, Diageo Australia, *Submission 70*, [p. 2].

⁷⁴ Interim report, pp. 81–89. The rate at which each country provides its pension is included in the interim report.

⁷⁵ Contergan Infoportal, *Finanzen & Recht* (trans: Finance and Law), https://www.contergan-infoportal.de/finanzen_recht/ (accessed 1 March 2019).

⁷⁶ See Interim report, p. 84.

⁷⁷ Interim report, p. 90.

Having money creates...the comfort of being able to afford things in the here and now; the reassurances of having 'insurance' to cover unexpected events; and the confidence that, if necessary, the resources are there to meet changing needs.⁷⁸

Gold Card

- 3.63 The Thalidomide Group Australia has requested that the Australian Government provide thalidomide survivors with a health care card or Gold Card to assist them with meeting the cost of their health needs.⁷⁹
- 3.64 As noted in the interim report, while some procedures are provided in public hospitals or are bulk-billed, many health services that people with disabilities require are not subsidised. For thalidomide survivors, this can result in significant out of pocket expenses.⁸⁰ A Gold Card would allow thalidomide survivors to access the medical, dental, chiropractic, exercise physiology and diagnostic imaging services they need at a subsidised or no cost.
- 3.65 The Department of Veterans' Affairs provides health care cards to eligible veterans, their spouses and dependants. Different health care cards entitle the holder of the card to different benefits. The Gold Card provides access to 'all clinically required health care treatment' at the Department of Veterans' Affairs expense.⁸¹ Veterans who qualify for the Gold Card also receive access to the Repatriation Pharmaceutical Benefits Scheme which only requires a \$6.50 co-payment.⁸²
- 3.66 By comparison, thalidomide survivors who receive the Disability Support Pension are entitled to receive the concessional rate on pharmaceutical drugs and out-of-hospital medical expenses, bulk-billed General Practitioner appointments and free hearing assessments and hearing rehabilitation with a Pensioner Concession Card.⁸³

⁷⁸ *Submission 63*, p. 5.

⁷⁹ Thalidomide Group Australia, *Submission 1*, p. 3.

⁸⁰ See, Interim report, p. 48; Name withheld, *Submission 21*, p. 3.

⁸¹ Department of Veterans' Affairs, *Factsheet HSV60 – Using the DVA Health Card – All Conditions (Gold) or DVA Health Card Totally & Permanently Incapacitated (Gold)*, <https://www.dva.gov.au/factsheet-hsv60-using-dva-health-card-all-conditions-gold-or-dva-health-card-totally-permanently> (accessed 6 March 2019).

⁸² Department of Veterans' Affairs, *Factsheet HSV60 – Using the DVA Health Card – All Conditions (Gold) or DVA Health Card Totally & Permanently Incapacitated (Gold)*, (accessed 6 March 2019).

⁸³ Note: The concessional rate for the Pharmaceutical Benefits Scheme and out-of-hospital costs are only available after a certain concessional safety net has been reached. Department of Social Services, *Pensioner Concession Card*, <https://www.dss.gov.au/about-the-department/benefits-payments/concession-and-health-cards/pensioner-concession-card> (accessed 13 March 2019).

- 3.67 Access to a form of health care card, like the Gold Card, would clearly make a substantial difference to the lives of thalidomide survivors, by providing access to clinically required medical and allied health services on a no cost or subsidised cost basis.
- 3.68 Currently, the Gold Card has not been extended beyond the defence context. The Department of Health advised the committee that it has provided advice to the Minister for Health about the possibility of providing a form of health care card to thalidomide survivors, but that it was not a matter that was under active consideration by the Department.⁸⁴

Extraordinary Assistance Fund

- 3.69 In its interim report, the committee noted that thalidomide survivors require very specific health supports and made recommendations in that report to ensure that health specialists could be identified to assist in the diagnosis and provision of such supports.⁸⁵
- 3.70 The Thalidomide Group Australia explained that an Extraordinary Assistance Fund of \$500 000 would allow thalidomide survivors to adapt their homes, environment and vehicles to accommodate their disabilities.⁸⁶
- 3.71 Canada operates an Extraordinary Medical Assistance Fund as part of the package of supports that it provides to its thalidomide survivors. Under the Canadian scheme, the survivors lodge applications to request funding from the Extraordinary Medical Assistance Fund. Funding can be provided to assist with specialised surgeries, home or vehicle adaptations.⁸⁷ Funding is then provided on a first come, first served basis.⁸⁸ If there is greater need than there are funds, then health needs are prioritised over other claims.⁸⁹
- 3.72 Currently, Canada's Extraordinary Medical Assistance Fund is provided with \$500 000 CAD per year.⁹⁰ However, the Canadian Minister for Health

⁸⁴ Dr Studdert, Department of Health, *Committee Hansard*, 2 November 2018, p. 27.

⁸⁵ Interim report, Recommendation 3, p. 98 and Recommendation 4, p. 99.

⁸⁶ Thalidomide Group Australia, *Submission 1*, p. 3.

⁸⁷ Crawford Class Action Services, *Thalidomide Survivors Contribution Program*, <http://tscp-pcst.ca/homeeng.html> (accessed 6 March 2019).

⁸⁸ Crawford Class Action Services, *Thalidomide Survivors Contribution Program – FAQs*, (accessed 6 March 2019).

⁸⁹ Crawford Class Action Services, *Thalidomide Survivors Contribution Program – FAQs*, (accessed 6 March 2019).

⁹⁰ Health Canada, *Minister of Health announces new financial support program for eligible Canadian thalidomide survivors*, 9 January 2019, (accessed 28 February 2019).

announced in January that as part of the new support program for thalidomide survivors, this amount will be increased to \$1 million per year.⁹¹

- 3.73 The existence of an Extraordinary Assistance Fund recognises that thalidomide survivors have needs that are extraordinary and significantly more complex than most people. It also recognises that the health system is not necessarily able to provide all of the services that thalidomide survivors require.⁹² Having access to these funds allows survivors to have the flexibility to access the care that they need when they need it without worrying about cost.⁹³

Committee view

- 3.74 The committee welcomes the Minister's announcement that there will be a memorial garden to recognise thalidomide survivors and their families at the National Arboretum, but considers that this is only a first step toward recognising the plight of Australia's thalidomide survivors and their families.
- 3.75 The committee notes that lump sum payments have been widely used by other governments around the world to either compensate thalidomide survivors and their parents for the government's role in the regulation of thalidomide or as a support payment to allow thalidomide survivors to invest in their health, home and car modifications or other supports they may need. Regardless of whether the payment is considered as compensation or a support payment, the committee notes that a lump sum would provide thalidomide survivors with the flexibility and independence to determine their own needs.
- 3.76 The committee notes that other countries around the world pay thalidomide survivors some form of ongoing pension, often in addition to a lump sum payment. The committee notes that most ongoing payments are provided on a scale according to the level of the survivor's injuries and provide a level of financial security for thalidomide survivors. The committee notes that in some systems there is a mechanism for thalidomide survivors to be reassessed if they consider that their condition has worsened. The committee considers that some thought should be given to how thalidomide survivors can be provided with increased support as they age.
- 3.77 The committee notes that there are a number of different mechanisms that may be able to be explored to ensure that appropriate payments can be made to thalidomide survivors.

⁹¹ Health Canada, *Minister of Health announces new financial support program for eligible Canadian thalidomide survivors*, 9 January 2019, (accessed 28 February 2019).

⁹² The Canadian Extraordinary Medical Assistance Fund recognises that the provincial public health systems are not set up to provide the specialised support that thalidomide survivors require.

⁹³ See, for example: Name withheld, *Submission 27*, [p. 1]; Name withheld, *Submission 40—Attachment 1*, [p. 1].

- 3.78 The committee considers that a health care card that entitled thalidomide survivors to free health or subsidised care for a broader range of services than is currently available with a Pensioner Concession Card would be extremely beneficial and would alleviate a significant financial burden.
- 3.79 The committee has already noted that the NDIS does not work for thalidomide survivors. Providing an Extraordinary Assistance Fund would alleviate a significant financial burden for thalidomide survivors and would be consistent with international approaches to supporting thalidomide survivors to obtain home modifications and vehicle adaptations that are unlikely to be accommodated under a thalidomide survivor's NDIS package.

Navigating supports

- 3.80 For thalidomide survivors to receive the greatest benefit from the services that currently exist and the supports that may be established, there will likely need to be some form of coordination. In its interim report, the committee noted that thalidomide survivors have experienced significant difficulty in applying for and obtaining the benefit of supports that have been made available to assist people with disabilities, including the Disability Support Pension, obtaining disabled parking permits and obtaining adequate support under the NDIS.⁹⁴ The committee also noted that, because of the particular and unusual nature of their injuries, thalidomide survivors' interactions with health professionals and public servants are frequently difficult and unsatisfactory.⁹⁵
- 3.81 These failures highlight a systemic lack of understanding about thalidomide injuries, meaning that thalidomide survivors have been left to educate others about the effects of thalidomide and how it affects their life.
- 3.82 Thalidomide survivors in other countries have the support of an organisation that can provide advice and coordinate access to services. In Chapter 4 of its interim report the committee recognised that in Japan, the United Kingdom, Canada and Germany there are organisations that exist to assist thalidomide survivors and to coordinate payments and services for thalidomide survivors. For example, as noted in the interim report, Ishizue, the Japanese support centre, manages payments, provides consultation for medical practitioners about thalidomide injuries, conducts research, consults on housing modifications and facilitates a mutual assistance forum to exchange information between survivors.⁹⁶

⁹⁴ Interim report, pp. 55–67.

⁹⁵ Interim report, pp. 49–52.

⁹⁶ Interim report, pp. 83–84.

- 3.83 In each of these countries the organisations that coordinate services for thalidomide survivors are funded by government.⁹⁷

Assistance with service agencies

- 3.84 In its interim report the committee recommended that a contact point in the Department of Human Services (DHS) be re-established and that contact points be established within the Department of Health and the NDIA to help thalidomide survivors to navigate the supports that are available within those agencies.⁹⁸
- 3.85 This recommendation was made after Mr Lance Fletcher, Founder and President of Thalidomide Australia Incorporated, told the committee that DHS had previously established a direct contact point that survivors could call as a 'one-stop shop for information regarding DHS inquiries and issues'.⁹⁹
- 3.86 Mr Fletcher informed the committee that the service worked well for survivors while it was established.¹⁰⁰
- 3.87 DHS confirmed to the committee that the direct contact point for thalidomide survivors no longer exists.¹⁰¹ DHS told the committee it operated the service for approximately two years from April 2013, however indicated that the service was ended due to low utilisation.¹⁰²
- 3.88 DHS responded to the recommendation in the committee's interim report calling for re-establishment of the position by advising that it did not consider that there was a need for a contact point:

[W]hile the Department appreciates the special and specific needs of thalidomide survivors, the Department does not see the need for a separate contact point and does not consider that separate contact points for each cohort of customers is the most effective way to provide services.¹⁰³

⁹⁷ See, for example, Ishizue, *Business Plan for fiscal year 2018*, p. 5 <http://www008.upp.so-net.ne.jp/ishizue/file/2018jigyokeikaku.pdf> (accessed 24 January 2019); Gov.UK, Health grant awarded to victims of thalidomide, 20 December 2012, <https://www.gov.uk/government/news/health-grant-awarded-to-victims-of-thalidomide> (accessed 14 January 2019); Thalidomide Victims Association of Canada, *Submission 59*, [p. 1]; Contergan Inforportal, *Special Payment*, https://www.contergan-infoportal.de/finanzen_recht/jaehrliche_zahlungen/sonderzahlung/ (accessed 22 January 2019).

⁹⁸ Interim report, Recommendation 2, p. 98.

⁹⁹ Mr Lance Fletcher, Founder and President, Thalidomide Australia Incorporated, *Committee Hansard*, 31 January 2019, p. 41.

¹⁰⁰ Mr Fletcher, *Committee Hansard*, 31 January 2019, p. 41.

¹⁰¹ Department of Human Services (DHS), answers to questions on notice, Question 1, [p. 1] (received 6 March 2019).

¹⁰² DHS, answers to questions on notice, Question 1, [p. 2] (received 6 March 2019).

¹⁰³ DHS, correspondence received 8 March 2019, [p. 1].

- 3.89 Instead, DHS suggested that customers with complex circumstances could access support 'through a Departmental service officer or specialist'.¹⁰⁴

Inclusion of unrecognised survivors

- 3.90 As noted in the interim report, there may be a group of thalidomide survivors in Australia who have not yet been recognised. During this inquiry the committee has been approached by individuals who consider they may be thalidomide survivors and are seeking assistance to have their injuries recognised. The Thalidomide Australia Fixed Trust has confirmed that it only receives funds for its 45 beneficiaries and that additional negotiation would be required to add any additional beneficiaries.¹⁰⁵ This means that, at present, there is no pathway for unrecognised thalidomide survivors to become recognised and access the same compensation and support as other survivors.
- 3.91 In Canada, Germany and the United Kingdom, the organisation that administers payments and coordinates supports for thalidomide survivors also manages the assessment of people who think they may be thalidomide survivors.¹⁰⁶
- 3.92 In the interim report, it was noted that the Royal Australian College of General Practitioners suggested that there should be a specialised assessment centre that unrecognised thalidomide survivors may be able to approach.¹⁰⁷ However, no such centre currently exists in Australia. If there was a specialised assessment centre with expertise in thalidomide injuries, it would enable people who thought they may be thalidomide survivors to have their injuries assessed and enable thalidomide survivors who have been identified with the ability to be reassessed if they believe their injuries have changed such that they require additional supports.
- 3.93 The committee has received evidence that there are a number of ways that thalidomide survivors can be assessed. One option is for a medical examination. In terms of determining whether a person is a thalidomide survivor, the committee received evidence that there are different opinions about when thalidomide can affect a foetus and what malformations thalidomide can cause. One view is that thalidomide primarily acts during a time sensitive window during which phocomelia and the other major damage that is usually associated with thalidomide is done.¹⁰⁸ A second view is that, if thalidomide is taken outside of that window, it causes mild damage to 'the

¹⁰⁴ DHS, correspondence received 8 March 2019, [p. 1].

¹⁰⁵ Thalidomide Australia Fixed Trust, correspondence received 19 March 2019, [p. 1].

¹⁰⁶ Health Canada, answers to questions on notice, Question 1, [p. 1] (received 28 February 2019).

¹⁰⁷ Interim report, p. 51.

¹⁰⁸ Professor Neil Vargesson, *Committee Hansard*, 31 January 2019, p. 5.

gastrointestinal tract, the cardiovascular system, the kidneys, the liver and the genitals'.¹⁰⁹ The committee heard that if the damage was only mild, it may not present until later in life.¹¹⁰ However, Professor Neil Vargesson noted that this more mild form of thalidomide damage is more difficult to assess as being caused by thalidomide exposure.¹¹¹

- 3.94 In terms of developing a consistent schema for determining the severity of thalidomide injuries, the committee noted in the previous chapter that the members of the team that conducted the assessments before the 2010 Diageo ex gratia payments commenced conducted their assessments in different ways.
- 3.95 The committee broadly understands that a holistic approach informed by the common law principles relating to the assessment of damages was used or at least reflects the payments that thalidomide survivors were ultimately awarded.
- 3.96 Another potential approach could be to recognise survivors based upon documentary evidence that their mother took a product containing thalidomide during pregnancy. In Canada, determining who is a survivor has been outsourced to the independent company that manage the thalidomide support program on behalf of Health Canada.¹¹² Applicants to that program are required to meet one of three eligibility criteria:
- verifiable information of the receipt of settlement from the drug company;
 - documentary proof of material use of a thalidomide product in the first trimester of pregnancy; or
 - have their name on a government list of thalidomide victims.¹¹³
- 3.97 Health Canada noted that given the passage of time those criteria are hard to satisfy. It noted that of 193 applications, only 25 were approved and most of these applications met the second criteria, documentary proof of use of thalidomide.¹¹⁴
- 3.98 A 2017 study by Canada's House of Commons Standing Committee on Health recommended that the Minister for Health review the eligibility criteria. Canada has announced that it is changing its approach to a 'fair and comprehensive approach to identifying thalidomide survivors that is based on international best practices'.¹¹⁵ However, as the new program has not opened

¹⁰⁹ Professor Vargesson, *Committee Hansard*, 31 January 2019, p. 6.

¹¹⁰ Professor Vargesson, *Committee Hansard*, 31 January 2019, p. 6.

¹¹¹ *Committee Hansard*, 31 January 2019, p. 6.

¹¹² Health Canada, answers to questions on notice, Question 1, [p. 1] (received 28 February 2019).

¹¹³ Health Canada, answers to questions on notice, Question 1, [p. 1] (received 28 February 2019).

¹¹⁴ Health Canada, answers to questions on notice, Question 1, [p. 2] (received 28 February 2019).

¹¹⁵ Health Canada, answers to questions on notice, Question 1, [p. 2] (received 28 February 2019).

yet, it is not clear what criteria the new program will use to determine eligibility.

Committee view

- 3.99 The committee considers that there needs to be a way of coordinating information, services and payments for thalidomide survivors. In its interim report, the committee made recommendations to improve the ability of thalidomide survivors to access information and services.
- 3.100 The committee notes that coordinating organisations have played a useful role supporting thalidomide survivors in other jurisdictions. This has included assistance to navigate the existing supports that thalidomide survivors may be able to access in addition to coordinating services that are specific to thalidomide survivors. For example, the Thalidomide Trust in the United Kingdom provides assistance to its thalidomide survivors with filling in forms to apply for forms of assistance they may be eligible for, in dealing with agencies and in explaining what thalidomide is and how it affects survivors.¹¹⁶ Evidence to the committee indicates that Australian thalidomide survivors would benefit from a similar form of assistance.
- 3.101 The committee also considers that regardless of the method used, there must be a mechanism for unrecognised thalidomide survivors to be identified and share in the supports that are available to thalidomide survivors. The committee considers that this needs to be done in a way that is fair and considerate to thalidomide survivors.

¹¹⁶ Thalidomide Trust, *Personal Independent Payment*, <https://www.thalidomidetrust.org/money-matters/benefits/pip/> (accessed 13 March 2019).

Chapter 4

Conclusions and recommendations

Our needs are real. Our needs are urgent. And our needs are immediate.¹

- 4.1 Throughout this inquiry, the committee has received evidence about the profound effect that thalidomide has had on the lives of survivors and their families. Thalidomide has left some of them with malformed limbs, robbed them of opportunities and has left them with progressively worsening health outcomes and severe pain.
- 4.2 In other countries, governments have recognised that in allowing products containing thalidomide to be sold they failed some of their most vulnerable citizens: pregnant women and their unborn children. In a bid to remedy their error and to apologise for the pain and suffering they caused, governments around the world have provided both financial support and non-financial support to maintain survivors' independence.
- 4.3 During the course of the committee's inquiry, other countries around the world have either decided to support their thalidomide survivors, or have increased their support. In January 2019, Canada doubled the size of the lump sum it offers survivors and increased the size of its Extraordinary Medical Assistance Fund to \$1 million CAD per year. In February 2019, Belgium announced a new scheme to support its thalidomide survivors. Australia's refusal to provide special measures for its thalidomide survivors is inconsistent with supports being provided in other countries.
- 4.4 With the exception of tax relief, the Australian Government has not provided financial assistance to thalidomide survivors. The Australian Government has not provided wheelchairs, or modified cars, or implemented special programs to provide assistance.

A moral obligation

- 4.5 The committee considers that the Australian Government has a responsibility to support Australia's thalidomide survivors. In Chapter 2 the committee noted that both the Australian and state governments had a role to play in the regulation of drugs in the early 1960s. The Australian Government was responsible for regulating importation of pharmaceutical drugs, while the state governments were responsible for regulating distribution and sale.
- 4.6 The Australian Government was warned as early as 1949 that it required additional controls on drugs that were being imported into Australia.² Those

¹ Thalidomide Group Australia, *Submission 1*, p. 3.

controls were not forthcoming. At a similar time, the United States of America and other countries already monitored drug safety.³ While the Australian Government worked on labelling and purity, it did not monitor the health effect that drugs might have on people, including unborn babies.

- 4.7 When it became clear in November 1961 that thalidomide was linked to birth defects and Distillers withdrew the drug from sale, neither the state governments nor the Australian Government took swift action to ban the importation of thalidomide or to prohibit its sale. Unlike other countries, no efforts were made to recall and destroy the product that was in doctors' clinics or pharmacies.
- 4.8 If the Australian Government had acted more swiftly, it has been estimated that approximately 20 per cent of Australia's thalidomide survivors may not have been affected.⁴
- 4.9 To date, the Australian Government has not accepted that it played a role in the thalidomide tragedy. For more than 50 years, the Australian Government has left thalidomide survivors without support and has maintained that Australia's constitutional arrangements, as they were understood at the time, mean that the Australian Government should not be held responsible for the thalidomide tragedy. The committee does not consider that joint responsibility during the 1960s absolves the Australian Government of its moral obligation to Australia's thalidomide survivors.

Apology

- 4.10 The committee recognises that the Minister for Health has announced the approval of a memorial garden at the National Arboretum in Canberra. In his statement, the Minister for Health acknowledged that the thalidomide tragedy was 'outside of the control' of the mothers of today's survivors. The committee recognises this is a welcome first step towards acknowledging the Australian Government's role, but thalidomide survivors both need and deserve 'more than just a plaque in a park'.⁵
- 4.11 Thalidomide survivors advised the committee that they consider an apology to be important both for themselves—for the years of inaction and lack of support—and for their mothers, many of whom blamed themselves for something that was beyond their control. An apology is an opportunity for the Australian Government to shoulder some of the responsibility for exposing

² Brett, *Historical recommendations by Governments, Royal Commissions and National Health & Medical Research Councils to prevent toxic and damaging pharmaceutical drugs entering Australia*, [p. 1] (tabled 31 January 2019).

³ John McEwen, *A History of Therapeutic Goods Regulation in Australia*, September 2007, pp. 10, 17.

⁴ Mr Peter Gordon, Senior Partner, Gordon Legal, *Committee Hansard*, 31 January 2019, p. 31.

⁵ Mary, *Committee Hansard*, 2 November 2018, p. 32.

these women and their children to danger. The committee considers that the Australian Government owes thalidomide survivors and their families a profound apology.

Recommendation 1

4.12 The committee recommends that the Australian Government apologise to Australian thalidomide survivors and their families.

Direct financial support

- 4.13 In the interim report, the committee recognised that the payments that thalidomide survivors had received to date were not meeting their specialised needs. The committee notes that the payments made by Diageo to both groups of thalidomide survivors have been calculated based on legal factors, including a consideration of what Diageo would be willing to pay.
- 4.14 As the Diageo ex gratia payments are not indexed to inflation and survivors' needs are growing, those payments are becoming inadequate to meet their increasing needs.
- 4.15 The Diageo ex gratia payments will expire in approximately 2028. Diageo has not ruled out the possibility of providing further financial support, but has advised the committee that any further financial support will not be of the same magnitude. Diageo advised the committee that in other countries governments have also made significant financial contributions to thalidomide survivors. Diageo told the committee that it would only consider further compensation after it understood the Australian Government's plan.
- 4.16 The committee notes that other countries around the world are taking steps to increase the level of support that they offer to thalidomide survivors.
- 4.17 The evidence the committee received throughout this inquiry demonstrates that thalidomide survivors have never received appropriate support to manage their complex healthcare and disability support needs. In the committee's view, direct financial support for each of Australia's thalidomide survivors by the Australian Government is long overdue. In addition, a mechanism must be developed to facilitate payment to those thalidomide survivors who have not yet been formally recognised.
- 4.18 The committee notes that in other countries thalidomide survivors have been paid a lump sum when they have first been recognised. In Canada and Germany this has been recognised as a payment to compensate for previous underinvestment in their health needs. In Belgium, a lump sum will be provided as compensation for pain and suffering.
- 4.19 The committee considers that the Australian Government should provide a lump sum payment as compensation for the considerable pain and suffering thalidomide has wreaked on survivors and their families. The committee

considers that the lump sum payment should be granted to the thalidomide survivors who were recognised in the 1970s, the group who were recognised through the more recent class action and any survivors who are identified in the future.

- 4.20 The committee notes that the Thalidomide Group Australia and other witnesses who appeared before the committee considered that tiered payments were a fair way to allocate payments. Provided people who may not yet be recognised as thalidomide survivors are able to be assessed on an equal basis with those who have been recognised, the committee considers that a lump sum payment that is scaled according to survivors' level of disability is highly appropriate.
- 4.21 The committee notes that this amount should not reduce the benefits or entitlements that thalidomide survivors are otherwise entitled to and should be exempt from income tax and the social security income test.

Recommendation 2

- 4.22 The committee recommends that the Australian Government provide all Australian thalidomide survivors who have been recognised by Diageo with a lump sum payment on a scale according to their level of disability that is exempt from income tax and the social security income test.**

Recommendation 3

- 4.23 The committee recommends that the Australian Government provide any person who has not yet received financial compensation with a lump sum payment as soon as they are recognised as a thalidomide survivor on an equivalent basis with those thalidomide survivors already recognised with a similar level of impairment.**
- 4.24 In other countries, governments have provided thalidomide survivors with an ongoing payment to provide them flexibility to invest in their needs as they see fit.
- 4.25 The committee received evidence that thalidomide survivors have very particular needs that may not be understood by someone that does not have a thalidomide injury. For example, in the interim report the committee noted that providing air conditioning or heating could potentially mean the difference between a thalidomide survivor being able to dress themselves and needing a carer to dress them.
- 4.26 In the United Kingdom, the health grant has provided thalidomide survivors with the flexibility to invest in what they need to manage their injuries and maintain their independence. In Germany, the increased annual payments meant that thalidomide survivors could receive the support they needed to live with dignity and manage their pain.

- 4.27 The committee notes that any ongoing government payment that is provided in Australia will be paid, at least initially, in conjunction with the Diageo ex gratia payments. The committee has already noted that the ex gratia payments are becoming increasingly inadequate because they are not increased with inflation.
- 4.28 The committee considers that ongoing annual payments will need to be indexed, not just so that they keep pace with inflation, but to take into account thalidomide survivors' increasing health needs.

Recommendation 4

- 4.29 The committee recommends that the Australian Government provide all Australian thalidomide survivors with an ongoing annual payment to provide them with flexibility to purchase the services they need. The committee considers that this annual payment should be increased over time to reflect thalidomide survivors' increasing health needs.**

Coordination centre

- 4.30 In Japan, Canada, the United Kingdom and Germany there is a centre, company, trust or foundation that provides payments and coordinates services for thalidomide survivors. In the interim report and in the previous chapter the committee noted the wide range of services that those centres provide and the benefits they provide to thalidomide survivors.
- 4.31 These centres provide a central point where thalidomide survivors can access support and where they can obtain reliable information, including about health professionals with an understanding of thalidomide injuries and who they should approach if they need modifications to a house or car to accommodate a lower level of mobility.
- 4.32 In the interim report, the committee asked the Department of Health to work with the relevant colleges to identify health professionals who have expertise in treating thalidomide injuries or would be prepared to develop a level of expertise in treating thalidomide injuries. Once those practitioners with relevant expertise have been identified, the committee considers that the central assessment and coordination centre could refer thalidomide survivors to the specialists in that network as needed.
- 4.33 The committee considers that there needs to be a way for a person who may not have been recognised as a thalidomide survivor to be assessed and share in the same financial and non-financial support as other thalidomide survivors. Even since the committee released its interim report, a number of people have approached the committee to ask how they can have their injuries assessed. The committee considers that a central coordinating point could facilitate and make decisions about eligibility to receive payments and other services based on international best practice.

Recommendation 5

- 4.34 The committee considers that the Australian Government should establish a centre to disseminate information and coordinate services for thalidomide survivors and currently unrecognised survivors.**

National Disability Insurance Scheme

- 4.35 Throughout this inquiry the committee has noted that the National Disability Insurance Scheme (NDIS) does not appear to work for thalidomide survivors. In particular the committee has noted issues regarding the adequacy of the packages and whether survivors' previous payments were being taken into account to reduce the level of support that may be available under the NDIS.
- 4.36 In the previous chapter the committee commented that it would be inconsistent if payments that were made to assist thalidomide survivors to purchase additional supports and were exempt from income tax and social security income tests were then considered in calculating the level of support available under the NDIS.
- 4.37 The committee notes that there is scope for the Chief Executive Officer of the NDIA to ignore the reduction amounts in certain cases. The committee considers that matters regarding compensation payments and any reduction amount involving thalidomide survivors should be referred to the Chief Executive Officer, or their delegate, for consideration.

Recommendation 6

- 4.38 The committee considers that the National Disability Insurance Agency should implement a policy to refer matters relating to compensation payments and reduction amounts involving thalidomide survivors to the Chief Executive Officer, or their delegate, for consideration.**

Extraordinary Assistance Fund

- 4.39 The committee notes that in other countries funds exist that can assist thalidomide survivors to modify their homes and vehicles. In the previous chapter, the committee set out how the fund works in Canada. Given evidence to this inquiry demonstrates that NDIS packages are inadequate to meet the costs of such modifications, the committee considers that a fund should be established to assist thalidomide survivors with major expenditure, such as modifying homes and vehicles.
- 4.40 The committee considers that such a fund should be administered by the centre that coordinates supports for Australian thalidomide survivors. The committee considers that this funding would be available to thalidomide survivors upon application, similar to the Canadian assistance fund.

Recommendation 7

- 4.41 The committee recommends that the Australian Government establish an Extraordinary Assistance Fund to aid thalidomide survivors to meet major expenses such as home and vehicle modifications.**

Health support

- 4.42 The committee notes that thalidomide survivors have very particular health needs. However, the need for access to a broader range of health services than bulk-billed General Practitioner visits and hearing tests and rehabilitation is not unique to thalidomide survivors.
- 4.43 The Thalidomide Group Australia requested a health card that would allow access to a similar range of services as those permitted under a Department of Veterans' Affairs Gold Card. The committee notes that no such card exists outside of the defence context. However, the committee believes that consideration should be given to developing a health care card that can be provided to groups of people whose injuries can, in part or in whole, be attributed to the actions of the Australian Government.

Recommendation 8

- 4.44 The committee recommends that the Department of Social Services and the Department of Health consider developing a health care card that could provide access to a broader range of health services than are available under the Pensioner Concession Card that could be provided to people in circumstances where they require a higher level of care or in special circumstances.**

Records of assessments

- 4.45 The committee notes that thalidomide survivors' bodies are deteriorating and their function is becoming more limited. On that basis, the committee considers that it is important for thalidomide survivors to be able to have access to records about their own health to assist them to demonstrate, if necessary, how their function has deteriorated over time.
- 4.46 The committee notes that Mr Peter Semmler QC had indicated that he retains copies of survivors' individual assessments from 2010 and Diageo has undertaken to investigate its records to find if it holds copies of survivors' assessments. The committee considers that having access to these records would assist thalidomide survivors and, with their consent, those people providing them with medical care.

Recommendation 9

- 4.47 The committee recommends that Diageo expedite the examination of its archives to determine if it retains copies of assessments of thalidomide**

survivors' disabilities and, if it finds relevant documents, offer to make copies of those documents available to the thalidomide survivors to whom they pertain at no cost.

Public interest immunity claim

- 4.48 The committee notes that Senator the Hon. Bridget McKenzie made a claim of public interest immunity over the contents of the Maddocks Lawyers' advice on the basis that it constitutes legal advice to government.
- 4.49 The committee does not consider that the Minister's claim satisfies the process the Senate has prescribed for public interest immunity claims. Specifically, the Minister's claim does not identify the harm to the public interest that could result from the disclosure of the document. As the advice would allow for a better understanding of the legal context in which the Australian Government is being asked to respond, the committee considers that it is in the public interest for the document to be released.

Recommendation 10

- 4.50 **The committee recommends that the Australian Government publish the Maddocks Lawyers' advice.**

Support from Grünenthal

- 4.51 The committee notes that Grünenthal is yet to provide any support to Australia's thalidomide survivors. The committee considers that Grünenthal as the manufacturer of the drug played a major role in the thalidomide tragedy in Australia and that Australia's thalidomide survivors deserve to have their injuries recognised by all parties concerned. The committee received some evidence that the Australian Government may be able to seek to recover money from Grünenthal to support Australia's thalidomide survivors. The committee considers that the Australian Government should investigate what possible options may be available to recover money from Grünenthal to help compensate Australia's thalidomide survivors.

Recommendation 11

- 4.52 **The committee recommends that the Australian Government consider options to recover money from Grünenthal GmbH to support Australia's thalidomide survivors.**

Senator Rachel Siewert
Chair

Appendix 1

Submissions and additional information

Submissions

- 1 Thalidomide Group Australia
 - Attachment 1
 - Attachment 2
- 2 Department of Health
- 3 Department of Social Services
- 4 UK Thalidomide Campaigns Team
- 5 Professor Richard Madden
- 6 *Name Withheld*
- 7 *Confidential*
- 8 *Name Withheld*
- 9 *Name Withheld*
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- 22 *Name Withheld*
- 23 *Name Withheld*
- 24 *Confidential*
- 25 *Name Withheld*
- 26 *Confidential*
- 27 *Name Withheld*
- 28 *Name Withheld*
- 29 *Name Withheld*
- 30 *Name Withheld*
- 31 NESOS Board of Dutch Thalidomide survivors
- 32 *Name Withheld*
- 33 *Confidential*
- 34 *Confidential*
- 35 *Name Withheld*

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- 43 *Name Withheld*
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- 47 *Name Withheld*
- 48 *Name Withheld*
- 49 *Name Withheld*
- 50 *Name Withheld*
- 51 *Name Withheld*
- 52 *Confidential*
- 53 Interessenverband Contergangeschädigter Nordrhein-Westfalen e.V. and
International Contergan / Thalidomide Alliance
 - Attachment 1
- 54 *Name Withheld*
- 55 *Confidential*
- 56 *Confidential*
- 57 *Name Withheld*
- 58 *Confidential*
- 59 Thalidomide Victims Association of Canada
 - Attachment 1
 - Attachment 2
- 60 *Name Withheld*
- 61 UK Thalidomide Society
 - Attachment 1
- 62 Professor Neil Vargesson
- 63 Ms Liz Newbronner
- 64 *Name Withheld*
- 65 Grünenthal GmbH
- 66 Mr Peter Gordon
- 67 Professor Janet McCredie
- 68 *Confidential*
- 69 *Name Withheld*
- 70 Diageo Australia
 - Attachment 1
- 71 *Confidential*

Additional Information

- 1 Journal article: The changing health of Thalidomide survivors as they age: A scoping review, E. Newbronner, K. Atkin and D. Phil, from Thalidomide Group Australia, received 1 October 2018
- 2 Report: Study on the current living conditions of Canadian thalidomide survivors and their projections for their future, Thalidomide Victims Association of Canada, from Thalidomide Group Australia, received 1 October 2018
- 3 Rebuttal to Department of Health's answers to questions on notice from Melbourne public hearing, from Thalidomide Group Australia, received 8 January 2019
- 4 Further information following appearance at Sydney public hearing, from Professor Neil Vargesson, received 1 February 2019
- 5 Response to comments from Thalidomide Group Australia regarding Department of Health's answers to questions on notice, from Department of Health, received 6 February 2019
- 6 Further information following appearance at Sydney public hearing, from Professor Neil Vargesson, received 6 February 2019
- 7 Further information, from Professor Janet McCredie, received 11 February 2019
- 8 Article: Maggie De Block keeps her word: sixty years later, 5 million euros for the victims of Softenon, from Thalidomide Group Australia, received 14 February 2019
- 9 Information relating to the 2010 Diageo assessment process, from Mr Peter Semmler QC, received 27 February 2019

Answer to Question on Notice

- 1 Answers to Questions taken on Notice during 2 November public hearing, received from Thalidomide Group Australia, 20 November 2018
- 2 Answers to Questions taken on Notice during 2 November public hearing, received from Department of Social Services, 27 November 2018
- 3 Answers to Questions taken on Notice during 2 November public hearing, received from Department of Health, 27 November 2018
- 4 Answers to written Questions on Notice, received from Thalidomide Group Australia, 24 January 2019
- 5 Answers to written Questions on Notice, received from Australian College of Rural and Remote Medicine, 25 January 2019
- 6 Answers to written Questions on Notice, received from National Disability Insurance Agency, 29 January 2019
- 7 Answers to written Questions on Notice, received from Northern Territory Government, 30 January 2019
- 8 Answers to written Questions on Notice, received from Department of Health, 31 January 2019

- 9 Answers to written Questions on Notice, received from Royal Australian College of General Practitioners, 1 February 2019
- 10 Answers to written Questions on Notice, received from Queensland Government, 1 February 2019
- 11 Answers to written Questions on Notice, received from Tasmanian Government, 5 February 2019
- 12 Answers to written Questions on Notice, received from ACT Government, 15 February 2019
- 13 Answers to written Questions on Notice, received from NSW Government, 21 February 2019
- 14 Answers to written Questions on Notice, received from WA Government, 26 February 2019
- 15 Answers to Questions taken on Notice during 31 January public hearing, received from Thalidomide Australia Fixed Trust, 7 February 2019
- 16 Answers to Questions taken on Notice during 31 January public hearing, received from National Disability Insurance Agency, 7 February 2019
- 17 Answers to Questions taken on Notice during 31 January public hearing, received from Department of Health, 22 February 2019
- 18 Answers to written Questions on Notice, received from Mr Peter Semmler QC, 27 February 2019
- 19 Answers to written Questions on Notice, received from Health Canada, 28 February 2019
- 20 Answers to written Questions on Notice, received from Gordon Legal, 1 March 2019
- 21 Answers to written Questions on Notice, received from Diageo, 1 March 2019
- 22 Answers to written Questions on Notice, received from Department of Human Services, 6 March 2019
- 23 Answers to written Questions on Notice, received from Department of Finance, 6 March 2019
- 24 Answers to written Questions on Notice, received from National Disability Insurance Agency, 7 March 2019
- 25 Answers to written Questions on Notice, received from Department of Veterans' Affairs, 8 March 2019
- 26 Answers to written Questions on Notice, received from Australian Taxation Office, 12 March 2019
- 27 Answers to written Questions on Notice, received from Department of Social Services, 13 March 2019

Correspondence

- 1 Letter from private individual, received 13 October 2018
- 2 Letter from private individual, received 12 October 2018
- 3 Letter from private individual, received 11 October 2018
- 4 Letter from private individual, received 10 October 2018

- 5 Letter from private individual, received 9 October 2018
- 6 Letter from private individual, received 9 October 2018
- 7 Letter from private individual, received 8 October 2018
- 8 Letter from private individual, received 8 October 2018
- 9 Letter from private individual, received 8 October 2018
- 10 Letter from private individual, received 8 October 2018
- 11 Letter from private individual, received 10 October 2018
- 12 Letter from private individual, received 14 September 2018
- 13 Letter from private individual, received 11 October 2018
- 14 Letter from private individual, received 23 October 2018
- 15 Letter from private individual, received 21 October 2018
- 16 Correspondence clarifying statements made at Melbourne public hearing on 2 November 2018, received from Thalidomide Group Australia, 20 November 2018
- 17 Letter from Minister for Communities and Minister for Disability Services and Seniors to Chair of the Community Affairs References Committee, dated 22 January 2019; and letter from Premier of Queensland to Prime Minister of Australia, dated 2 September 2015, received from Queensland Government, 22 January 2019
- 18 Response to conclusions and recommendations contained in the interim report, received from Department of Human Services, 8 March 2019
- 19 Response to conclusions and recommendations contained in the interim report, received from Department of Health, 12 March 2019
- 20 Response to conclusions and recommendations contained in the interim report, received from Royal Australian College of Physicians, 12 March 2019
- 21 Correspondence clarifying the role of the Trust, received from Thalidomide Australia Fixed Trust, 19 March 2019
- 22 Response to conclusions and recommendations contained in the interim report, received from Department of Social Services, 22 March 2019

Tabled Documents

- 1 Historical recommendations by Governments, Royal Commissions and National Health & Medical Research Councils to prevent toxic and damaging pharmaceutical drugs entering Australia, tabled by Brett, at Sydney public hearing, 31 January 2019

Appendix 2

Public hearings

Friday, 2 November 2018

Flagstaff 1 and 2 Room
Radisson on Flagstaff Gardens Hotel
380 William Street
Melbourne

Thalidomide Group Australia

- Ms Lisa McManus, Director

National Advisory Council to the Thalidomide Trust

- Miss Michaelina Argy, Deputy Chair

Barbara-Ann, private capacity

Rick, private capacity

Nola, private capacity

Alice, private capacity

Andrew, private capacity

Mary, private capacity

Amanda, private capacity

Department of Health

- Ms Lisa Studdert, Deputy Secretary
- Ms Elizabeth Flynn, Assistant Secretary, Preventive Health Branch

Department of Social Services

- Ms Nerida Hunter, Acting Group Manager
- Mr Shane Bennett, Group Manager, Payments Policy Group
- Mr Terry Strong, Acting Branch Manager, Disability Employment Services
- Mrs Kath Paton, Acting Branch Manager, Families and Pensions

Thursday, 31 January 2019

Macquarie Room
NSW Parliament
6 Macquarie Street
Sydney

Professor Janet McCredie, Private capacity

Dr Debra Kennedy, Private capacity

Professor Neil Vargesson, Private capacity

Ms Elizabeth Newbronner, Private capacity

Thalidomide Australia Fixed Trust

- Mr Tim Kelly, Trustee

Lance, private capacity

Vicki, private capacity

Andrew, private capacity

Mark, private capacity

Patricia, private capacity

Susan, private capacity

Joanne, private capacity

Fiona, private capacity

Gordon Legal

- Mr Peter Gordon, Senior Partner

Rightside Legal

- Mr Michael Magazanik, Partner

Michelle French and Associates

- Ms Michelle French, Director
- Ms Amanda Cullen, Director

Thalidomide Australia Incorporated

- Mr Lance Fletcher, President and Founder
- Mrs Lesley Fletcher, Former Secretary and Founder

Ken, private capacity

Suanne, private capacity

Brett, private capacity

Greg, private capacity

Lou, private capacity

Department of Health

- Dr Lisa Studdert, Deputy Secretary
- Dr Jane Cook, First Assistant Secretary, Medicines Regulation Division, Health Products Regulation
- Ms Jacinta McDonald, Director, Chronic Disease Policy, Population Health and Sport Division
- Dr John McEwen, Medical Adviser, Therapeutic Goods Administration

National Disability Insurance Agency

- Ms Vicki Rundle, Deputy Chief Executive Officer
- Ms Chris Faulkner, General Manager Advisory Services