



Stillbirth  
Foundation  
AUSTRALIA

# Submission to the **Senate Select Committee** on Stillbirth Research and Education

June 2018

[www.stillbirthfoundation.org.au](http://www.stillbirthfoundation.org.au)

**MORE NEEDS TO BE DONE TO ADDRESS THIS HEALTH CRISIS  
ARE YOU ON OUR SIDE?**



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# Message from the CEO

Six babies are stillborn every single day in Australia.

Families go through unimaginable grief, are too often provided with little explanation and instead of taking home a newborn baby, they take home a lifetime of questions and pain.

Stillbirth Foundation Australia submits that health policy in Australia has failed these babies and their families and that serious action must be taken to save more lives.

The numbers have not improved in decades and that is just not good enough.

The Senate Select Committee on Stillbirth Research and Education can begin a journey towards replacing heartbreak with hope. The Foundation urges it to do so.

Australia is a generous and rich nation, with a proud history of medical innovation, advancement and first-class health care.

The establishment of the Committee offers the first real opportunity to drive positive change from the Federal Government at a national level, and we urge the Committee to seize this opportunity.

The Foundation strongly believes that research and education holds the key to saving more lives. This submission will expand on this thesis, highlighting the current deficiencies in data collection, research, education and communication and potential avenues for reform.

The Foundation accepts and understands that the Committee is not specifically examining issues around clinical care and hospital management, as this is predominantly an issue for the states, and as a result this submission does not explore this. The Foundation however notes that this is an extremely important aspect of improving the current situation, which is worth discussing soon.

The Foundation thanks the Committee for the opportunity to provide this submission and would welcome the opportunity to elaborate further in a public hearing.

For more information about the Foundation, visit [www.stillbirthfoundation.org.au](http://www.stillbirthfoundation.org.au) or contact the Foundation on 02 9557 9070.

Yours sincerely,

Victoria Bowring  
Chief Executive Officer



# Executive Summary

This submission has been prepared by the Stillbirth Foundation Australia (**Foundation**) in response to the establishment by the Senate on 27 March 2018, of the Select Committee on Stillbirth Research and Education (**Committee**) to inquire and report on the future of stillbirth research and education in Australia.

The Foundation thanks the Senate and the Senators on the Committee for their work with this Inquiry and welcomes the opportunity to provide this submission.

The Foundation is the first Australian charity dedicated to stillbirth research. We are 100 per cent community funded.

The Foundation is recognised nationally as a leading voice on stillbirth and represents the voices of thousands of Australian families who have been touched by stillbirth.

Our mission is to significantly reduce the incidence of stillbirth through research, education and advocacy.

As the Foundation has no vested interest in to the provision of a service or a single research entity, we are uniquely positioned and have complete sector visibility and support the work done across the spectrum of stillbirth, from funding research into prevention, to time of loss support and to post-loss initiatives. As such the Foundation is the appropriately positioned entity to partner with on new initiatives.

The Foundation notes that health policy in Australia has so far failed in regard to addressing stillbirth and that a comprehensive approach needs to be taken to address the issue.

This Inquiry presents an opportunity to do five key things:

- increase awareness about the issue in the community;
- focus the minds of our political leaders on the issue;
- allow families and individuals touched by stillbirth to be heard;
- analyse and invest in more research so families can be given answers; and,
- create real, tangible change in policy settings that will result in lives being saved.

The Foundation argues for a greater focus and more research on identifying the causes and factors that we don't know about, as well as more education to better communicate with parents and medical practitioners alike, about the risk factors, mitigation strategies and warning signs we do know about.

Ensuring we have reliable data is key and securing predictable and targeted levels of funding for research, education and awareness raising is also vitally important.

Ideally, this will be achieved by a strategic and well-considered policy response from Federal Government, which is long overdue. Not a piecemeal approach but rather, a coherent policy



roadmap that sets out priorities, has measurable targets and the necessary funding behind it.

In this submission we outline the issues and recommendations in relation to the four core mechanisms that the Foundation considers need to be better addressed to reduce the rate of stillbirth in Australia:

- Medical practitioner education;
- Public education;
- Research; and,
- Data collection

Each of these areas in and of themselves can contribute to the reduction of the rate of stillbirth, however the Foundation is hopeful that a more coordinated approach is adopted so as to achieve that goal.

**Therefore, our principal recommendation is that a National Action Plan for Stillbirth be developed and implemented, in a process which involves key stakeholders such as medical practitioners, midwives and nurses, health bureaucrats, families who have experienced stillbirth and representative groups such as the Stillbirth Foundation Australia.**

This submission has been informed by the Foundation's experience, the input of bereaved parents and the input of experts.



# Stillbirth Snapshot

*Terms of Reference subparagraph (g):*

*Quantifying the impact of stillbirths on the Australian economy.*

In Australia, it is commonly accepted that six babies are stillborn every day on average, making it the leading cause of death in children under twelve months of age.

The Australian Institute of Health and Welfare defines stillbirth in Australia as the birth of a baby who is 20 or more completed weeks of gestation or of 400 grams or more birthweight who is expelled or extracted from his or her mother and shows no signs of life such as a heartbeat, voluntary muscle movement or pulsation of the umbilical cord<sup>1</sup>.

A significant proportion of these deaths go unexplained, and the stillbirth rate has remained largely unchanged for several decades<sup>2</sup>.

As well as this tragic human cost, according to a 2016 PwC report, *The Economic Impacts of Stillbirth in Australia*<sup>3</sup>, commissioned by the Foundation, the economic cost of stillbirth is estimated to be \$681 million over the five years from 2016 to 2020.

About \$170 million of this total is made up of additional direct financial costs (e.g. hospital fees, investigations, counselling) and about \$510 million includes indirect financial costs (e.g. funeral costs, absenteeism, productivity losses, divorce and government subsidies). Significantly, this figure only accounts for the first 12-months post loss and does not include the economic impact of parents who never enter the workforce because of stillbirth.



Table 1 Economic Impact of Stillbirth. Source: PwC

<sup>1</sup> Definition from National Health Data Dictionary (AIHW 2012)

<sup>2</sup> <https://www.aihw.gov.au/reports/mothers-babies/perinatal-deaths-in-australia-1993-2012/contents/table-of-contents>

<sup>3</sup> <http://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf>



# Medical Practitioner Education

*Terms of Reference subparagraph (e):*

*Research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education.*

## Issue

Significant issues occur at the medical practitioner level, including:

- inconsistent practice by health professionals when pregnant women express concerns;
- inconsistency in following the list of recommended core investigations following a stillbirth as per the Clinical Practice Guideline for Perinatal Mortality published by the Perinatal Society of Australia and New Zealand (PSANZ);
- inconsistency in following the PSANZ guideline in relation to management protocols for clinicians caring for women presenting with decreased fetal movement (DFM);
- inconsistent and misleading information provided to expectant mums by health care professionals, media and health literature; and
- admitted hospital errors, but failure to rectify the system.

While some of these issues may fall outside the scope of the Committee's Inquiry, the Foundation is of the strong view that relatively simple measures, which the Federal Government could initiate, can be put in place.

As mentioned above, PSANZ produces two key guideline: the Clinical Practice Guideline for Perinatal Mortality and the Care pathway for women presenting with DFM guideline.

### Clinical Practice Guideline for Perinatal Mortality

The first guideline outlines how to provide high-quality, systematic care around the time of a perinatal death.

It includes investigations and audits, and bereavement care for parents across Australia and New Zealand.

### Care pathway for women presenting with DFM guideline

The second guideline is an evidenced-based approach to improve the management and outcome of care for women with DFM.

This guideline covers two key areas: information provided to pregnant women regarding DFM, and management protocols for clinicians caring for women presenting with DFM.

This guideline has recently been updated, and details a care pathway that should be adopted for women presenting with DFM from 28 weeks' gestation (see Appendix A).



## What the Foundation is currently doing

As part of the Foundation's public health campaign outlined further below, clinicians and health professionals will be provided with resources to inform them about best practice approaches to managing stillbirth.

## Recommendation

**1.1** The Foundation recommends that the Federal Government encourages the States and Territories to mandate the use of the PSANZ guidelines.

**1.2** The Foundation also recommends improving understanding and awareness of stillbirth among health professionals working at every stage in the clinical pathway. This would be achieved through the development of resources which are made available online that address common scenarios to improve practice. These resources would include the current PSANZ guidelines on DFM, but would address topics such as:

- Management of growth restriction;
- Recognising and addressing risk factors;
- Supporting families at time of stillbirth diagnosis;
- Discussing benefits of an autopsy with parents;
- Best practice around investigation of a stillbirth;
- Ongoing support of families after stillbirth;
- Review of contributing factors around a stillbirth;
- Timely reporting of stillbirth; and
- Completion of perinatal death forms.



# Public Education

*Terms of Reference subparagraphs (e) and (f):*

*Research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education; and*

*Communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy.*

## Issue

Public education campaigns are vitally important if we are to affect real behavioral change in regard to the stillbirth rate.

Too often, families are not informed about the risks of stillbirth and the potential preventive steps that can be taken during pregnancy. An extremely common refrain to the Foundation is from families who have experienced stillbirth, yet were uninformed about the potential or possible risks of a stillbirth occurring, or the ways that they could reduce the chances of it occurring.

This must change. We can invest in research, but if we are not translating those research outcomes into practical information for expectant mothers, the research is not doing its job and not fulfilling its potential.

## What the Foundation is currently doing

The Foundation is currently developing a public health campaign to inform the community about the importance of maternal sleep position and settling to sleep on your side during pregnancy.

Research supporting this is available at Sydney Stillbirth Study<sup>4</sup> and additional international studies that corroborate this research are the MINESS Study<sup>5</sup> from the UK and the New Zealand Multi Centre Stillbirth Study<sup>6</sup>.

This campaign will be first aimed at bereaved parents to reduce guilt associated with the retrospective information. It will then be aimed more broadly to the public with positive messaging around the importance of side sleeping for expectant mothers. Clinicians and

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<sup>4</sup>[https://journals.lww.com/greenjournal/Fulltext/2015/02000/Sleep\\_Position,\\_Fetal\\_Growth\\_Restriction,\\_and\\_.10.aspx](https://journals.lww.com/greenjournal/Fulltext/2015/02000/Sleep_Position,_Fetal_Growth_Restriction,_and_.10.aspx)

<sup>5</sup><https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/1471-2393-14-171>

<sup>6</sup> <https://www.auckland.ac.nz/en/about/news-events-and-notice/news/news-2017/06/sleeping-on-back-increases-stillbirth-risk.html>



health professionals will also be a focus, and it is hoped that this campaign alone could potentially save 200 children annually in Australia – just by getting better information out there.

The campaign is currently being funded through community donations.

## **Recommendation**

**2.1** The Foundation strongly recommends that funding be allocated to publically communicate research outcomes in a practical and informative way to target audiences across multiple channels.

This would work to inform the community of the warning signs, risk factors and known ways to reduce stillbirth.

Messaging should also work to destigmatise stillbirth, build community understanding and reduce the impact on grieving families.

This should include culturally and linguistically appropriate information for Aboriginal and Torres Strait Islander families and multicultural families.

It should not fall to the fundraising efforts of people who have experienced stillbirth (and their friends and family) to raise awareness about the factors that can reduce the chances of it occurring. The evidence is available to governments and medical practitioners, and they should have respective roles in funding and disseminating the critical information.



# Research

*Terms of Reference subparagraphs (c), (d) and (e):*

*Partnerships with the corporate sector, including use of innovative new technology;*

*Sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support; and*

*Research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education.*

## Issue

Research plays a critical role in understanding stillbirth and its prevention. Currently, there is a lack of coordination and long-term planning on identifying research priorities and funding them appropriately.

There is also a lack of collaboration between the private sector, potential philanthropic supporters and government in regard to research and innovation.

Pregnancy is a unique period and represents an opportunity when research can be done at a greater scale than the current traditional approaches.

The Foundation is in a unique position to work across these three sectors and has significant experience in working with them individually however, a lack of resources and coordination at a government level makes this difficult.

We are confident that a more strategic, properly funded and comprehensive research approach will improve prevention techniques and save more lives – and the reason for that confidence is that it's happened before.

When effort was focused on SIDS from about 1986, governments and the charity sector worked together to reduce the rate by 86 per cent through education programs and research.

While there are still SIDS tragedies – the rate is far lower compared to what we saw before. The same approach could deliver the same kind of results for stillbirth.

## What the Foundation is currently doing

The Foundation has been a consistent supporter and funder of research initiatives throughout the country. Since 2009, Foundation supporters have funded more than \$1 million in research projects.



As well as funding traditional research projects, the Foundation is currently planning to partner with existing technology suppliers such as Fitbit, Apple Health and Google to harness data on pregnant women and develop innovative preventative stillbirth solutions.

The Foundation believes that one big research breakthrough has the potential to lead to a significant reduction in the stillbirth rate. To ignore the potential offered by the large advances in technology, in the form of data aggregation, computer learning and wearable monitoring devices would be negligent. In the search for a solution no stone should remain unturned and every opportunity evaluated carefully. As the Foundation has no vested interest in any particular area of research facility, it is appropriately independent and would relish the opportunity to partner in progressing a broad and comprehensive research program of works.

Central to research efforts must also be a recognition that whilst stillbirth does not discriminate, there are health inequities that cannot be tolerated, including amongst Aboriginal and Torres Strait Islanders and other culturally and linguistically diverse communities.

## **Recommendation**

**3.1** The Foundation recommends an audit of current Federal Government funding dedicated to stillbirth research.

**3.2** The Foundation also recommends the introduction of a dedicated stillbirth research fund administered by an independent organisation with clear priorities and predictable, annual funding. The Foundation would like to be considered as the partner entity to perform this important and independent role.

This research should examine the potential causes of stillbirth, including known and unknown risk factors.



# Data

*Terms of Reference subparagraph (a):*

*Consistency and timeliness of data available to researchers across states, territories and federal jurisdictions.*

## Issue

While it is commonly accepted that six stillbirths occur every day in Australia, there are significant discrepancies in the figures held by government agencies and internationally, and the associated methodologies.

There are some issues where we need to transcend the constraints of our federated health system.

Stillbirths are currently reported by the Australian Bureau of Statistics (**ABS**), Australian Institute of Health and Welfare (**AIHW**) and internationally by the World Health Organisation (**WHO**), amongst others.

Inconsistency occurs across all agencies in figures published, how they are reported and when they are reported.

In 2016, AIHW reported that there were 2,255 stillbirths in 2012, while the ABS reported the figure at 1,832 for the year 2012. A similar discrepancy was also evident for 2011.

### Australian Institute of Health and Welfare

Year	2011	2012
Stillbirths	2,230	2,255

*Table 2 Number of stillbirth deaths, 2011 and 2012, Australia. Source: AIHW*

### Australian Bureau of Statistics

Year	2011	2012
Stillbirths	1,748	1,832

*Table 3 Number of stillbirth deaths, 2011 and 2012, Australia. Source: ABS*

## What the Foundation is currently doing

The Foundation has been consistently calling for improvements to the way data is collected, reported and analysed. If you can measure it, you can identify it, and fix it and it is clear greater consistency and reliability in the data is required.



## Recommendation

**4.1** The Foundation recommends an audit of existing published data, including methodologies, be undertaken to determine its reliability.

**4.2** In order to achieve this, the Foundation recommends the harmonisation of legislation and processes in each state and territory across Australia, such that there is more timely and accurate reporting. There needs to be a national standard so that all deaths are reported within four weeks, reviewed within three months, and contributing factors reported within six months.

The Foundation is of the view that a more comprehensive and consistent approach to data collection, stillbirth review and publication be implemented, which could include mandating reporting from one agency, either as a standalone report or as part of a broader health report.

This data should include raw data broken down at a granular level so that trends can be extrapolated, including data on Aboriginal and Torres Strait Islander communities, by postcode, ethnicity and the like. This data should be made available to the private sector, researchers and relevant organisations to encourage a collaborative environment.

# Principle Recommendation - National Action Plan for Stillbirth

A strategic and well-considered stillbirth policy response from the Federal Government, in the form of a National Action Plan for Stillbirth, is the Foundation's principle recommendation.

This Action Plan incorporates the recommendations outlined above in one coherent policy response.

In this submission we have outlined the issues and recommendation that need to be better addressed to reduce the rate of stillbirth in Australia:

- Medical practitioner education;
- Public education;
- Research; and
- Data collection

Ultimately, it is the Foundation's strong view that these recommendations and issues should be considered together in a comprehensive way through a National Action Plan.



This approach would see the Federal Government partner with organisations like the Foundation, bereaved families and experts, to develop a comprehensive approach to addressing stillbirth.

An Action Plan would deliver a coherent policy roadmap that sets out priorities, has measurable targets and the necessary funding behind it.

The Foundation recommends the establishment of this Action Plan be initiated as soon as possible and that it set out specific goals as we have articulated above. In summary, these are:



- Development of resources for medical professionals (recommendations 1.1, 1.2);
- Development of community educational resources (recommendation 2.1);
- Development of an ambitious research strategy (recommendations 3.1, 3.2); and
- Improved data processes (recommendations 4.1, 4.2)

Australia should be ambitious in how it addresses this scourge of stillbirth, and the Foundation believes a National Action Plan for Stillbirth is the optimal approach.

We have seen a similar approach recently with the National Action Plan for Endometriosis being developed by the Federal Government, and a similar model could work for stillbirth.

A further example in the United Kingdom demonstrates a suitably ambitious approach. Recently, the United Kingdom set out to halve the rates of stillbirths, neonatal and maternal deaths and brain injuries occurring during or soon or after birth by 2025, bringing forward their previous 2030 target. If achieved this would save more than 4,000 thousand lives.<sup>7</sup>

Under the banner of *Improving the safety of maternity care in the NHS*, the UK package included some very worthwhile approaches:

- Significant investment in training NHS staff to better deal with maternal care;
- Investment in research and a pilot program to improve maternity care;
- Standardising and updating data;
- A new national Maternal and Neonatal Health Quality Improvement program that will allow health districts to exchange ideas and best practice – a similar scheme in Scotland was linked to a 19 per cent decrease in stillbirths over a 3 year period; and
- Consultation to develop a 'safe space' to allow clinicians to speak openly about things that go wrong without fear that information they disclose may be used against them in court or professional misconduct hearings.

There is no reason why Australia could not be as ambitious as the UK and the Foundation urges the Committee to consider this recommended approach to save more babies' lives.

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<sup>7</sup> <https://www.gov.uk/government/news/new-maternity-strategy-to-reduce-the-number-of-stillbirths>



# Conclusion

In this submission, the Foundation has outlined the key issues concerning stillbirth research and education.

We have focused on medical practitioner education, public education, research and data collection. As we have articulated, there are a number of issues that we believe can be addressed and must be addressed, through a coordinated policy response.

If we do this, we can go a long way to fixing a public policy crisis that has not received the attention it deserves.

For too long, too many families in Australia have suffered and continue to live with the pain of stillbirth. Together we can change this for the better and save more lives in the future.

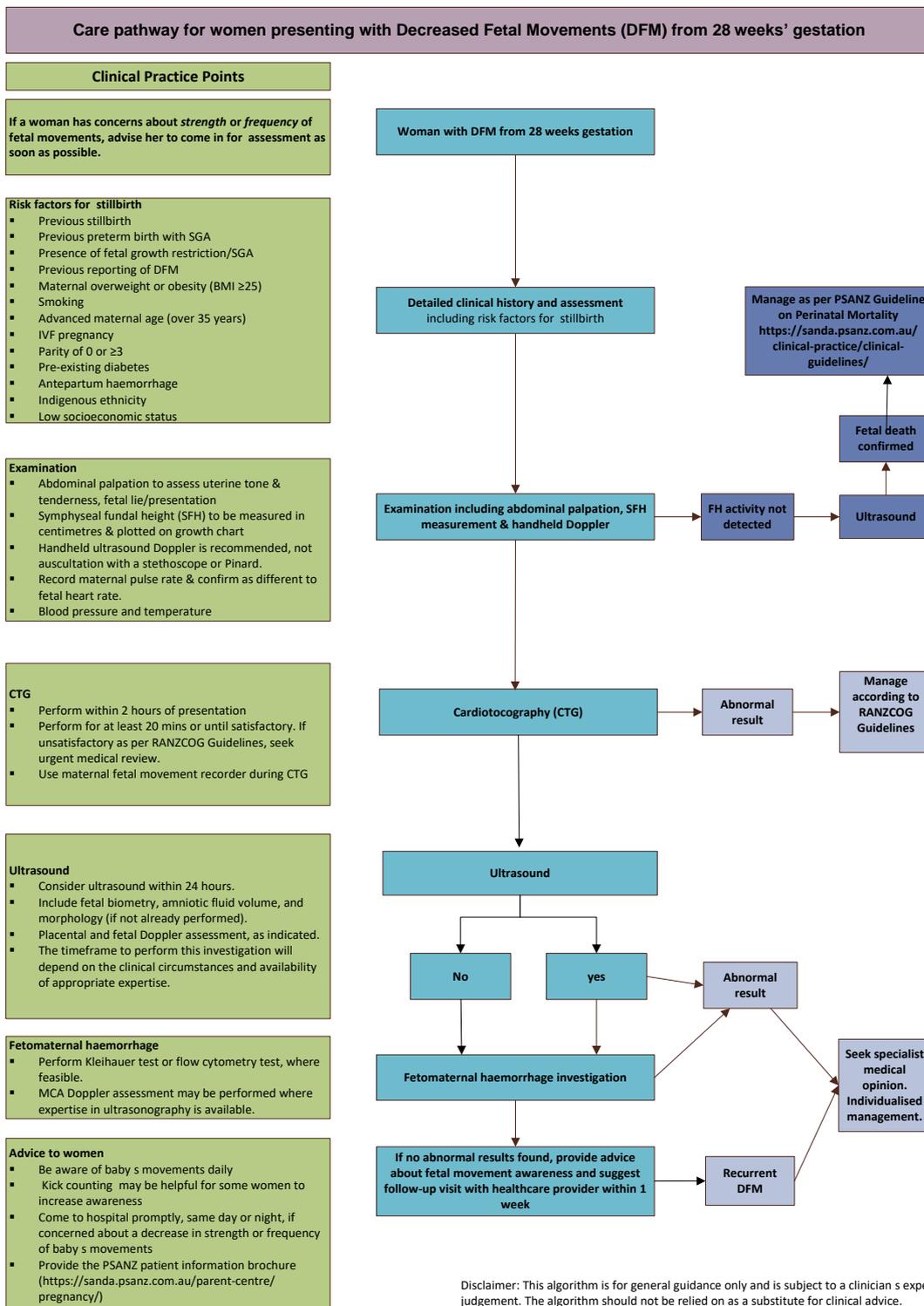
As stated in the beginning of this submission, this Committee can begin a journey towards replacing heartbreak with hope and the Foundation stands ready to play a role in this vitally important journey.

The Foundation thanks you for your consideration of this submission and the Foundation welcomes the opportunity to discuss this further in a public hearing.



# Appendix

PSANZ Guideline – Care pathway for women presenting with DFM from 28 weeks’ gestation.



Disclaimer: This algorithm is for general guidance only and is subject to a clinician’s expert judgement. The algorithm should not be relied on as a substitute for clinical advice.