



GETTING INVOLVED IN

Stillbirth Research

A guide for bereaved parents

Purpose

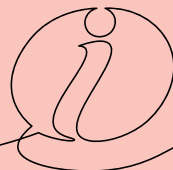
The purpose of this guide is to support and encourage you, as a bereaved parent, to be involved in stillbirth research.

As a parent who has experienced the tragedy of stillbirth, your voice can make a real difference to how research is designed and conducted. Your involvement can help reduce stillbirth rates and ensure that parents and families receive the best possible care when a baby dies.

This is a practical guide which aims to provide you with suitable information on how to engage in stillbirth research confidently and effectively. We want to demystify the research process.

For researchers in stillbirth, the [PSANZ Research Toolkit](#) (developed by the Perinatal Society of Australia and New Zealand Consumer Advisory Panel) helps guide how we collaborate with parents. It is important when conducting research that everyone involved can work together effectively through a common language and shared understanding of the research process. However, nothing currently exists for bereaved parents to learn about the research process and encourage them to be involved in it.

We hope this guide will provide you with the tools, terminology, and knowledge of the research process and encourage you to become involved in current and future projects.



Who developed this guide?

A team of researchers and bereaved parents worked together to develop this guide. They utilised other support resources, as well as their own experiences, to design the guide in a way that is sensitive and informative for parents who have experienced loss.

Whilst there are references to stillbirth research throughout the guide, much of the information is relevant for any bereaved parent who has experienced the loss of their baby at any stage of pregnancy or soon after birth (neonatal loss).

This guide was led by the Centre for Research Excellence in Stillbirth (Stillbirth CRE) and funded by Stillbirth Foundation Australia.



Acknowledgement

We acknowledge the Traditional Owners of this land and their ongoing custodianship. We pay our respects to their Ancestors and their descendants, who continue cultural and spiritual connections to Country.

We acknowledge the diversity across Aboriginal and Torres Strait Islander cultures, languages, and practices and that it is vital that all researchers respectfully manage consultations and provide a culturally positive experience for Aboriginal and Torres Strait Islander people when researching Sorry Business.



Indigenous artwork, 'Protection', created by Leona McGrath for use across the Stillbirth CRE programs of work.

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How to use this guide to research involvement

This guide was written with and for bereaved parents and covers all aspects of how to be involved in research. This includes participating in research through to becoming a parent researcher, helping co-design studies, and turning research into ‘real-world’ change. Your voice is so important to stillbirth research. This guide will help you find the information and support needed to become involved in the way that is important to, and works for, you.

Not all topics will be relevant to you, so please turn to the topics that are most helpful for you and skip over those that are not.

In this guide we have included quotes from bereaved parent researchers who have shared some things they found helpful, as well as examples you may find useful. You can also find links to websites with top-quality research and general resources to support your involvement with research at the end of this guide.

We would like to clarify that this guide does not cover the latest research evidence on the causes of stillbirth for finding out why your baby died, nor does it provide research projects for you to become involved with.

A note on the use of the word ‘consumer’ and phrase ‘consumer engagement’.

The terms **consumer** and **consumer engagement** are often used in research, but what do they mean and who are they referring to? In the context of health, these terms are used to describe people who have lived experience with a particular medical issue. However, in this guide, which has been designed with parents, we prefer to refer to bereaved parents involved in research as **bereaved parent researchers as an alternative to consumers.**

“I would like to add that it is ok to put this guide down and pick it up whenever you need it. That it is ok to not feel ready right now. We hope this guide plants a seed for you to want to engage with research, and whenever that is in your grief, we- bereaved parents and researchers alike will welcome you.”

Danielle Pollock - Bereaved parents and member of the
*Getting Involved in Stillbirth Research - A guide for
bereaved parents development team*

This guide is to help you become more familiar with how the research process works and what to expect when you participate in the research process. Links to where you can become involved as a parent researcher are at the end of this guide.

You might have noticed that we refer to bereaved parents throughout this guide. We chose to use the term ‘parents’ rather than bereaved ‘community’ to respectfully acknowledge the identity of bereaved parents who have experienced stillbirth. However, this guide can be used by family members such as grandparents and siblings, and others in the broader bereaved community.



Respectful acknowledgement of babies

For most people, the death of a baby during pregnancy or soon after birth is a *silent* tragedy. And yet, every day in Australia, six babies are stillborn, and two babies die during the neonatal period (first 28 days after birth). Together, these deaths are called 'perinatal deaths'.

In the last two decades, the overall stillbirth rate has not changed. There have been some improvements in stillbirth rates in late gestation (after 28 weeks), and this is likely due to improvements in care. There has also been a slight decline in the rate of neonatal deaths.

Conducting research to understand why these perinatal deaths continue to occur can help reduce the number of babies dying each day in Australia and around the world.

This document is in honour of the eight babies lost each day in Australia. It is in honour of your baby, and your own experience.

We hope this resource will enrich your own capacity to participate in research, and that it will highlight and recognise your experience as a parent.





A little life,
not a little loss.

A need for information about the stillbirth research process

We know many bereaved parents would like to engage with and be involved in research. However, it can be difficult to know where to start and how to find ways to participate.

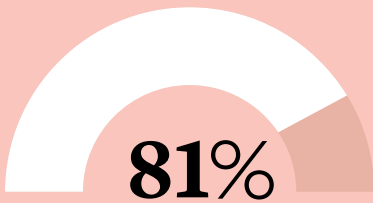
Whilst creating this guide, we conducted a survey to find out what information and support bereaved parents felt they needed most.

Here is a snapshot of what we found:

90 bereaved parents completed the survey

64% of the parents had experienced their loss in the last 5 years

Future participation in research



were interested in participating in research in the future

Barriers to participation in research. The top 3 reasons for not participating in research previously were:

- 1.** Have never been asked to participate (60%)
- 2.** Don't know where to find out how to participate (27%)
- 3.** Lack of knowledge or confidence in the research process (14%)

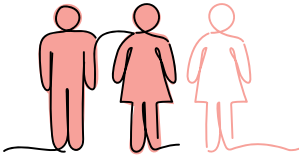
89%

agreed that this proposed research guide would be helpful

41%

of bereaved parents said that some parts of the guide brought up painful memories, however most expressed that it would not prevent them from participating in stillbirth research.

2/3



of respondents had never participated in stillbirth research before

“I think it is triggering but part of the healing process for me is to make use of the grief, so although hard emotionally, I don’t think it would prevent me.”

The top 3 reasons for wanting to participate in future research were:

74%

To leave a legacy for their (or their family/ friend’s) baby

64%

Wanting to know the outcomes and results of research

36%

Wanting to learn about the research process

How did discussions with bereaved parents influence this guide?

Many components of this guide were based on bereaved parents' feedback including:

- The topics that were of most interest and importance to include
- The addition of examples and stories from bereaved parents about their involvement
- Key design aspects such as colours, graphics and images used



“It hurts to relive the experience which to me, emphasises how important it is that her death wasn’t for nothing. Bereaved parents helping design research is fundamental in creating change. I think pregnant women are more likely to engage with research from women who have gone through this and bereaved families are more receptive to research developed from lived experience.”

- Bereaved parent survey response

What is stillbirth research and why do we need it?

Research is the process of creating new knowledge to help understand why something has happened and identify a way forward to ensure that it doesn't happen again.

Research allows us to answer important questions, such as:

What is the risk of sleeping on your back in pregnancy and stillbirth?

What is the experience of bereaved parents in their next pregnancy after stillbirth?

What is the most effective way to support bereaved parents in their grief?

What causes stillbirth?

The answers to these questions, and many others, will deliver important information toward the development of guidelines, policy, and services for health care workers to refer to and learn from. This way, they can provide parents and families with the best possible care that is based on the best available evidence.

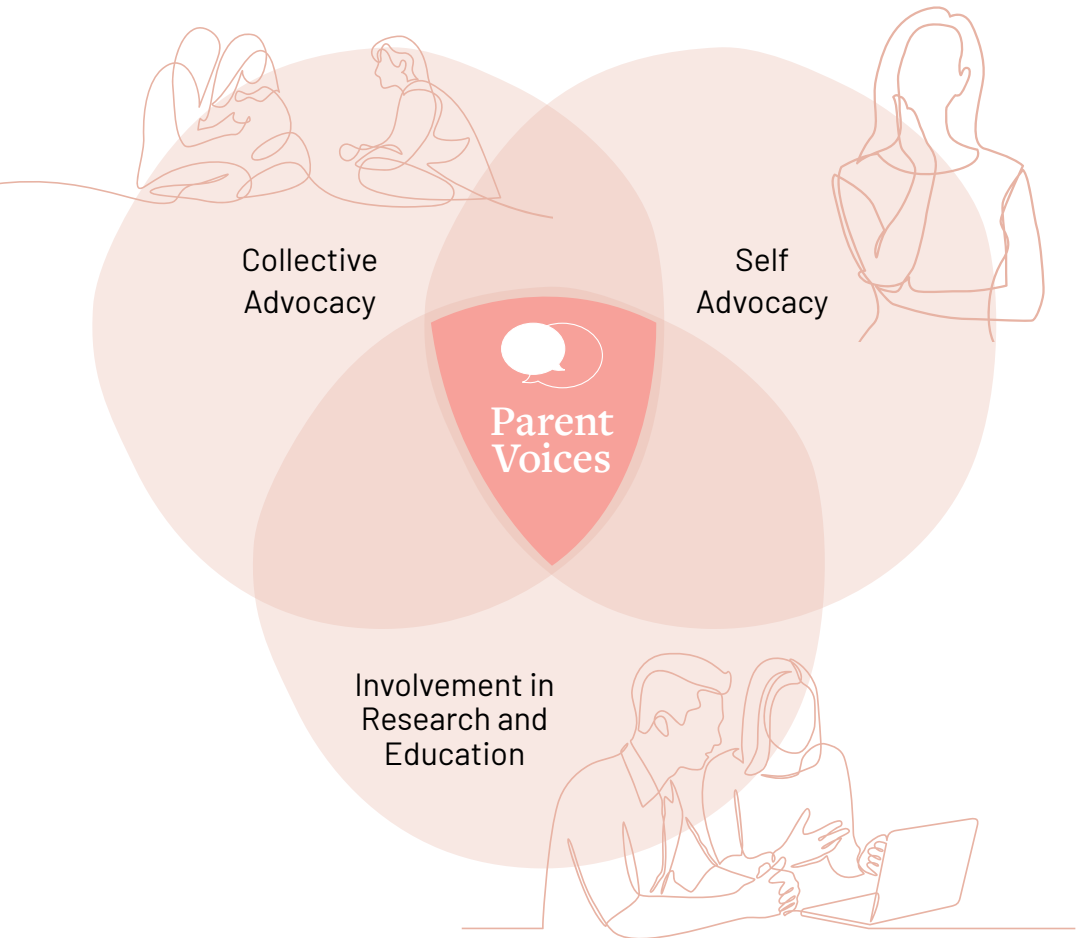
Your voice is important

Traditionally, research was often led and conducted by researchers without including the people it aimed to benefit most (the 'consumers'). However, this is changing. Involving those with lived experience improves the quality of the research conducted and the way in which the results are translated to create change. The research then becomes more relevant to the community and to those impacted most.

Your voice
can create
change.

Bereaved parents' voices and involvement can play a vital role in bridging the gap between stillbirth research and practice, and advocating for stillbirth policies that make a difference.

Engaging in research is a form of advocacy



Within the perinatal loss community, we have seen how change can occur through the work of bereaved parents and the support organisations they have founded, including (but not limited to) the [Stillbirth Foundation Australia](#), [Still Aware](#), [Red Nose/SANDs](#) and [Miracle Babies](#).





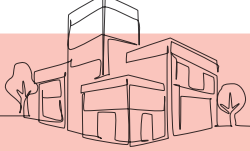
“I have been on multiple committees as a consumer representative. As a bereaved parent it has been so important to have a voice at the table, often bereaved parents are the forgotten group when health decisions are being made. Health services don’t want to ‘upset’ bereaved parents, this results in assumptions being made by health services/professionals to make decisions that do not reflect what parents wants. On a personal and maybe a more selfish note, I get the opportunity to talk about my son and ensure his life has meaning and leaves a legacy that will positively impact future bereaved parents”

Melanie McKenzie, Harrison’s mum.

Nuts and bolts of stillbirth and neonatal death research

Different models of research

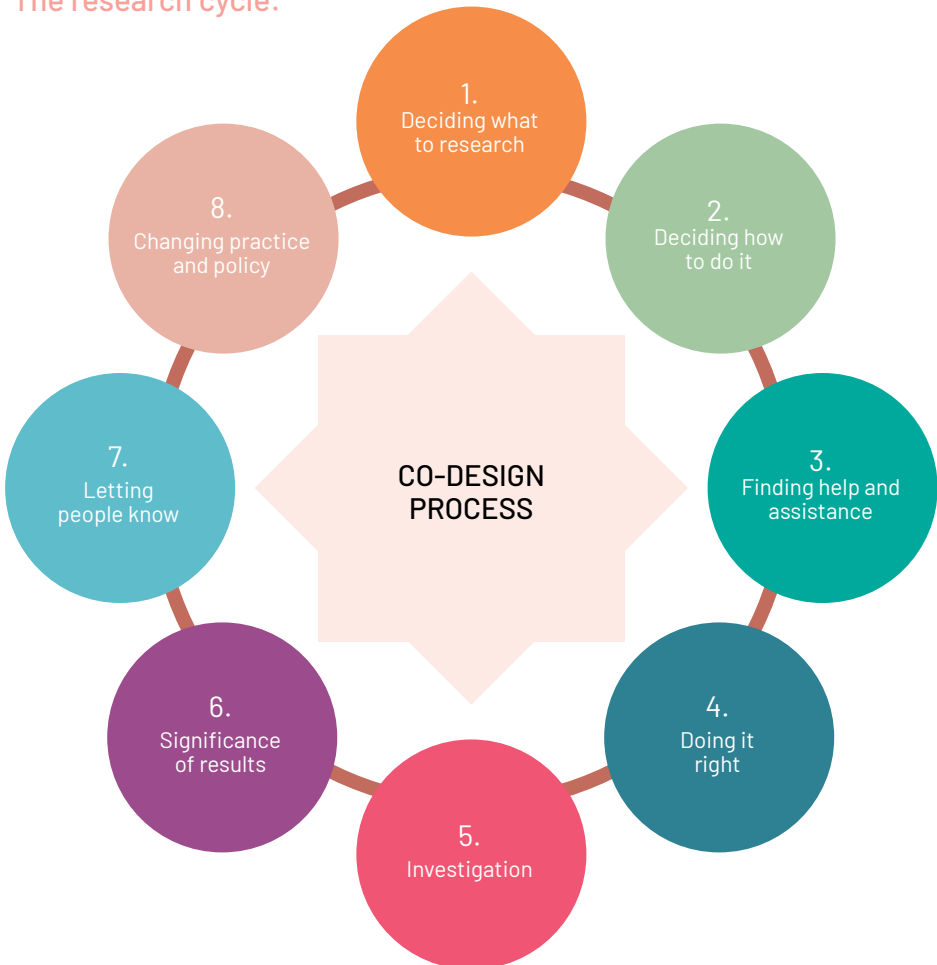
There are three main types of health research: basic, clinical, and public health.

	 Basic	 Clinical	 Public health and health services
What	Study of cells and molecules	Research with human participants	Population and health data
Where	Laboratory	Hospital, clinic or community	Anywhere, databases
How	Basic research looks at the body's cells and molecules to understand a disease better	Clinical research is conducted on people to understand a disease or test treatments	Public health and health services research looks at things on a group (population) level to identify patterns and trends
Example	Studying placentas to identify signs of pregnancies at risk of stillbirth (Placental Consortium) Read more >	Trialling a mobile phone app promoting awareness of baby movements to see if this could reduce the number of stillbirths (My Baby's Movements Trial) Read more >	Studying the causes of stillbirth among refugee women (Drivers of stillbirth in refugee women in VIC Study) Read more >

An explanation of the research cycle

Research follows a process, known as the research cycle. As part of co-design, bereaved parents can, and should, be involved at all stages of the research cycle.

The research cycle:





1. THE IDEA

All research begins in a similar way: with a research question, or 'idea' (also known as a *hypothesis*). Overtime, the idea grows. Researchers will discuss their idea to get a clearer picture of what the actual idea is and look at previous studies from around the world that have focused on a similar research question (known as a literature review). This helps researchers identify any current knowledge about their idea, and if there are any gaps that need to be filled.

and interviews will be very different in their design to experimental studies like clinical trials, and thus their proposals will also be different.



3. FUNDING

Usually, before researchers can move forward with their idea, they will need to submit a grant application for funding. Grants can be obtained from a variety of sources: the government, charities, or not-for-profit foundations.



4. ETHICS APPROVAL

Even once researchers receive funding, they can't start investigating until they receive ethics approval. In Australia, an accredited Human Research Ethics Committee (HREC) must approve all research that involves human participants, to ensure they are ethically acceptable.



5. DATA COLLECTION

This is the part of the study where researchers collect the information (data) they need to further investigate the idea. Depending on the type of study, this could involve collecting any of the following:



2. THE PROTOCOL/ PROPOSAL

Once researchers have formed a specific idea, they must develop a research proposal. This proposal should include:

- The purpose and design of the study
- The objectives of the study
- Any necessary study documentation required, such as participation consent forms or plans for recruitment.

The design or type of study will depend on the research question. For instance, descriptive studies like surveys

- Biological samples, such as blood and placenta samples
- Clinical information from medical records, such as ultrasound scan and blood test results
- Survey or interview responses
- Data from databases (such as information about the mother and their babies that was collected around the time of birth)
- Published research.

The collection of data can take anywhere between a matter of weeks to years.



6. ANALYSIS AND INTERPRETATION

Once the data has been collected, researchers will analyse the information to answer the research question. Statistics (interpretation of numbers) and qualitative analysis (interpretation of words) are common approaches. This process allows researchers to break down the information gathered so others can make sense of it. They can present their findings in different formats including tables with results, graphs, or images.



7. OUTPUTS

It's important for researchers to report on the results achieved in the study – even if the findings are not what they expected. These findings will be published in peer-reviewed journals (publications where experts in the same field examine the research findings). This process of publishing results is important, so that similar studies around the world can then come together in a review (often called a systematic review) and ultimately help to form guidelines which are used by health care workers to provide care.



8. IMPLEMENTATION

Putting the research findings into practice doesn't happen automatically, it requires support, guidance, and often advocacy for this new knowledge to be applied. Researchers, bereaved parents, and healthcare workers also determine the best approach to take so that the patient receives the top care and treatment available.

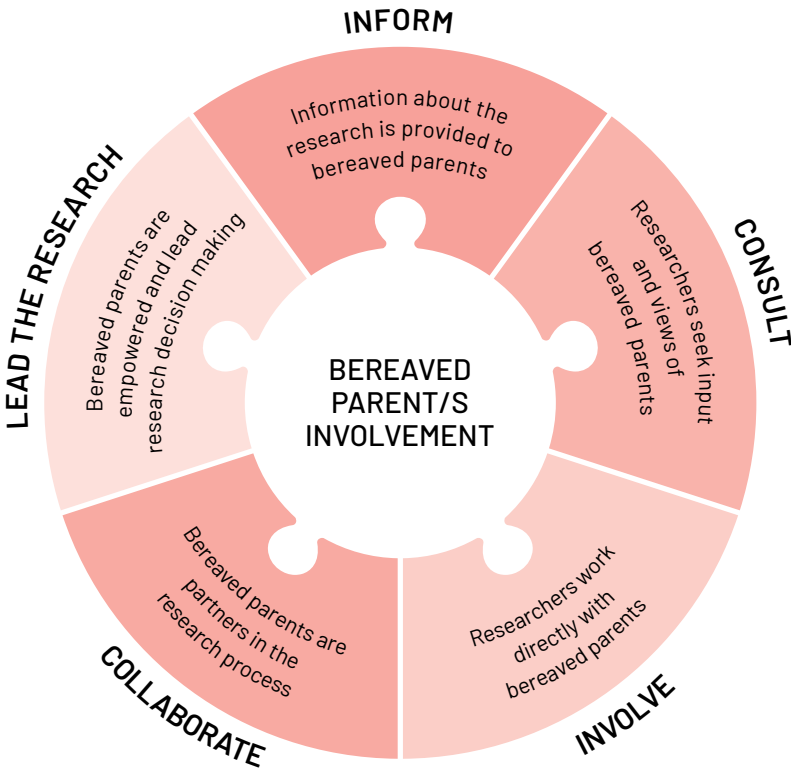
“I want to be a part of a like-minded group who want to participate in research to bring awareness and make resources known for those going through this and to make change.”

- Anonymous

Engaging in Research

Range of Involvement

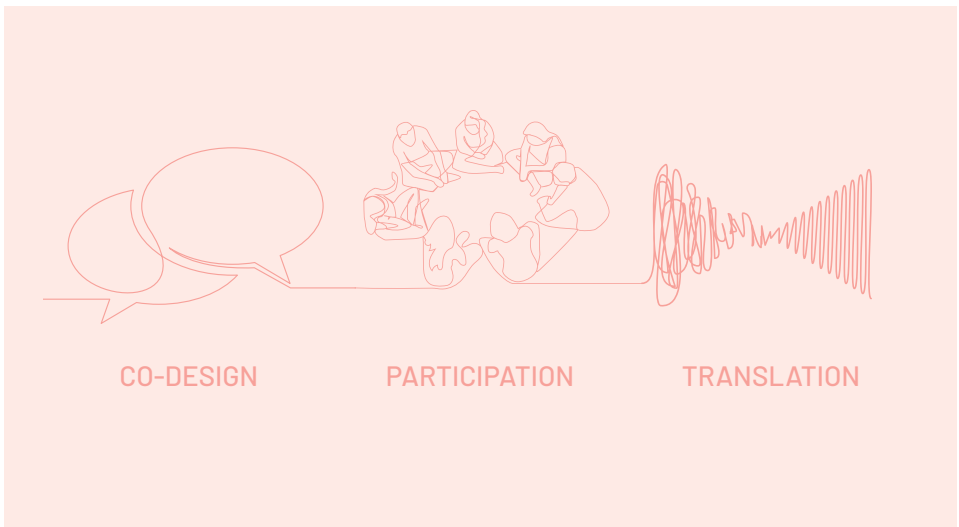
There are different levels of involvement bereaved parents can have across stillbirth research. Options may be different depending on the type of research. Understanding the range of options and what level of involvement is required may help in your decision to become involved.



Range of involvement- Adapted from The International Association of Public Participation (IAP2) spectrum.

How can I make a difference by engaging in stillbirth research?

We know from our conversations with bereaved parents that many would like to participate in research. Below we highlight three ways in which you can engage with the research process, which we have loosely defined as **co-design**, **participation**, and **translation**.



You do not need any extraordinary skills or knowledge to be a co-designer/investigator, participant, or translator. Your lived experience as a bereaved parent is enough. Your experience is incredibly valuable and should be recognised no matter where you fit in. We also note that not all these opportunities are available to everyone all the time, and you can take on as much or as little of the process as you would like. It is completely up to you.



Engaging with research as a co-designer/ investigator

Those in research are recognising the need to include people with lived experience as team members/ investigators from the beginning of a project. This would mean that researchers and bereaved parents should work together closely right from the start to define the following:

- What project needs to be done
- What the project will be
- How the project will work
- How long the project may take
- How the project may be funded.



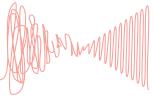
Engagement with research as a participant

You may have seen an advertisement to engage with research as a participant.

This may include completing a survey, an interview or being part of a focus group. It could be sharing information from tests you may have had following your loss, such as blood tests or an autopsy report.

It is important to note that in providing this information, you can remain anonymous and there are tough privacy policies around *data collection*, which means you and/or your baby's identity is not allowed to be shared or published.

Your participation is crucial to the research, as without it, some important answers may never be found.



Engaging with research as a translator

While you may not feel as though you are being actively involved in research, you can use your networks to share the findings of a research study – spread knowledge – and be a research translator.

Research translation includes ensuring that the people that need to know about new research findings, such as parents, communities and health care workers, know about it. This is extremely important as they are the ones who will use this new information when caring for parents and families.

In the case of preventing stillbirth and other perinatal loss, it is often the case that those who have lived experience are in the best place to help educate others who may become pregnant in the future.

For researchers, new research is usually shared by publishing an article in a scientific or academic journal, and by presenting results at

conferences. As a bereaved parent research translator, you could be involved in this process in various ways:

- Helping design and write the journal article
- Helping to write a plain English summary of the study to be included in the article
- Helping to develop a plan that will see new findings put into practice.



You can also share research findings by using materials from organisations, such as social media posts or brochures, which aim to spread the message about preventing stillbirth, or how we can improve the bereaved parent experience.

Danielle Pollock - Journey from bereaved parent to academic career: where involvement can take you.

Before the stillbirth of my daughter Sofia on the 22nd of February 2014, I had envisioned a very different life to the one I live now. Sofia's death remains the most tragic and heartbreaking moment of my life; it was also a wakeup call.

After Sofia's death, I wanted to know why her stillbirth occurred, and why people struggled to talk to me about Sofia. I searched online and discovered a community of researchers also trying to answer questions related to the prevention and bereavement care of stillbirth.

I started googling stillbirth researchers in Adelaide and found Associate Professor Jane Warland and having had completed a Psychology (Honours) degree we discussed the option of me doing a PhD and focusing on the stigma surrounding stillbirth. My PhD was a fantastic and incredibly challenging experience as I grappled with the grief of losing Sofia, and at the same time became a mother again. Trying to understand new concepts and statistics was also difficult as that was something I had

always struggled with. In the end I recognised my strength – that my lived experience of stillbirth was needed in research. My PhD would not have been possible without the stillbirth community and their wonderful support throughout the project.

During my PhD I saw the power and impact research can have and saw the start of change in Australia about how we talk about stillbirth. My PhD also helped me find ways to continue to honour Sofia, and her name is even mentioned in government documents through the Australian Senate Inquiry into Stillbirth.

I finished my PhD in 2020, and since then I continue to work in stillbirth research. I have become passionate about ensuring other bereaved parents can join in helping researchers answer questions, so that no other parent has to experience the loss of a child. And also, that if it does happen, that they receive support from not only the hospital, but also their community.



What does involvement look like in practice?

Examples of involvement

The following are some examples of different ways you could be involved in the co-design of research:

RESEARCH PRIORITY SETTING EXERCISES

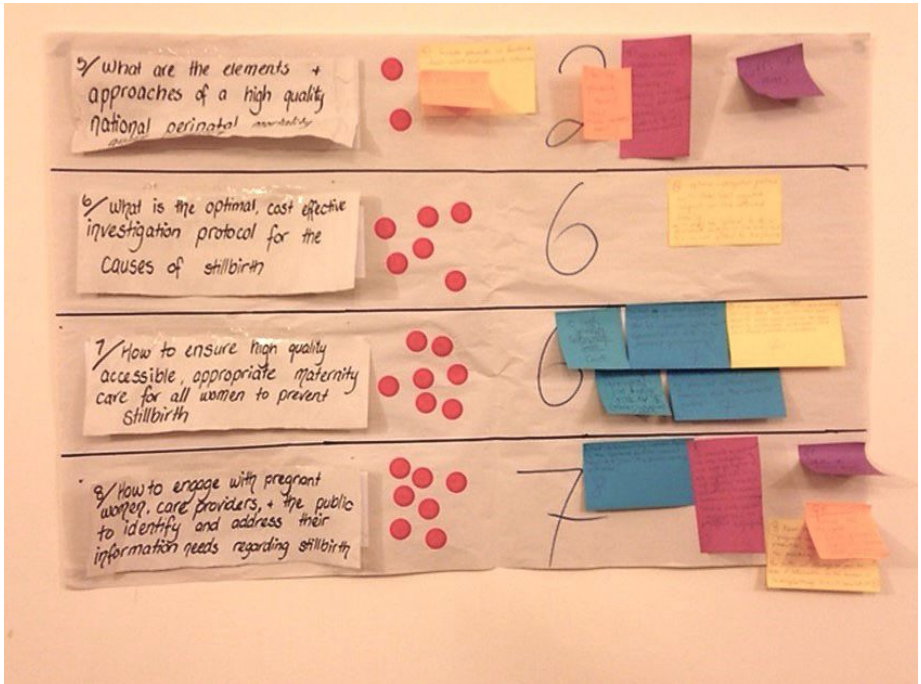
This kind of research exercise is designed to identify priorities for future research by asking people about what they feel is most important. These planning exercises provide new ideas and ensure researchers work on the most relevant questions – which in turn will influence their decisions about which projects to work on next.

Bereaved parents were fundamental in setting research priorities for the Stillbirth CRE in 2015. Participants were surveyed about what research topics were a top priority, as well as what actions needed to be taken. These included questions such as:

“What do you think we still need to know more about to help prevent stillbirth, and/or to help parents who have a stillborn baby?”

and

“What do you think should happen now with what we already know to prevent stillbirth, improve management and improve bereavement and postnatal care?”



This information was brought to a research priority-setting conference, attended by bereaved parents. At the conference, after discussions, each participant was given five coloured dots to place beside their top five research priorities (see image) and the result was a total list of 17 research priorities that would help to guide ongoing and new research projects.

Pictured above: Butchers paper from the wall of a 2015 Stillbirth CRE research priority-setting exercise involving researchers and bereaved parents.

PROJECT PLANNING:

Being a member of a research project committee or working group allows you to be involved and take part in the co-design throughout the entire project. Your contribution can help make sure the project runs successfully, and the direction of the research stays on track, so it is relevant to those affected.

What bereaved parents say about this:

“Being on the QLD Safer Baby Bundle Committee was so important for me for multiple reasons. There are some stillbirths that are avoidable, and if I can be a part of a project that prevents one family going through the devastating heart ache of losing a baby, I wanted to be involved. I also thought it was extremely important to have a bereaved Mothers voice at the table, I wanted to help influence and shape information to health professionals how they can have more real and transparent conversations with women.” Melanie McKenzie, Harrison’s Mum.



'I very clearly remember my first meeting. I was a little nervous, but as soon as the initial discussion was underway, I was overcome with gratitude that such incredible medical professionals were dedicating time and effort towards reducing the incidence of stillbirth. I felt like I was part of something that would generate real change for women and families. I felt like my experience of grief and loss was being channelled into something meaningful.'

Ann-Maree Imrie, Xavier's mum.

FUNDING DECISIONS AND GRANT APPLICATIONS

You can be involved by becoming a member of a funding review panel. This would involve helping to ensure (along with other panel members) that funds are being used for the projects that matter most to the bereaved parents' community. You could even assist with writing a funding bid by giving feedback, so the grant application is easier to understand and the research priorities are reflective of the group of people who would be impacted the most from the research.



DATA ANALYSIS AND INTERPRETATION

Collaborate with researchers to make sense of the results – what do these research findings mean? Help to ensure that the research focuses on the most important outcomes to bereaved parents and highlights results which are most relevant to them.



"I was honoured to be involved with The Stillbirth Foundation, sitting on a committee to award funding for grant applications. It was eye opening and encouraging to see the types of research projects that are underway to help reduce the incidence of stillbirth. It gives me hope that some of these projects will lead to discoveries that will help save many babies in the future. Being included on this committee really helped me honour Elke's life, and I feel my contribution helps continue Elke's legacy in a small way. Her time here was short, but I am determined that her life will make a difference." Emma Bowes, Elke's mum.

DESIGNING MATERIALS AND RECRUITMENT FOR RESEARCH STUDIES:

This kind of involvement includes helping with ideas and contributing to a new resource (such as a course, brochure, or poster), or providing feedback on survey questions or study consent forms included in a research study. Through this co-design, you might improve the way a question or information is presented, so the messages conveyed in the research project are appropriate, sensitive, and easy to understand. This also involves co-designing recruitment plans for research studies. For example, where to find potential participants and how to approach them sensitively and appropriately.

Pictured right: Example page from the Living with Loss online grief support program for parents



Living with Loss

Welcome to

The Living with Loss Program

Emotional support for parents following stillbirth or neonatal death.

RECRUITMENT HAS NOW CLOSED.

Please note, this program is currently only available as part of a research study. We look forward to providing all parents and families with access to the Living with Loss program following completion of our research.

Welcome to the Living with Loss online grief support program.

We are truly sorry for your loss. We understand that the death of a baby during pregnancy, birth or soon after is a life-changing event for many parents. Feelings such as deep sadness, anxiety, anger, confusion, distress, and emptiness are a normal part of grief when a baby dies, but these emotions can sometimes seem overwhelming.

Facing a future without your baby can be hard. It may be that your loss is quite recent, or it may be a little longer since your baby died.

There is no set time frame for grief and there is no set way to grieve the loss of a baby. Bereaved parents often have different needs for support at different times. Support can come from different places, including family and friends, local and online support groups, telephone helplines and seeing a health professional. Sometimes a mix of support is what is needed. This program offers another option for support that we hope you may find helpful.

"Sometimes the smallest things take up the most room in our hearts." A.A. Milne

A team of researchers, bereaved parents, and healthcare professionals at the Stillbirth CRE worked together to develop an online grief support program for parents called Living with Loss (LWL). The aim of this online program is to provide support to parents and families who are grieving after the loss of their baby. The program includes a range of topics that bereaved parents and healthcare professionals have highlighted as important (such as the impact on their relationships and returning to work) and also practical coping strategies.

EVENT PARTICIPATION

Get involved by being a chair or panel member, giving a speech, or co-presenting research findings at a research event. When we hear directly from bereaved parents, it helps to motivate researchers and ensure that lived experience remains at the centre of discussions.

Pictured above: Media coverage of the Safer Baby Bundle launch at Westmead Hospital in NSW- Minister Bronnie Taylor and consumer representative Ann Marie Imrie.



The Safer Baby Bundle (SBB) is a nationwide program that aims to address key areas where better practice can help reduce the number of stillborn babies. At the launch of the NSW SBB at Westmead Hospital in February 2020, bereaved parent Ann Maree Imrie bravely spoke about the stillbirth of her baby Xavier. Attendees all agreed that hearing Ann Maree's personal story was one of the most powerful and important aspects of the day. Ann Maree says....

'Having the opportunity to share my story in the media and in a room full of medical professionals has been such a privilege. It personalises the work of the NSW SBB Steering Committee. It makes it real. Since my son, Xavier was stillborn, the most important thing to me has been ensuring his memory shines. Doing this work has allowed me to do just that - say his name out loud; have him be known; have his little light shine through storytelling.'


COMMUNICATING RESULTS

Communicating results to participants and the wider community is another way to get involved. You could actively share the results with people who want to use them and provide a realistic view on whether the results are genuinely useful. Also, giving feedback on the public messages about new research findings, for example summarise them in 'plain language' so that others can interpret the findings easily.

Pictured below: SBS podcast series, 'Stillbirth: Prevention and Aftercare', developed, researched, and presented by bereaved parent Yumi Oba.

The SBS "Stillbirth: Prevention and Aftercare" podcast series sheds light on how the tragedy of stillbirth can be made worse if bereaved parents are not approached in a culturally sensitive way.

Bereaved parent researcher Yumi Oba reflects; *'This has been something that has always been at the back of my mind, since my own experience of stillbirth now almost 9 years ago. When I had the opportunity to produce content for the International Pregnancy and Infant Loss Remembrance Day, I decided to investigate this, through interviewing researchers, healthcare professionals and bereaved mothers.'*



Stillbirth: Prevention and Aftercare
Podcast

The death of a baby is one of the most traumatic and isolating experiences a mother and family can go through. For the culturally and linguistically diverse communities of Australia, without the cultural context and sensitivity, the tragedy can be even more amplified.

Get the SBS Radio app

Download on the **App Store** | GET IT ON **Google Play**



ADVOCACY AND SUPPORTING POLICY DEVELOPMENT

By campaigning for and promoting the need for stillbirth research and education, you can help to make positive changes to policies and practices, that will eventually lead to better outcomes for mothers and babies.

Heidi and Ned Mules have become strong advocates for stillbirth research and education since the loss of their daughter Sophie, born still in 2011. They say, 'connecting with researchers is vital for more effective advocacy'. Heidi and Ned partnered with researchers from the Stillbirth CRE to give evidence at the Australian Stillbirth Senate Inquiry. This resulted in the National Stillbirth Action and Implementation Plan being issued – a plan that outlines an approach to reduce the number of stillbirths in Australia.

Pictured above: Bereaved parent Heidi Mules addressing politicians and researchers at the launch of the Safer Baby Bundle education program at Parliament House, Oct 2019.

IMPLEMENTING STRATEGIES TO PREVENT STILLBIRTH

Partner with researchers and other expert teams on projects to put knowledge into action. For example, by using the latest research, you could help develop and promote education programs for healthcare professionals on stillbirth prevention.

Pictured right: Promotional videos for the Safer Baby Bundle eLearning featuring bereaved parent Ann Maree Imrie and Medical Practitioner and bereaved parent Dr Meleseini Tai-Roche.

To promote stillbirth prevention education programs, the Safer Baby Bundle team ran a social media video campaign involving healthcare professionals, researchers, and bereaved parents. The short videos encouraged Australian midwives and doctors to complete the online education program and show their support for reducing Australia's stillbirth rate.



Things to consider before saying ‘yes’ to involvement

Many bereaved parents feel strongly that they never want another parent to feel the way they do after the devastating loss of stillbirth. Getting involved in research is a way parents can be empowered to share the story of their child. However, before saying ‘yes’ to being part of a research activity, here are some things to consider:

Is this a good time?

Grief and healing are a journey that take their own time. You need to reflect on where you are on the journey because research participation will be an emotional experience. This doesn’t mean you won’t feel sad telling your child’s story, however your feelings may change over time. It is also common for many bereaved parents to be more engaged with research at certain times and then step back to recharge for a little while. With every invitation ask yourself, ‘is this a good time for me?’

Who is the Research Leader?

The team leader of the research project will set the tone for your experience and given that you are

sharing your story of love and loss, it’s important that you have a good relationship with them. Chatting to your team leader to understand the research project is a great way to work this out and establish a good connection from the start.

What is the commitment?

Make sure you understand the time commitment, the scope of the research and when and where it will take place. For instance, will it be virtual or in person? Will the meetings be at a convenient time for you? Understanding what is required will help you decide whether getting involved is right for you.

What is the research format?

The formats of research can differ greatly - an online survey is very different than a face-to-face interview, which is different again to a group research project. The various formats may affect how comfortable you are sharing your story and experiences, so be sure to understand what your participation method will be before you say yes.

'I always say no to commitments that fall on Aurora's birthday. Even though being involved in stillbirth research is my passion and completely in honour of her, that day is sacred. I don't want to hear about stillborn statistics and research on that day, I just want to think about her, who she might have been and eat cake.'

- Kirstin Tindal, Aurora's mum.



Will I be paid?

Compensation / payment for participation in research will vary:

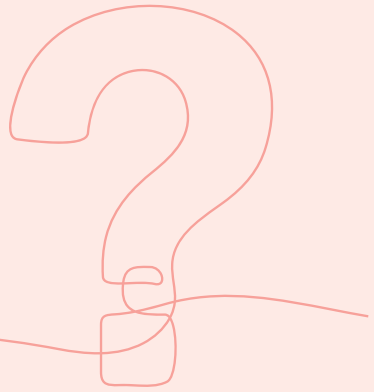
- Completing a survey – the expectation is that you will not be paid;
- Participating in an interview or focus group – you may receive a small gift payment, such as a gift card;
- As a co-researcher – you should be paid as you may have to attend multiple meetings and even possibly take time off work.

Asking about compensation is very reasonable, and accepting or declining payment for involvement in research activities is an individual choice.

What if I say yes and then realise, I should have said no?

It's OK to pull out of the research project at any time for any reason. Given the sensitive topic, researchers will understand if you do not wish to participate – and remember, you have agreed voluntarily to participate, and this will be respected.

Questions for the Researchers



Do not hesitate to ask the researcher/team leader/organiser questions before saying yes.

Examples of questions you could ask are:

- What is the purpose of the research?
- Why is my involvement valuable?
- What will the research format be?
- What is the time commitment?
- Where and when will the research be conducted?
- Will I be paid for my time?
- What happens if participants are triggered and become upset, will there be support available?
- What will you do if there is a disagreement in the team?

Research Participation FAQs

Do bereaved parent researchers need any qualifications in conducting research?

Bringing your lived experience and understanding to a research team is highly valued - you do not need any other qualifications. You are not just a 'bereaved parent', you have countless life-skills, either professionally or personally, that add value to any research team.

Do researchers do any training for involving bereaved parents in stillbirth research?

Speaking the same lingo is important and even though researchers are experts in their field, they may have only limited experience when it comes to co-designing research with bereaved parents. We want to assure parents that we know grief and loss is a sensitive area, and we recognise the importance of educating researchers on how to manage this delicately. Therefore, we encourage all researchers to engage in training and education, so they are well-equipped to be sensitive to grief.

How do I manage disagreements?

Sometimes disagreements happen when working in a team. If you ever find yourself in a disagreeable situation with a fellow researcher, arrange a conversation so you can both come to a resolution. Don't be afraid to ask a third person to join as a mediator / peacemaker, for example a representative from a parent support group.

What should I do if I become distressed or overwhelmed while participating?

Sometimes engaging in research and answering questions may trigger strong emotions and intense feelings. It is okay to feel overwhelmed at times particularly as you learn and become more familiar with how the research process works. We strongly encourage you to reach out to your support network if you are feeling overwhelmed or distressed. Your wellbeing is important and should always take priority over any research.

Where to find support

If you decide to become involved in research, your supports will include your fellow researchers and the research leader of the project. Most studies are conducted over many months or years, and many parents find it helpful to take breaks to recharge and reset throughout the process.

If you feel that you need support, or just want to talk to someone who understands, we encourage you to access the following parent support organisations:

- **Red Nose/Sands:**
Access 24/7 peer support and professional counselling on 1300 308 307 or visit www.rednose.org.au or www.sands.org.au
- **Bears of Hope**
Access professional counselling support on 1300 11 HOPE or visit www.bearsofhope.org.au
- **Pillars of Strength**
www.pillarsofstrength.com.au
- **Centre of Perinatal Psychology** – offers a national network of perinatal psychologists who have training and experience in supporting parents following loss- visit https://www.centreforperinatalpsychology.com.au/?post_type=psychologists&s=&counsellingtype=perinatal-loss&location=

How do I get started?

Now that you have read this guide, you may have decided that you want to be involved in research, so what next?

Getting started is easy. *The Stillbirth Research Involvement Registry* brings parents and researchers together in stillbirth research.

The first step is to register your name and contact details. To do this, scan the QR code or [click here](#).



By joining the Stillbirth Research Involvement Registry you get to decide:

- How you would like to be contacted about research opportunities (e.g., a welcome chat with a Stillbirth CRE team member or contact only through newsletters)
- How much or little you want to be involved

“Just making the information easily accessible, I think would benefit a lot of people.”

- Bereaved parent survey response

Where can I find more information and resources?

There are many valuable resources that have been developed to support those who would like to understand more about involvement in research. Here are some resources we think are useful:

- **Free online education for Consumers: An introduction to consumer and community involvement in health research hosted by Telethon Kids Institute (Western Australia)** <https://training.telethonkids.org.au/courses/consumer-introduction/>
- **Australian Clinical Trials Alliance (ACTA) Consumer Involvement and Engagement Toolkit** <https://involvementtoolkit.clinicaltrialsalliance.org.au/>
- **Cancer Australia** <https://www.canceraustralia.gov.au/about-us/who-we-work/consumer-engagement>
- **Consumer and Community Involvement Program (CCI Program)** <https://cciprogram.org/>
- **National Health and Medical Research Council** <https://www.nhmrc.gov.au/about-us/consumer-and-community-engagement>
- **South Australian Health and Medical Research Institute (SAHMRI)** <https://sahmri.org.au/research/community-engagement-in-research>
- **Victorian Comprehensive Cancer Centre** <https://vccc Alliance.org.au/our-work/consumer-engagement/>
- **INVOLVE United Kingdom** <https://involve.org.uk/>

- Telethon Kids Institute (Western Australia)
<https://www.telethonkids.org.au/globalassets/media/images/pagesections/research/help-shape-our-research/the-green-book-mar08.pdf>

https://www.telethonkids.org.au/globalassets/media/images/pagesections/research/help-shape-our-research/purple_planning_book_271015.pdf
- Patient Centred Outcomes Research Institute (PCORI) United States
<https://www.pcori.org/>
- Strategy for Patient-Oriented Research (SPOR) Canada
<https://cihr-irsc.gc.ca/e/48413.html>
- Consumers health forum of Australia
<https://chf.org.au/>
- The Health Consumers Council WA
<https://www.hconc.org.au/>
- Health Care Consumers Association of the ACT
<https://www.hcca.org.au/>
- Health Consumers NSW
<https://www.hcnsw.org.au/>
- Health Issues Centre
<https://hic.org.au/>
- Health Consumers Queensland
<https://www.hcq.org.au/>
- International Stillbirth Alliance- Parent Voices Initiative
<https://www.stillbirthalliance.org/parent-voices-initiative/>

Glossary of Terms

This glossary contains terms used within this guide. For general research terms, we recommend the following resources:

- <https://involvementtoolkit.clinicaltrialsalliance.org.au/glossary/>
- <https://www.invo.org.uk/resource-centre/jargon-buster/>

Advisory Group: Research projects often have an advisory group (sometimes referred to as a steering group), that helps develop, support, advise and monitor the progress of the project.

Co-author: An author who collaborates on a piece of text with one or more other authors.

Co-design: The process that brings stakeholders / partners together to enable them to deliver services together in partnership.

Consumer: Refers collectively to:

- People who use services
- Carers
- Organisations representing consumers' interests
- Members of the public who are the potential recipients of services
- Groups asking for research to promote good health or other such products, services, etc.

Consumer engagement: When individuals become proactively involved in decisions and activities that affect them.

Co-researcher: A person who participates in a research activity with another.

Dissemination: Communicating information to a wide range of people. This could include the findings of a research project, surveys, or resources. Dissemination can occur through producing reports, publishing articles in journals or newsletters, issuing press releases, or giving talks at conferences / events.

Ethics: A set of principles that guide researchers. Ethical principles are designed to protect the safety, dignity, rights, and well-being of the people taking part. They include the requirement to ask everyone to give their informed consent to take part in the research project.

Ethics committees: The job of an ethics committee is to make sure that research carried out respects the dignity, rights, safety, and well-being of the people who take part. Increasingly ethics committee approval is needed for health and social care research.

Ethics committee members include researchers and health care professionals as well as members of the public. You may see this referred to as a HREC (Human Research Ethics Committee).

Focus group: A small group of people brought together to talk. The purpose is to listen and gather information. It is a good way to find out how people feel or think about an issue or to come up with possible solutions to problems.

Grant: A sum of money granted by either a government or organisation for a specific purpose.

Guideline: A statement, developed methodically, to assist consumers and health care professionals make appropriate decisions relating to healthcare.

Hypothesis: An idea or explanation for something that is based on known facts but has not yet been specifically tested.

Implementation: Involves putting research findings into practice. This means using research findings to make appropriate decisions and changes to health and social care policy and practice.

Investigator: The researcher conducting the research study. Researchers leading the team are referred to as a Chief Investigator (CI) or Principal Investigator (PI).

Neonatal death: The death of a live newborn baby during the first 28 days of life.

Participation: The action of taking part in something.

Participant information sheet and consent form (PICF/PIF):

A document for the participant explaining all the relevant study information so they understand the expectations and requirements of participation in a research study.

Protocol/research protocol: A protocol is a plan for a research study. This should include the purpose and design of the study, aims, and any necessary study

documentation. For example, participation consent forms or plans for recruitment.

Quantitative research: Collecting and using numerical data to understand the relationship between variables. These data can be counted or measured, such as time in years or number of stillbirths.

Qualitative research: Collecting and using non-numerical data to understand beliefs, experiences, attitudes, behaviour and interactions. For example, a researcher collects opinions about a topic or experience through interviews.

Stillbirth: The death of a baby more than 20 weeks into pregnancy.

Systematic review: A method used to identify, analyse and combine the findings of many studies in a very thorough way.

Translation: The process of translating research findings into practice.

Acknowledgements

The Australian Centre of Research Excellence in Stillbirth would like to acknowledge our partnership with the Stillbirth Foundation Australia, as well as the many parents, health care professionals, researchers and other individuals who supported this project.

We thank parent advocacy organisations Still Aware, Red Nose/SANDs, Bears of Hope and Miracle Babies for supporting the baby loss community. We also thank the Mater Foundation.

We are grateful to Brewster Creative for their respectful and beautiful design of this guide.

Finally, we would like to acknowledge the nearly 3,000 Australian families impacted by stillbirth and neonatal death each year.

We see you and recognise your grief and loss.

We hope this guide will help you find the information and support needed to become involved in research in the way that is important to you.

Bereaved Parent Research Co-Design Group

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Acknowledgements

We thank the bereaved parents who participated in our survey, their valuable input helped us shape this resource.

By naming them here, members of the Bereaved Parent Research Co-design Group respectfully acknowledge and create a legacy for their babies born still.



Aurora, daughter of Kirstin,
stillborn 2013



Sofia, daughter of Danielle,
stillborn 2014



Marie, daughter of Yumi,
stillborn 2013



Phoebe, daughter of Nicky,
stillborn 2011



Kaya, daughter of Brad,
stillborn 2011

“Despite undertaking a full autopsy and every other test available in Australia, like so many other families affected by stillbirth, we have no cause of death for our son. We simply cannot accept that so many babies are dying without a known cause. We share our story to help raise awareness and empathy, in the hope that it will trigger desperately needed research. We cannot save him, but we hope he is proud of all the work we do in his honour to try and save other families from the same fate.”

- anonymous

