

Dear Committee members,

I am writing this submission with a number of different hats on, but first and foremost as a bereaved parent. My daughter Emma was stillborn 25 years ago, her death at 38 weeks gestation was unexplained then and remains so today. Her death has most certainly shaped and directed my life since then. However, with respect to this committee's terms of reference I am also writing this submission as a:

- Midwife with more than 30 years experience including caring for many families experiencing stillbirth.
- Associate Professor (teaching into an undergraduate midwifery program)
- Stillbirth researcher
- Author
- Mother and
- Grandmother

In this submission I address the committee's terms of reference (a,c,d,f,and h) and I provide the following executive summary:

I ask that the Australian Government:

- implement, as a matter of urgency, a Federally funded, National perinatal confidential inquiry into all stillbirths. That this be conducted by an independent expert review panel with provision for parents to be involved. This process will ensure clinical staff understand what they could have done differently and make the necessary changes to their practice in future.
- instigate a standardised verbal autopsy from parents to supplement and enhance data collection following every stillbirth.
- improve and enhance funding opportunities for stillbirth research:
 - to make stillbirth research a NHMRC national health priority Area (NHPA) and specifically named as an additional "practical research challenge" (PRC) under the ARC research priority of "health".
 - so that Category 2 funding bodies are "seeded", incentivised or otherwise encouraged to fund a broad range of commissioned projects which target stillbirth education and reduction.
 - so that Government supports all existing category 3 funding bodies to provide Australian stillbirth researchers with funds, specifically for important pilot and feasibility trials in stillbirth awareness, prevention and reduction.
- mandate policy for maternity care providers (MCPs) to provide important lifesaving information to ALL pregnant women at key points in their pregnancy irrespective of their apparent or perceived risk so that:
 - ALL pregnant women know about stillbirth and steps they can take to reduce their risk
 - All maternity care providers are required to have full and frank discussions with ALL pregnant woman (irrespective of perceived risk) about the woman's risk of stillbirth and evidence based ways to keep the baby safe
 - ALL Australians are aware of the risks of stillbirth and support pregnant women to keep their baby safe
- avoid funding wearable devices , especially not at the expense of innovative technology needed to better support maternity care providers to detect and manage the fetus at risk
- fund specialist care of women at high risk of stillbirth i.e. previous stillbirth in all obstetric tertiary referral centres across Australia

a. consistency and timeliness of data available to researchers across states, territories and federal jurisdictions;

Problem: Maternity care providers are not learning from their mistakes. In the 25 years that I have been a bereaved parent and the 30 since I became a midwife I have heard many hundreds of stories from parents of stillborn babies. Tragically many of these stories are startlingly similar and even more sadly, it is my view, that many deaths could have been prevented if the care provider had acted more appropriately. It is concerning that maternity care providers are not currently being given proper opportunities to learn from their mistakes neither are they even brought to account when a stillbirth occurs. There are multiple reasons for this but chief among them is that the stillborn baby is currently not recognised as a legal entity and therefore the Coroner has no jurisdiction to investigate the baby's death. This means that the maternity care provider can essentially be entirely responsible for the baby's death but because of this legal loophole they can literally get away with murder.

Solution:

- implement, as a matter of urgency, a Federally funded, National perinatal confidential inquiry into all stillbirths. Australia can look to the UK confidential inquiry called MBRRACE for an effective model on which to base this type of inquiry www.npeu.ox.ac.uk/mbrrace-uk. In the UK selected perinatal deaths are reviewed in detail against national guidelines and standards, using a standardised review tool www.npeu.ox.ac.uk/pmr by a panel of expert clinicians, including midwives, obstetricians, neonatologists, neonatal nurses and pathologists who consider every aspect of care. Interestingly in their most recent report it was the panels' view that for 80% of the deaths, different care may have resulted in a different outcome for the baby. Importantly, that inquiry only currently investigates "Term, singleton, intrapartum stillbirth and intrapartum-related neonatal death" however ALL stillborn babies and their families should be entitled to this level of investigation. In fact as the MBRRACE report itself states " *We owe it to those left behind, and to ourselves, to learn from the death of a baby and to make changes for the future to prevent other babies from dying*" An Australian national stillbirth confidential inquiry will allow a meaningful multi-disciplinary review of each and every stillbirth and thereby facilitate the development of action plans to ensure lessons are learnt and recommendations translated into actual clinical practice.
- It is my hope that once this enquiry has been established that it will become self evident that the law needs to change to give the Coroner Jurisdiction over stillborn baby deaths

Note: The committee may be aware that most States and Territories already have perinatal subcommittees who regularly meet to classify cause of death. While this existing process may seem to be serving some of the role that a proposed confidential enquiry would, it falls too far short of the mark in that these committees do not review the case against national guidelines and standards neither do they determine preventable factors present other than in broadly general terms, BOTH of these are necessary in order to assist maternity care providers to learn from their mistakes, and indeed to be held to account for sub-standard care.

Problem: Investigation of stillbirth does not currently include rigorously collected data from the bereaved parents. However, asking the parents for their views and experiences leading up to the stillbirth of their baby is incredibly important, as it may shed light on what happened. For example, if the woman experienced an alteration in her unborn baby's activity but did not report it then this would not be captured in the current data collection, similarly if she experienced itchiness (a sign of Obstetric Cholestasis) but did not report it, this too would be important information that could easily be missed.

Solution: In addition to the existing clinical data collection, that a standardised verbal autopsy should also be obtained from the parents as soon as possible following the stillbirth. This verbal autopsy should include questions about whether or not the mother noticed changes in her body and / or her unborn baby's behaviour in the days leading up to the stillbirth, what she did or didn't do about it and also what her maternity care provider did, or didn't do, about it.

d. sustainability and propriety of current research funding into stillbirth, and future funding options, including government, philanthropic and corporate support;

Problem: As a stillbirth researcher I would like to express my concern at the current state of play of funds available specifically for stillbirth research in this country and suggest some strategies which may help to improve the situation.

Solutions:

Seeking Category 1 funding from the NHMRC and ARC is necessarily a competitive process. However, stillbirth researchers do start at something of a disadvantage because stillbirth is often assumed to be a rare event which cannot be prevented. I know that the Senate committee know that neither of these assumptions is true. We know that many stillbirths are preventable and that stillbirth contributes significantly to the burden of disease in Australia, therefore increasing funding for research into its causes, risk reduction, prevention and impact is warranted...indeed overdue.

My recommendation to assist stillbirth researchers in this country gain Category one funding is to make stillbirth research a NHMRC national health priority Area (NHPA), and that a "targeted call for research" (TCR) into stillbirth be instigated. Furthermore, that there also be an ARC funded "special research initiative" call, specifically focussing on stillbirth.

Category 2 funding specifically for stillbirth research is simply not occurring in Australia, this includes research income from Australian Government business enterprises, state and local governments and state government business enterprises. My email box is constantly bombarded with calls for EOI for Category 2 funding available from these bodies. While some of this commissioned research may be in the area of maternal and child health, none are ever in the area of stillbirth. It is therefore my recommendation that the Australian Government "seed," incentivise or otherwise encourage Category 2 funding bodies to fund a broad range of commissioned projects which target stillbirth awareness, education and reduction.

Category 3 funding from Australian industry or Australian Government agencies, foundations and charities provides incredibly important opportunities for researchers to fund pilot and feasibility work, which in turn significantly strengthens Category 1 funding applications. There are a number of agencies and hospital foundations that do provide funding for research that stillbirth researchers can currently access, but there is currently no Category 3 funding specifically for stillbirth research in this country. While the Rednose foundation provide this level funding for research into infant death (including stillbirth), in the last two funding rounds this has only been for TransTasman collaborations and not for solely Australian based researchers. The Stillbirth Foundation historically had an annual funding round specifically for stillbirth research but for the past 2 or 3 years they have instead provided these funds directly to Stillbirth CRE even though this center already has NHMRC funding. There have been calls, in certain circles, to suggest that there only be one charity in Australia to fund stillbirth research. I would suggest that such a monopoly would not be helpful, any more than suggesting that there only be one charity to fund cancer research or one for mental health awareness and suicide prevention. Furthermore, if we look to a country like the UK there are multiple agencies, charities and foundations all with a slightly different focus but all with a mission to raise awareness and reduce preventable stillbirth. Therefore, the Australian Government should support the efforts of all existing charities working in this space and support each to provide Australian researchers with funds specifically for important pilot and feasibility trials in each of these charities areas of strength or focus.

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

As a mother of two granddaughters I was naturally concerned about their safe arrival. My daughter Cate had a beautiful baby girl her first.... in November 2016. It is not an over exaggeration to say she is very lucky that she has me as a mother because if not for me, things may well have been very different for her and her baby. Here is why.....

On the last Sunday of her pregnancy as we were eating family dinner she suddenly shook herself and said "gosh I'm itchy" My midwife lizard brain was immediately on high alert as this is a cardinal sign of Obstetric Cholestasis, a condition that puts the unborn baby at significant increased risk of stillbirth. It turns out that she was indeed diagnosed with a nasty case of Obstetric Cholestasis and after an anxious few days waiting, her labour was induced. Putting it frankly she was induced at 37 weeks in order to prevent stillbirth. While we will never know how close she actually came to losing her baby this has caused me to reflect on what we tell pregnant women and ...what we don't.

During Cate's pregnancy it was interesting to hear when and where she was told information and the nature of that information. She knew to avoid alcohol altogether and understood to avoid soft cheeses and uncooked meats. She was immunised against whooping cough and told that it would be wise to ask her family members to get a booster too. When she presented with itchiness her care providers followed the SA perinatal practice guidelines to the letter. All of this reflects superb care that I, for one, was very impressed with. So what is my point? ...well it's this. She had outstanding care and she took amazing care of herself yet she still came uncomfortably close to stillbirth. Why didn't Cate know that itchiness during pregnancy is not normal and should be reported? Because no one told her. Why didn't they tell her? Well that is an interesting question. Obstetric Cholestasis is rare BUT so is fetal alcohol syndrome and Listeriosis. Whooping cough in the newborn is vanishingly rare yet she knew all about these risks and took appropriate steps to avoid them.

I think the reason why she didn't know about Obstetric Cholestasis came down to her care providers (excellent as they were) not being prepared to have a conversation with her which was about preventing stillbirth. I have no doubt that this was motivated by a desire to avoid "making her anxious" but if by possibly avoiding a little anxiety you end up with a stillborn baby, then that's a huge risk that should not be taken. Avoiding alcohol, Listeriosis and whooping cough did NOT make her anxious, it empowered her and enabled her to demonstrate she is a good mother. Therefore, withholding information which could well be the difference between life and death, for fear of provoking a little anxiety is not only totally unethical, but simply WRONG and needs to STOP.

Thank God, she and her baby were ok, but she was lucky, lucky that she happened to mentioned it to me, lucky that I knew it wasn't normal even if she thought it was. BUT a baby's life should not come down to luck. Maternity care providers need to ALWAYS give ALL mothers ALL information ALL of the time to keep their baby safe BUT we know we face significant maternity care provider reluctance¹. It is therefore my suggestion that maternity care providers be mandated to ALWAYS give ALL pregnant women, ALL the information they need to keep their baby safe from the devastation of stillbirth. This includes a mandated policy that a discussion about the importance of fetal movements in the middle of pregnancy take place, and that a similarly mandated conversation about symptoms of emerging medical conditions, that may put the mother and baby at risk, such as headache, itchiness, blurred vision, central abdominal (epigastric) pain, spotting, bleeding etc. also occur sometime in the third trimester (when these problems typically emerge).

¹ Fretts, RC. (2015) "The stillbirth 'scandal'." *BMC pregnancy and childbirth*. Vol. 15. No. 1.
<https://doi.org/10.1186/1471-2393-15-S1-A11>©

- **c: partnerships with the corporate sector, including use of innovative new technology;**

Great care needs to be taken when funding the development of innovative new technology. I am not at all saying that such developments shouldn't occur they should and they must ...BUT...pregnant woman are already treated as if they are somehow delicate and need to be protected. Pregnant woman are already not told important things because we fear making them anxious. Pregnant woman are already not being listened to, especially if the technology currently available (CTG and ultrasound) suggests things are "normal." It is a great concern of mine that 'wearable' technologies are currently being developed because I fear, whether that is the intention or not, that they will replace the woman's own knowledge of her baby, meaning that care providers have yet another excuse to point to what a device is indicating and not to listen to the mother.

I am aware that there has been some work, both in Australia and the USA on development of wearable devices that externally monitor fetal movements. While it makes intuitive sense that such a monitor might assist the mother to convince care-providers to assess fetal wellbeing, my concern is that it is equally likely that the woman may be tempted to trust the device and not her own feelings and knowledge of her baby, or that she will be aware of changes this machine cannot possibly detect and her concerns are not given appropriate credence because the machine doesn't support her experience. My fear is that once this equipment becomes available it will be rushed into home use and clinical practice, rather than wait for large scale studies to prove its benefits, and/or highlight its risks. Trying to shut the gate after the horse is bolted is significantly more difficult than closing it in the first place.

We already see this problem with home use of fetal heart rate monitors. Some mothers have concerns about their baby's movements and do not seek care because they think they can hear a heart beat, sometimes with catastrophic results. Tommys have recently released a media campaign in the UK asking UK women not to use hand held dopplers,² pointing out that midwives and other care providers learn for many years how to interpret the fetal heart sounds and that women who have concerns about their unborn baby should not try to listen to the heart rate themselves, but instead present to their care provider. Similarly there cannot possibly EVER be a device built that will be as sensitive and reliable as the mother getting to know her unborn baby and reporting her concerns. In fact I have unfortunately seen several occasions where the mother presented to her care provider with concerns, everyone was reassured by the technology (CTG and ultrasound) and she came back a few days (or even hours) later with a stillbirth.

I would therefore like to suggest that the Australian government not put any money into development of wearable devices for the woman to home monitor her fetus especially if this is at the expense of not seeding innovative technology that is designed to assist maternity care providers to better detect and manage the fetus at risk of stillbirth when the mother presents with concerns about her unborn baby...technology that is desperately needed

² <https://www.tommys.org/pregnancy-information/about-us/tommys-midwives-blog/word-us-home-dopplers>

- **h any related matters.**

Care in a subsequent pregnancy following a stillbirth

Problem: Women with a history of stillbirth are at increased risk for subsequent stillbirth, even once a live birth has occurred. A recent meta-analysis³ shows that women with a previous stillbirth have an almost five-fold greater rate of stillbirth in subsequent pregnancies compared to those women without this history. These women are also at higher risk of other poor pregnancy outcomes, such as preterm birth and a growth restricted baby. Mothers with prior stillbirth need specialist maternity care. The problem is that, apart from some isolated pockets (eg the iSail clinic⁴) such care is not routinely provided in Australia.

Solution: What is needed is for specialist subsequent pregnancy care to be set up in ALL obstetric tertiary referral centres in the Australia. These need to be staffed by skilled and experienced care providers who are knowledgeable about maternity care in subsequent pregnancy and beyond. Such clinics can provide a range of services starting soon after the stillbirth, throughout the period when the couple are trying again, and throughout the subsequent pregnancy. This care should include consistent and timely obstetric, midwifery, neonatal, medical and psychosocial care, services, and support by skilled and familiar care teams as well as peer to peer support. Care provision can be modelled on Professor Alexander Heazell's "rainbow clinic" in Manchester⁵ using a recently developed international consensus statement to guide care⁶. This kind of specialist care certainly saves baby's lives and dramatically reduces the risk of repeating the devastation of stillbirth. The rainbow clinic in Manchester has a stillbirth rate that is the envy of many in the world because in this "high risk" pregnancy clinic the repeat stillbirth rate is currently Zero.³

I would like to thank the committee for the opportunity to make this submission and trust that this senate inquiry will ultimately make a difference to the unacceptably high rates of stillbirth in this country.

Yours sincerely

Jane

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Please note the views and opinions expressed in this submission are my own and do not necessarily reflect the official policy or position of any organisation that I work for or am associated with.

³ Lamont, K., et al (2015) Risk of recurrent stillbirth: systematic review and meta-analysis. Bmj, 350, p.h3080.

⁴ <http://www.health.nsw.gov.au/innovation/2016awards/Pages/pp-isail.aspx>

⁵ Stephens L et al Improving quality of care in pregnancies after stillbirth- an improvement science project in two UK maternity hospitals BMC Pregnancy Childbirth. 2017; 17(Suppl 1): B1. Published online 2017 Sep 21. doi: 10.1186/s12884-017-1457-7

⁶ Ladhani et al (2018) Consensus Statement: Management of Pregnancy Subsequent to Stillbirth [draft]