

Committee Secretary
Select Committee on Stillbirth Research and Education
Department of the Senate
PO Box 6100
Parliament House
CANBERRA ACT 2600
AUSTRALIA

Dear Committee Secretary;

Re: The future of stillbirth research and education in Australia

In April 2016, I delivered my son Oliver at 41 weeks gestation after a low-risk normal pregnancy. The difference between myself and the other mothers in the hospital on the same day as me is that my son was born sleeping or stillborn to use the medical term. Using my own personal experience, I wish to refer to the following terms of reference:

- research and education priorities and coordination, including the role that innovation and the private sector can play in stillbirth research and education;
- communication of stillbirth research for Australian families, including culturally and linguistically appropriate advice for Indigenous and multicultural families, before and during a pregnancy;
- quantifying the impact of stillbirths on the Australian economy

I write to you with the goal of the influencing the committee to recommend a commitment to funding research into stillbirth, which would aim to better understand indicators of stillbirth in low-risk pregnancies. I also hope to see a national public health campaign that provides correct and accurate information about stillbirth indicators and finally I wish to see better training for professionals who work with families throughout pregnancy and following a loss.

The Need to Fund Stillbirth Research:

I am a healthy woman with no medical conditions. I didn't suffer from diabetes or high blood pressure throughout my pregnancy, my son was developing normally according to all scans and tests. I followed all of the 'rules' of pregnancy. I took my vitamins, I ate healthily, I exercised, I attended every medical appointment and had every scan, I slept on my left-hand side, I knew the patterns of my baby's movements each day, I went to the antenatal classes and I contacted my midwifery care team each time anything felt a little out of sorts.

Yet, here I sit submitting a letter to an enquiry on stillbirth with no answer as to the cause of my son's death or what steps could be taken to ensure that this doesn't happen again in future pregnancies.

The lack of research and understanding into the causes of stillbirth is frightening. Each day, six babies are still born in Australia. That is six families who leave a hospital with empty arms. In around half of these cases, they leave like I did with no answer.

Families who have lost children are begging for research. They are funding research, they are participating in research, they are always looking for answers. They are looking for answers so that it doesn't happen again. They want to make sure that we know enough so our friends and families and wider communities never have to lose a child and not understand why. I have participated in approximately 10 research studies since losing Oliver 2 years ago. I work at a university, I know the

importance of research and I understand the importance of participation and the value of data which is collected to tell a bigger story.

However, most of the research I have come across is about your experience after stillbirth. I have yet to participate in a single study asking for my demographics and my case history to understand why it could happen in the first place. This type of research costs a lot of money and requires skilled medically trained professionals. Well-funded research looking into why would hopefully reduce preventable stillbirth and break silence. It would lead to a focus on prevention. The research into Sudden Infant Deaths, is a relevant example of how research can achieve all of this.

Through research we can understand why this is occurring and how we can prevent it. Without funding research cannot happen, it should not be up to the families who have lost children to fund research. This is the responsibility of the government. With funding, stillbirth research is more attractive to universities and research institutes. It allows for the provision of qualified and experienced staff, the development of tools and resources and the delivery of projects. Without adequate funding none of this can happen. There are already thousands of families who are ready participants, wanting to work with practitioners to understand and work towards prevention and reduce the numbers of babies who die for no known reason each and every day.

A Public Health Campaign to Raise Awareness about and aim to Reduce Preventable Stillbirth:

Stillbirth happens in silence. There is no social script for responding to learning someone's baby died. There is no public awareness as to what happens when a baby is stillborn and there is no understanding of the cause and the prevalence of stillbirth in our community. There is no public health campaign on digital media, there is no written brochures or flyers in the waiting rooms at hospitals, there is no in-depth conversation in your antenatal classes. It is widely recognised by the community that once you are past the first trimester that you will deliver a healthy baby.

As a result stillbirth happens in silence. You are expected to grieve in silence, you are expected to return to work in silence, you are expected to participate in your community in silence, and you are expected to be silent. Sometimes, people even pretend your precious baby who you gave birth to didn't exist. It's all silent.

When you are pregnant again, you are asked all of the usual questions "is this your first?" "are you enjoying your pregnancy?" "how old is your other child?" and given all of the accolades "you won't know yourself once your child is born" "oh a boy, how lucky for dad" "labour is so painful" "children are so lovely" "you will be an amazing mother/father". Sometimes you might feel brave enough to break the silence, other times you nod, smile and exit the situation as quickly as you can tears streaming down your face. Imagine if there as a well-understood conversation around pregnancy that involved loss and stillbirth. Research could change this.

You learn though, that the silence exists only outside of anyone who has experience this loss. The parents of stillbirth children are very loud. They are turning to each other for support, they are donating and raising money for research and support services. They are writing blogs, they are sharing their stories with media. Yet, to the outside world there is silence. They are begging for more families to be told about stillbirth and known the risk factors. They want research to be able to tell us why we lost our children, they want to understand. We participate in every research project that we come across. We put ourselves through the anguish knowing that we need research to shine a light on, understand and prevent stillbirth.

You walk a very fine line of wanting to tell every pregnant woman to understand their own pattern of movements, to sleep on their left hand side and to feel comfortable being an advocate for their

baby. You also don't want to scare them. Because of the public silence, talking about stillbirth to pregnant women is considered scare-mongering and that you are not 'over-it', and that you shouldn't put your own agenda on others. You end up being the walking public health campaign, but with whispers and through sharing posts on social media.

Stillbirth is one of the leading causes of death of children under the age of one and in some cases it may be preventable. For nearly every other cause of death where there are some known risk factors there are flyers, ads, conversations, media campaigns. Yet where is this for stillbirth? Where are the television ads about understanding movements, where are the ads about sleeping on your left-hand side. There is no government funded public health campaign educating the wider community about stillbirth. A few simple strategies could change this, organisations such as Still Aware and the Stillbirth Foundation have material created- but this material needs to be within reach of the wider public. This would help to break down the silence, take the pressure off parents of stillborn children and most importantly could save lives. I imagine a world where well directed campaigns could reduce the rate of preventable stillbirth through government funded health initiatives.

It should also be noted that I think a separate campaign needs to be launched around grief and loss following the death of a child. This campaign would have a focus on how to acknowledge, support and discuss grief and loss within the wider community. Whilst noted, I understand that this is not the focus of this enquiry.

Better Training for Health Professionals in Working with Families during and following Stillbirth:

It would be interesting to compare how much training obstetricians, midwives and social workers receive through their education in working with families during and following stillbirth. Also, how much this is a focus of their continuing education.

Overall, I can comfortably say that there are many working on maternity wards within my local area who are not sensitive to or have recent training in working with parents who have experienced stillbirth. We were fortunate that the obstetrician and midwives who were caring for us through Oliver's birth were supportive, respectful, sensitive and patient. What wasn't sensitive, caring, patient or respectful was some of the care we received from hospital staff following Oliver's birth. I will never forget having to walk down a crowded maternity ward carrying my dead son. I will never forget having to share a bathroom with mothers who have happily given birth and I will never forget the total lack of respect shown to my family by the social worker in arranging counselling and the organisation of Oliver's funeral. We were pushed towards a funeral director and a timeline we were not comfortable with. In a time of deep grief my husband had to take control and make arrangements for the transfer of Oliver's body with the funeral company we elected. We were told the only counselling services available to us were the chapel in the hospital once a month for a service. I organised our own psychological support through my GP.

Many of the midwives on the ward did not know how to speak to us or care for us. Aside from the two obstetricians involved in my care and a few wonderful midwives everything was treated as procedure. I will never forget the kindness of one midwife agreeing to not leave Oliver alone when he was having tests done that I could not go to. I received minimal follow-up care. It was like it was forgotten I had just given birth and I had the same physiological processes occurring that any other new mother would.

During my subsequent pregnancy I went privately through an amazing obstetrician who understood our loss and the anxiety, fear and grief that was being processed alongside that. There were instances where I had to have routine appointments with the hospital where Oliver was made out to

be a difficulty in an otherwise healthy pregnancy story. I felt typecast based on his loss, as an anxious first time mother (even though I wasn't) who had no idea what I was talking about when discussing movement patterns, feelings of unease and at times when I was unwell. I learnt that the notes regarding Oliver were not accurate, stating that he was lost at 21 weeks not 41 weeks during labour. I feel that staff on the ward did not have enough experience in understanding stillbirth, in discussing stillbirth, in knowing the indicators of stillbirth. On more than one occasion I was told inaccurate information about changes in movement patterns that I knew was incorrect. On the night before my second son Charlie's birth, which was one year to the day we lost Oliver I was admitted to hospital due to a drop in Charlie's movements and was ignored overnight on the ward. This highlights to me how much continuing education is needed by staff as part of their CPD annual allocation. I found myself constantly having to advocate and educate on stillbirth and remind staff that I had experienced a very healthy pregnancy previously and that I knew my body well.

Considering there are six babies lost each and every day in Australia it is likely that staff will need to work with a family who have experienced loss quite often. I would hope that a training program being embedded in compulsory development would help to keep staff up to date and give them confidence in how to treat a mother following stillbirth or pregnancy loss in subsequent pregnancies.

I would like to acknowledge the amazing care team we had throughout my second pregnancy and draw attention to their skill and the respect they showed both Oliver and Charlie. We were fortunate to have a fantastic obstetrician who made us feel safe and comfortable to raise any concerns and to also enjoy the moments we could in my pregnancy with Charlie. We were referred for constant monitoring for the dual purpose of tracking Charlie's progression but also for our own reassurance. We had also connected with a psychologist who supported us following Oliver's loss and throughout my second pregnancy.

In summing up I would like to again thank the Senate for allowing submissions from those who have experienced stillbirth firsthand. I feel as though our personal experiences are varied but will help to create a picture of the horrible experience of having to deliver a child you do not get to watch grow old. I would like to pay my respect to all of the families who have gone through this tragedy and send you strength as we advocate for a better understanding and focus on stillbirth. I thank the organisations that have provided me with information and support as I have navigated my own journey with loss. These include the Stillbirth Foundation, Sands, Still Aware and Bears of Hope.

Finally, I am willing to be contacted to discuss my recommendations further. My focus for these recommendations is for future families to not have to experience loss where it could be prevented or where appropriate intervention during pregnancy can save a child's life. I believe by being brave, open and honest when advocating about stillbirth I am acknowledging the life of my beautiful first son, Oliver.

Yours sincerely,

Simone Kate Balzer.