

Australian Senate Inquiry into Stillbirth Research and Education

Thank you for the opportunity to contribute to the Senate Inquiry into Stillbirth Research and Education process. We are writing this submission on behalf of our daughter Leilani who was stillborn on the 11.11.2015. We value the opportunity to tell about our daughters birth and loss and explain where there is, in our opinion, need for improvement in the current pregnancy care. We will also specifically address the Inquiry's Terms of Reference as part of this submission.

Our Story

Our beautiful baby girl Leilani was born forever sleeping on the 11.11.2015 at 26 weeks gestation. Leilani was my 5th pregnancy. Our first 2 children, now 8 and 6 years old, were born after normal, low-risk, 'text book' pregnancies. Sadly, our next two pregnancies ended in loss during the first trimester at 10 and 12 weeks. I was very anxious finding out we were expecting a baby again after those losses but tried to be optimistic. Everything went well during the first few weeks and after 12 weeks I was hoping to be able to relax a little. Unfortunately, a borderline measurement for the nuchal translucency was discovered during an ultrasound overseas. The obstetricians in our local hospital back in Australia said it looked completely normal to them but we were worried about it and chose to do a Harmony Test (a non-invasive prenatal test, NIPT). The results were great and showed that our baby did not have any of the most common genetic conditions Trisomie 13, 18 or 12. It also showed that we were expecting a girl. We were very happy about the news and named our baby Leilani. I was finally able to relax a little and enjoy my pregnancy more. I became concerned again after a few more weeks as I felt Leilani was not moving as much as my first two babies had. I mentioned this at my 20 week scan but was told everything looked good and our baby was developing completely normal. This reassured me for a few days but I still felt uneasy and increasingly worried that something was not right. Leilani's movement still felt weak and very infrequent to me. I mentioned this as well as my concerns about my daughters movement at my next midwife appointment at 23 weeks gestation. The midwife told me that every baby is different, and I should not compare her with my two previous babies. I was also told that I was probably just being anxious because of the miscarriages I experienced before and should stop worrying and enjoy the pregnancy as there was nothing to worry about. After this I was very reluctant to phone the hospital again as I thought I was just being anxious and overly concerned like the midwife had said. At 25 weeks the movements had still not increased but had further weakened therefore I phoned the birth suite and told them my concerns. I was told to come to the hospital for an assessment. The midwife tried for a long time to find my daughters heartbeat with a fetal doppler but was not successful. She tried to reassure me saying the baby might just be in a difficult position

but in my heart I knew that my little girl had died. The delivery suite was very busy, so I had to wait for a doctor to perform an ultrasound. The doctor could not find a heartbeat and I was told my daughter had died. This was confirmed by a second doctor on duty. I was then discharged and told to come back the next morning. When I returned to the delivery suite the next day with my husband I was given medication to prepare my body for labour and was told if labour does not start spontaneously after this I will be induced with a different medication in another 48 hours. We left the hospital again to go home and tell our older children that their little sister had died. The next two days are a blur, dealing with the devastating news that our baby had died, trying to prepare myself to birth my daughter and trying to explain the unexplainable to our two living children. Labour did not start spontaneously therefore we returned to the hospital again two days later. We decided it would be best if my husband would stay home with our children as they were very upset and did not understand what was happening and we do not have any family close by. After labour was induced our beautiful little girl Leilani was born a few hours later. While I was in labour and giving birth to my daughter I could hear other babies crying in the adjoining rooms. I do not have the words to describe how devastating this was as I knew I would never hear my daughter cry. The midwife took photos and prints of her little hands and feet and measured and weighed her. I was given the option to stay in the hospital with Leilani or go home 4 hours after birth. I was very grateful our local hospital has a cuddle cot which meant I could stay with Leilani for a while. I chose to stay overnight with my daughter and my husband and children came in to visit us. We were transferred to the maternity ward in a special bereavement room. While a lot of effort was made to make this room comfortable and nice I could hear other families next door, sharing the excited news about their baby's arrival, families and friends visiting them and their babies crying. I had to share the bathroom and toilet with other mothers and saw them happily walking around with their newborn babies. After a few hours I felt like I just wanted to get out of there I couldn't bear listening to those mothers and their babies anymore, but it would have meant leaving my Leilani already, so I stayed. Leaving her at the hospital the next day was one of the most difficult things I ever had to do.

Despite sending her for autopsy and having lots of other tests done we, like so many other parents of stillborn babies, never found out why our Leilani died. I will be forever thankful for the support and compassion I received from the midwives and doctors that looked after us in the hospital. We were given a beautiful memory box to take home which we will always treasure. The box also contained a book from Pregnancy Loss Australia, with lots of information about giving birth to a stillborn baby, creating memories, services like Heartfelt and information about online support groups. I wish this book would have been given to me earlier, before my daughter was born. I found out about lots of services and ways to create memories when it was already too late. The two only photos we have of our daughter, apart from the hand and feet ones the midwives took, are from the pathology in South Australia and I cannot express how grateful I am for those.

After being discharged from the hospital I felt very alone. The midwives told me I can ring up anytime if there are any problems, but I definitely did not want to return to the maternity ward or the delivery suite. Despite having medication at the hospital to prevent my

breastmilk coming in I developed very engorged and painful breasts. I felt I had no one to turn to for help and support apart from my immediate family. After the birth of my living children the midwives and then the Child and Family Nurses were visiting us at home to make sure everyone was ok. I was frequently checked for postnatal depression during the weeks and month after their birth as well as assessing the bleeding, signs of mastitis... in the first couple of weeks. After the birth and loss of my daughter Leilani there was no follow up care whatsoever.

Terms of reference:

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

The rates of stillbirth in Australia are very high and have not improved for years. There is currently no government funding for stillbirth research. More funding is needed to lower the unacceptably high rates of stillbirth in Australia.

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

The general awareness of stillbirth needs to be increased to help prevent stillbirth and the care and support for families experiencing stillbirth needs to be improved. The importance of getting to know your baby's movements and maternal sleeping positions needs to be communicated.

Women need to be empowered to always ask and talk to their health professionals about their concerns.

More research is needed to identify causes and factors contributing to stillbirth to be able to develop interventions, technologies and other methodologies to prevent stillbirth.

We like so many other parents of still born babies never found the cause for our daughter's death. The autopsy revealed only that she was small for her gestational age but otherwise healthy. All blood tests and swabs came back normal.

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

Pregnant women need to be educated about the importance of getting to know their baby's movements, they need to be encouraged to present to their care provider when they have any concerns.

Health professionals need to be educated to give information to pregnant mothers. Women are receiving information about listeria, what to eat and not to eat, the possibility of genetical conditions are discussed but the risk of stillbirth are not mentioned. Health professionals need to listen to mothers and take their concerns seriously.

Not once, in all my pregnancies was the risk of stillbirth mentioned to me, I was never told how important the monitoring of the baby's movements is. After my daughter was born I found out that she was very small already at the 20 week scan, no one told me this. The fact that she was very small, that her movements were weak and infrequent were not normal and also that I had the feeling something was not right. The obstetrician told me that nothing could have been done to prevent my daughter's death, but I will always wonder if she would be here today if I would have been more adamant in voicing my concerns, if someone would have listened to me and checked on her before it was too late.

In my subsequent pregnancy after losing my daughter I was always encouraged to voice any concerns, to ring anytime if I felt something was wrong and to come in immediately to get checked if there was a change in the baby's movements. I feel every women should receive this level of care and be listened to and taken seriously about any concerns she may have.

g. Quantifying the impact of stillbirths on the Australian economy;

I had planned to take 12 month maternity leave after the birth of my daughter. After losing her I took 4 month off before returning to my part time position working as a nurse in a busy Intensive Care Unit. Going back to work was even more difficult than I imagined. Despite me asking my manager to inform all staff about my daughter's stillbirth lots of staff members were not aware of what happened. This created lots of very awkward moments with people congratulating me and asking who is looking after my baby while I was working.

I also found that I was not emotionally strong enough to continue working in the Intensive Care Unit and I have since changed my career.

h. Any related matters

While I understand the need for mothers to give birth to their still born babies in the delivery suite in case of complications I believe it is unnecessary to admit mothers and their stillborn baby to the general maternity ward. A special bereavement room on a different ward, away from newborn babies and their families would be a much better option. There is a great need for standardised Bereavement Care and follow up care once the family/parents are at home.

The hospital referred me to SIDS and Kids NT after my discharge but in the initial stages after losing my daughter it took all my strength and energy to support and look after my two children who were very confused and upset. I did not have the strength to call SIDS and Kids or anyone for support. I believe the midwives and Child and Family Nurses should get special education on Bereavement Care and follow up with the families providing home visits much like the service that is provided after giving birth to a living child.

A few month after my daughter Leilani was still born I discovered I was pregnant again. I had high levels of anxiety during this pregnancy. I was very well cared for by the obstetrician and midwives at the hospital and our son was frequently monitored with CTG and Scans. I was always encouraged to ring the delivery suite if I have any concerns about my baby's movement or anything else.

I found it very difficult to find emotional support in the form of counselling. I could not find anyone specialising in grief and loss or pregnancy after loss. I feel there is a need for specialised care facilities for subsequent pregnancy after stillbirth. Information and support about grieving children is also very difficult to find. Our two children are still grieving for their little sister and had lots of behavioural changes after the loss of our daughter. It would have been very helpful to have information about children and grief on hand from day one.

Thank you again for giving us the opportunity to share our daughters story as well as helping to address the Inquiry's Terms of Reference with our submission.

Kind regards,

Julia and Debden Whaanga