

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

28 June 2018

Dear Committee members

We are writing this submission as bereaved parents. Our son Sandy was born on 8 April 2018 at 20 weeks and 4 days gestation. We were told that Sandy passed away a few weeks earlier, however there were no signs of miscarriage, and we found out at the routine 20-week scan, that he had passed away. The cause of Sandys death is not clear, however the most recent information we have is that it is likely there was a problem with the placenta. We were shocked when we found out how high the rate of stillbirth is in Australia. As other developed countries (particularly Nordic countries) have much lower rates of stillbirth, we think that must be a lot more that can be done to prevent stillbirth in Australia.

Our experience is relevant to the terms of reference listed below:

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

- We declined an autopsy as it was too distressing at the time to think about having my baby cut up into pieces.
- However, had I been aware of the high rate of stillbirth in Australia prior to experiencing this, I may have been more open to having an autopsy on my baby thus generating data from our experience, in the hope that this would help to reduce the rate of stillbirth and save someone else from going through such a devastating experience.
- For example, in the material that is provided to parents when they have an initial appointment with their obstetrician or with a midwife at the public hospital, some information about the risks of pregnancy loss could be provided at the beginning.
- Further, 3 months later we don't have a clear reason why Sandy died. Perhaps if my husband and I had been aware of the high rate of stillbirth in Australia and had talked about autopsy (before we found out our baby died), in the same way organ donation is discussed (before a person dies), we both may have been in a position to agree to an autopsy which may have meant further data about our son added to existing data registries available to researchers.

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

- We live in a large town in regional Queensland and there does not appear to be any local support available in person for bereaved parents.
- Whilst there is online and telephone support available from Sands and Red Nose, the nearest support group to where we live is in Brisbane, a 90-minute drive.
- Exploring future funding options for groups such as Sands and Red Nose to provide in person support and/or support groups in more regional locations

would potentially open up the conversation about stillbirth and work towards reducing any stigma and/or taboo that there is in talking about this.

- We were also shocked when we found out the small amount of funding that Sands received in 2017 was \$411,546 from the Commonwealth and less than \$90,000 from the Queensland government (see Queensland and Sands Australia Annual Reports). We think that exploring funding options for groups such as Sands would be a positive step towards increasing awareness of stillbirth and indirectly work towards reducing the high rate 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

- Based on our experiences, we think that an important area to investigate and prioritise is research into whether more frequent scans and checks during pregnancy would reduce the rate of stillbirth.
 - In our case, there may not have been anything that could have been done, other than finding out sooner that our baby had passed. However more frequent scans may have picked up that there was a problem with the placenta.
 - I have also heard anecdotal evidence, stories from other women, where more frequent scans, especially in the last few weeks of pregnancy, may have meant that their child would have lived.
- Another area that we think is important to investigate as a research priority, is the effect that alternative medicine has on pregnancy and pregnancy loss. Whilst there must be some research exploring the effects of alternative medicine (such as acupuncture and naturopathy) on preventing and reducing the rates of stillbirth and miscarriage, we think that it is worth funding further robust research into the effects of alternative medicines on pregnancy outcomes.

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

- We think there is a need for better communicating stillbirth research to the wider community as well as families that experience pregnancy loss, and that opening up a public discussion about stillbirth would potentially work towards reducing the number of stillbirths in Australia.
- As a relatively educated person with post graduate qualifications and having been pregnant twice (my daughter is 4 years old), other than knowing that sometimes people had miscarriages and that sometimes babies were born dead, I did not know anything about stillbirth. I was not given any information around stillbirth and/or miscarriage from medical professionals during either of my two pregnancies.
- The Queensland public hospital where I gave birth to a stillborn baby was so prepared, with the midwives, doctors and social worker knowing exactly what to do, it became clear to us that stillbirth must happen a lot. I was then shocked when I looked up the statistics and found out that six babies are stillborn in Australia each day, and that this rate has not reduced in 2 decades. Everyone has heard about sudden infant death syndrome, but until I

experienced giving birth to a baby that had already died, I had not heard much about stillbirth.

- Another piece of information that we were not aware of was that the rate of miscarriage and stillbirth increases with age. We were aware that it is harder to get pregnant as the parents age increases, but if we had known that the rate of miscarriage and stillbirth also increases with age, we may have started trying for second child sooner.
- In Australia there are a lot of public health campaigns for various illnesses and disease that cause death. Yet no one talks about stillbirth. Until I personally experienced this, I only knew of three mothers who had experienced a stillbirth or miscarriage. Now that I am talking about this with the people I know, a large number of people in my circle (including people I only know a little or have recently met), have come out with their own stories of tragedy. We think there needs to be a public health campaign to raise awareness of stillbirth and open the conversation that no one wants to have about babies dying.
- Having read a lot of information in the last 3 months, we think that there is information that can potentially prevent stillbirth and warning signs for pregnant women to look out for, that could be better communicated to parents and reduce the rate of stillbirth in Australia.
- We think there is also a need for researching how to communicate with and support siblings that experience the death of a baby. When our baby died, we were at a loss as to how to communicate to our daughter (age 4) that the baby brother she had been looking forward to for a while, was dead. We decided to tell her as close to the truth as possible, and to keep reinforcing that it was nobody's fault. Our daughters' kindergarten was very helpful and had a few books in their library about death and one book about a family where a little person had died however they did not have any books specifically where a family had a baby die before being born or at birth. A good friend was able to find online two children's books (both are American) about families that had a baby die in mummy's tummy. Sands also recommended some books. These books provided us with much needed guidance on how to talk about and communicate with our daughter in an age appropriate way about how her brother had died and about what had happened. Researching and funding the publication of some Australian children's books would help a lot with communicating to young children.
- We think there is a need for better training of clinicians in how to communicate to parents, the findings of any tests done on a baby and/or placenta of a baby that has died. We had an appointment at the gynaecology clinic at the public hospital where I gave birth to our son Sandy. Unfortunately, this was not a positive experience. The registrar that we met at the appointment was unable to provide a clear explanation of the tests the hospital had done. We had to go to our GP with print outs the hospital gave us, and our GP was able to provide a clear, succinct explanation of the information she had of what tests had been done and was able to explain the results of the tests to us.

g) quantifying the impact of stillbirths on the Australian economy

- Costs to employers

- My husband had six weeks off work. Now that my husband is back at work, at this point in time (3 months after Sandy was born), his productivity at work has been affected.
- I am currently on maternity leave from my job and will not be able to work for the duration of the 14 weeks.
- Centrelink has also informed me that they will pay out the paid parental leave.
- My mother had to take some carers leave from her job, as she needed to stay with us (she lives in a different state to us), to provide both emotional and practical support by caring for our 4-year-old daughter during the birth, and in the week following the birth of Sandy.
- Cost to the public health system – we had 24 hours in a public hospital to give birth to our son Sandy and have had many medical appointments in the last ten weeks, a lot of which Medicare has subsidised.
- Costs to families – we had to pay the crematorium and a funeral home to cremate our baby.
- Any work to reduce the high rate of stillbirth in Australia would have a positive effect on the Australian economy, by reducing the costs described above.

h) any related matters

- We found out at a routine 20-week scan that our baby had died a few weeks earlier. Whilst trying to come to terms with this devastating experience, we could at least be grateful that my scan was booked past 20 weeks and not before - we found out that Australian law counts babies born after 20 weeks as a birth, and prior to 20 weeks as a miscarriage.
- For us, it was very important that we were required by law to register our son's birth, and that there are official records of our son's birth. We understand that there needs to be a cut-off point in the law, however had we found out a week earlier that our baby had died, we would not have had nearly as much support available to us, nor would we have had a birth certificate and official records that my daughter had a sibling.
- I read that in 2015 WA has now changed their rules to allow parents who give birth to a baby before 20 weeks with the option to apply for a 'recognition of loss' certificate, and that Qld and NSW already have this certificate in place. Ensuring that parents in any state in Australia can have this option, would assist parents to have a public record of their dead baby.

We think that there is a clear need to fund research to reduce the very high rate of stillbirth in Australia and are grateful for the opportunity to share our story, in the hope that in some small way it will contribute to reducing the rate of stillbirth in Australia and mean less people have to experience the tragedy of stillbirth.

Yours sincerely

Ruth Steinbring and Adam Cowell