Submission to the Senate Select Committee on Stillbirth Research and Education

Thank you to the Committee for the opportunity to make a submission to its inquiry into the future of stillbirth research and education in Australia. This submission seeks to address issues that are directly relevant to the Committee's terms of reference (ToR).

Recognise the "no-man's land" between miscarriage before 12 weeks and stillbirth from 20 weeks (relevant to ToR h)

I delivered our baby when I was 15 weeks' pregnant with her in 2011. We had announced the pregnancy to our friends and family. She wasn't "stillborn" because my pregnancy ended before 20 weeks, but I was able to hold her. I can't imagine the anguish of someone whose baby dies at 20 weeks or beyond, but I know I felt (and feel) anguish that our baby did not survive.

(I recognise moves to encourage people to be more open about miscarriages before 12 weeks also, but I want to ensure that the intermediate "late miscarriage" period is also considered).

Provide a properly funded perinatal pathology service – autopsy report issued within 6 weeks (relevant to ToR d)

Please ensure that perinatal pathology services around Australia are funded to a level that enables every perinatal autopsy report to be issued and available to the family within 6 weeks. My baby's autopsy report was not issued until 8 ½ months after my late miscarriage. I was desperate for the results. I was 41 years old at the time I miscarried and wanting to have another child, but concerned that there may be some condition present relevant to managing any future pregnancy (and I also wanted more information to help with grieving).

Ensure 24 hour, 7 days a week fully functioning obstetric ultrasound services in hospitals (commencing with major teaching hospitals) (relevant to ToR d and h)

During my two visits to hospital (a major teaching hospital) over two weekends, a portable heart beat monitor was used to detect my baby's heartbeat on two occasions. I was told that it was not possible to do a full ultrasound scan at the time. Although I may never really know, it is highly likely that my pregnancy ended due to an infection of the placenta. I still wonder to this day if a full ultrasound analysis could have assisted in detecting this infection so that antibiotics could be administered. Women do not bleed conveniently only between 9am and 5pm on weekdays. Fully functioning obstetric ultrasound services should be available 24 hours a day in major teaching hospitals around Australia.

Dramatically increase funding for research into the causes of miscarriage and stillbirth (relevant to ToR a, d and f)

Compared to other medical events and diseases, my husband's and my strong sense is that miscarriage, late miscarriage and stillbirth are very under-studied phenomena. There seems to be very little information available to parents of stillborn children or to parents who have suffered late miscarriages or miscarriages as to the actual causes of these events or how to prevent them occurring (cue vague statements about 'it's just something that happens' and 'it's nature's way of dealing with chromosomal defects'). I understand from media reports around this Senate inquiry

that stillbirth rates are not declining. Are there also statistics on the rate of late miscarriages? A dramatic and rapid escalation of research funding is needed, and more coordination of research, data collection and analysis is required. No researcher has ever contacted me for my medical records. I would be happy to make them available, to help prevent anyone else go through what my husband and I have had to experience.

Focus on the role of group B streptococcal infection in miscarriage and stillbirth (relevant to ToR a and e)

In Australia, the risk of Group B streptococci (GBS) infection in newborn babies is recognised and managed via screening and IV antibiotics use during labour. There has been a significant decrease in the incidence of neonatal GBS infection since the 1980s, when widespread use of intrapartum antibiotics began (see L Gilbert, S Garland, H Gidding, D Isaacs, A Daley, D Burgner, A Keil, J Faoagali, C Cooper, "Neonatal Group B Streptococcal (GNS) Sepsis – Final Report" on page 22 of www.apsu.org.au/assets/publishing/annual-reports/47892-APSU-FINAL-REPORT-0708-WEB.pdf).

However, I understand that GBS infection can also occur across ***intact*** amniotic membranes (see V Katz and WA Bowes, "Perinatal group B streptococcal infections across intact amniotic membranes" J Reprod Med 1988 May;33(5): 445-9; see also DJ Desa, CL Trevenen, "Intrauterine infections with group B beta-haemolytic streptococci" Br J Obstet Gynaecol. 1984 Mar;91(3):237-9). I think there is an urgent need to investigate the role of GBS in causing miscarriage and stillbirth, and to see if antibiotic use in subpopulations of at-risk women could reduce the rates of miscarriage and stillbirth.

Group B Strep International, a group formed to promote awareness and prevention of GBS disease worldwide, has proposed a new sub-type of GBS disease – Prenatal-onset Group B Strep (POGBS) Disease (see https://www.groupbstrepinternational.org/-what-is-group-b-strepprenatal-onset-3.html). I have attached an article examining POGBS in more detail as the appendix to this submission (the original article can be accessed at http://www.obgyn.net/pregnancy-and-birth/prenatal-onset-group-b-strep-pogbs-disease).

My own baby was affected by GBS infection - the microbiology result in the autopsy report indicated a heavy growth of beta haemolytic Streptococcus Group B from lung and gastric cultures, while the placenta had an amniotic fluid infection, with advanced stage, severe grade maternal inflammatory response (necrotising acute chorioamnionitis), and early stage fetal inflammatory response. I know or am aware of other women who have also suffered late miscarriages due to GBS-related sepsis or infection, including countless women's experiences to be read on the internet. I am uncomfortable relying on anecdotal evidence and the internet. Are there statistics on the prevalence of GBS infection in miscarriages and stillbirths in Australia? If not, these should be collected.

I am aware of the argument that resistant strains of bacteria could emerge if antibiotics are used widely during pregnancy, but I am not advocating that all pregnant women should receive antibiotics. A possible subpopulation is those women experiencing a large extramembraneous haemorrhage, where blood clots are able to pass through the cervix, indicating a potential opportunity for ascending infection. This subpopulation is surely smaller than the women who receive antibiotics for a caesarean or those who receive IV antibiotics in labour following a positive test for GBS.

A clinic in America has conducted a small-scale trial of antibiotic use to address GBS infection during pregnancy – see http://www.fertilitysolution.com/Latest-Research/Miscarriages-Associated-with-Group-B-Strep.html. See also K Loi, KT Tan "Massive pre-placental and subchorionic haematoma" Singapore Med J 2006; 47(12):1084, where antibiotics were used following the detection of GBS infection in the presence of haematomae. More research is needed.

Research, and educate pregnant women about, the risks of internal examinations (relevant to ToR d, e, f and h)

I understand that GBS, and other infectious agents, can move through the vagina and into the uterus (see "Do Not Strip Membranes in the Presence of Group B Strep and Here's Why" by Dr James A. McGregor, which has ultrasound footage illustrating active uterine transport in both a non-pregnant and pregnant patient). More research should be done on how to minimise the opportunities for infection created when internal examinations (via speculum, ultrasound probe or otherwise) or membrane stripping occur. Pregnant women should be educated about these risks.

Dramatically improve the care in hospital of women experiencing stillbirth or miscarriage (relevant to ToR d-h)

Research should be undertaken and action taken to determine which hospital wards women whose baby may or has died should be placed in. I think relevant criteria include:

- **a single patient room**. There's a lot of blood (I was at one point placed in a shared 4-bed ward, and remember, after using the shared toilet, prodding massive blood clots in the toilet bowl to check that my baby wasn't in them, then cleaning out the bowl so the other patients could use the toilet). It's an active physical process. Let alone the emotional side.
- **nowhere where newborn baby cries can be heard or living newborn babies seen**.
- **somewhere where there are experienced obstetric medical staff**. My baby died in a mixed surgical ward in a major public teaching hospital. I delivered my baby with no medical staff present. I was not diagnosed as being in labour, I was offered no midwife care, and had one phone call from an obstetrician prior to miscarrying. I found out I was miscarrying when I put my hands between my legs and felt my baby there. The first nurse my husband called into the room was obviously distressed, and later told me that this was the first dead baby she had seen. A different nurse later told my husband words to the effect that the ward was not set up for this kind of thing. The ward doctor who came to see me after I'd delivered my baby with no medical staff present put my baby in a bucket, and placed what I understand he thought was the placenta in the same bucket on top of my baby. It turned out several hours later that I hadn't delivered the placenta (the doctor had instead put a large blood clot in with my baby), and I had to have a D&C. The obstetric doctor from the maternity ward who came to see me after the D&C said they hadn't visited me in the mixed surgical ward while I was miscarrying because I "wasn't hosing" (I assume she was referring to blood loss). (Regarding the bucket in which the doctor put my baby, it is worth noting that the next day we discovered what seemed to be an identical bucket in my hospital room, and opened it up to discover that the bucket still contained a blood clot. We didn't look underneath the clot).
- **somewhere where there is clear information about what happens when your baby dies**. The hospital gave us conflicting information about what would happen to our baby's body, and we left her in the hospital essentially not knowing what would become of her (we found

out several weeks later, after ringing the hospital, that she would be cremated with other babies and her ashes scattered over a garden at a different hospital). Much more support is needed. Printed information needs to be accurate, and include contact details for support services.

- **somewhere where there are compassionate medical staff**. The ward doctor never said he was sorry that my baby had died. As I left the hospital with my husband after being discharged in mid December, filled with inchoate grief and loss, the ward doctor wished us a "merry Christmas" instead.

In this submission I have not addressed the emotional toll my late miscarriage and experience in hospital has had on me, my husband and our family. I was changed utterly. I cannot write about it.

In conclusion, I want to thank the Committee again for the opportunity to contribute to its consideration of its terms of reference. I have found writing this submission to be extremely challenging, as, in doing so, I have revisited the highly traumatic experience of my late miscarriage. I will never know if our baby could have survived the GBS infection if it had been detected earlier. I do know that I could have received better care in hospital. To be left unattended to deliver my own baby seems mediaeval. It's time to bring the care of women experiencing stillbirth, late miscarriage or miscarriage into the 21st century.

Appendix

Extracted from http://www.obgyn.net/pregnancy-and-birth/prenatal-onset-group-b-strep-pogbs-disease as at 25 June 2018

Prenatal-onset Group B Strep (POGBS) Disease

- James A. McGregor, MDCM
- John MacDonald

Oct 27, 2011

- Pregnancy and Birth

Group B strep (GBS) can definitely infect babies before birth, yet there is not an official name designated for GBS disease when it causes babies to be miscarried or stillborn. To further awareness and prevention of GBS disease in all stages of a baby's development, Group B Strep International is giving a name to GBS disease acquired before birth: Prenatal-onset Group B Strep (POGBS) Disease.

Most medical literature mentions only two types of GBS disease: early-onset and late-onset. The majority of known GBS infections in newborns occurs in the first week of life. These GBS infections are designated as early-onset GBS (EOGBS) disease. So far the primary focus of GBS disease prevention has been treating GBS positive women during labor so that their babies do not become infected during passage through the birth canal. Currently both the United States and Canada have active prevention guidelines in place to test all pregnant women at 35-37 weeks of pregnancy and, if positive, treat them with IV antibiotics during labor. These guidelines have been very successful in reducing the rate of early-onset infection by more than half from 0.7 cases per 1000 live births in the U.S. in 1997 to 0.32 cases per 1000 live births in the U.S. in 2004.[1]

Currently the secondary focus of GBS disease prevention is late-onset GBS (LOGBS) disease which occurs in infants over 1 week of age usually up to the first three, but sometimes even six months of life. LOGBS can be caused by sources other than the mother, including hospital personnel. Prevention consists mainly of promoting thorough hand washing prior to anyone handling the baby and breastfeeding to give the baby important antibodies. Recognizing symptoms of GBS infection can result in better outcomes for the baby if prompt medical treatment is initiated.

However, a baby can definitely succumb to GBS infections long before the bacteria are transmitted during delivery. Since this is not yet a recognized disease it is unknown how many babies have been miscarried or stillborn due to GBS. Pathology testing is not mandatory and not even always suggested to the mother. At minimum, placental culturing may tell the cause of death. This is important especially since having a baby infected by GBS puts a mother at higher risk for subsequent babies being infected by GBS.

Perhaps the reason that prenatal-onset GBS disease has not been officially recognized is that the general medical opinion considers GBS-caused miscarriages and stillbirths to be rare occurrences. However, among GBS awareness groups, there are far too many parents who have had their baby's autopsy or placental testing report cite GBS as the cause of death for prenatal-onset GBS disease to continue being regarded as rare.

Fortunately there are at least four main courses of action to help prevent prenatal-onset GBS disease:

1. **Increase awareness among care providers, pregnant women, and their families as to how invasive procedures can cause GBS to cross even intact amniotic membranes.** The August 16, 2002 CDC MMWR specifically states that GBS can cross intact amniotic membranes.[2]

   GBS germs can travel or be transported into the womb by digital exams even early in pregnancy. GBS microorganisms have special attractant molecules that can take hold of genital tract tissues. These microorganisms also have special molecules that can dissolve through the mucus plug.[3] GBS can then penetrate membranes and infect the baby or damage the placenta[4] which eventually results in miscarriage or early pregnancy stillbirth. Later in pregnancy, GBS may be introduced to the baby during routine cervical checks and other invasive procedures such as intrauterine fetal monitoring, application of cervical ripening medications, and "membrane stripping" sometimes known as "membrane sweeping."

   The benefits of invasive procedures may outweigh the risks, but other times invasive procedures are merely used for convenience or as part of routine examinations. Perineal and vaginal ultrasounds offer an alternative to digital examination.

   Membrane stripping can introduce infection[5] although there is a debate about whether or not it is directly related to a higher incidence of GBS infection. However, it has been proven via dye tests that small particles can ascend through the cervix. Case studies of dead or very sick babies at birth point to a direct correlation. Common sense alone dictates that if a gloved hand or instrument is moved through the lower third of the vagina (where GBS usually colonizes) and then up into the cervix that GBS or other bacteria can be moved closer to where the baby can be harmed. A recent legal case examines the potential for litigation regarding membrane stripping.[6]

2. **Ensure prompt attention to vaginal and urinary tract infections during pregnancy.** Even though health care providers do not widely recognize GBS vaginitis, GBS can cause yellow or green discharge as well as vaginal burning and/or irritation. These symptoms may be mistaken for a yeast infection or bacterial vaginosis. Vaginal and bladder infections caused by GBS have been linked to preterm births and can indicate a heavy amount of GBS colonization that can potentially harm the baby.[7]

   Pregnant women should be promptly evaluated and treated appropriately for any symptoms of vaginitis. "Tests of cure" should be routine. Extreme caution should be used regarding any invasive procedures in a woman experiencing symptoms of vaginitis.

3. **Periodic urine cultures for GBS should be performed during pregnancy.** The presence of GBS bacteriuria in any concentration in a pregnant woman is a marker for heavy genital tract colonization and possibly absent maternal immunity which can put the baby at greater risk. These women do not need vaginal and rectal screening at 35-37 weeks.

   The CDC recommends that women with any quantity of GBS bacteriuria during pregnancy should receive intrapartum chemoprophylaxis. The CDC also recommends that women with urinary tract infections, both symptomatic and asymptomatic, receive appropriate treatment at time of diagnosis according to the current standard of care for UTI's in pregnancy.[2] In addition to intrapartum chemoprophylaxis, parent-based groups advocate treatment at time of diagnosis as well as a recheck for any quantity of bacteriuria to further protect the baby. ACOG recommends that a urine culture be performed at the first prenatal visit as well as in the third trimester (28-40 weeks.[8]) Testing urine more frequently may be prudent.

4. **Consider treating GBS positive women with intramuscular benzathine penicillin G in the late third trimester. (Alternatives for this treatment for penicillin allergic women are not yet reported.)** Although this strategy is not currently a CDC or ACOG recommendation, two studies have shown that treating GBS positive women with 4.8 million units of intramuscular benzathine penicillin G eradicates or significantly reduces their GBS colonization at delivery when given in the late third trimester.[9,10] This treatment appears to be effective for at least 4 weeks after injection.[10] Another more recent study using 2.4 million units of intramuscular benzathine penicillin G suspension (Bicillin L-A) in the late third trimester showed a smaller yet still significant decrease in the rate of GBS colonization upon admission to labor and delivery.[11]

   Two of the studies noted in their conclusions that their respective treatments may be useful as a supplement for women who are at risk for not receiving the appropriate amount of intrapartum antibiotic prophylaxis against GBS.[9,11]

Current protocol actively addresses early-onset prevention. However, prevention of prenatal-onset GBS and recognition of symptoms of GBS infection in babies once born can further reduce the effects of GBS disease in babies before and after birth. For symptoms including fever, lethargy, and any kind of distress in the baby, please visit http://www.groupbstrepinternational.org/brochure.html. GBS information is available in both English and Spanish.

References:

Group B Strep International (GBSI) is an organization formed to promote awareness and prevention of Group B Strep disease worldwide. To further these efforts GBSI is sponsoring International Group B Strep Awareness Month in July as an official observance on the 2007 National Health Observance Calendar.

Please join us at www.groupbstrepinternational.org in the fight against GBS disease before and after birth.

Your comments and feedback are appreciated. Please feel free to e-mail us at info@gbs-intl.org

This article is for informational purposes only and does not constitute medical advice.

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