Dear Senate members,

We are writing this submission as representatives of the International stillbirth Advocacy Working Group (SAWG), which is connected to the International Stillbirth Alliance. Our vision, simply, is to live in a world in which preventable stillbirths no longer occur, and care for families and health workers after stillbirth is compassionate, high-quality, and culturally appropriate. We try to achieve this vision through the following strategies:

1. Develop and support a **network** that advocates for stillbirth prevention and care within the existing global architecture (Global Strategy, Every Newborn Action Plan, Quality-Equity-Dignity, etc.)
2. Ensure key **evidence and data** are visible, resourced, tailored appropriately for key audiences, and linked to **accountability** at country level and globally
3. Seize **key moments** to advocate for stillbirth prevention and care
4. Empower "bottom-up" advocacy from **parents** and parent groups

Our network includes stillbirth researchers and parent organisations from high, middle and low-income countries. This allows us to have a global perspective on stillbirth and help make it visible to government organisations to try and implement change.

On a world-wide scale, Australia has shown slower progress in reducing stillbirth than many other high income countries[1]. In comparison, New Zealand has achieved a 2.8% and the Netherlands a 6.8% annual rate of reduction of stillbirth per year[1]. Of particular concern are disparities with Australian Aboriginal women and women of South Asian and African origin all at increased risk of stillbirth[2].

[1] Flenady, V, Wojcieszek, AM, Middleton, P, Ellwood, D, Erwich, JJ, Coory, M, et al. (2016). Stillbirths: recall to action in high-income countries. The Lancet, 387 (10019), 691-702.

[2] Gordon, A, Raynes-Greenow, C, McGeechan, Morris, J, Jeffery. (2013) Risk factors for antepartum stillbirth and the influence of maternal age in New South Wales Australia: A population based study. BMC Pregnancy and Childbirth, 13:12

Losing a baby before birth is unimaginable, and bereaved parents grieve the future they had imagined for that child during their pregnancy. This is a loss that cannot and should not be forgotten. Bereaved parents need significant psychosocial support after stillbirth[3]. However, bereaved parents who have had a stillborn baby often face psychological and social consequences for many years after the death. For example, it is currently estimated that worldwide 4.2 million mothers experience depression after stillbirth[2]. Other common experiences after stillbirth for bereaved parents often include feelings of isolation, silence and stigma. The social, psychological and economic impact of stillbirth may be felt for years to come by bereaved parents. In Australia, this is often exacerbated with limited support and no formalised approach for helping bereaved parents.

Stillbirth also carries a great economic cost. A Price Waterhouse Cooper report commissioned by the Stillbirth Foundation estimated that between 2016 and 2020, stillbirth will cost the Australian government approximately $681.4 million. Within this estimate, direct (stillbirth investigations and counselling); indirect costs (funeral costs and absenteeism, etc) and intangible costs (mental well-being) were all considered[4].

There persists a fatalistic attitude towards stillbirth, with many people falsely believing that it is inevitable[5]. The Scotland government provides an example of how structural changes made at a government level can create real progress at a national level in stillbirth prevention and support[6]. They implemented a policy which required health care providers to discuss fetal movement and its association to stillbirth with pregnant women throughout their pregnancy. This discussion then needed to be documented to ensure that all women were informed about the importance of fetal movement. This and other actions at national and local levels have resulted in a 19.5% reduction in the number of stillbirths since 2011 in Scotland[6]. This is an excellent example of how Government action can influence stillbirth rates, is easily reproducible and if adopted in Australia is very likely to reduce stillbirth.

Stillbirth rates can be reduced e.g. through cessation of smoking, identifying the small for gestational age infant prior to delivery for special care during pregnancy, and educating mothers and their families about the things she can do to keep her baby safe such as the

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[3] Heazell, EP, Siassakos, D, Blencowe, H, Burden, C, Bhutta, ZA, Cacciatore, J, et al. (2016). Stillbirths: economic and psychosocial consequences. The Lancet, 387 (10018), 604-616

[4] PwC "The economic impacts of stillbirth in Australia" available from http://stillbirthfoundation.org.au/wp-content/uploads/2016/10/Economic-Impacts-of-Stillbirth-2016-PwC.pdf

[5] Woods, J.R., & Heazell, A.E.P (2018). Stillbirth: is it preventable? Obstetrics, Gynaecology & Reproductive Medicine, 28,5, 148-154.

[6] Love C. (2017) "Stillbirth in Scotland: Scottish government update" available from https://ihub.scot/media/2849/drcorinnelove.pdf

importance of maternal sleep position and monitoring of fetal movement[5]. Further research could also improve understanding, identify more reasons as to why stillbirths occur and craft and promote health messages to inform pregnant women and families about modifiable health behaviours which could make a difference to pregnancy outcomes.

It is encouraging to see the Australian Government's Bipartisan support for the Senate select committee to inquire and report on the future of stillbirth research and education in Australia and we hope that by addressing the following terms of reference (**a, b, d, & h**), we may offer a global perspective on stillbirth advocacy:

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

As part of the 2016 Lancet series on Ending Preventable Stillbirths, a global priority action was to create indicators which measure impact and monitor progress on stillbirth prevention and support. Being able to count how many stillbirths are occurring in a quick and timely fashion is important in being able to identify trends and implement interventions. Australia currently has one of the better perinatal data collections in the world. However, as is the case in many high income countries there is currently a two year time lag between data collection and publication of the data. This means that any risk reduction strategy, such as a public awareness campaign cannot be measured at population level for at least two years, steps to (at the very least) publish the annual rate sooner may assist.

Additionally there is not yet a consistent system which classifies the causes and associated conditions of stillbirth, used globally[7] and this is recognised as a major impediment to stillbirth prevention[8] both in Australia and overseas. There is an international movement including leadership by the Australian NHMRC funded Stillbirth CRE to explore development of a global classification system consistent with ICD-PM. If this could be achieved this would be of significant benefit both in Australia and overseas. We call for the senate inquiry to recommend that this occur and be appropriately resourced.

Furthermore, we suggest that a system which counts 'near misses' through the development of a composite score to be calculated via current perinatal data collection may be helpful. We suggest this score could include information about small for gestational age status, the baby's

[7] Hopkins-Leisher, S., et al (2016). Classification systems for causes of stillbirth and neonatal death, 2009-2014: an assessment of alignment with characteristics for an effective global system. BMC Pregnancy and Childbirth, 16 (1), 269.

[8] Flenady, V., et al (2011). Stillbirths: the way forward in high-income countries. The Lancet, 377, 1703- 1717.

ability to cope in labour, visual review/histology of the placenta, NICU admission, and other factors which could allow further identification of the gaps currently within stillbirth research and help us understand how some babies survive and others do not.

b. coordination between Australian and international researchers;

As seen in our own working group, international collaboration allows for valuable information to be disseminated quickly and effectively across the globe. There are several examples of how creating international collaborations can make a real difference to understanding, awareness and advocacy.

However, efforts made by these international collaborations are hindered by limited funding. Often, researchers are participating in this working groups in spare time frequently motivated by their passion and dedication for preventing stillbirth and creating better care environments for the bereaved parent. Formalised funding opportunities that are specifically targeted at assisting these groups to do their good work such as travel grants to meet and see other researchers and their centre would be welcomed.

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

Stillbirth contributes a significant burden of disease in Australia but is not currently appropriately recognised in funding distribution. In order to address this disparity we ask that stillbirth be included as a National Health Priority Area (NHPA) so it is seen as equally important to other current NHPAs (ie Cardiovascular, obesity and mental health). By making it a NHPA, the public will become aware of the importance of stillbirth and researchers will have access to more resources to address this major health issue and create specific action for reducing stillbirths in Australia.

Such research could align with the identified key global stillbirth research priorities[8]. These priorities were developed and scored by international stillbirth working groups. They include but are not limited to the following: ‘Characterising the fetal response to an adverse intrauterine environment to develop improved means of clinical assessment of fetal wellbeing;’ and ‘What maternal lifestyle factors are associated with stillbirth…?” These areas and others like them are ripe for research funding, with Australian stillbirth researchers well placed to led ground breaking research[8].

h. any related matter;

We also ask for the following to be considered:

Involvement of Government champions in stillbirth education and research.

The dramatic drop in the stillbirth rate in Scotland (19.5% in less than 5 years)[6] was driven by Dr Cath Calderwood a consultant obstetrician and gynaecologist and the Chief Medical Officer for Scotland. From her position and in consultation with clinicians, she enacted policy which has directly reduced the stillbirth rate in that country. This success clearly demonstrates that when government and clinicians work together baby's lives can be saved.

We therefore call for those who are in a position to make key decisions on maternity policy and practices become involved in Stillbirth Education and research by e.g. attending and addressing national and international stillbirth conferences. This would help start the dialogue between researchers and government and assist in informing an understanding of the impact, scope and strategies on preventing stillbirth.

We thank you for the opportunity for our group to give insight and recommendations for changing stillbirth rates in Australia

Yours Sincerely

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On behalf of the Stillbirth Advocacy Working Group