



## International Stillbirth Alliance Conference 2017

Bringing researchers, clinicians, and parents together to prevent stillbirth and improve bereavement care

### The Challenge

Stillbirth is a major health burden. Few complications in a maternity hospital are as emotionally devastating for parents and clinicians as the death of a baby during pregnancy or at birth. In recent years, there has been a global call to reduce the numbers of preventable stillbirths and increase public awareness about the incidence and impact of stillbirth. The lived experiences of bereaved parents have much to contribute to developing the research agenda and clinical care.

The multidisciplinary Pregnancy Loss Research Group (PLRG) based at the INFANT Centre and the Department of Obstetrics & Gynaecology at University College Cork and Cork University Maternity Hospital, has an established practice of active engagement and participation of people with lived experience in its activities. This partnership provided the catalyst to model a similar collaborative approach between clinicians, researchers and bereaved parents when the PLRG was successful in their bid to host the International Stillbirth Alliance (ISA) Annual Conference in 2017.

### Our Research

Professor Keelin O'Donoghue chaired the Organising Committee for ISA 2017, and led a large multi-disciplinary team involving obstetricians, midwives, scientists, services users, perinatal pathologists, chaplains, educators and researchers and bereaved parents. The aim of the conference was to challenge healthcare professionals to constantly strive for excellence in stillbirth awareness, research and bereavement care.

The conference attracted an international faculty and attendees, and this served as an excellent opportunity for researchers, clinicians and industry to meet, exchange ideas and form future collaborations. Establishing a culture of collaboration, support and mutual respect in the field of pregnancy loss, requires scientists, clinicians and parents to be brought together so each can be informed by the other in the efforts to prevent stillbirth and improve bereavement care.

A sub-committee of staff and parents was established to ensure that the voice of parents could contribute to the research agenda and developments in clinical and bereavement care. A creative workshop specifically for parents, followed by a parent assembly were organised to facilitate this. Remembrance activities, organised by the parent committee, were central to the conference and actively engaged in by parents, clinicians and researchers.





### Our Impact

- Over 400 national and international delegates attended ISA Cork 2017, making this the most successful conference in the history of the ISA
- Delegates came from 26 countries – 20% of delegates were non-healthcare professionals – bereaved parents and parent support groups
- Human experiences of stillbirth bereavement from both bereaved parents and healthcare professionals were shared
- Programme included plenary talks with invited speakers and >130 submitted presentations – talks and posters
- Pre-conference workshops were successful – led to ongoing collaboration across ISA's bereavement and classification working groups

**Commentary – written collaboratively by a parent, a chaplain, a bereavement and loss specialist midwife and a consultant obstetrician – published in Research Involvement & Engagement outlines key messages that arose from reflections on the conference:**

- Value of active partnership between clinicians and patients
- Use of creativity as a unifying expression of grief and as a means to facilitate learning
- Value of collaboration with global stakeholders in raising awareness about stillbirth
- Importance of facilitating meaningful patient/public engagement in scientific research



### Other standouts

- Parents Workshop and Assembly – unique original and well attended
- Exhibition from charities and support groups
- National media coverage – print, radio and TV
- First public viewing of a moving and beautiful short film “When my baby died”, made by the Local Organising Committee in collaboration with small group of bereaved parents

“ The International Stillbirth Alliance’s (ISA) mission is to **raise awareness of stillbirth** and to **promote global collaboration** in the effective **prevention of stillbirth** and provision of appropriate **care for parents** whose baby is stillborn. As our own National Standards for Bereavement Care following Pregnancy Loss and Perinatal Death were implemented in 2017, it was significant that this conference was held in Ireland as it demonstrated a significant step forward in our **commitment to compassionate care for parents** and the impact that bereavement brings. ”

– **Professor Keelin O’Donoghue, Chair of the Organising Committee of ISA2017 and Lead, Pregnancy Loss Research Group**

