This year’s International Stillbirth Alliance Annual Conference will be held in Cork, Ireland from 22-24th September 2017 at the University College Cork campus. The Conference will include a mixture of plenary and concurrent sessions from invited speakers and selected presentations from conference abstracts. We expect participants from across the globe. Pre-conference, an IMPROVE workshop (Improving Perinatal mortality review and Outcomes via Education) will be held on Friday 22nd September and is an outstanding way to learn more about stillbirth evaluation, education, and bereavement. Full details of the scientific programme, IMPROVE workshop, social programme, and registration details are available at http://isacork2017.com/ It is not too late to join us, and we welcome parents, scientists, researchers, and clinicians from any country to this multidisciplinary conference to share and
The Scientific Committee of ISA has been very active in 2017. In addition to helping organise the content of ISA conferences (Cork 2017, Glasgow 2018 and beyond), the focus has been on scientific output and visibility, to improve the standards of care and prevention globally.

Example outputs include a statement and leaflet on decreased/reduced fetal movements, papers for the upcoming BJOG Stillbirth Themed Issue edited by members of SAC, and current collaborative work to improve classification, increase frequency of audits, and strengthen understanding of the global causes of stillbirth. Other projects aim to involve parents in perinatal mortality review processes, to reach a consensus on principles of bereavement care for both high and low/middle income countries, and to harmonise outcome measurements for bereavement care research.

Some examples of projects and publication are included in this newsletter and we encourage members of ISA to send updates of their current and completed work so we can help publicise it. SAC have also agreed to help supervise and provide input to robust proposals (for grants, studies and manuscripts) by members, on a case by case basis.

The scientific committee will work closely with individual and institutional members, to ensure stillbirth remains high on the global agenda, and that ISA remains at the centre of international action to improve prevention and care through rigorous scientific research.

Of Interest From the Literature...

In a systematic review of 36 studies on temperature exposures (hot or cold) during pregnancy, there was stronger evidence for adverse birth outcomes from heat than cold. Both extremes were associated with higher risk of low birthweight and preterm birth but only exposure to high temperatures was associated with stillbirth. Researchers noted the

Multiple members of the ISA Board and the Scientific Advisory Committee presented at the annual Star Legacy Stillbirth Summit 2017 held in Minnesota, U.S. in June 2017.

Speakers included Dr. Jane Warland who gave the Keynote Address: “I Have a Dream” as well as the lecture: “STARS Hidden Gems and Further Opportunities for Collaboration.” Dr. Warland also won the 2017 Star Award for Stillbirth Research presented by the Star Legacy Foundation.

Dr. Alexander Heazell gave two talks: “Rainbow Clinic: A Model for Antenatal Care in Pregnancies After Stillbirth,” and “Using Maternal Perception of Reduced Fetal Movements to Improve Pregnancy Outcome.”

Margaret Murphy presented jointly with Joann O’Leary, and they spoke on: “Finding Hope: The Journey from Loss to the Embracing a Baby That Follows.”

A successful IMPROVE workshop (Improving Perinatal mortality review and Outcomes via Education) was also held at the conference.
Upcoming Global Stillbirth Events

Compiled by Susannah Leisher
ISA Board Treasurer

July 2017

August 2017

September 2017
section=information&subSeccion=
welcome

October 2017
No date yet: Ethiopia: launch of progress report on Ending Preventable Child and Maternal Deaths (no link available yet)

November 2017

December 2017

The ISA Board would like to thank Leanne Raven of Red Nose (formerly SIDS and Kids Australia) for her service on the Board from 2016-2017. She has elected to step down from the Board effective July 2017.
Globally, preeclampsia and other hypertensive diseases of pregnancy are a leading cause of maternal and infant illness and death, resulting in 76,000 maternal and 500,000 infant deaths every year.

The WHO has highlighted that the condition has a highly disproportionate impact on low-to-middle income countries (LMIC), where over 99% of preeclampsia cases occur. It is estimated that 16% of maternal deaths in LMIC are the result of hypertensive diseases of pregnancy.

It is the leading cause of maternal mortality in the Americas accounting for a quarter of all maternal deaths in Latin America and a tenth of maternal deaths in Africa and Asia.

**DID YOU KNOW?**

Pre-eclampsia dramatically increases risk of stillbirth, particularly when it develops early in pregnancy. In a very large study in Norway, risk of stillbirth was 3.6/1000 overall but 5.2/1000 in pregnancies with pre-eclampsia. (Harmon QE et al, Obstet Gynecol, 2015)

In a study of low-income countries, pre-eclampsia nearly doubled the odds of perinatal death (stillbirth plus infant death in the first 7 days). (Bilano VL et al. PLOS One, 2014)
Annually, more than 1.3 million babies begin labor alive and die before birth. This is known as antepartum stillbirth.

In February 2017, the governments of nine countries (Bangladesh, Cote d’Ivoire, Ethiopia, Ghana, India, Malawi, Nigeria, Tanzania, Uganda), together with support from WHO, UNICEF, and partners from all stakeholder groups, launched a Network for Improving Quality of Care for Maternal, Newborn and Child Health (The Quality of Care or “QoC” Network).

The QoC Network aims to support every pregnant woman, newborn and child with good, quality health services. The aim is to halve maternal and newborn deaths and stillbirths in participating health facilities within five years in the nine participating countries. ISA, as a co-chair of the Stillbirth Advocacy Working Group, is also an invited member of the QED Working Group where our mission is to ensure that stillbirth prevention and post-stillbirth bereavement care are fully incorporated into the global discussion.

As part of the Quality of Care Network learning activities, they have organized a series of webinars. The list of upcoming webinars can be viewed at: http://www.qualityofcarenetwork.org/about/network-activities

**Quality, Equity, Dignity**

**QED Vision:**
Every woman and baby, everywhere, receives quality, dignified maternal and newborn health care.

**QED Goal:**
Accelerated progress toward the Global Strategy targets, and ultimately an end to all preventable maternal and newborn deaths.
ISA Represented at the World Health Assembly

World Health Assembly

The 70th World Health Assembly took place in Geneva, Switzerland on 22-31st May 2017. The Assembly is the decision-making body of WHO. It is attended by delegations from all WHO Member States and focuses on a specific health agenda prepared by the Executive Board.

The main functions of the World Health Assembly are to determine the policies of the Organization, appoint the Director-General, supervise financial policies, and review and approve the proposed programme budget. The Health Assembly is held annually in Geneva, Switzerland.

This year, the views of ISA were represented at the Assembly by Dr Maria Tejada de Rivero Sawers, an obstetrician and bereaved mother who is undertaking an MA in Public Health from the London School of Hygiene and Tropical Medicine. Maria is from Geneva but based in Mexico.

Dr de Rivero Sawers shared her experience of stillbirth while living in Mexico. Health systems, she said, must be better equipped to support parents who experience loss. The issue of stillbirths must be brought out of the shadows to receive greater attention and investment, with far stronger national monitoring processes to enable better counting and global policy attention.

Dr de Rivero Sawers’s call was echoed by Anneka Knutsson of UNFPA, who provided closing remarks at the event. “We have heard many key words this evening, including leadership, demand, data, and the need for domesticated standards of care.” People are at the centre of health systems, and their experience of care matters.
From 2009-2014, 81 different systems to identify and classify cause of stillbirth were in use, two-thirds exclusively in high income countries.

—From Flenady V, Sem Fetal Neonatal Med, June 2017

ISA Board & SAC Members: Sampling of Our Current Stillbirth Research

Who tells a mother her baby has died? Communication and staff presence during stillbirth delivery and early infant death. 

Gold KJ, Treadwell MC, Mieras ME, Laventhal NT. (under review). A survey among 900 bereaved and 500 live birth mothers revealed that bereaved mothers were less likely to have hospital staff at their delivery and African-American mothers with stillbirth to have been given this news by a physician or midwife compared with Caucasian mothers.

Are participants in face-to-face and internet support groups the same? Comparison of demographics and depression levels among women bereaved by stillbirth.

Gold KJ, Normandin MM, Boggs ME. J Arch Womens Ment Health. 2016. Online versus face-to-face support groups were compared in bereaved mothers: depression symptoms were similar among participants. Women of color, poor, and less-educated women were starkly underrepresented in both types of groups highlighting the need to optimize support options for these populations.

Perinatal death investigations: What is current practice?

Nijkamp JW, Sebire NJ, Bouman K, Korteweg FJ, Erwich JJHM, Gordijn SJ Semin Fetal Neonatal Med. 2017. This is an overview of current practice after stillbirth which offers a step by step approach for postmortem analysis.

Classification of causes and associated conditions for stillbirths and neonatal deaths.


Semin Fetal Neonatal Med, June 2017

From 2009 to 2014, a total of 81 new or modified classification systems were identified, primarily in high-income countries (HICs). The new ICD-PM system is an important step forward and improvements will be enhanced by wide-scale use and evaluation. Implementation requires national-level support and dedicated resources.

Reducing the impact of perinatal death - The case for increased understanding of underlying causes to inform change to save babies' lives.

Alfirevic Z, Heazell A. Editorial heading a full issue in Seminars in Fetal and Neonatal Medicine on stillbirth and early neonatal death for which Dr. Heazell was co-editor.
Stillbirth Research (continued)

Systematic review of parents and healthcare professionals’ experiences of care after stillbirth in low and middle-income countries.
Shakespeare C, Merriel A, Bakhbakhi D, Storey C, Siassakos D (study in progress)
Aims to identify what is known about care in LMICs, as a foundation for ongoing efforts to identify optimal bereavement.

Developing a global consensus on bereavement care after stillbirth.
Siassakos D, Storey C, Flenady V, Blencow H. (study in progress)
This piece aims to improve care after loss, but also develop a baseline package that can be harnessed for advocacy going forwards.

iCHOOSE: International Collaboration to Harmonise Outcomes for Bereavement Care Research
Siassakos D, Flenady V et al (study in progress)

All bereaved parents are entitled to good care after stillbirth: A mixed-methods multicentre study (INSIGHT)
Siassakos D, Jackson S, Gleeson K, Chebsey C, Ellis A, and Storey C for the INSIGHT Study Group
BJOG July 2017
35 bereaved parents and 22 members of staff took part in focus groups. Women reported that sometimes there were long delays before the death of the baby was confirmed, and before action was taken, and discharge planning was inconsistent. Staff communication with parents was not always sensitive.

Parents’ Active Role & ENgagement in The review of their Stillbirth/perinatal death Study: The PARENTS 1 Study.
Bakhbakhi D, Siassakos D, Burden C, Jones F, Yoward F, Redshaw M, Murphy S, Storey C
BMC Pregnancy and Childbirth (in revision)
An ethnically diverse sample of women and their partners who had experienced a perinatal death were supportive of parental involvement in the perinatal mortality review process. They recommended an individualised approach which considers the emotional, as well as clinical, aspects of care. Parents wanted reviews to include antenatal, postnatal, neonatal and community based care and requested opportunities for parents to give feedback on their care.

Interventions to prevent stillbirth.
Page JM, Silver RM
Sem Fet Neonat Med, 2017
Reviews limitations to using risk factors to screen for stillbirth and recommends augmenting care for high risk women through the use of antenatal testing, fetal growth measurement, Doppler velocimetry, and planned delivery.
The Centre of Research Excellence in Stillbirth (The Stillbirth CRE) is a national collaboration in Australia addressing the neglected tragedy of stillbirth. Through a priority driven program, the Stillbirth CRE aims to reduce the rate of stillbirth and improve care for parents and families experiencing stillbirth in Australia.

The Stillbirth CRE is a partnership of organisations across Australia with the main coordinating centre at the Mater Research Institute, University of Queensland and led by Vicki Flenady, a former Chair of ISA and the Current Co-Chair of the ISA Scientific Advisory Committee. The Stillbirth Foundation Australia is an integral partner of the Stillbirth CRE. Partnerships with other stillbirth advocacy and support organisations of Red Nose, Still Aware, SANDS, and Bears of Hope will ensure parents are heard and relevant stillbirth priorities addressed. Active engagement with researchers, clinicians, professional organisations and policy makers will ensure maximum benefit of CRE initiatives. The Stillbirth CRE has strong links with the International Stillbirth Alliance (ISA) through many years of collaboration which is strengthened through annual ISA conferences and ISA’s scientific committee. Working closely with ISA will enable the work of the CRE to interact with other global initiatives to ensure benefit to women and families beyond Australia. Collaboration with ISA will be showcased at the ISA 2020 Conference to be held in Brisbane, Australia, hosted by the Stillbirth CRE. To find out more please visit our website: stillbirth.centre.uq.edu.au.

Update from the ISA Chair

Dr. Alexander Heazell

Dear Supporters and Member Organisations of ISA, I would like to thank you for your continued interest in ISA and hope that the different items in the newsletter catch your attention. This is the last newsletter during my period as Chair of ISA which started in 2014. I would firstly like to thank all the board members who have served ISA during that time. As I am sure you are aware, ISA is reliant on the time and dedication of its board, all of whom give their time voluntarily. Without this commitment we would not be able to achieve what we have.

Over the last three years we have held ISA meetings in the countries of Georgia, Vietnam, Canada and Uruguay. These meetings have brought important messages about stillbirth and care of parents and given those regions impetus and external support to reduce stillbirths and improve care for parents. We were one of the lead organizations for the Ending Preventable Stillbirth Series in the Lancet and BMC Pregnancy and Childbirth.

ISA has also worked with high-level international organisations to ensure that stillbirths will be counted to assess the performance of the Global Strategy for Women’s, Children’s, and Adolescents’ health. I think we have made an impact far beyond the size of our organisation.

It is also time to look forward. I am very excited about our meeting planned for Cork in 2017 which promises to be the largest ISA meeting for many years. There will be over 150 different presentations from all over the world. I warmly encourage parents and professionals to attend. We will then meet again with ISPID in Glasgow in June 2018.

ISA is now beginning to play an even greater role in raising the profile of stillbirth and coordinating international efforts to have stillbirths counted and their impact recognised. To do this effectively we need to increase our income in order to attend vital events such as the World Health Assembly. We will be sending a fundraising letter shortly. If you would like to support ISA financially, please make a donation here, http://stillbirthalliance.org/donate/. I hope, like me, you are excited about all the opportunities for ISA. I hope to see you in Cork!

Join ISA on Social Media!

Please “Like” us on Facebook!

We are up to 925 “Likes” on our Facebook page. Please add your “Like” to stay in touch with stillbirth prevention progress across the globe.
Subsequent pregnancies after perinatal death – PSANZ congress breakfast session by The Australian Stillbirth CRE

This 2017 Perinatal Society of Australia and New Zealand (PSANZ) annual congress was held recently in Canberra, Australia.

The Australian Centre of Research Excellence in Stillbirth (Stillbirth CRE) was pleased to host a breakfast session on subsequent pregnancies after perinatal death, highlighting the general lack of adequate services for pregnancies after loss, and the importance of addressing parents’ unique needs in these pregnancies.

We were delighted to welcome Louise Stephens, specialist midwife at St Mary’s Hospital, Manchester, to share her experiences providing care to parents who have previously had a stillborn baby, through Manchester’s Rainbow Clinics.

Other pockets of excellence in care after perinatal death and subsequent pregnancy care were highlighted by Adrienne Gordon and Aleena Wojcieszek, including the integrated Services After Infant Loss (iSAIL) clinic in Sydney, Australia, and the Pregnancy After Loss Clinic (PALC) at the Mater Mothers’ Hospital in Brisbane, Australia, led by Liana Quin-livan.

We were thrilled to see a full room in attendance and many parents and professionals participating in discussions led by David Ellwood. We would especially like to thank Vanessa Postle, who manages the iSAIL clinic, for sharing her subsequent pregnancy experiences with her children Harriet and Angus, after her baby Charlie was stillborn.
Save the Dates! 2018 ISA Conference in Glasgow

We are already planning the 2018 International Conference on Stillbirth, SIDS and Baby Survival! The conference will be held June 6-9, 2018 in Glasgow, UK and is a collaboration between ISA and ISPID, the International Society for the Study and Prevention of Perinatal and Infant Death. Baby survival rates across the globe are improving year on year. However, there is still a lot to be done as the number of babies dying is unacceptably high. The power of the International Conference is in bringing attendees together to share knowledge, and crucially, for this to be cascaded by each of us after the event. This Conference is about breaking down barriers and uniting participants who have a common goal in working towards reducing the rates of stillbirth, SIDS and other unexpected baby deaths. It is an opportunity for each of us to extend our own knowledge base, to forge new partnerships and initiate new work together, as well as strengthening our existing relationships. The Conference is our time to focus on improving the support provided to families.

2019 ISA Conference in Madrid

Umamanita (www.umamanita.es) will host the 2019 ISA Conference in Madrid, Spain in the first weekend of October to tie in with Umamanita’s annual babyloss awareness event. The 2019 conference in Madrid will focus on bringing multidisciplinary teams together to talk about topics identified as both locally and globally important, such as stillbirth prevention and respectful care.

2020 ISA Conference in Brisbane

In 2020, the ISA Conference will be held in Brisbane, Australia and hosted by the Stillbirth Centre of Research Excellence (https://stillbirth.centre.uq.edu.au) in the Mater Research Institute of the University of Queensland. Conference dates are set for October 13-17, 2020.
Stillbirth affects millions of families worldwide. The International Stillbirth Alliance (ISA), established in 2002, is a volunteer-led consortium of leading stillbirth scientists and researchers, healthcare professionals, and bereaved parents, with nearly 60 member organizations on six continents. We work at a regional and global level to raise awareness and promote research and collaboration for the prevention of stillbirth and improvement of bereavement care worldwide. ISA is a small organization which relies on donations for our efforts. Our board and Scientific Advisory Committee staffed by unpaid volunteers from all over the world. ISA is tax-exempt under section 501 (c)3 of the U.S. Internal Revenue Code and all gifts are tax deductible.

DONATE HERE: http://stillbirthalliance.org/donate/

A huge THANK YOU!! to all of the individual donors who made contributions to the International Stillbirth Alliance in 2016. We are so grateful for your contributions which allow us to do all the work that we do.

We would like to formally recognize these incredible supporters:

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