

ISA Newsletter

2016 ISSUE 2

DECEMBER 2016

SPECIAL POINTS OF IN- TEREST:

- **ISA 2016 Conference in Uruguay was a great success!**
- **Please donate to ISA this holiday season; every contribution makes a difference! (p.15)**

INSIDE THIS ISSUE:

ISA in Uruguay	1
Parents join the ISA Conference	4
A Parent's Story, from Argentina	6
Save the Date! Cork 2017	7
Greetings from the Chair	9
Global Stillbirth Events	10
ISA Research	11
New Board Members	13

ISA/ISPID Uruguay Conference

This year's joint meeting of ISA and ISPID was held in Montevideo, Uruguay from 8th-10th September. This was the first time that an ISA conference has been held in South America and was held jointly in English and Spanish. The meeting opened with a plenary session which reminded us of the global impact of stillbirth both in terms of numbers and the effect it has on individuals. Presenters from South America eloquently highlighted the disparity between different countries and highlighted that stillbirth remains taboo and unrecognised in many areas of the continent. Parents groups have begun to challenge this and have made progress which was greatly aided by the presence of the conference in Montevideo.



The plenary sessions highlighted the overlap between stillbirth, infant and maternal mortality and how improvements in care aimed to address one of these elements can lead to improvements in all three areas.

Original presentations covered a huge variety of topics including new ideas in stillbirth prevention which explored more work on mothers' sleep position, fetal movements and detection of infection and problems with the placenta. (Continued on page 2)



Dr. Alexander Heazell, Chair of ISA, presenting in Uruguay

Uruguay ISA Conference a Success

(Continued from page 1)

Work has also progressed on how best stillbirths should be investigated, particularly involving examination of the placenta and genetic tests and how parents experiences of care can be incorporated into case reviews. Several presentations demonstrated that good quality perinatal audit is central to identifying the cause of stillbirth and determining the proportion of stillbirths which are potentially preventable. Throughout the meeting attendees were reminded about the wide

psychological effects of grief and the importance of high-quality bereavement care in several high-quality sessions with a focus on respectful care for mothers and their babies. However, a transition to respectful care needs to be underpinned by training for midwives and doctors as highlighted by several presenters. Overall, the meeting conveyed the breadth of work that is being done to understand and prevent stillbirths and improve care.

Right Photo:
Clockwise from
far left: Jessica
Ruidiaz, Marga-
ret Murphy
(both from ISA
Board), Vicki
Flenady, Aleena
Wojcieszek,
Fran Boyle,
Hannah
Blencowe, Bob
Silver, Alex
Heazell, (ISA
Board
President) J.J.
H.P. Erwich,
and Jillian
Cassidy





Dr. Jan Jaap H.M. Erwich (University of Groningen, The Netherlands and recent ISA Board Member) and **Dr. Vicki Flenady** (Mater Research, University of Queensland, Australia and current Co-Chair, Scientific Advisory Committee, ISA)



Jillian Cassidy (ISA Board Member and cofounder and president of Umamanita, a charity foundation in Spain supporting parents through stillbirth and neonatal death)



Dr. Jane Warland (School of Nursing and Midwifery, University of South Australia)

From left: **Dr. Hannah Blencowe**, (London School of Tropical Medicine and Hygiene), **Dr. Alexander Heazell** (ISA Board Chair), **Jessica Ruidiaz** (ISA Board Member and President of the Foundation Era en Abril)



Parents joined researchers in Uruguay

**By Jessica Ruidiaz,
President, Era en Abril
Foundation**

type. A group of mothers attended, and we were very uncertain, but also very willing to represent both our children and the children of so many families who had placed their expectations on us. Most do not speak English, and there we discovered that many of us share the same language, the pain of having lost a child and the desire to transform that pain."



For the whole team it was very gratifying to be able to share their experiences with other groups of parents from different parts of the world. It was a huge incentive to confirm that the path that we have been going along for several years is the correct one.

There were many very exciting moments throughout the Congress, but without a doubt, the Memorial was the most

important of all. The mothers of the staff of the Foundation of Argentina together with the parents who are part of the Uruguayan help group, achieved a magical afternoon where we focused on honoring our children. Poems, music, flags with their names, and the closing where we lit candles naming our children. Natalia reported: "*Seeing the professionals who attended and took their candle in honor of their child was very emotional, and I appreciated the respect there. To see so many flags with the name of each child and so much light that the candles emitted was the global language of love.*"

The opportunity to have been part of this Congress is something that we will surely stay in our hearts with great pride and gives us the strength to continue working together with other parents and professionals every day for prevention and research, and for parents not to suffer their pain alone.

For the first time in almost 10 years of work, the Era en Abril Foundation had the incredible opportunity to be a co-organizer, exponent and participant of the First ISA/ISPID Latin American Congress, together with its founder and current president, Jessica Ruidiaz.

Ten staff members, including mothers and professionals, attended the Congress and were able to live the wonderful experience of being part of an international movement that unites researchers, professionals and parents in order to join efforts to prevent perinatal deaths. Everyone agreed on how amazing it was to see how the groups of parents are so respected in the rest of the world by professionals and researchers committed to the subject.

Andrea Natalia Olmos Davies, one of the members of this group, said:
"At first I was hesitant to attend, I had never participated in a Congress of this

**98% of
stillbirths take
place in low-
income and
middle-
income
countries.**

Padres se unieron a investigadores en Uruguay

**By Jessica Ruidiaz,
Presidenta,
Fundacion Era en Abril**

Por Primera vez en casi 10 años de trabajo, la Fundación Era en Abril tuvo la increíble oportunidad de ser

co-organizadora, exponente y participante del Primer Congreso ISA/ISPID de Latinoamérica, de la mano de su fundadora y actual presidenta, Jessica Ruidiaz.

Diez integrantes del staff, entre ellas madres y profesionales, asistieron al Congreso y pudieron vivir la maravillosa experiencia de ser parte de un movimiento internacional que une a investigadores, profesionales y padres en pos de aunar esfuerzos para prevenir muertes perinatales evitables. Todas coincidieron en lo asombroso que fue ver cómo los grupos de padres son tan respetados en el resto del mundo por los profesionales e investigadores comprometidos con la

muchos compartimos el mismo lenguaje, el dolor de haber pasado por la pérdida de un hijo y las ganas de transformar ese dolor"

Para todo el equipo fue muy gratificante poder compartir sus experiencias con otros grupos de padres de distintas partes del mundo. Poder captar la esencia y la importancia de estos grupos que, con diferencias lógicas de idiosincrasias locales, com parten muchos puntos en común y buscan los mismos objetivos en todo el mundo, fue un incentivo enorme para confirmar que el camino de ayuda que venimos transitando hace varios años es el correcto.

Hubieron muchos momentos muy emocionantes durante todo el Congreso, pero sin lugar a dudas el Memorial fue el más importante de todos. Las madres del staff de la Fundación de Argentina en conjunto con los padres que forman parte del grupo

de ayuda de Uruguay, lograron una tarde mágica en donde honrar a nuestros hijos fue lo principal. Poemas, música, banderines con sus nombres, y el cierre: encendido de luces nombrando a nuestros hijos. Al respecto nos cuenta Natalia: *"Ver a los profesionales que asistieron y llevaban su velita en honor a su hijo fue muy emotivo y agradezco el respeto que se vivió en ese momento. Ver tantos banderines con el nombre de cada hijo y*



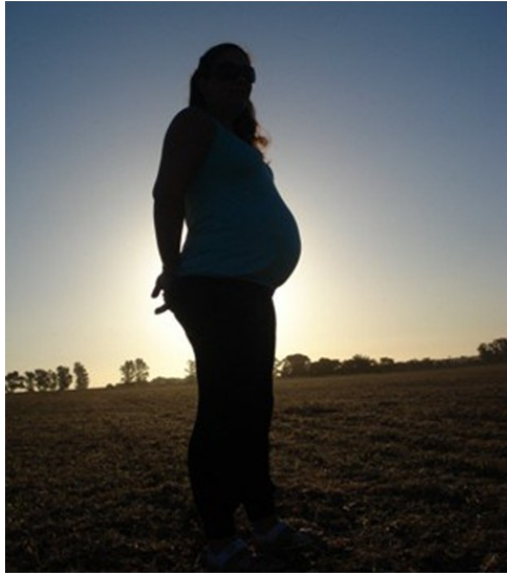
temática.

Andrea Natalia Olmos Davies, una de las integrantes de este grupo, dijo: *"Al principio tuve dudad de asistir, nunca había participado de un Congreso de este tipo. Fuimos un grupo de mamás y nos unía mucha incertidumbre, aunque también ganas de representar tanto a nuestros hijos, como los hijos de tantas familias, que habían depositado sus expectativas en nosotras. La mayoría no hablamos inglés, y allí descubrimos que*

tanta luz que emitieron las velas fue el lenguaje global del amor"

Realmente la oportunidad de haber sido parte de este Congreso es algo que seguramente guardaremos en nuestros corazones con mucho orgullo y nos da la fuerza para seguir trabajando junto con otros padres y profesionales día a día para la prevención e investigación, y para que menos padres sufran su dolor en soledad.

A Parent's Story from Argentina



**Written and Contributed by
Caroline Kaplan, Argentina**

My name is Carolina Kaplan, I'm from Argentina. I have a little angel called Santiago that lives in my heart. I never stop thinking about him: he's in my thoughts whenever I wake up, go to sleep, see another baby, or just daydream about him in my arms.

I had a perfect pregnancy: relaxed, no nausea, no pains, a healthy baby, and a happy mum. We dreamed of a life with him, a family, the three of us together. Santi was our first child and our family's first grandchild.

36 weeks had passed. All his little clothes were ready, his little bed, his carriage. Everything had been chosen for him carefully and lovingly. Our house and our hearts were ready to welcome him.

But one day, Saturday March 20th, destiny decided the opposite. That day, I didn't feel him move (and he was usually quite an active little one!). I couldn't even feel one of his sweet little kicks. I talked to him, moved him, ate sweet things, and...nothing. I panicked. After a couple of hours, something inside of me knew what had happened. But I didn't want to accept it. I went for a walk with my husband, went

shopping, pretended nothing was happening.

When the evening came, I asked my husband to take me to hospital. The doctor couldn't find his heartbeat. He tried once and again, different machines, different positions. But nothing. His heart was not beating any more. And that's when the nightmare started. A flood of emotions, together with a lot of decisions to take--in the moment in which I was the least ready to take them. Natural birth or C-section? Autopsy or not? To see him or not? Why is this happening to me??

When I opened my eyes again, my life was not the same. My son was dead. And now I had to go through a whole bunch of things I was not prepared for: go through all the pain of an operation, calling our loved ones to tell them that our baby was gone, paperwork in the hospital and in our health service, explanations and more paperwork. And to cap it all, we had to think about what to do with the little body.

When we went to the cemetery for more paperwork, I burst into tears when I saw that my son meant nothing to them. All the papers mentioned him as NN, no name, no gender, no identity. No birth certificate, no ID. For them, for the law, for the papers, he didn't exist. I cried my heart out when I had to sign those papers. That was not my baby. My baby has a name, a surname. He exists. His name is Santiago and he lived with me for almost 9 months in my belly.

Luckily, after everything, I came across Era en Abril, an international organization which was started in my country to accompany parents and their families through the process of grieving after the loss of our babies. Now I serve as its translator and an active member. They have helped me, and lots of other women, to realize we are not alone in this, and that life goes on, and our babies will live forever in our hearts.



**In Argentina,
nearly
14/1000
babies
(1 of every 71
births) is
stillborn.
(McClure EM et
al. Reprod.
Health, 2015)**



The 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 take place over two days, Saturday and Sunday, with a mixture of plenary and concurrent sessions from invited speakers and selected presentations from conference abstracts.

Pre-conference, an IMPROVE workshop will be held on Friday 22nd September

(<https://sanda.psanx.com.au/clinical-practice/improve/>).

The call for abstract submissions will go live in January 2017. A lively social programme is planned to integrate with the Conference. For further information please see <http://www.isacork2017.com/> and follow the Conference on Twitter @isacork2017. We look forward to your continued support and hope you will be able to attend.

September

22-24, 2017

Cork, Ireland



"Save the Date"

Friday 22nd September – Sunday 24th September 2017

The 2017 International Stillbirth Alliance Conference will take place at University College Cork.

<http://www.isacork2017.com/>

BMC Pregnancy and Childbirth

Highlights Stillbirth

By Dr.
**Alexander
Heazell, ISA
Chair**

2016 has been a strong year for research publications that raise the profile of stillbirth. In January, the [Lancet Ending Preventable Stillbirth Series](#) of 5 papers explored progress to date in reducing stillbirths, providing up to date estimates of the number of stillbirths each year and where and why they occur and the psychological, social and economic impact of stillbirth. The Lancet Series focussed on a call to action in low, middle and high-income countries to achieve an end to preventable stillbirths by 2030. Another series of ten papers in [BMC Pregnancy and Childbirth](#) was launched in October 2016. These papers were edited by Frederik Frøen and Alexander Heazell from ISA and present some of the data underpinning the

papers in the Lancet Stillbirth Series including issues regarding how information about stillbirths is collected and recorded, which is critical to how researchers and clinicians make use of that information to reduce the number stillbirths. The papers also remind us that stillbirth cannot be reduced by healthcare alone and that social and economic determinants need to be addressed. Lastly, the BMC series presents the human impact and cost of stillbirth, emphasising the role of respectful bereavement care in reducing stigma and social isolation of parents. All these papers are free to access and read at <http://www.biomedcentral.com/collections/epstillbirths>



Greetings from the ISA Chair



Dr. Alexander Heazell

Greetings! On behalf of the board members of the International Stillbirth Alliance I would like to thank you for your continued interest in ISA.



We have had a busy year in 2016. Many of the board and scientific advisory committee were involved in developing and writing material for two new series of papers in the Lancet and BMC Pregnancy and Childbirth both entitled Ending Preventable Stillbirths. ISA played a key role in the launch events for the series around the world. ISA also produced lay summaries in 11 different languages (all available at <http://www.thelancet.com/series/ending-preventable-stillbirths>) to ensure that parents and professionals can access this important work. ISA also worked with other organisations to ensure that stillbirths are going to be counted and recorded to assess the performance of the international Sustainable Development Goals.

It was great to see many people join our joint conference with ISPID in Uruguay. This was a great opportunity to highlight the issue of stillbirth to local politicians and clinicians and to share some of the great research that is being done. I came away with a sense of the passion underpinning the work of so many people in our field.

If you would like to keep up to date about what ISA is doing we now have Facebook and Twitter accounts, please publicise the work that we do and engage with parents and professionals by sharing our status. I encourage everyone to think how we can build on this year, and work together to end preventable stillbirths and ensure that when a baby dies the best possible care is available.

With very best wishes, Alex

Making *every* mother and baby count.

The majority of maternal deaths and stillbirths, and **75%** of newborn deaths, are preventable.

In order to **prevent future deaths**, WHO is helping countries to:

-  Produce a birth and death certificate for everyone, including stillbirths
-  Form death review committees
-  Create policies to report and review all deaths

Collect at least the minimum data for each birth and death

Mother's age	☒
Place of delivery	☒
Mode of delivery	☒
Birth weight	☒
Gestational age	☒
Birth outcome	☒

Every misclassified or unrecorded death is a *lost opportunity* to ensure other mothers and babies do not die in the same way.

 World Health Organization



Without knowing the true number of deaths or the causes, countries are not able to adequately:



Improve quality of care



Prevent future deaths



Improve vital statistics



Allocate resources



Reach global targets

Upcoming Global Stillbirth Events

The September 2015 launch of the United Nations' Sustainable Development Goals and the Global Strategy for Women's, Children's, and Adolescents' Health, and the January 2016 launch of the Lancet's Ending preventable stillbirths series on which ISA was a close collaborator, were defining events for global stillbirth advocacy work.

Since then, ISA has contributed inputs on stillbirth to the 2016 Global Sustainable Development Report and the United Nations' High-Level Working Group on Health and Human Rights of Women, Children and Adolescents. The latter is one of the first times that stillbirth prevention/post-stillbirth support has been clearly identified as a human right.

One of our board members, Susannah Leisher, was recently supported by the World Health Organization to give a spark talk on the Lancet's EPS and Every newborn series at the annual American Public Health Association (APHA) conference in Denver, Colorado, as well as presenting on her experiences as the bereaved

mother of her stillborn son Wilder. ISA is also an active member of the United Nations' Partnership for Maternal, Newborn and Child Health's (PMNCH's) Stillbirth Advocacy Working Group. Upcoming events include a Stillbirth Advocacy Working Group webinar on stillbirths in December and the annual World Health Assembly (WHA) in Geneva, Switzerland, May 22-31, 2017. ISA will be liaising with partners to learn more about opportunities for civil society advocacy on stillbirth prevention and post-stillbirth support at the WHA.



Susannah Leisher, ISA Board Member and mother to Wilder, who was stillborn.

How Do We Classify Stillbirths?

Recently ISA Board and Science Advisory Members published two papers on classification systems for causes of stillbirths and neonatal deaths in the journal BMC Pregnancy & Childbirth. The papers note that a total of 81 systems have been used, created, and/or modified between 2009 and 2014, with about ten new or modified systems each year. Despite this, none of the systems were well-aligned with a set of 17 expert-identified characteristics for an "effective global system" (such as requiring the most important cause leading to death to be identified, including other factors associated with

the death, and having a comprehensive enough list of possible causes to ensure that the percent of deaths classified as "other" is minimized). Moreover, the vast bulk of classification occurs in high-income countries (the site of most system creation and use), despite the fact that most stillbirths occur in low- and middle-income countries. The situation highlights the reality that there is yet no ideal system, yet knowledge of causes is crucial to inform strategies for prevention.

Leisher SH et al. BMC Preg Child, 2016;



**More than
7300
stillbirths
occur every
day**

ISA Research

Members of the ISA Board and Science Advisory Committee have been busy with research on stillbirth prevention and care. Here is a sample of recent research studies

Care in subsequent pregnancies following stillbirth: an international survey of parents. (Wojcieszek et al, BJOG, 2016) Survey of more than 2700 parents from high and middle-income parents. Two-thirds of parents reported conceiving within the year of stillbirth. About half of parents felt their post-loss care was respectful. Parents with losses at or past 30 weeks gestational age were more likely to receive bereavement support.



eRegistries: indicators for the WHO Essential Interventions for reproductive, maternal, newborn, and child health. (Flenady V et al, BMC Preg Child, 2016). Only a third of the 45 WHO Essential interventions were collected in publically-available global surveys and datasets. This widespread lack of data substantially impedes progress in global reproductive health.

Depression and posttraumatic stress symptoms after perinatal loss in a population-based sample. (Gold KJ et al, J Women's Health, 2016). Women with stillbirth or infant death in the first month had nearly 4x odds of depression and 7x odds for PTSD at nine months after loss. There were no significant differences based on type of loss.

The global network antenatal corticosteroids trial: impact on stillbirth.

(Goldenberg RL et al., Reprod Health, 2016) The study is a cluster-randomized trial in 6 countries focused on preterm birth. There was a non-significant increase in stillbirth risk possibly related to higher rates in intervention groups before the trial, differences in obstetric care, and increased maternal infection.

Evaluation of an international educational programme for health care professionals on best practice in the management of a perinatal death: Improving Perinatal mortality Review and Outcomes Via Education (IMPROVE).

(Gardiner PA et al, BMC Preg Child, 2016) This was a pre-post questionnaire of 758 participants including midwives (55%), doctors (24%), and others. Participants showed significant improvement in knowledge and confidence for all 6 teaching stations.



Welcome Baby Michael

While we often spend these pages honoring babies, this month we welcome a new one. Dr. Dimitrios Siassakos (ISA Board Member and co-chair of the ISA Scientific Advisory Committee) and his wife had experienced three miscarriages. This summer, during a fourth pregnancy, they had the scare of premature preterm rupture of membranes at 23 weeks

gestation which can be life-threatening if a baby's lungs are not well-enough developed. Fortunately, they were able to keep baby Michael in utero until 31 weeks when he was born. Michael is feeding and growing in the NICU and both parents and baby are doing well.



In November, Susannah Hopkins Leisher drafted feedback to the High-Level Working Group on Health & Human Rights of Women, Children & Adolescents on behalf of the ISA Board of Directors.

ISA Weighs in on Global Stillbirth Policy as a Human Rights Issue



international
stillbirth alliance

Input to the High-level Working Group on Health & Human Rights of Women, Children & Adolescents, submitted November 6, 2016, by the International Stillbirth Alliance

THE PERSISTENCE OF PREVENTABLE STILLBIRTHS AND INADEQUATE BEREAVEMENT CARE: A FAILURE TO ASSURE HUMAN RIGHTS

By Susannah Hopkins Leisher¹ for the International Stillbirth Alliance
Based on and adapted from [1] and [2]

We submit this input to make the case that stillbirth prevention and respectful support for families after the death of their children are a neglected matter of human rights which can only be addressed by consistent, high-level inclusion of and action on stillbirth within a rights-based framework for equitable health for women and children.

New ISA Board Members-2016

The ISA Board regrettably says goodbye to several of our long-standing board members who have now served out their terms.

Dr. J.J. Erwich

Dr. Vicki Flenady

Dr. David Elwood

We welcome several new board members from around the world. These members will serve up to two three-year terms.



Dr. Lynn Farrales is a family physician based in Vancouver, BC, who is committed to patient engagement through community-based participatory research with families whose babies were stillborn.



Leanne Raven is CEO of Red Nose (formerly SIDS and KIDS) in Australia and a Director of ISPID, the International Society for the Study and Prevention of perinatal and Infant Death.



Margaret Murphy is a midwife, researcher, and academic employed as a lecturer at the School of Nursing and Midwifery, University College Cork, Ireland. Her doctoral research explores perinatal loss and the pregnancy that follows.



Dr. Sanne Gordijn is an obstetrician in Groningen, The Netherlands. In 2009 she finished her PhD on perinatal mortality with a focus on classification of perinatal mortality and postmortem investigations.



Dr. Glenn Gardener is an obstetrician and director of the Center for Maternal Fetal Medicine at Mater Mothers' Hospitals in South Brisbane, Australia.

Please Join ISA on Social Media!

Please “Like” us on Facebook!



And Follow Us
on Twitter!





international
stillbirth alliance

Support the fight against stillbirth
this holiday season!

**Please Donate to the
International Stillbirth Alliance**



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.

This holiday season, please support our work to prevent stillbirth!

ISA is a small organization which relies on donations for our efforts. Our board and Scientific Advisory Committee are comprised of unpaid volunteers from all over the world.

ISA promotes research, advocacy, and bereavement care on a global level for families who experience stillbirth. We could not do this without your support.

If you are a bereaved parent or family member, consider a donation in honor of your baby, to help other families around the world avoid the tragedy of stillbirth.

If you are a health professional who cares for families with stillbirth, consider a donation to support both families and health professionals in coping with loss.



If you are a researcher or scientist, consider a donation to help encourage continued scientific efforts to prevent stillbirth and optimize bereavement care. We are grateful for donation of any amount, and thank you for your generosity.

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/>