“Collaboration for the understanding and prevention of stillbirth”
www.stillbirthalliance.org

What’s Inside

Upcoming Events

Poem, My Dad is A Survivor

ISA Member Organisations: Focus parent founded organisations in Australia and New Zealand

News from around the World
Spain
United Kingdom
United States
Australia and New Zealand

The ISA 2009 Conference in South Africa
Message from ISA2009 Chair
Bereavement track
Scientific track
Local attendees

Meet ISA’s new board member Caron Millard
Caron’s personal journey

Stillbirth facts/research

Letter to the Editor
Melanie Human on the ISA 2009 Conference

Welcome new member organizations
UPCOMING EVENTS

Next ISA Research Alert due 6 July 2009
The ISA research alert provides plain language summaries of recent publications about stillbirth. To view older research alerts please visit the ISA website at www.stillbirthalliance.org.

Sands New Zealand Biennial Conference, 7-8 August 2009
Sands New Zealand is holding its biennial conference in Auckland on the 7th and 8th of August this year. The theme of the conference is – ‘A Little Life, Not a Little Loss’. The conference will begin with a remembrance service and includes workshops and presentations. Topics include: grief in the workplace, the vanishing twin syndrome, mothering our babies when they have died (exploring identity), initial findings of The Auckland Stillbirth Study (TASS), the care of parents and families who are facing a medical termination or induction, and the role of support groups. A parents’ panel will discuss all aspects of baby loss and there will be support group sessions and self care workshops during the conference. The completed (and long awaited) documentary ‘Five Hours With Raja’ will be shown. For further information about the conference or to download a registration form, please visit www.sands.org.nz.

International Stillbirth Alliance (ISA) and International Society for the Study and Prevention of Infant Death (ISPID) joint conference, October 2010, Sydney.

The 2010 Conference Committee welcomes you to Sydney Australia for the joint ISA/ISPID Conference in October 2010. We promise great Aussie hospitality and an opportunity to collaborate in reducing stillbirth and infant deaths and ensuring quality bereavement care for affected families. For more information visit www.stillbirthalliance.org.

International Pregnancy and Infant Loss Month is in October
October is dedicated throughout the world to raise awareness of infant and pregnancy loss and to honour and remember babies and infants who died due to miscarriage, stillbirth, neonatal death, SIDS and all infant deaths. Various activities, walks, and services are held across the globe on different days throughout the month in support of this cause. To learn what activities organizations, groups, hospitals, and individuals are organizing throughout the world, visit www.pregnancyandinfantloss.org and for more information about International Pregnancy and Loss month and its history visit www.stillbirthalliance.org.
My Dad Is A Survivor

My Dad is a survivor too…
Which is no surprise to me.
He’s always been like a lighthouse
That helps you cross a stormy sea.
But, I walk with my Dad each day
To lift him when he’s down.
I wipe the tears he hides from others.
He cries when no one's around.
I watch him sit up late at night
With my picture in his hand.
He cries as he tries to grieve alone,
And wishes he could understand.
My Dad is like a tower of strength.
He's the greatest of them all!
But there are times when he needs to cry…

Please be there when he falls.
Hold his hand or pat his shoulder…
And tell him it's okay.

Be his strength when he's sad
Help him mourn in his own way.
Now, as I watch over my precious Dad
From the Heaven's above…
I'm so proud that he's a survivor…
And I can still feel his love!

Kaye Des 'Ormeaux
From the Compassionate Friends
Newsletter August/September 2001

ISA MEMBER ORGANISATIONS: Focus on parent founded organisations in Australia and New Zealand

Sands New Zealand (Stillbirth and Newborn Death Support) is a voluntary, parent-run, non-profit organisation set up to support parents and families who have experienced the death of a baby. Most of the members/supporters are also bereaved parents. They offer empathy and understanding, and are not counsellors and do not give formal advice, but they do offer an opportunity and environment to share experiences, to talk and to listen. Sands promotes awareness, understanding and support for those dealing with the death of a baby in pregnancy, birth or as a newborn, and due to medical termination or other forms of reproductive loss.

www.sands.org.nz

SANDS Australia is a not-for-profit organisation promoting awareness, knowledge, support, and understanding following the death of a baby from the time of conception through to infancy. There are organizations in Queensland, South Australia, Victoria, and Tasmania. www.sands.org.au

SIDS and Kids Australia is a not-for-profit organization founded in 1977, is dedicated to saving the lives of babies and children during pregnancy, birth, infancy and childhood and to supporting bereaved families. SIDS and Kids deliver on their vision through world-class research, evidence based education and bereavement support and advocacy. The National Office is located in Melbourne and there are nine member organizations in the Northern Territory, Queensland, New South Wales, Hunter Region of NSW, ACT, Victoria, Tasmania, South Australia, and Western.

www.sidsandkids.org

Bonnie Babes Australia, The Bonnie Babes Foundation was founded in 1994 and is a non government funded, non-profit, volunteer based charity which provides some of the following: medical equipment for premature babies, research into pregnancy loss, education and training for health professionals, 24 hour support for bereaved families, health, nutrition, and wellness advice to women prior to and during pregnancy, support with infertility issues and support for babies with abnormalities, and more. www.bonniebabes.org

The Stillbirth Foundation Australia is the first charity in Australia dedicated to the sole understanding of stillbirth operating to reduce the incidence of stillbirth by: funding and encouraging research into stillbirth, and increasing public awareness about stillbirth. www.stillbirthfoundation.org.au
Australia and New Zealand Stillbirth Alliance (ANZSA) is an alliance of organisations (both professional colleges and parent founded organisations) in Australia and New Zealand which work together to reduce stillbirth and improve care for parents who have a stillborn baby. Each organisation brings different expertise and focus and by working closely together a much greater benefit for parents will be realised. ANZSA is a regional office of ISA and as such addresses the objectives of ISA ensuring relevance to the Australian and New Zealand setting and in doing so contributes to the global effort on stillbirth. For more information please visit the website at www.stillbirthalliance.org/anz

“Grief can be delayed, but cannot be denied.”
“Grief is like an onion, it comes off in layers and you cry a lot.”

NEWS FROM AROUND THE WORLD

Spain  (Jillian Cassidy, new Parent Advisory Committee (PAC) member)
In Spain there is no stillbirth registry. Any baby who dies before 24 hours of life can be registered as Female Fetus of Jillian Cassidy. We have been pushing for and hoping that the congress will vote to change the registry law in Spain. We managed to bring this to the Senate where it was passed by the skin of its teeth: 120 votes to 123. Curiously the socialists voted against it because the Spanish government (which is mainly socialist) are renewing the abortion laws here. Sadly, one should not have to have anything do with another. We are now waiting for it to be brought to Congress and voted on there; it should happen sometime over the next few months.

These are two smaller things that we are involved in
1. A seminar in Llerida, Cataluña about perinatal death on the 21st of May.
2. ENCA (European Network of Childbirth Associations) are having their annual meeting in Madrid this year and we have been asked to do a 20 minute presentation. It will be mostly attended by midwives.

Please email info@stillbirthalliance.org to contact Jillian Cassidy (new Parent Advisory Committee member) for more information about what is happening in Spain.

United Kingdom  (Sue Hale, PAC member)
Please note that June is Pregnancy Loss Month in the UK. Many activities will be held throughout the country. To learn more visit www.uk-sands.org.

We were thrilled with the turn-out for our parliamentary reception to launch our Saving Babies’ Lives Report; held on 4th March in the House of Commons Terrace Pavilion, a purpose-built marquee with stunning views over the River Thames. As well as MPs and Peers, guests included parents, health professionals, professional organisations, Department of Health representatives, scientists and researchers, Sands staff, trustees and patrons.

Sands called for greater awareness of the issues surrounding the deaths of 17 babies every day making headline news on BBC Breakfast television as well as Radio 4’s news agenda-setting Today programme and almost a dozen BBC regional morning radio broadcasts. During the day we were also featured on GMTV and ITN news.

We have Sands parents to thank for the incredible turn-out. Almost 200 parents approached Sands in the months ahead of March 4th offering to contact their local MPs and encourage them to attend our parliamentary launch event. Our newly-
developed Lobbying Guide gave parents information and tips on how to best communicate the issues to their MP. Many parents received letters back from their MP, with some MPs expressing a desire to become more closely involved in the work of Sands and offering their help in various ways.

Please email info@stillbirthalliance.org to contact Sue Hale (Parent Advisory Committee member) for more information about what is happening in the UK.

United States

Research Symposium for Parent and Health Care Advocates and Lobby Day on Capitol Hill, March 23-25, 2009 (Sherokee Ilse, PAC Co-Chair)

The 150 or so people who attended were all very impressed with the researchers, parents, health care providers, organizational leaders, and First Candle staff. Both SIDS and Stillbirth researchers presented. It was a collaborative effort led by First Candle, also supported by Cribs and Kids, National Stillbirth Society, SIDS Center of Indiana, The Simon Project, Northwest Infant Survival Alliance, First Breath, and Compassionate Passages, Inc, and CJ Foundation for SIDS.

Dr. Ruth Fretts gave a good background on what is happening and then announced the new (March 09) ACOG bulletin for Stillbirth Management. It is to be a very good start and promotes the collection of more data, standardization, promotion of autopsies, and some guidance on movement towards the end of pregnancy. She talked about risk assessment and the importance of looking at the slow down of movement at the end of pregnancy as a potential indicator of trouble. No standard protocol for gathering data and autopsies is common in the US which adds to the problem of understanding what causes stillbirth.

Wes Duke reported on the ongoing multi-centre stillbirth studies sponsored by the National Institute of Health. Dr Jason Collins spoke about the research that supports cord issues and their influence on stillbirth. Dr Mana Parast spoke about restriction of umbilical blood flow that may be ‘causal in a subset of unexplained stillbirths,’ (Parast, Crum, and Boyd March 08.)

Parent advocate, Master's candidate Suzanne Pullen shared the results of her study Giving Birth to Death which found that few parents even know what stillbirth is before giving birth, and she reported on the level of parent satisfaction of information received from the news deliverer, the patients’ perceptions of patient centeredness of the news deliverer and how it affected their grieving process, and how stillbirth patients report their lives changed after their diagnosis.

Legislation/Lobby Day

About 70 of us were split into teams (thanks to Marian Sokol who worked endlessly with the lobby firm FC has hired). Congressional aides were deeply moved by the stories (like the couple who read about this on the internet and drove up from Tennessee… never, ever having done anything like this. But they needed to tell about their son Hunter who died of SIDS while dad was in Iraq and mom was all alone far from family!). They were moved by the beautiful book we created that shared about 70 beloved babies. The feedback we received was that this book made a huge difference in the visits, making these babies real to young people who often have no children.

Peer Support

More and more bereaved parents and grandparents are asking to be trained to befriend others at the time of their loss. Future training options are possible. Contact US ISA regional coordinator Sherokee Ilse: info@stillbirthalliance.org
GAPPS meetings Seattle (Ruth Fretts, SAC co-chair)

*International Conference on Prematurity and Stillbirth.*

On May 7 – 10, approximately 2000 maternal, newborn and child health leaders gathered in Seattle, WA, USA to raise awareness of this immense global health burden, propose a roadmap for future research efforts and build a foundation for policy changes that support prevention and treatment globally. Presentations of this ground breaking meeting are available on line at [http://www.gapps.org/](http://www.gapps.org/).

Workshops included:
1. Normal Gestation Biology and Labor
2. Abnormal Gestation Biology and Physiology
3. Genetic and Environmental Factors
4. Stillbirth Epidemiology
5. Preterm Birth Epidemiology
6. Intervention Development
7. Prioritization of Interventions for Scaling Up
8. Community-based Strategies and Constraints
9. Facility-based Strategies and Constraints
10. Advocacy and Policy
11. Resources and Development Funding
12. Ethics and Social Justice

Reports and goals that were developed in these workshops will be made available. Each section was asked to develop priorities and timelines. Dr Fretts, Dr Gardosi and Dr Frøen all members from the scientific committee of the ISA participated in the Stillbirth Epidemiology. This group’s priorities centred on development of a minimal dataset, and the development of a classification system that would be applicable in the developing and developed countries, consider the timing of stillbirth (intrapartum and antepartum), the level of evidence available and the up-coming ICD 11 codes.

**Australia and New Zealand** (Liz Conway PAC member and member of the ANZSA Board and Vicki Flenady Chair ISA and Board member ANZSA)

Down Under’s most exciting news is the upcoming 2010 ISA conference. The conference will be held in Sydney in October 2010 as a joint conference with ISPID. The conference will be co-hosted by ANZSA (for ISA) and SIDS and Kids for ISPID. We encourage parents, researchers and care providers from around the world to come to the conference for a very special Australian welcome. The weather in Australia at that time of the year will be pleasantly warm (hot for some). Planning is underway and we are keen to hear what you would like to see in the programme – in the areas of bereavement, research and clinical practice. Please contact ANZSA at anz@stillbirthalliance.org for more information or to send your suggestions.

The PSANZ (Perinatal Society of Australia and New Zealand) recently held a successful conference in Darwin. A number of members of support organisations attended the conference and it is heartening to see that there is good collaboration developing between health care professionals, parents and researchers. One of the pre conference workshops was the Perinatal Mortality Education session developed by the ANZSA and PSANZ for midwives, doctors and other health care professionals using the SCORPIO technique. The education session is a system of educating health care professionals on best practice in care around the time of a stillbirth or neonatal death including what investigations should be undertaken, how to apply the classification system on the causes and contributing factors of death and how to communicate with parents about an autopsy examination. It is valuable for parent advocates to be involved as sometimes parents see things from a different perspective and can affect change. The SCORPIO method is very effective and hopefully more centres around Australia and New Zealand will introduce this system of training.
ANZSA is currently embarking on an extensive research collaborative that aims to establish high quality research data collection for stillbirths in Australia and New Zealand. Please see the ANZSA website for more details about activities in Australia and New Zealand: www.stillbirthalliance.org/anz.

### ISA2009 CONFERENCE IN SOUTH AFRICA

| Pictured: Elaine Thorp, Erica Stewart and Neal Long | Pictured: Ruth Fretts, Janet Scott and Jan Jaap Erwich |

From the 2009 Conference Chair, Professor Bob Pattinson, Director, MRC Maternal and Infant Health Care Strategies Research Unit, Pretoria, South Africa

The Drakensberg Mountains made a spectacular setting for the ISA 2009 Annual Conference. Over 100 parents, midwives, health professionals and advocates came together to share their views and knowledge on stillbirth. The conference was made possible by the generous support of Perinatal Priorities (www.perinatalpriorities.co.za) and its Chairman and convener Dr E Buchmann; Saving Newborn Lives (especially Joy Lawn), and SANDS UK. Many of the delegates that attended the Priorities in Perinatal Care conference came a few days early to attend the ISA conference. The Priorities group were mainly clinicians and for them it was novel and very worthwhile to have joint sessions with the parents and to get more information on bereavement counselling. An informal network of delegates has been set-up to discuss issues around counselling bereaved parents in South Africa. Who knows, in future it might become an organisation like Sands providing bereavement counselling for parents.

All conference presentations will be placed on the ISA website very soon.

Special thanks to the organising committee of Vicki Flenady, Sue Hale, Liz Conway, Frederik Frøen, Ruth Fretts and to Cathy and Roz of Workshops Anonymous who organised the conference.

**The Bereavement Track**

Sands UK, Sands Australia and Sands Antigua and Barbuda were jointly asked to create a programme for the bereavement track for ISA in South Africa, to create a ‘product’ which would not only help staff in their work of supporting bereaved parents but leave behind the very real possibility of setting up parent support in South Africa.

Many cultural, traditional and religious issues were considered, as well as practical considerations in the care of a family after a baby dies. The bereavement programme was relevant and interactive and also the participants had the chance to get to know each other and form links that would continue beyond the conference.

Over 40 people attended the first session, mostly midwives, psychologists and counsellors from South Africa and Uganda. They were warm and welcoming. It became clear that the issues they wanted to discuss were very similar to health professionals elsewhere – how to break bad news, seek post-mortem consent, offer...
support and ‘get it right’. It was also clear that they have some very specific difficulties. Many hospitals lack funding and facilities, so it may not be possible for parents to spend time with their baby away from other healthy mums and babies, and to have a camera to take photos after a baby has died is unlikely. Many families travel considerable distances to have their baby in a hospital and so the follow up of support is difficult once they have returned home. Many babies are born in remote communities and the families have limited access to health care.

These issues and more were discussed during the workshops and the delegates were very focused and enthusiastic. Even though privacy might not be available, dads and families were encouraged to be at the hospital for support. Also midwives could have almost immediate support themselves following the death of a baby, with an ‘open door’ policy from their managers.

A lasting memory came during the walk back from the chapel service in the warm evening rain. In front were three African women delegates, one was weeping and the other two were supporting and comforting her as they walked along. The short, poignant and moving service had clearly been an emotional experience for the woman in the middle, and her colleagues’ response illustrated how universal and cross-cultural sensitive appropriate support is.

There was lots of positive feedback and a belief that changes can be introduced. There was also a definite commitment to try and set up parent support in both Uganda and South Africa.

**The Science Track**


Joy Lawn discussed the barriers for stillbirth being a priority health issue and the reasons why stillbirth is often overlooked. Stillbirth often happens in countries where the death of a baby is simply ‘accepted’, therefore 2/3 of the data is missing. Furthermore, multiple classification systems confuse the data – one is required. Joy suggested ways to make stillbirth count such as improving verbal autopsy (since majority of stillbirths occur in the home), improving data (quantity and quality consistency) and investment in research.

Joy made a powerful point when she translated the Sands’ *Saving Babies Lives Report* 2009 figures: In the UK it is Why 17? In South Africa it would be why 115? For the world, Why 19 000?

**Verbal autopsy**

Verbal autopsy involves mothers being thoroughly interviewed to discuss what happened before their baby died and afterwards. This is a wonderful idea - listening to the mother who knows the most about her pregnancy and what happened. Maybe we can borrow such things from our developing countries, while we also share with them.

**Classification of stillbirths**

During the meeting the opportunity was taken to gather the experts in the scientific track to have a workshop on developing a stillbirth classification that can be used by all countries. The following are principles that were decided on during the workshop:

- Each country would be able to produce a table that could be compared with all other countries, i.e. it would be able to include verbal autopsy results, as well as full pathological autopsy results.
- There would a classification of the maternal conditions at the time of the death of the baby and a classification of the fetal/neonatal condition at the time of death. These would link to the maternal death classification system developed by the WHO and the neonatal and child classifications used in ICD.
• The approach would be layered, going to increasing depth, depending on the facilities available at the site to perform sophisticated investigations,
• The classification would be aimed at programmatic use rather than a strict causal approach
• The system developed would be compatible with the ICD coding system

The group present agreed to these principles and a draft classification was drawn up and circulated by Professor Jason Gardosi. The draft has been circulated many times amongst the team and its draft 5 version will be presented to the WHO working committee on the classification of maternal and perinatal deaths at the end of June 2009.

Spotlight on local attendees at the ISA 2009 conference

**Wihelmina Felix**, also a midwife from Groote Schur Hospital, came to the conference to learn more about bereavement support in order to start up a service to support families in South Africa. Wihelmina reported that she learned so much while at the conference. According to Wihelmina, the National Health body needs to change their policies and nurses need to be consulted so they can help initiate change. Her sense is that there needs to be a ‘ground-up’ approach to improve care in South Africa.

**Cecilia Peters**, from Groote Schur Hospital in Cape Town, has been a midwife for 30 years. She has a deep passion and love for her patients. At the conference she shared her own personal grief and her passion to start a support group while at the conference, in addition to her years of experience. While at the conference, she learned a lot from parents and how much health care professionals miss by not hearing from the parents. Cecilia thinks financial constraints and government red tape get in the way of providing the kind of care that she would like to be able to offer patients in South Africa.

**Sophie Davids**, a mother and midwife also wants to help establish support services in South Africa, especially for mothers who experience more than one loss and still don’t have an explanation. While at the conference, she found hope that there are systems in place as well as support services in developed countries that can be useful for South Africa. Sophie feels that poverty, culture, government restrictions, and a lack of empowered knowledge and political will restrict South African hospitals from giving the best care.

**Prof Sue Fawcus**, of Cape Town, is an obstetrician who chaired the scientific session: Evidence for community interventions and linkages. Sue learned that cooperation between parents and professionals is very important, especially because there is so much the parents can teach the professionals. Professor Fawcus believes there is a serious lack of funds to facilitate the sharing of expertise and knowledge that is necessary, especially in the area of bereavement support in her South Africa.

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Meet New Board Member Caron Millard

Tell us about yourself? I am British - lived in Birmingham in UK - now living in Antigua in the Caribbean. I wanted a more relaxed lifestyle and more time with my family, husband Tony, sons Tom & Jack - 17 & 14
What is your area of work and background? I am a midwife who qualified in 1990. Since 2000 I have specialized in bereavement, which has always been an active part of my career.

How did you learn about ISA? I was recommended to ISA by Sue Hale & Neal Long – I know Sue through Birmingham Sands. She thought I would be a good midwife representative for the board.

What are some of your goals and hopes for your involvement in ISA? By being involved with ISA - I hope to understand the needs of parents when their baby dies and I want to improve the standard of bereavement care globally - especially in the Caribbean - on many different islands.

ISA Conference 2009 - A Personal Journey, Caron Millard

For me this journey started back in November 2008 at the ISA Conference in Norway. I had managed to secure a stipend as the founder of Sands Antigua and Barbuda from the organizers, and I knew that I was going to be nominated as a Midwife Representative for the Board – and indeed I was elected, and so became officially part of ISA.

In Norway I became aware that I would be involved in the next in South Africa in March 2009. It was soon established following our return home that I would be part of the Bereavement Track alongside Sue, Ruth and Liz and so began the many conference calls to organize the programme – thanks Liz for getting up so early! Subjects were discussed and lesson plans prepared – I was given four areas to cover within this, with the main one being a presentation on how I set up a Support Group here in Antigua in the Caribbean.

The journey was a long one – taking me 48 hours get there with 22 hours actual flying time- and flying is my worst phobia so it actually felt like I was never going to get there! Once I arrived in the Drakensburg though, I was amazed and stunned by the scenery and natural aura of the place – it really is an amazing and serene place.

Once the conference started, my excitement turned into fear – on seeing everyone gathered together I got quite nervous. I was able to relax a little bit the next day, and the group started to become individuals, and the individuals started to become people, the people had personalities and they were all lovely, eager to learn and very interested in what our team had to say. What a relief!

Our Bereavement Track Team worked very well together and I will never be able to admire or respect enough, parents such as Sue, Erica and Liz who are able to stand up and tell the stories of their precious babies - and in their honour are able to support and help not only other bereaved parents, but also educate Health Care Professionals from around the world.

Everyone’s sessions went very well and I was stunned by how thirsty the delegates were for information and just how supportive they were to each other and to us as well. They just soaked up everything we had to say and I know that they are going to do their best within their own areas when they return to their own countries. This was something that was very special to me as Antigua is not like that at all. In fact it is the
opposite – people here are extremely resistant to change and I personally struggle with this when we are providing a totally free voluntary service and the hospital staff will not pass on our leaflets or cards to the bereaved mothers.

I was particularly touched by Monica Taylor and her daughter Mahzira’s story- thank you so much for sharing your story with us – you touched the hearts of many people that day and I am sure you will continue to do so in the future – God bless you!

The second evening saw the Memorial Service for all the babies – I found this service particularly touching, maybe for a few reasons; where it was held, for instance – right in the middle of the Drakensburg Valley – at the heart of nature in South Africa: the chapel was tiny, but oh so peaceful and beautiful; but mainly for the amount of health care professionals who not only attended the service but actively participated lighting candles of love to represent babies whom they had cared for.

The final day of the conference had arrived and it was time for me to present to the whole group of Conference Delegates. I felt honoured when quite a few of the scientists actually came to find me to say how they had enjoyed the session – maybe they did learn something from me after all.

I think the point that I really wanted to get across as a Midwife is that yes, we need lots and lots of research to prevent as many of these baby deaths as possible – but we are human and a certain amount of babies will always be stillborn, no matter what we do – it is part of nature at it’s cruellest. For that reason alone, it is even more important that we focus on providing the best care and support to parents who find themselves in this very sad situation. It is for this reason that I finished the presentation with soft music and photos of some of the special babies I have cared for here in Antigua. I let the babies and mothers speak for themselves - as they say – a picture says a thousand words...

I am thoroughly enjoying being part of ISA now and as I get to know the other board members more as people and not so much as intelligent voices on a conference call. I am starting to relax and realize that we all have an important part to play in not only reducing the number of global stillbirths, but in also working together to improve the care and support offered to parents when their baby dies.

I would like to dedicate this journey to the memory of Frances Moore whom I was honoured to care for in 2000, daughter of Dawn and Darren and older sister to Billy and Freya - she is the one who started my real journey into bereavement care.

I would also like to thank Sands UK for their belief in me and their financial support - not only to allow me to partake in the conference, but also for their very generous donation following my final presentation.

THE STILLBIRTH FACT/RESEARCH CORNER

Excerpts from the upcoming ANZSA/ISA Research Alert on recently published key research papers are provided here. In this edition we focus on recent papers on classification systems for stillbirth and list recommended readings of recent high quality reviews on stillbirth.
Classification of stillbirths

Introduction. Audit and classification of stillbirths is an essential part of clinical practice and a crucial step towards stillbirth prevention. However, the use of different and perhaps suboptimal classification systems around the world is a major impediment to the global efforts in stillbirth prevention. ISA promotes and supports the important work of developing a universal classification system by providing forums for networking and discussion.


In this paper, Frøen and colleagues present, following testing across diverse settings, a new classification system for stillbirths and neonatal deaths (CODAC Version II). The testing (see paper by Flenady et al below) identified areas of potential improvements in the ability to retain existing information and ease of use. The main categories of CODAC consist of three key contributors to global perinatal mortality (intrapartum events, infections and congenital anomalies), two crucial aspects of perinatal mortality (unknown causes of death and termination of pregnancy), a clear distinction of conditions relevant only to the neonatal period and the remaining conditions arranged in the four anatomical compartments (fetal, cord, placental and maternal). For more detail there are 94 subcategories, further specified in 577 categories in the full version. CODAC is designed to accommodate both the main cause of death as well as two associated conditions, and we suggest the reporting not only of causes of death, but also of common scenarios of combined conditions and events.


This article presents an evaluation of the performance of six contemporary classification systems for the purpose of informing the development of an internationally accepted approach to classification of stillbirths. Systems evaluated were; Amended Aberdeen, Extended Wigglesworth, PSANZ-PDC, ReCoDe, Tulip and CODAC. These systems were applied to 857 stillbirth cases across seven countries (two developing country settings). CODAC, performed best in terms of retaining important information and ease of use. PSANZ-PDC and ReCoDe also performed well overall and Tulip performed best in terms of inter-observer agreement. Aberdeen and Wigglesworth showed very poor agreement and resulted in the highest proportion of unexplained stillbirths - CODAC and Tulip resulted in the lowest. The authors stated that the Extended Wigglesworth and Amended Aberdeen systems cannot be recommended for stillbirths and also recommended further studies on the performance of classification systems in the context of developing countries. The investigators acknowledged ISA in facilitating this project.

This article presents a systematic, multilayered approach for the analysis of perinatal mortality. This approach is based on information related to the moment of death, conditions associated with death, as well as the underlying cause of death, using a combination of approaches from existing classification systems. Existing classification systems were compared, regarding definitions, complexity, inclusion of factors, and viewpoint. Systems were also sorted into categories: ‘when’, ‘what’ or ‘why’, depending whether the focus of the system was based on the moment of death (when), clinical conditions associated with death (what), or the underlying cause of death (why). For in depth analysis of perinatal mortality, using combinations of, ‘when’, ‘what’ and ‘why’ systems are recommended developed, as well as developing countries, where resources to investigate death are often limited.

These reviews are recommended reading


Research underway

The Australian and New Zealand Stillbirth Alliance (ANZSA) in collaboration with the Perinatal Society of Australia and New Zealand Perinatal Mortality Group (PSANZ PMG) is undertaking a survey of doctors, midwives, nurses and social workers providing maternity and/or neonatal care across Australia and New Zealand to identify the needs of staff regarding communication and consent for autopsy following a perinatal death. This survey, which is supported and endorsed by ISA, has now become international with the inclusion of the UK lead by Dr Alez Heazell and supported by Sands UK. A study is underway to identify the needs of parents by surveying parents who have a stillbirth shortly after the birth and then again at around 8 months. For more information please see the ANZSA website or contact Vicki Flenady at info@stillbirthalliance.org

Each issue of ISAN will highlight key stillbirth-related facts and research. We welcome submissions.

LETTER TO THE EDITOR

I had the privilege to attend the ISA conference in the Drakensberg during March 2009. Because it was my first conference of this kind, I wasn’t sure what to expect. The following is a short summary of what the ISA conference meant to me.
Being a social worker, working with bereaved parents is something I need to do quite often. Although bereavement counselling was part of my training, this conference helped me to focus again on what are the best practices when it comes to bereavement counselling in the case of perinatal death.

I attended the bereavement track sessions and it was a wonderful experience to be part of these sessions. The whole group interacted with each other and all the members of Sands made these sessions unforgettable. What I valued the most was the fact that bereaved parents were present to share their own experience with us. It helped me as a professional counsellor to once again value the different emotions and reactions a bereaved parent might be experiencing.

Another positive aspect of the conference was meeting with other conference delegates and realizing that they also experience the same hurdles in this process. I felt strangely positive about the fact that there are other people who also have a passion to help bereaved parents and who want to make a difference in these people’s lives.

South Africa is in need of proper support structures for parents who have lost a baby. Currently there is no formal structure regarding support groups and if there are support groups, these are still functioning solitarily and it is necessary for us in South Africa to take hands and start to form proper support structures. Forming a parent support group in South Africa must become our long-term goal. I am convinced that this goal is achievable in the near future.

I conclude by saying that what I have learned from this conference is that the only thing a bereaved parent takes home is memories, and if we can offer sufficient counselling and follow-up support, we are helping these parents to at least have memories of caring people. People with time and compassion for them. I want to thank the ISA Organizing Committee for presenting an excellent conference.

Thank you.
Melanie Human, Social Worker, Tygerberg Hospital, Western Cape

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**ISA Strategic Direction and Goals 2009-2013. NOW AVAILABLE!**

This document outlines the mission, vision, guiding principles, strategic direction and goals for ISA over the next 5 years. For further information or to volunteer to help ISA to achieve these goals, please go to the web www.stillbirthalliance.org or contact the International Stillbirth Alliance secretariat at info@stillbirthalliance.org.

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**ISA would like to thank its generous donors in memory of these precious babies:**

AIDAN HARRISON BLUE, CONNER ATLAS DOWNS, CRISTIAN KAHLID CHAVEZ-KERR, LEO ARMANDO GRAZIOSI, MATTHEW RCYCEK, STEPHANIE FUOCO, SOFIA MAE & CHRISTOPHER EDWARD CALDWELL, VLADIMIR SPTIZKOFF, THOR EHRSTINE HEINEMAN, WADE RAUY WASHBURN, AIDAN ALAN & ISABELLA ANN CREW, WILEY, JOSEPH COOPER, LUCIA PAZ YINGST, SIMON BENJAMIN SHAFFER, ELIJAH COTE, ALEXANDRIA GRACE BOYD, DANIEL JORDAN, MATTHEW HYLAND, LEV LABOWITZ, DRAKE MENDEZ

If you would like to make a donation to ISA or honour a baby please visit our website at www.stillbirthalliance.org.
ISA WELCOMES NEW MEMBERS

New Zealand
Sands NZ (Full Member)
www.sands.org.nz
Sands New Zealand is a network of parent-run, non-profit groups supporting families who have experienced the death of a baby.

Spain (Full Member)
www.umamanita.es
Umamanita exists to support parents through stillbirth & neonatal death, to improve training for hospital staff and to change the registry law in Spain so that stillborn children or children who die before 24 weeks can be registered.

USA (Full Member)
1st Breath
www.1stbreath.org
1st Breath is committed to providing education, advocacy, and public awareness of stillbirth in addition to assisting families and medical professionals dealing with the death of a baby.

Angels Names Association (Associate member)
www.angelnames.org
The Angel Names Association is a nonprofit charitable organization dedicated to assisting families of stillborn children through programs designed to provide financial assistance for end-of-life expenses and counselling services, and funding for stillbirth research.

A Place to Remember (Associate member)
www.aplacetoremember.com
Uplifting support materials and resources for those who have been touched by a crisis in pregnancy or the death of a baby.

If you are part of an organisation that you think should join ISA please contact Anais (ISA secretariat) at info@stillbirthalliance.org. Joining is free and can be applied for via the ISA website under ‘Join Us’. We are always looking for new members to expand our community across the globe.

Volunteers Wanted
We need your help. If you would like to be a part of the creation, editing or design of this newsletter please contact Anais (ISA secretariat) at info@stillbirthalliance.org. We would love to hear from you.

ISA Board
Vicki Flenady (Australia), Chair; Neal Long (UK), Vice-Chair; Deb Boyd (US), Treasurer; Frederik Froen (Norway), 2008 Conference Chair; Leanne Raven (Australia), Secretary; Bob Pattinson (South Africa), 2009 Conference Chair; Ruth Fretts (US), Scientific Advisory Committee Chair; Sherokee Ilse (US) co-chairs Parent Advisory Committee; Stephanie Fukui (Japan); Carron Millard (Antigua); Belinda Jennings (Australia).

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Members: Carolyn Bray, Marion Currie, Vicki Flenady, Stephanie Fukui, Moni Ryzeck, Marian Sokol,

2010 Australian Conference Committee

New Committee!
A new ISA committee will focus on Public Awareness and Health Promotion to reduce stillbirth and improve bereavement care for parents who have a stillborn baby. More information about the activities of this group will be provided in the next newsletter.

Join a Committee!
These committees always need new members. If you would like to be involved, please visit our website or email info@stillbirthalliance.org

ISA Members and Associate Members
Become a member organisation and contribute in a meaningful way to the work of ISA!
Please see the ISA website for details on how to become a member.

Australia
Australian College of Midwives
Bonnie Babes Foundation
National SIDS Council of Australia Ltd - SIDS and Kids
Perinatal Society of Australia and New Zealand
SANDS Australia National Council Inc.
Stillbirth Foundation Australia
The Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG)

China
Hong Kong Polytechnic University School of Nursing (Associate Member)

Italy
Ciao Lapo Onlus

Japan
SIDS Family Association Japan
Japan Academy of Midwifery (JAM)
Luke’s Group for Parents of Angels/St. Luke’s College of Nursing (Associate Member)
With Angels in the Sky (WAIS) (Associate Member)

Netherlands
Fetal Medicine Foundation
Groningen Centre for Perinatal Mortality – Dept. Obstetrics and Gynaecology

New Zealand
Sands NZ
SIDS New Zealand
FEEDBACK

FEEDBACK WANTED!
Let us know how we’re doing. Email info@stillbirthalliance.org with your comments on this newsletter. What helped most? What helped least? How could we make it more useful to you?

SEEKING SUBMISSIONS!
Submissions for the next edition of the newsletter are welcomed. Submissions become the property of ISA; they may be edited for length and clarity and cannot be returned. Due to space restrictions, not all submissions can be printed; we appreciate your understanding. Every effort has been made to avoid errors; the Editorial team takes responsibility for any that remain. Please email your submission to: info@stillbirthalliance.org

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