



international
stillbirth alliance

THE INTERNATIONAL STILLBIRTH ALLIANCE NEWSLETTER

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“Collaboration for the understanding and prevention of stillbirths”

www.stillbirthalliance.org

ISA/ISPID Conference: Only 4 Weeks Away!

There are still spaces available for the ISA/ISPID 2010 Conference, "Precious lives: global collaboration in stillbirth and infant death" conference held in Sydney, in just four weeks time.

Abstracts have been accepted, the program's finalised and ISA and ISPID are honoured to announce that the Governor General of the Commonwealth of Australia, Quentin Bryce will officially open our conference. With a keen interest in the health and wellbeing of mothers and babies globally, she will be a valued addition to this rare event. We hope to see you there!



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Send in your Awareness Events to www.october15th.org

This website collects events for all of October which is **Pregnancy and Infant Loss Awareness Month**. October 15th is **Pregnancy and Infant Loss Awareness Day**. Any activities such as Walks to Remember, Fundraisers, Runs, Memorial Services can be added to the worldwide list.

A note from the chair



Welcome to the first ISA newsletter for 2010. It's been a busy year with one of our major focuses the ISA/ISPID Conference, 'Precious Lives: Global Collaboration in stillbirth and neonatal death' on October 8-10 in Sydney. After many months of planning, it's shaping up to be an exciting few days! A jam packed program has been finalised with presentations on important work carried out by a diverse range of experts from around the world. Invited key speakers on stillbirth include: Joy Lawn, Robert Goldenberg, Gordon Smith and Frederik Froen.

We are very excited that parents, researchers, and health care providers worldwide are provided with this unique opportunity to exchange information on successful programs, activities and research aimed at reducing stillbirth and infant death rates globally. Additionally we have just received news that seven delegates from low – middle income countries have been given the rare opportunity to attend this conference. Through the AusAID International Seminar Support Scheme (ISSS) delegates from Vietnam, South Africa, Ghana, Uganda, Nigeria, Sudan and Nepal will visit Sydney, Australia next month to gain insight into the way in which many countries aim to reduce stillbirth and infant death rates. We look forward to learning from the knowledge and experiences of these seven delegates and thank AusAID for their support.

ISA has been busy with facilitating the work of an international group of experts in research for inclusion in a series of publications on global stillbirth prevention planned for publication in The Lancet next year. We thank the GATES Foundation for their support of this important work and the many organizations involved.

In other conference news, ISA is currently calling for bids to host future ISA conferences. We are planning the 2011 conference to be a smaller meeting held in sunny Barbados. The 2012 conference is planned to be of similar scope to this year's conference and ISA welcomes bids from member and partner organizations.

Nominations are currently being sought for Board elections which will take place at the ISA General Assembly at the ISA/ISPID Conference in Sydney. ISA is particularly interested in strengthening parent and business representation on the Board. Please see further details within the newsletter.

This edition will highlight upcoming events, international news, and research. Please look out for the piece on the value of having one's baby at home after death and a piece on how to slow down the rush to deliver the baby after hearing one's baby has died. These are both very worthwhile reads for any parent or clinician hoping to listen to parents' perspectives. The second newsletter of the year will be out in the next six months and we welcome submissions.

Best wishes
Vicki Flenady

Sometimes love is for a moment,
Sometimes love is for a lifetime,
Sometimes a moment is a lifetime."
--Martin Luther King, Jr

ISA News



ISA/ISPID Conference

CALLS FOR SPONSORSHIP

ISA and ISPID would like to announce that sponsorship opportunities are still

available for Precious lives: global collaboration in stillbirth and infant death" conference in Sydney during October, 2010. Speakers are set, abstracts have been accepted, and delegates are registering. Even if you can't attend, your organisation can still show your support of our conference through sponsorship. With only two months to go, please express your interest as soon as possible by contacting Leanne Raven at leanneraven@sidsandkids.org.

International Key Note Speakers

We are very lucky this year to have two international keynote speakers, Dr Joy Lawn and Prof Robert Goldenberg who are both leaders in their respective fields.



Joy Lawn is Director of Global Evidence and Policy with the Gates funded Saving Newborn Lives programme of Save the Children-US. She is an African-born paediatrician and perinatal epidemiologist. She completed a medical degree and paediatric training in England, and then worked in several African countries for 4 years providing newborn care services and training. After this she worked at WHO and then the Institute of Child Health whilst completing a Masters of Public Health and a PhD. Joy co-leads the Neonatal Group in the Child Health Epidemiology Reference Group (CHERG), which developed the first systematic cause of death estimates for 4 million neonatal deaths each year, published in *The Lancet* Neonatal series and the World Health Report 2005. The CHERG Neonatal group is leading work for the Global Burden of Disease regarding stillbirths, neonatal deaths and morbidity. Joy is based in South Africa, working with governments and partners to integrate, scale up and evaluate newborn care, particularly in Africa. She recently co-led the team of 60 authors from 14 organizations working on the book "Opportunities for Africa's Newborns" as well as the 7 country teams from the African Science Development Initiative for the report "Science in Action – Saving the lives of Africa's mothers, newborns and children".

Robert L. Goldenberg, M.D. is Professor of Obstetrics and Gynecology and Director of Research in The Department of OBGYN at the Drexel College of Medicine at the University of Alabama Birmingham (UAB) and has served as the director and/or chair of several prominent health committees and boards; publishing over 500 journal articles. With Dr. Goldenberg as P.I., UAB participated in the March of Dimes Prematurity Prevention Study, the NICHD-funded study of risk factors for growth retardation, the NICHD Preterm Prediction Study, and the AHCPR Low Birthweight Patient Outcomes Research Team. He was co-P.I. for the UAB site of the NICHD MFMU Network for over 8 years, and was the P.I. for the NIAID HIVNET 024 study of antibiotics to prevent chorioamnionitis – related maternal to child transmission of HIV. For the last 15 years, he has directed the National Program Office on Smoking in Pregnancy for the Robert Wood Johnson Foundation, managing and overseeing more than 40 individual grants. He is also P.I. for the Drexel/Aga Khan University site (Karachi, Pakistan) for the Gates/NICHD Global Network. He was a founder of CIDRZ, the Center for Infectious Disease Research in Zambia that in addition to undertaking substantial research on maternal and neonatal health and HIV MTCT, now has more than 200,000 HIV infected people under care.



For more information about the program, how to register for the conference or to become a sponsor for this event visit www.isaispid2010.com.

We would value your participation in this conference; it is with our collective efforts that the loss of these precious lives will be reduced and the support and care of families suffering this loss will be improved. Please visit the [website](#) for more information.

Pre-Conference Workshops

There will be a series of ISA/ISPID conference workshops held on the 7th and 10th of October in conjunction with the Joint Conference of ISA and ISPID. Lead by international experts these workshops are focused on perinatal audits of suboptimal care and classification on perinatal mortality. Please see an outline below:

Pre Conference Workshops	
<p>ISA Board</p> <p>Date: Thursday 7th October 2010</p> <p>Time: 12:00pm – 1:00 pm</p> <p>Venue: Masonic Centre</p>	<p>The ISA Board meets via teleconference once a month. Once a year the board is given the opportunity to meet face to face to discuss the activities of the last year.</p>
<p>Perinatal audit on suboptimal care</p> <p>Date: Thursday 7th Oct 2010</p> <p>Time: 4pm – 6pm</p> <p>Venue: Rm 3, Masonic Centre</p> <p>Chaired by: Prof David Ellwood, Dr Jan Jaap Erwich, Prof Jason Gardosi and Dr Alison Kent</p>	<p>Assessment of the quality of care provided for pregnant women, their partners and babies should be part of a continuing audit cycle performed by the health care professionals. Several techniques are in use to organise and conduct facility based audits to improve perinatal care. Substandard factors are being identified and need to be resolved to prevent recurrence.</p> <p>In this workshop we will address several issues regarding these meetings, how to organize, creating a blame-free culture, making them effective, confidentiality-privacy issues, chairperson competences, etc.</p>
<p>ISA General Assembly</p> <p>Date: Friday 8th Oct 2010</p> <p>Time: 12:30 pm – 1:30pm</p> <p>Venue: Masonic Centre</p>	<p>The ISA General Assembly is an opportunity for ISA's member organisation to meet to discuss the past year's activities and explore ISA's direction for the following year. The ISA 2010/2011 Board will also be elected here. All members are invited to attend.</p>
<p>Classification of perinatal mortality</p> <p>Date: Sunday, 10th October 2010</p> <p>Time: 1pm – 2pm</p> <p>Venue: Masonic Centre</p> <p>Chaired by: Dr Adrian Charles, A/Prof Vicki Flenady, Prof Jason Gardosi and Dr Jan Jaap Erwich.</p>	<p>Over the last year, from ISA 2009, new initiatives have been developed towards a globally working classification system(s). These developments will be discussed, including the current state of the MAIN classification, WHO initiatives towards new ICD coding, translation of other systems into MAIN, comparison issues between countries/systems, value of verbal autopsy. The participants will be up-dated on these issues and are invited to share their views on how to proceed.</p>

ISA Recent stillbirth research updates

Successful Gates Foundation Grant

In collaboration with an international team of experts and organisations, The International Stillbirth Alliance through the Mater Medical Research Institute has received a grant to support the production of a series of papers for *The Lancet* placing stillbirths as a priority within the context of maternal, newborn and child survival. It will have a specific focus on low to middle

BILL & MELINDA
GATES foundation

income countries which bear the majority of the burden. The overarching purpose of this body of work is to reduce the unacceptable rates of stillbirth worldwide and, in so doing, improve overall maternal and newborn health outcomes. The series is due to be published in March 2011.

Meet Board Member Jan Jaap Erwich



Professor Dr Jan Jaap Erwich is an obstetrician from the Netherlands, trained in Leiden and the Hague and after a 2 year period in Adelaide Australia he now works at Groningen University, the Netherlands. As a medical student, he was interested in the amazing process of how two cells develop into an embryo and beyond, as well as in the function of the placenta. Prof. Erwich, (JJ) has a PhD in prostaglandins and placenta function. During specialty training he was very touched by women/couples who experienced fetal death or perinatal mortality. Finding the cause and proper bereavement care became one of his major goals.

His basic research looks into why some placentas do not function properly to sustain the baby. Not only with fetal death as a consequence, but also with long term effects on the baby's as an adult.

Presently, JJ is focusing on classification of perinatal mortality, which is needed to give insight into the causes and into the actions that need to be taken for prevention. His clinical work is based on caring for pregnant women in a third level referral center working with the very young pregnancies, very sick women or with babies who have anomalies.

JJ is also organising a nation-wide perinatal mortality audit system for identification and repair of substandard factors in the care for pregnant women and their babies as managing director of the Foundation for Perinatal Audit in the Netherlands (PAN) www.perinataleaudit.nl (in Dutch).

"I am involved with ISA because every baby counts and I still get nauseated when I do not find a fetal heartbeat when doing an ultrasound". He also writes, "I am very fortunate to have my wife and two boys (10 and 12 yr), and every time I look at them I wish everybody could have the same experience as a parent."

News from our regional office: ANZSA

Annual Workshop Focuses on Fetal monitoring, Cultural Diversity in Bereavement Care and Stillbirth Priorities

Wellington, New Zealand was the location for the 2010 ANZSA and Perinatal Society for Australia and New Zealand (PSANZ) Perinatal Mortality Group (PMG) Annual Workshop. Held in March, this workshop provided an opportunity for those interested in perinatal mortality to meet face to face to discuss antenatal fetal monitoring, cultural diversity in bereavement care and priority setting in stillbirth research in the ANZ region. If you would like to view the booklet of proceedings please contact info@stillbirth.org.au

Perinatal Mortality Education Program to IMPROVE Clinical Practice in Australia

ANZSA and Perinatal Society of Australia and New Zealand Perinatal Mortality Group are rolling out a package to implement the PSANZ Clinical Practice Guideline for Perinatal Mortality into practice which includes the educational program for care providers: IMproving Perinatal Mortality Review Outcomes Via Education (IMPROVE) Program. With accreditation from the Royal Australian and New Zealand College of Obstetricians and Gynaecologists (RANZCOG), the Australian College of Midwives (ACM) and the New Zealand College of Midwives (NZCOM), these workshops, aim to educate medical professionals and bereavement specialists on communicating with parents about autopsy, post mortem and placental examination, investigation, clinical examination, classification, and the psycho-social aspects of bereavement care.

The Perinatal Loss eLearning package is an initiative of the Women and Newborn Health Service through the Statewide Obstetric Support Unit (SOSU) and King Edward Memorial Hospital to provide a self directed eLearning package on Perinatal Loss - incorporating primarily the PSANZ Perinatal

Mortality Guidelines and is included as a component of the rollout of the PSANZ Guidelines project across Australia.

Another aspect of the rollout of the PSANZ Guidelines is the **National Perinatal Mortality Clinical Audit** which is currently being piloted. If you would like to view this tool please contact ANZSA Research Midwife Mrs Teresa Walsh at teresa.walsh@mater.org.au

The evaluation of this program, which is funded by SIDS and Kids Australia, is hoped will provide valuable information to ensure this initiative is sustainable over time. For further information on the IMPROVE Program please visit: <http://www.stillbirthalliance.org.au/education.htm>

New Guideline for the Management of Women who report Decreased Fetal Movements

The Clinical Practice Guideline for the Management of Decreased Fetal Movement from the Australian and New Zealand Stillbirth Alliance (ANZSA) aims to provide clinicians in maternity hospitals with direction to improve the processes and outcomes of care for women who feel a decrease in their baby's movements. To access this guideline please contact: info@stillbirthalliance.org.au

News from our members and member organisations: Around the globe

Disclaimer: ISA does not necessarily endorse everything in this newsletter. Members and supporters are invited to share their work, research, projects, and news whether the information is officially 'endorsed' by ISA or not. ISA endorsed research and projects are listed under the ISA News section. In no event are the authors, editors, ISA, or any other parties held responsible or liable for any errors or consequences arising from the use of the information in the newsletter.

SIDS & Kids (Australia) www.sidsandkids.org

Improving Clinical Practice in Maternity Hospitals

SIDS and Kids Australia is funding a research project which will allow the Australia and New Zealand Stillbirth Alliance (ANZSA) to properly evaluate an important education program for health care professionals.



In Australia and New Zealand 10 babies die every day through stillbirth and neonatal death. On average 30% of these deaths are unexplained leaving parents to wonder "what went wrong". A better understanding of these deaths will enable practice changes aimed at reducing the number of deaths into the future.

The Perinatal Society of Australia and New Zealand developed and implemented a national clinical practice guideline in collaboration with professional colleges, SIDS and Kids and SANDS organisations. From the experience drawn from this multidisciplinary team it was clear that improvements in the care provided to parents who had experienced the sudden and unexpected death of their baby were urgently needed. A recent review of the introduction of the clinical practice guidelines revealed that many midwives and doctors throughout Australia and New Zealand were still not following the recommended guidelines.

IMPROVE (*Improving Perinatal Review and Outcomes via Education*) an interactive educational tool will be introduced to maternity hospitals in Australia and New Zealand during 2010 to assist health care professionals to embrace the change in clinical practice around stillbirth and neonatal death. The main aim of IMPROVE is to further enhance the information available on the causes and contributing factors for stillbirths and neonatal deaths with the ultimate outcome being to reduce the number of deaths across Australia and New Zealand. Coupled with this is the additional outcome of improving their bereavement support services following stillbirth and neonatal death in a maternity hospital setting.

For further information on this research project please contact Leanne Raven, CEO, SIDS and Kids on (03) 9819 4595 or email national@sidsandkids.org.

Ask Online Library Update

Our ASK Online catalogue has experienced significant developments in the past few months with over 30 papers being added to our collection. ASK Online now boasts a collection of over 4,000 records. A snapshot of the recent additions to the ASK Online Library including the following topics:

Stillbirth:

Factors that increase the risk of stillbirth including maternal smoking, infection during pregnancy and advanced/young maternal age and maternal obesity.

Infant Mortality remains high for Indigenous Communities:

A recently published government report showed that since early this decade the infant mortality rate has declined in Australia from 5 deaths per 1000 live births to an average of 4.6 deaths per 1000 live births. However, despite this significant improvement infant mortality rates for Indigenous children are still markedly higher than for non-Indigenous children.

Sudden Unexpected Death in Infancy (SUDI) including SIDS:

The latest statistics show that 1 baby in every 4,000 died suddenly and unexpectedly in their first year of life in Australia in 2008. The tragedy of SUDI affects many families each year in Australia making the need for our Safe Sleeping Education and Messaging even more important.

Internationally researchers continue to study SIDS and most recently a number of papers focusing on genetic factors have been added.

Adult and baby bed sharing is unsafe and can increase the risk of sudden and unexpected death in infants (SUDI). Sharing a sleeping surface (bed, couch, mattress) with baby by anyone (adult or other children) can increase the risk of sudden and unexpected death in infants (SUID)

Grief:

Researchers found that the emotional exchange between partners after the death of a child is really important in their grief process.

The brothers and sisters of babies who died in the first weeks of life need psychological support. Family rituals and photos are important vehicles of communication, grieving, and memory for siblings and parents alike.

If you'd like more information on any of the topics mentioned above please email our Ask Online Librarian at librarian@sidsandkids.org or phone (03) 9819 4595.

Star Legacy (USA) www.starlegacyfoundation.org

*"When someone
you love becomes
a memory, the
memory becomes a
treasure."*

Star Legacy recently held the 5th Annual Charity Golf Benefit for Education and Research, Golfing for Garrett, The Star Legacy Foundation

The Star Legacy Foundation was started by family and friends of Garrett Jamison Wimmer, stillborn on July 31, 2004. Nearly 100 families endure this same tragedy everyday — 30,000 each year in the United States and nearly 4.5 million world-wide. The cause of most of these stillbirths is never known. Our focus is to raise money and

awareness so that better technology, education, and research are available to families and health care providers. The last four years, we were able to provide contributions to The Pregnancy Institute. For more information on our current initiatives and projects or other ways you can help, visit us at www.starlegacyfoundation.org The Star Legacy Foundation is a 501 (c) (3) organization. All donations are deductible to the limits of the law.

The Star Legacy Foundation Presented: *Stillborn – But Still Born! Emerging Evidence in the Prevention of Stillbirth*

Speaker: Jason H. Collins, MD
The Pregnancy Institute
New Roads, Louisiana
Friday, July 30, 2010

This event focused on the emerging research and work (over 1000 families) that uncovers one cause of stillbirth which deserves more exploration and awareness – the cord issues that do end in stillbirth.

This presentation was for physicians, nurses, ultrasound technicians, parents, families and all others interested in the care of the pregnant mother and unborn child.

Learning Objectives:

At the conclusion of this presentation, participants will be able to:

- Identify concerning presentations of the umbilical cord and placenta related to stillbirth.
- Identify indicators of fetal stress.
- Discuss management of pregnancies identified with high risk placental and umbilical cord presentations.

Physicians, hospitals, ultra sonographers and so on are welcome to contact Star Legacy Foundation for more information on the meeting or Pregnancy Institute (www.preginst.com) to discuss a program in their community.

First Breath (USA) www.1stbreath.org



1st Breath continuously strives to provide resources to address the many issues of stillbirth. Their motto of “Honoring those born who never took a breath...Serving so all born may have a 1st Breath” has opened many opportunities that allow them to connect parents and the medical community to new resources.

1st Breath was chosen by Medart Studios to share a brand new resource with a number of women who have previously experienced the stillbirth of a child and are now pregnant again. The Sprout™ - Pregnancy Essentials iPhone/iPod Touch applications provided by Medart Studios to 1st Breath has the potential of allowing the contemporary woman to become more educated and empowered in her pre-natal care. When partnered with other resources that are becoming available, 1st Breath hopes it may have the positive affect of helping to save lives.

Sprout™ Features Include

- *My Baby - Lifelike fetal imagery and information about fetal development*
- *Doctor Says - Week by week specific pregnancy advice from the experts*
- *Pregnancy Timeline - Personalized due date specific milestones*
- *3D Models - Industry first interactive 3 dimensional fetal models*
- *Organizer - Easy to use M.D. visit planner and checklists*
- *Tools Section - Including contraction timer, weight tracker and kick monitoring*

More information about Sprout - Pregnancy Essentials may be found at <http://www.medart-studios.com/> or by visiting the company Facebook page. To see if you qualify for a free Sprout application you may email 1st Breath at info@1stBreath.org. If you would like to volunteer or learn more about 1st Breath please visit www.1stBreath.org.

First Candle (USA) www.firstcandle.org

- First Candle's *Kicks Count!* campaign is gaining speed! More than 100,000 brochures have been distributed to parents and healthcare providers around the nation, a Facebook page has been launched and



a partnership with the What to Expect Foundation will ensure that lifesaving kicks count information is delivered to high-risk moms in our nation's most underserved populations. For more information, contact Dana Kaplin at dana@firstcandle.org.

- Learn more about kick counting and download an easy-to-use *Kicks Count!* chart at www.firstcandle.org/new-expectant-parents/kicks-count.
- Charity Gala 2010 will take place on October 28 in New York City. We hope you will consider joining us as we raise money to help save our nation's babies. For more information, visit www.firstcandle.org.
- Exciting legislative news! Michigan has successfully passed critically needed legislation on stillbirth and kick counting education and awareness through the House of Representatives. Next steps are to push through the Senate during its next session. Learn more at www.firstcandle.org.
- First Candle is pleased to announce that it will be hosting the 2012 ISPID International Conference on stillbirth, SIDS, and SUID in the United States. It will be held in October of that year in the Washington DC area. More details to follow . . .

Pending Legislation will Support Education and Prevention Efforts for Stillbirth, SIDS and other Sudden, Unexpected Infant Deaths (SUID)) [S1445](#), [HR3212](#) (www.firstcandle.org).

First Candle has been influential in the introduction of Stillbirth and SUID Prevention, Education and Awareness Act of 2009 which was filed on July 14 by Senator Frank Lautenberg, D-NJ. A companion bill was filed in the House by Frank Pallone, Jr., D-NJ-6. This bill would improve the collection of critical data to determine the causes of stillbirth, SIDS and SUID, increase education and awareness about how to prevent these tragedies in the future and expand support services for families who have experienced a stillbirth, SIDS or SUID loss.

The bill would expand activities to identify the causes of stillbirth, identify ways to prevent it in the future and increase education and awareness about the issue among healthcare providers and parents.

US citizens are encouraged to contact their House and Senate members as soon as possible to help by seeking co-sponsorship, which will help it pass more quickly through a LETTER-WRITING CAMPAIGN. To help:

- Visit www.house.gov to get contact information for the Congressman in your District. You will need your 9-digit zip code. If you do not know your 4 digit extension, you can get it at <http://zip4.usps.com/zip4/welcome.jsp>. You will then be able link directly to your Representative's website.
- Visit www.senate.gov to get contact information for your state's two Senators. Simply select your state from the drop down menu to connect to your Senators' websites.
- Call representatives directly, or set up an appointment to meet with them face-to-face. Writing a letter or sending an email can be effective as well. Emails can be sent directly through your representatives' websites.

A [sample letter](#) is available on the website. Sharing a personal story is very effective. Copy First Candle on the letter or an email detailing your conversation with your representatives for their files.

Sands NZ (Vicki Culling, Chairperson) www.sands.org.nz

Sands NZ is preparing for our annual national training which is being held in Wellington from August 20th to 22nd. We hold a three-day training weekend in our non-conference years (our conference is held every second year and we usually hold a training day preceding the conference). Sands NZ raise enough money to cover all costs for our participants for the whole three days – this includes travel, venue hire, accommodation, meals and technology requirements. We see this as one way we can thank our volunteers for the valuable work they do in their communities. We expect to have between 45-55 people attending our training from throughout New Zealand.

This year we have a variety of topics and for the first time we will break into two concurrent streams –

one for people new to Sands and one for the more experienced. We will start the training with a memorial service and some team building exercises so people can get to know one another. We will have speakers talk to us about grief, working with Maori (indigenous) and Pacific Island families, supporting parents and families through complaints processes, funding and fundraising, working with 'high needs' parents and families, and providing support and running a support meeting. We also take a half day to discuss organisational issue such as funding, branding, policies and guidelines, strategic planning and future direction for Sands NZ.

Previous training weekends included clinicians talking about perinatal pathology, maternal/fetal medicine, microbiology, bioethics and mortality review. We have covered topics such as support following the termination of a pregnancy, telephone support skills, media training, and peer support and in 2008 we had a very successful session with a government panel of all agencies whose policies affect bereaved parents and families.

We always try and have a dinner during the weekend so people can relax and meet each other informally (this is always cost dependent) and we provide a baby-friendly environment. This year we are hoping to provide a crèche for a small number of babies that will be accompanying their mothers to training.



Sands

If you are considering organising a training seminar for your local group and would like ideas, templates or just want to discuss the basics of putting together such an activity, please email Vicki Culling, Sands NZ Chairperson and training organiser, on contact@sands.org.nz or v.culling@paradise.net.nz. For information about Sands NZ, please see www.sands.org.nz.

We have recently released the following document promoting our Three-Point Model of Care

How Can A Health Professional Support a Bereaved Family?

Sands New Zealand is a parent run, not for profit, nationwide group supporting families who have experienced the death of a baby. Most of our supporters are also bereaved parents. We offer empathy and understanding. We are not counsellors and do not give advice but offer an opportunity and environment to share experiences, to talk and to listen. We promote 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. Sands offers phone contact, support meetings, library books, newsletters, Sands booklets, and Moses baskets and babies' clothing in some hospitals.

Various international journal articles discuss parents' experiences of stillbirth and neonatal loss and suggest ways that health professionals might support and assist them. There are very few articles that feature New Zealand research and relate directly to New Zealand parents' experiences. These are the suggestions that have come about from working with bereaved parents, families and whanau. We have distilled our message into three main points:

Sands New Zealand Three-Point Model of Care

1) Slow Down

There is no need to rush. In the case of stillbirth, once baby is born things can slow down, the post-mortem does not have to happen immediately and the family can spend some time with their baby. Many parents have reported feeling a sense of urgency once their baby was born and a need to make decisions quickly. As a result, parents, families and whānau make decisions that have a lifelong impact - they don't want to see their baby, they don't want to bath their baby, they don't want to take their baby home, they don't want their other children to see this baby. This can also be the case with a neonatal death, again we emphasis the need to take things slowly.

We encourage the health professionals that are supporting and working with a bereaved family to *gently ask again*, to gently provide as much information as possible in order for the family to make an informed

decision. The family now has a limited time with their baby physically (whether it is hours or days). Slowing down means the next two points are able to happen more easily.

2) Assist in Active Parenting

Even though their baby has died, the parents, family and whānau are still caring for and parenting this precious member of their family. Making decisions, showing love in physical, emotional, spiritual and social ways, caring for our child – these are the ways we parent our children.

Because things have slowed down, the opportunity to parent their deceased baby is enhanced. Parents, families and whānau have the time to think about their decisions – the name of their baby, whether they will have a funeral, who they will invite to see their child, what they will dress their baby in...what will happen next. The more we can encourage the families to actively parent their baby, the better the opportunity to create memories.

3) Help to Create Memories

In actively parenting their baby, memories are created. The time available for parents, families and whānau to physically spend with their baby is now finite. At this point families are encouraged to do as much as possible (under the circumstances) – to take photos and videos, to have handprints and footprints done, to dress baby in special clothes, to bath baby, to cut a lock of hair, to take baby home. There is also the chance to take baby to a significant or special place. These memories can sustain a family when things seem very bleak. Do not underestimate their importance.

Practicalities

There is some information that is helpful for you as a health professional to know. It is possible that parents may ask you about any of these points. If you do not know the answer, please make the effort to find out the information so the parents are in the best possible place to make a decision.

- Knowing what baby might look like – at 20 weeks, at 30 weeks, full-term, and a neonatal death, being able to tell parents what to expect (the colour or state of the skin, the appearance of a baby with a certain condition).
- Taking baby home – refer them to the Sands NZ 'Transportation of a Deceased Baby' guidelines.
- Organising a funeral/service – giving parents as much information as possible, a list of funeral directors, costs, funeral grants, knowing they don't have to use a funeral director if they choose not to.
- Keeping baby cool/cold – the logistics in doing this (using ice, a refrigerator of some sort), fridge temperature, warming a blanket when people want to hold baby.
- Knowing about the physiological changes – seepage from baby's body, natural processes of deterioration.
- Having an idea about grief (different theories and physical symptoms) and the post-natal experience – being able to talk about what they might expect to experience over the next few days, few months, few years; what will happen from a maternity perspective (six week check, midwife visits, the appointment with the hospital to receive the post-mortem results)
- Resources – having information available for bereaved parents, families and whānau on books, DVDs, groups, agencies

If you would like to talk to someone about Sands or make a donation, please contact your nearest Sands group under the 'Local Groups' section on our website www.sands.org.nz, or send your correspondence to Sands New Zealand, PO Box 13 435, Johnsonville, Wellington 6440.

Uma-manita (Spain) www.umamanita.es



Guia para la atención a la Muerte perinatal y Neonatal (Guide for the Attention of perinatal and neonatal deaths) up on our website. It's a guide for health practitioners that we wrote with another association here in Spain that rallies for respected births. It's probably the first of its kind and can be downloaded for free from our site.

Board Member (Belinda Jennings, Perth, Australia)

We have started a qualitative research project for residents of Perth, entitled "Empty Cradles: Understanding Women's Experiences of Pregnancy Loss in the First, Second and Third Trimester- see attached Information Letter for Women. It is Esther Kints PhD project - so it will be conducted over several years. We can't wait to see the analysis - hopefully will enable the community to understand better.

Recently, pregnancy loss and its specific associated grief has gained more attention. However, the experience of pregnancy loss for women and the meanings they assign to such an event has received less attention. The proposed study will attempt to address this gap by exploring how women experience, interpret and react to their loss, as it has been suggested that any theory specific to pregnancy loss would need to incorporate meaning-making as an essential component of the theory. A qualitative research design, specifically, a hermeneutic phenomenological approach will be employed to understand the meanings that a select group of women assign to their experiences of bereavement following pregnancy loss. Approximately fifteen bereaved women will be selected for participation in the study, according to the gestational period during which their loss occurred. Women will be interviewed in-depth, on three separate occasions (at 4-6 weeks, 6 months and 13 months post-loss). This information is needed to explore what it means to women to experience a pregnancy loss, how they understand the ways in which they endure the experience and will give tools for health-workers how to care for them.

For further information please contact Esther on 0439 753 3336, or Belinda Jennings (Clinical Midwife Coordinator, Perinatal Loss Service, KEMH) via switchboard at KEMH 08 9340 2222 pager 3430. If you have any concerns or complaints regarding this study, you can contact the director of Medical Services at KEMH (Telephone No: (08)9340 2222). Your concerns will be drawn to the attention of the Ethics Committee who is monitoring the study.

If you are part of an organisation that you think should join ISA please contact Maddie (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.

Other News

Helping Babies Breathe is an initiative of the American Academy of Pediatrics and many partners that aims to develop and implement an evidence-based curriculum adaptable to clinical and training use wherever babies are born using a neonatal resuscitation curriculum for resource-limited circumstances. It was developed with input from the World Health Organization (WHO) on the premise that assessment at birth and simple newborn care are things that every baby deserves. The initial steps taught in HBB can save lives and give a much better start to many babies who struggle for oxygen at birth. The focus is to meet the needs of every baby born. For more information visit savingnewbornlives@savechildren.org

New research out of Scotland

One hundred babies die unnecessarily every year - because they are born outside working hours, shocking new research has revealed. A major study of births in Scotland discovered tots who didn't arrive between 9am and 5pm were more at risk of losing their lives because of a lack of oxygen. Experts believe one reason for the worrying toll is a lack of immediate access to senior medical staff at weekends and during evenings. Professor Gordon Smith, who carried out the research, said: "These babies have grown normally. We would have expected they would have a normal life expectancy. "But something has happened around the time of birth that has asphyxiated them."

The findings come after recent research revealed hospital patients were more likely to die if they were admitted at weekends. A report in June blasted the NHS for being "too reliant" on trainees outside

normal working hours. Read more at:
<http://www.thescottishsun.co.uk/scotsol/homepage/news/3056739/100-out-of-hours-babies-die-a-year.html>

Stillbirths rate continues to fall

A report from the Centre for Maternal and Child Enquiries (CMACE) found the death rate for babies around the time of birth fell from 8.3 per 1,000 births in 2000 to 7.5 per 1,000 in 2008. The number of stillbirths fell from 5.4 per 1,000 in 2000 to 5.1 in 2008.

Rates of stillbirth and deaths in the first month of life have fallen for twin births, which have raised concerns due to the numbers of twins born as a result of IVF. The report also highlighted well-known risks for stillbirth and infant death, including that they are higher among mothers under 25 and over 40.

Women living in the most deprived areas are also 1.7 times more likely to have a stillbirth and more than twice as likely to have their baby die in the first month compared to women in the wealthiest areas. Mothers from ethnic minorities are also at greater risk of having their infant die in the first few weeks.

Read more at: <http://www.nursingtimes.net/nursing-practice-clinical-research/clinical-subjects/midwifery/still-birth-death-rates-continue-to-fall/5017483.article>

Two initiatives moving forward in the US

The 'Slow it Down, Prepare' Initiative

There is a movement afoot to encourage parents to slow down the 'Race from Getting the News to Being Induced.' A crisis occurs when a fatal diagnosis is given...then the crisis is compounded by a rush to 'get it over with.' Sadly, this means families have no, or very little, preparation time and they can only operate out of shock and fear. As they create the 'foundation of their healing' in those few hours and days, it is understandable that mistakes will be made, important information lost, and regrets formed.

Over and over it is becoming clear, that the families who spend some time at home – hours to a few days, have time to let the news sink in, make the calls, pack their bags, and contemplate the many life altering decisions that come next in a more calm environment. This can only occur if they are given reading materials and others to talk with who can offer gentle guidance and the perspective of longer term, rather than short term decisions based on fear of the unknown.

Author, educator, and bereaved parent, and ISA volunteer, Sherokee Ilse has a contribution to give to this movement—a video entitled: 'A Gift of Time: I Hardly Knew You...What Happens Next.' This promotes the idea that better experiences can come for families who have the 'Gift of Time', a concept coined by parents/video participants Paul and Eileen who have no regrets about their hospital experience because, "We had the gift of time and a 'Birth Planner' to assist us in knowing what was ahead and helping us pre-plan."

To further support this initiative, our Sands NZ team share this email from a parent, "As upset as I was at learning we had to wait over the weekend to be induced, it's actually turned out to be a good thing, as it's given us time to come to terms with things, find out all the information we need, and discuss what we're going to do. We finally chose names last night, and I feel so much more at peace since doing that. I've just been in to the hospital this morning to have the first pill. I was so scared, but it wasn't as bad as I thought, and so far I'm feeling okay, so hopefully I won't get too many side-effects over the next 48 hours.

The hospital staff gave us more information today about the whole labour process, as well as our options for what we can do with baby afterwards. All that has helped to take away the scary unknown somewhat.

So now we are just waiting for Tuesday. In a way we are both looking forward to it as we will get to see our baby, and it will bring (hopefully) some closure. Gosh this is such a roller coaster ride of emotions. I'm so glad to have the support in here of mums who have been through similar circumstances - thank you all :)"

The value of having one's baby at home after death

Through out time and even our world today, there are many cultures, countries, and individuals who have their deceased infant in their home for a while before burial or cremation. Before hospitals and funeral homes were common in many developed countries it is interesting to remember that birth and death took place in the home. It is only the past few generations who have given up the care of the dying process to 'professionals'. And having the baby at home for awhile is standard fare in New Zealand and most non-western countries throughout the world.

What happens at home depends on each family and culture.

Paul and Eileen talk openly about how important it was to their family to take their stillborn baby Olivia home after she died. Her siblings met her in the safety and comfort of their home and the family now has precious memories of their time together. The time spent talking to her, creating memories in their home, introducing her to her two older brothers. The sterile hospital time they had with Olivia, could not compare to the quality time they spent in the safety and privacy of their own home.

In the NZ video, *4 Hours with Raja*, the extended family took over the hospital room and also had little Raja at home prior to and after his death. The special time, ceremonies, and healing that took place was almost magical.

Rose and Mike were told not to come to the hospital, to let nature take its course...so they did. Little Ricky was miscarried at home. Pictures were taken in their arms and Rose's hands, and in the Bay Memorial Baby Casket. They have no regrets, only gratefulness, that they had their baby with them at home.

The growing Hospice movement in some cultures and countries is bringing the naturalness of dying back to the home. Having the baby at home for a few hours or even a few days is something that every family needs to be told they can do if they wish. While some may not choose it, many will once they realize the private, personal time their family can have in their own home.

**Yesterday father, you fathered me.
Today dear mother, you birthed me.
I was there, you were there
We all stood witness.
I heard your whispers,
that you love me.
I heard you tell each other
how beautiful I was viewed
in my eternal quietude.
I even felt your soft caress
as you held me to your breast.
On this morn, mourn not for me.
With ethereal grace I have a name.
I have a home, I have a life...
To live through all eternity.
~Author Unknown~**

Good Grief - What a Big Grief

What does grief look like?

When parents experience the death of their baby they can be plunged into a world in which they have previously had no knowledge. They will embark on a journey they could not foresee having to make.

There are no road maps, no GPS for this journey. As parents struggle to come to terms with the new reality of their lives they may also have to take care of family and friends. They may have to educate their circle of carers about the most appropriate way to support them on their journey.

How can friends or family possibly know what this experience is like or how things have changed for the parents? They are spectators while parents are the players. They are the audience while parents are the actors. Observers looking in and not participants. Family and friends may feel compassion and empathy particularly at the immediate time of the death of the baby. How are they to know what the new life for parents really is all about? How can they know the length of time it will take to create another 'normal' when parents themselves don't know the answer?

The concepts of 'moving on' and 'closure' are frequently bandied about by observers (family and friends). This can be their way of indicating that they are ready to move on. The grief associated with the death of a baby is not an illness; not a broken limb; not a graze on a leg from a fall. Bereaved parents don't need to move on – they will have to integrate the experience into their lives and find a place in their hearts for this big grief.

The term closure when used in the wider community can indicate a business shutting down, the closing of a door, the closing of a file. When talking about 'Closure' and grief and loss is something entirely different. Shutting or closing an emotional door on such a life changing event is not something that parents could do or should do. Some bereaved parents find the pain of the loss too great to manage and will shut the door or pull the rug up and sweep the emotional dirt under it.

Thirty or forty years ago, parents were told to do exactly that – go home and have another baby. As if by doing what they were told and having another baby, one baby would replace the heartache of the loss of the other. Some parents who were bereaved many years ago make contact with Sands to ask for assistance in finding details of their baby – where was their baby buried? Was their baby buried? This contact demonstrates that heartache doesn't go away and in some instances feelings that haven't been managed and dealt with may cause trauma, much like an emotional volcano that one day may erupt.

For many observers of the Big Grief, standing by, watching, supporting may be simply too hard. Being in another person's pain is often not a comfortable place to be. An event such as the death of a baby will often 'sort out' the fair weather friends – those people who will only make contact when they feel that it is safe for them to do so.

Bereaved parents may find themselves very disappointed with the level of support they have received from their circle of immediate family and friends. Human beings often don't act in predictable ways. You may never know the strength of a person until they have been tested by life. Most people try to do the best they can and many are genuinely concerned for the welfare of the bereaved parents. Somewhere in the midst of grief, parents may need to find the grace and patience to forgive people who have little knowledge of life.

The rituals of grief we observe often do not give bereaved parents enough opportunity to share their grief. A funeral held a few days after the death of their baby is often the only public space that parents are given to openly grieve for their baby. Permission from observers will allow parents to cry openly, to share their grief at that ceremony. All too soon that may change and the name that parents need to hear – that of their baby, is not said. If the parents mention the baby's name there is sometimes an awkward silence and a quick change of topic.

Fortunately, most parents find a gem amongst their family and friends. Someone who will listen without judgment, say the name of the baby, openly talk about the journey. The people who will walk the journey with you may not be the ones you thought you could rely on.

The journey doesn't really have an ending as the memory of the baby is in the hearts and minds of parents forever. Parents change – anyone who has been through the death of a baby will change. The changes may be tiny – a shift in values or perceptions. Other changes may be much more significant –

a person's core values may shift and a new perspective gained. The Big Grief can change to become smaller, more manageable. One day bereaved parents may realise that the sun is shining in their world and there are not as many clouds. How long it will be until this time is different for each individual person. The rollercoaster ride of grief is only predictable because of its unpredictability.

One day the mask of grief may start to slip and the memory of this time will be in a safe place in the hearts and minds of parents. Other parents who have walked this journey can tell you about it's difficulties and it's ups and downs. They can also tell bereaved parents and others of the lessons they have learned. The lessons are learnt gladly as no one would wish that their baby died in vain. Look forward to the sun that comes out after the rain.

Liz Conway, Sands (Australia)

Recent stillbirth research and publications

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Books

A Bereaved Father, Steve Younis (Australia), Create Space, Amazon.com 86 pgs \$8.95

I am a bereaved father. I have lost not one, but two children. My only two children. While I have no children living in my house, I am still a father. Being a bereaved father is not something I ever considered, nor something I wanted to be. However, it is now who I am. In many ways it defines me. Being a bereaved father is complicated. It changes your life... forever. "A Bereaved Father" tells the story of my own experiences as a bereaved father, while giving other parents the opportunity to identify similarities with their own experiences, and find some solace in knowing that they are not going crazy, they are not abnormal, and they are not alone. (Amazon Editorial)

Losing Emily: A Journey Through Stillbirth to Finding Peace and Embracing New Hope, Tammy Anderson, Inkwater Press, Feb 2010, (Canadian author) 82 pages, \$16.95

A powerful and moving must read story based on the author's own heartfelt, painful journey of surviving the stillbirth of her daughter Emily at 37.5 weeks of pregnancy. Losing Emily reaches out to help grieving parents as they embark on their journey of healing by offering words of comfort and peace, a much needed connection to someone who has been there and understands the struggle and true depth of the unimaginable pain of losing a baby. Whether your loss be from a miscarriage, stillbirth or early infant death; there is no greater heartbreak than losing your much loved and wanted child. Through Emily's tragic death, her legacy lives on by sharing a message of new hope to help bereaved parents as they move through the difficult process of healing while finding new strength and courage to carry on without your child. Amazon review

From Crisis to Purpose: A Mother's Memoir Tonya N. Dorsey, Xulon Press

Tonya shares her sincere, candid, and authentic story about her journey after the loss of her daughter in 2001. "Recounting her soul gripping determination to conquer tormenting grief, Tonya offers validation and inspiration to those who know the agony of unexpected loss. Celebrate the power of resilience as Tonya finds the strength to persevere in the face of disappointment and despair." (from the book cover)

They Were Still Born: Personal Stories About Stillbirth (soon to be released), editor Janel Atlas, is a collection of personal essays by people who experienced the death of a baby between 20 weeks' gestation and birth. The stories in this book are not easily told, but for the many thousands of families each year who endure the silent tragedy of a stillbirth, they offer a welcome voice of solidarity and guidance. Janel Atlas, familiar with the pain of losing a child, has selected the firsthand accounts of mothers, fathers, and grandparents, all of whom have reached out to offer readers the comfort of knowing they are not alone on this painful path. Through these stories, the writers found validation of their babies' lives and have now shared the same gift with others. Contributors include, Dr. Joanne Cacciatore, Dr. Ruth Fretts, Sherokee Ilse Monica Murphy LeMoine, and Tim Nelson. The book is set for a fall 2010 release, from Rowman & Littlefield Publishers, and is available for pre-order on

Amazon.com.

For Children

Where Is Chloe? Donna A. Wilkins, M.D., neonatologist, Credo House Publishers

This beautiful book touches and teaches children ages 4-8 after their infant sibling has died. Answering questions such as "Am I still a big sister?" "Was it something I said or did?" "Can I travel to heaven?" is only one of many reasons this book will give comfort and understanding to younger children who are

wondering what happened. Written from a Christian perspective, this book offers hope in Jesus and the hope of seeing Chloe in heaven one day.

My Baby Big Sister, Cathy Blanford,

Ms. Blanford, author of *Something Happened*, has written a new book especially for those children who are born after there has been a pregnancy loss or infant death in the family. My Baby Big Sister is now available from Amazon or Centering Corporation (www.centeringcorp.org). This book is illustrated by children and simply tells the story so that the subsequent child can understand who this baby, older sibling was and be a part of the family's story. Each page has words for parents to help them as they explain this important family event to their subsequent child.

Music

MusicbyNaomi.com,

From My Heart: An inspirational, emotional album with songs that touch parents' hearts. Brady's Song and Danielle's Song are written in memory of her two stillborn babies. Not again is a lament and a song of hope. Classical piano, strings, and some voice.

Serenitymusic.com

You will find many calm, relaxing, supportive songs on the Serenity CDs. A popular one is-- *Reflection* is an album that is great for introspection, healing touch, relaxation, prayer, and reflection. Created around light piano with gentle orchestration touching the listener at the deepest level. www.serenitymusic.com

Looking for music to play at baby funerals? Visit www.APlaceToRemember for sheet music and CDs. The booklet *Planning A Precious Goodbye* (www.wintergreenpress.com) has a list of some of the favorite songs gathered from many places including Facebook stillbirth/miscarriage/SIDS groups

Paul Alexander - *We Live on Borrowed Time*. Following a loss, many people realize how important it is to cherish each day. Listeners will find comfort in titles such as: "We Can be Kind," "Let me be the Music," "Listen to My Heart," and "We Live on Borrowed Time." www.AplacetoRemember.com

Video (CD and DVDs)

Forever Baby (free) A poignant gift to others from a mom who experienced an early miscarriage.

'The Gift of Time: I Hardly Knew You...What Happens Next?' (CD/DVD Set for caregivers -10 minutes and newly bereaved parents - 19 minutes. Comes with Guidance Handouts). Intro. Price - \$65+ s/h until Sept. 1, 2010. \$100 regular price.

Both available at www.BabiesRemembered.org (USA)

Grief in the Workplace, Liz Conway and SANDS, (QLD, Australia)

"Since a positive return to work is fundamentally important for bereaved employees, their employers, and the business, this well done DVD, by Liz Conway and the SANDS (QLD) Inc in Queensland, Australia, is a must.

\$80 per set which includes 1 DVD, 10 colour brochures, and 1 A4 Poster www.sandsqld.com

In a baby castle, just beyond my eye
My baby plays with angel toys that money cannot buy
Who am I to wish them back into this world of strife?
No, play on, my babies, you have eternal life
At night when all is silent and sleep forsakes my eyes,
I'll hear their tiny footsteps come running to my side
There little hands caress me, so tenderly and sweet
I'll breathe a prayer and close my eyes
And embrace them in my sleep

I have a treasure that I can rate above all other
I have known true glory - I am still their mother

Unknown

SANDS (SA) June Newsletter 2001

WE NEED CONTRIBUTIONS TO THE NEWSLETTER - Send in your favorite websites, resources, new research you have learned about, ongoing studies, etc.

ISA: Who we are

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; Carron Millard (Antigua); Belinda Jennings (Australia)

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

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Feedback

FEEDBACK WANTED!

Let us know how we're doing. Email feedback@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: submission@stillbirthalliance.org

EDITORIAL/WRITING TEAM: Sherokee Ilse, Dylan Maaka, Madeleine Elder

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