A note from the chair

October is International Infant and Pregnancy Loss Month, with October 15th the focal day. This month and day give the many organisations focused on addressing stillbirth a chance to organise inspiring events, raise funds, and remember 3.2 million precious stillborn babies who die during pregnancy across the globe every year.

This month’s feature article is written by ISA board member Stephanie Fukui and explores the role of bereavement care in Japanese society. The rest of the newsletter provides the usual information on upcoming events, international news, and research.

Last month one of ISA’s regional offices, the Australian New Zealand Stillbirth Alliance (ANZSA), released its first newsletter which is available on the ANZSA website at www.stillbirthalliance.org.au. The newsletter has generated a lot of much welcomed interest in the Australia and New Zealand region.

We are busily organising our next conference to be held jointly with ISPID October 8-10 in Sydney Australia. I hope to see you there!

This will be the last newsletter for this year. As ISA chair, I would like to thank you sincerely for your support during 2009 and look forward to working with you all again in 2010. Our next newsletter is due March 2010.

Best wishes
Vicki Flenady
Rites of Bereavement in Japan by Stephanie Fukui

Author’s Note: If my daughter Ema could have survived, she would be 23 years old on November 6, 2009. As a trisomy 13 baby unable to survive outside the womb, Ema died at birth in 1986. When my husband and I moved to Japan in 1987 raw, and at the same time numb from loneliness for our baby, the ancient Rites of Bereavement in Japan guided us through. Twenty-three years and two beautiful sons later, I still have a fierce love for my Ema and such gratitude. Her little birth and death taught me big things and changed my life path. I am also thankful that I have experienced the soothing quiet of Japanese temples and shrines and the timeless ceremonies that helped me towards peace.

Introduction
Western society has distanced itself from death. Since the 18th century Westerners have moved towards putting all faith into science. Death has come to be seen as a medical problem, not a spiritual process. The “medicalization” of death has put pressure on health professionals. Medical solutions, doctors, hospital staff, and mental health professionals have taken a place that used to be reserved for the priest and the family’s faith forcing health professionals to become ritual specialists [1]. The recent trend in hospice care is an attempt to re-introduce the spiritual dimension into death and dying. However, even if health care systems start to include an awareness of the importance of spirituality for psychological and physical health, these systems are not sufficient as a support system because they are only peripherally involved after death.

Western society has distanced itself from death further by emphasizing the value of youth- physical and mental prowess, and by making death a taboo subject in our every day lives. For this reason, people with secular attitudes may be shocked by death and unprepared for it. The shock may be much more acceptable for traditional societies, such as Japanese society, where formalized strong bonds with the deceased make death a part of every day life.

Though there is the need for medical attention, support groups, and psychological counseling for the family after a death, in Japan traditional Buddhist/Shinto practices provide comforts that medical systems cannot. These traditions satisfy some of the needs of the grieving family and help the bereaved transition towards recovery and acceptance after the death.

The Japanese Belief System
The Japanese rites are born from the unique mix of Buddhism and Shinto that makes up the Japanese belief system. The procedures followed after a death tend to be mainly based on Buddhist practices though influences from Shinto can be found throughout.

Buddhism came to Japan in the 2nd century BC with the opening of the Silk Road. Afterwards introductions of new doctrines came in waves and at least five schools of Buddhism exist today in Japan. Buddhism is more a philosophy than a religion in that the objective is not to preach doctrines but rather to teach a method of attaining insight and a transformation of consciousness. The goal is to feel your fundamental existence as part of the total energy of this universe [2].

Shinto is the indigenous religion of Japan. It has a deeply-rooted association with agriculture that is focused on the life cycles of the land and its people and has been practiced for over 2000 years. Shinto is characterized by expressing gratitude to the “kami” (gods) through ritual. These gods represent the life force of objects, places or spirits. Past emperors and ancestors are deified as well as common objects. Many of the divinities personify aspects of the natural world such as the rice harvest (this god has now expanded to business!), rocks, trees, the sky, thunder, and heavenly bodies. One of these gods, the Sun Goddess, is believed to be the founder of the Japanese nation [3].

Buddhist/Shinto Philosophy and the Grieving Process
Shinto is based on a belief in the divinity of nature and its natural cycles and processes. When the pain is so great, it may be comforting for bereaved families to contemplate nature and the natural processes for perspective. Here death and life are not necessarily “bad” or “good” they just “are.”

Being exposed to Buddhist principle of “impermanence” may help families in their grieving
process. According to this philosophy, nothing endures, everything is always moving through cycles. There is the idea in Japan that children are “other-worldly” or close to the gods so that they slip with ease (or in other words are vulnerable to death) back into the other world, soon to be reborn [4]. Since a baby is robbed of life so soon after it began, the idea of reincarnation may be more comforting than thinking that the baby is gone forever. It is a way to learn to live without the baby as a physical being but accept him as a spiritual being who will continue to have a place in the home and heart of the family, as well as the opportunity to live again.

During the grieving process, there is the challenge and necessity of “letting go.” “Nirvana” means to exhale, to let go. According to Buddhist philosophy attachment causes suffering: do not cling and you will be in a state of Nirvana. With emphasis on honoring, protecting, and caring for the baby’s spirit, the Japanese rites move the bereaved actively, but gently away from attachment and towards acceptance of the death. The rites formalize the process of letting go with a myriad of ceremonies.

**Schedule of Ceremonies**

After a death, an elaborate schedule of ceremonies allow families the place and time they need to say goodbye gradually to their babies. Families can opt to have ceremonies and family gatherings for their child long after the child has died and the ceremonies can even be passed on to future generations.

**The Wake, Cremation and Funeral**

When a baby dies the parents are allowed to take the baby to their home. There they can spend a last night with the baby, clothing the baby or bathing it.

The wake traditionally takes place in front of the “saian” a temporary shrine that is erected in the home. However, recently many people are having the wake at the temple or crematory. During the wake, candles are lit and a flame is lit in a special lantern called a “chochin” in the belief that the soul of the beloved baby will be guided to his loved ones by the light. Incense is also kept burning during the wake. Family members take turns staying up at night to make sure that it is burning. The smoke from the incense is believed to float to the land of the dead to make sure that the baby will know where the family is.

After the wake, the body is taken to be cremated, then to the funeral “sougi” at the temple, a memorial for the dead child, consolation for the soul and to repose the dead child’s spirit. Parents can bring the child’s photo or special toy which will be displayed on the ornate altar during the ceremony. The ceremony includes chanting of scripture by the monk to ask the god Jizo to protect the beloved baby that died.

The Buddha, Jizo, the god of compassion and protector of children, is believed to rescue the lost souls of children in the other world. The world is envisioned symbolically as being divided by a river, the land of the living on one side and the land of the dead on the other. During the funeral ceremony Jizo is asked to help the lost souls of the babies (since they are babies they are considered vulnerable) to cross the river, move into the world of the dead, and to later be reincarnated. The chanting during the funeral also works to transfer merit for the benefit of the deceased, making sure his next life will be a good one.

The wake, cremation, and funeral are followed by the Seven-day Ceremony, a Memorial Service every month on the same day of death if desired and then the Forty-nine Day Ceremony.

**Forty-nine Day Ceremony and Others**

There is a memorial service for the baby 49 days after the death that includes taking the urn that has been kept at home to the cemetery and putting it into the small vault that is built into the family gravestone. Sometimes the box is opened and the ashes are put directly into the vault to mix with the ashes of other family members to become part of the family of ancestors, however some stillbirth parents opt to keep the ashes at home. The number forty-nine has special significance in Japan because four “shi” and nine “ku” are synonyms for death and hardship. This day is important because it is believed to determine the destiny of the soul [5].

Another service then takes place 100 days after the death (this is originally a Shinto tradition).
Afterwards memorial services will be held at one, three, seven, thirteen and thirty-three years if following the Buddhist schedule or 50 days, 100 days, one year and ten years if following the Shinto schedule. Families will also sometimes have a memorial service every month on the same day the baby died or every year on the anniversary of the death.

These services can be for family, friends, business associates, and neighbors though recently it is often just the nuclear family attending. Most families invite relatives until the third-year ceremony and thereafter only the nuclear family observes the tradition. After many years the family can ask the temple to perform these rites.

Festival of the Dead
Another opportunity to honor the baby takes place every year in August throughout Japan when there is a festival of the dead called “obon.” It is believed that during this celebration the gates to the other world are open so that departed spirits can return to earth for a brief time to celebrate with their families. At this time most Japanese return to their family home to honor their ancestors as well as younger family members who have died. Parents can offer special treats for the baby at the shrine in the house and the monk usually comes to the home to perform a short ceremony. A festival is held throughout Japan where the Bon Festival dance welcomes the spirits. The dance movements tell the story that the living welcome the spirits from the other world and are comforted by their presence, then send them back to the land of the dead until they can meet again next year. The “chochin” (lanterns) are lit to light the way for the soul to find his loved ones. This flame is extinguished on the last day of “obon” to send the soul off back to the land of the dead.

Opportunities to Grieve
The many opportunities to grieve show there is an understanding that progress in grieving takes place little by little. In Japan, death is a part of every day life. Ancestors are worshipped and considered part of the family at the altar in the home. Small corner shrines embedded throughout Japan’s fields, towns, and cities, as well as the large temples, offer opportunities for the bereaved to have a moment for spirituality in their every day lives.

Offerings at the “Butsudan” in the Home
A “butsudan” is a small shrine that is fit into an alcove in the home especially designed for it. This shrine is a small house-like structure made of carved wood. The area in front of the shrine is set up with a photo of the baby who died, candles, flowers, and incense as well as an “oihai,” a wooden plaque bearing the baby’s saint name written in calligraphy. The child’s favorite toy or one the parents want to give the baby and other mementos are also placed before the shrine. Rice, water, fruit, and food the child loved most are also prepared in tiny portions and offered on little plates. This gives family members the opportunity to think, talk about, honor, and care for the baby on a daily basis. It is an opportunity for siblings in the family to ask questions and come to a better understanding of death. It is also a way to say good-bye to the baby gradually while honoring him still. Little by little daily offering may become less and eventually food is only offered on special occasions like holidays or anniversary of the death [6].

Visiting the Temple
Visiting the shrine or temple and/or visiting the grave is something that can be done any time, as much or as little as desired. It is an opportunity for prayer, meditation, and remembering the baby.

When families go to the temple, first at the entrance they must wash their hands to purify themselves before entering. Visitors then light incense at the altar. The beautiful scent is said to refresh the mind and allow them to wear a beautiful scent for the gods. It is believed that the lovely scent floats to the other world to reach their baby. A large rattle hanging before the altar is then shaken by the attached rope and the hands are clapped twice, the sound of the rattle and clap is believed to get the god’s and loved one’s attention before prayer [7].

Caring for “Mizuko” and Protecting the Baby
Parents have a strong urge to “parent” their beloved baby who is no longer with them. The Japanese rites allow ways to care for and honor the baby after death such as writing messages to baby on “kifuda” (wooden tablets) offering food and toys to the baby at the shrine at home, buying a “mamori” (charm) to protect the baby, or a “mizuko” (votive statue) at the temple and taking care of it by dressing it and washing it.
A stone statue, “misuko,” (literally meaning “water baby” suggesting that the baby goes back to the primal waters from which life comes) can be bought with name painted on a stationary flower vase at its base. The “mizuko” is also stationary. Hundreds or thousands of these statues are erected at certain temples that specialize in performing the rites for children. The stone statue is chubby and child-like. The statue represents both the “misuko” or deceased baby and the Buddha Jizo that takes care of him in the other world. The statues are erected to commemorate the lost child, to pray for fertility or the blossoming of a new baby, and to protect the children born into the family from now on. These include abortion, miscarriage, stillbirth, and infant death to about two years old. According to Buddhist beliefs, babies have souls from the time they are conceived. (The old way of counting age was from conception, so that at birth the baby was one year old, at the first birthday two years old, etc.)

Visiting family members pour water over the child-like figurines to cool them and quench their thirst. Dressing the special statues with bibs or hats and offering gifts of toys, food, and flowers are all opportunities to “parent” the child, to care for the child who died.

**Conclusion**
Taking the time to grieve by using opportunities in every day life and following the schedule of ceremonies allows families to work towards acceptance of the death while honoring and caring for their beloved baby. The Shinto/Buddhist philosophy of impermanence, life cycles, and natural processes may help also.

**References**
6. Ohtei Toshi, Editor, *Hito Me de Wakaru, Kankou Sousai no Chishiki Hyakka*. Shugu to Seikatsusha, Japan 1988

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**ISA NEWS**

- **ISA POSITION STATEMENT RELEASED AS CONSULTATION DRAFT**
  ISA has released its first position statement on Decreased Fetal Movement as a consultation draft. ISA is welcoming comments and feedback from the entire stillbirth community. Please click [here](#) to view and provide feedback.

- **ISA OPENS CALL FOR BIDS TO HOST FUTURE CONFERENCES**
  We welcome submissions to host ISA conferences in 2011, 2012 and beyond. For more information and to submit a bid please click [here](#).

- **ISA/ISPID 2010 JOINT INTERNATIONAL CONFERENCE WEBSITE LAUNCHED**
  In progress is a special stillbirth series in *The Lancet* journal that will be launched at the 2010 conference. This is a very exciting opportunity for the conference, and the main authors will be giving keynote addresses at the conference.

  The conference committee continue to plan the program for the event and are welcoming expressions of interests from attendees, potential speakers, and particularly potential sponsors. Sydney, Australia is a beautiful city and the conference offers a perfect opportunity for sponsors to promote their brand alongside the International Stillbirth Alliance (ISA) as well as the International Society for the Study and Prevention of Infant Death (ISPID).

  Please visit the [website](#) for more information.

**NEWS FROM OUR REGIONAL OFFICE: ANZSA**

**Modifiable risk factors for stillbirth**

ANZSA has completed a systematic literature review of modifiable risk factors for stillbirth relevant to the Australian and New Zealand setting supported through funding by the Stillbirth Foundation Australia and also supported through ANZSA secretariat funding by the Department of Health and Ageing, Canberra.

The key findings of the review showed the top ranking risk factors with a combined Population Attributable Risk (PAR) of 45% were Maternal overweight and obesity; Maternal age >35, and Smoking. Therefore, at a population level, these factors are priority areas to reduce the stillbirth rate in Australia and New Zealand.

**Uptake of the PSANZ perinatal mortality audit guidelines: A survey of midwives and doctors in Australia and New Zealand.**

Deficiencies in investigation and audit of perinatal deaths results in loss of information and limits future prevention. Such deficiencies led the Perinatal Society of Australia and New Zealand to develop clinical practice guidelines for perinatal mortality. This survey, of 133 lead maternity care providers in birth suites in 69 large maternity hospitals across Australia and New Zealand, was undertaken to determine the use and views of the PSANZ Guidelines, focusing on the investigation and audit aspects of the guideline, two years after dissemination of the guideline.
The IMPROVE workshops have since been developed as a way to implement the guidelines in an interesting and effective way. The ANZSA IMPROVE program is an interactive education facility to teach clinicians, obstetricians, gynaecologists, pathologist, midwives, bereavement specialists, and other professionals working in perinatal medicine how to incorporate the PSANZ Guidelines for Perinatal Mortality Audit into clinical practice. IMPROVE adapts the guidelines into six hands-on and interactive stations, with each station based on a component of the guidelines: perinatal mortality classification, investigation, autopsy consent, placenta and post mortem examination, baby examination, and perinatal bereavement.

**NEWS FROM OUR MEMBER ORGANISATIONS AROUND THE GLOBE**

**SIDS & Kids Australia**

Researchers look to video games in hope of saving babies lives

In a world first, researchers at several Australian hospitals are using technology normally found in video games and car airbags to better understand the high incidence of stillbirth.

This groundbreaking research has been partly funded by SIDS and Kids and incorporates the accelerometer, a tiny electronic device that was originally developed for car airbags and is now used in Nintendo Wii, the Apple iPhone, and Nike+iPod shoes.

The fetal monitor is being tested at the Royal Women's Hospital, The Royal Brisbane & Women's Hospital (RBWH), and the Mater Mothers’ Hospital. It uses the accelerometer technology to measure babies movements over a prolonged period of time.

"Lack of fetal movement causes anxiety for mothers and we hope that our research will assist in alleviating this stress," said RBWH research director, Professor Paul Colditz. "We would not be able to conduct this crucial research without the generous donations from fundraising activities such as Red Nose Day."

The team has two major aims for this research. One, that it provides a framework to understand what a ‘normal’ pattern of movement is for a baby in the final term – a topic that is vastly under-researched. And two, that it potentially leads to a low cost, non-invasive device that could be attached to the stomach of mothers who are concerned about lack of movement. "Ultimately, we hope that the fetal monitor could be as straightforward as a heart rate halter monitor. It allows us to follow the movement of a baby over a longer period of time, which the current ultrasound technology does not allow," said Royal Women's Hospital midwife and research co-ordinator Dr Christine East.

The fetal monitor is currently in clinical trial stage and researchers hope to have conclusive data about the clinical usefulness of the monitor when their studies are completed.

**Parent Survey**

SIDS and Kids Victoria surveyed some of their parents and asked them: “What was helpful and what would have been helpful when in hospital after your baby died?” This is a summary of their findings.

**WHAT DO BEREAVED PARENTS WANT HOSPITAL PROFESSIONALS TO KNOW?**

- **ALL professionals need orientation & ongoing inservicing on grief and loss.**
- **Bad news needs to be given in a sensitive manner and support given immediately.**
- **Information needs to be given clearly, repeated, given slowly, not all at once.**
- **Information is ‘taken in’ better before an induction or medical termination.**
- **Parents need time to understand complicated information and make decisions.**
- **Making too many decisions for parents is disempowering**
- **Dressing their baby in their own clothes or given ones of appropriate size helps.**
- **Having reasons for the baby’s death helps with the grieving process.**
- **Some parents regret not having an autopsy.**
- **Parents need alternatives to autopsy eg. non-invasive tests of the placenta, x-rays...**
- **Minimal sedation during labour– memory of the birth is helpful in grief.**
- **Specialists need to clearly identify themselves and explain their role.**
- **Staff need to network with family members – this promotes better support.**
- **Privacy is essential when delicate matters are discussed, for grieving and support.**
- **The baby's name needs to be used at all times, be shown dignity and respect.**
- **All relevant persons and departments need to be given details of the death.**
- **Signs/symbols are needed to denote the death on doors and files.**
- **Bereaved parents need time on their own but not to be left on their own.**
- **It helps when staff show their sadness, cry with parents and attend the funeral.**
- **Photos and memorabilia need to be kept by the hospital until parents are ready.**
- A checklist is needed to ensure all mementos are taken.
- Parents need as much time as they request with their baby and may need explanation as to how this will help them in their grieving.
- Parents need information, support, and encouragement to plan the funeral/memorial service.
- Clothing worn by the baby needs to be returned to parents – they become precious.
- Sensitive and non-judgmental support is required after a medical termination.
- Registration of the birth of tiny babies helps acknowledge the baby’s existence.
- Information on different types of delivery needs to be given in prenatal classes.
- Support when leaving the hospital ‘empty handed’ is crucial.
- Information about drying up the milk and breast pumps needs to be given.
- A streamlined process for referral to support agencies is needed.
- Many parents receive no support once they left hospital and feel let down.
- Staff need to follow up all parents 6-8 weeks after the death. This is often when parents hit a ‘brick wall’ and may need a referral for counselling and support.
- Parents often cannot ring for support so a referral ensures outreach to them.
- Referral to genetic counselling is often required.
- Parents may need to return to the hospital to assist the process of closure.
- Separate prenatal classes for those having a subsequent baby are required.

Prepared by Petra den Hartog
Counsellor/Educator, SIDS and Kids, Victoria.

**Sands UK (Sue Hale, PAC member)**

Sands welcomes Steven Guy, the newest staff member as Regional Coordinator in Northern Ireland. Steven’s involvement in Sands began 16 years ago when his daughter, Danielle, was stillborn. He has had many different roles since then but throughout this time his passion to help other parents and to carry forward the three aims of Sands in Northern Ireland has always shone through.

Mr. Guy will provide support to existing groups and help new groups open by acting as a mentor and facilitating training. To ensure the existing high level of bereavement care in the region is maintained, he will strengthen the existing working relationships with each hospital in Northern Ireland and also the Health Board. To properly assess the provision of bereavement care in the region and to identify training needs he hopes to introduce an audit and monitoring system across Northern Ireland. Steven will be a key organiser in the presentation of our Saving Babies Lives Report 2009 to Stormont in Spring 2010 in support of the Why 17? campaign. He will also work closely with Sands research and media teams to implement the campaign.

**Sands begins to fund research.**

Research is desperately needed if we are to understand why so many babies die before or soon after their birth. Some causes of stillbirth, such as pre-eclampsia and pre-term labour are known and there is limited research going on into these areas. However, much more work is needed, especially into those deaths which are unexplained.

We have begun by establishing our own research fund with money raised through the hard work and dedication of our many volunteers. It is critical that we invest that money, time and effort in research that is most likely to transform the care of mothers and babies, and to save lives. This summer took an important step towards making that research a reality as we are now in a position to consider proposals for research from clinicians and scientists.

Like all research funding charities we need guidance from research experts to help us pick out proposals for research that are good quality and will make the most difference, seeking to be transparent and impartial.

So we have teamed up with Wellbeing of Women (WoW), a charity that already has over 40 years of experience in funding research into reproductive health. WoW works in close partnership with the Royal College for Obstetricians and Gynaecologists (RCOG) and their Research Advisory Committee is drawn from RCOG members including leading experts in fetal and maternal health. WoW has a tried and tested – and highly regarded - system for assessing and selecting research proposals that are well designed, aim to answer relevant questions and are most likely to produce results that count. The experts will review all the proposals that we receive and recommend which are of an acceptable standard. Sands trustees will then participate in the final selection of what to fund to ensure our views of the research priorities are incorporated.

The first funding round is offering a maximum of £150,000 over three years. The advertisement for proposals was placed in the main medical research journals in June, and a number of researchers have already expressed great interest in applying.

WoW and Sands are both delighted to be collaborating in funding research to prevent babies’ deaths. By combining our resources and knowledge we believe we are well placed to attract and fund the best projects.
At the launch of the Saving Babies Lives Report 2009 at Westminster in March this year Neal Long, Chief Executive, pledged to raise £3 million in the next five years to fund research which will help prevent the deaths of more babies, and called on the government to match that £3 million. We hope this is just the start of stillbirth and neonatal research receiving the funding it needs.

For more information about WoW go to: www.wellbeingofwomen.org.uk. Please email info@stillbirthalliance.org to contact Sue Hale for more information about what is happening in the UK.

**First Candle (USA)**

Suzanne Pullen, ISA committee member and supporter, wins Galinson Scholarship

Suzanne Pullen, full time Communication Masters student and single mom to a toddler, turned the personal crisis of the death of her baby Avery into an opportunity to help others cope with the tragedy of an infant death in stillbirth. For her public service and academic work, she has been selected by the California State University Foundation as a Trustee Murray L. Galinson Scholar, distinguishing her among this year's 23 winners of the William Randolph Hearst/CSU Trustee's scholarships.

Receiving one of the top awards given at the state’s 23 CSU schools gave Suzanne another platform to raise awareness and compassion for families who have a child die prior to birth. Suzanne has been active with First Candle and ISA for the past 4 years. Last year, she completed a study of 624 bereaved parents entitled, "Giving Birth to Death" focusing on care provider communication during news delivery of a stillbirth diagnosis. Many parents perceived their care provider communication during news delivery of a stillbirth diagnosis. Most patients had minimal exposure to stillbirth prior to their diagnosis (11%), weren't satisfied with information they received during diagnosis, and virtually all reported that their lives had changed significantly. Other findings were: most would have liked peer contact info from the person who gave them the news, and they remembered the exact words used during news delivery.

Suzanne is now working on a qualitative study of memorable messages present in stillbirth news delivery in order to recommend better communication strategies for care providers, designing stillbirth news delivery simulations and applying to PhD programs to continue her research when she graduates this year. For more info, email her at lifeafterstillbirth@yahoo.com.

**KICKS Counts Initiatives**

Approximately 80% of women who had a stillbirth describe having noticed decreased movement shortly before their baby died. (Editors’ Note: Many other moms have noted decreased movement yet their babies lived). There is a shared goal in some countries and regions to see if ‘movement awareness’ will ultimately save babies lives. Moms are encouraged to monitor movement, call their doctors if change occurs, go in to be checked, and if appropriate-their medical caregivers will intervene to save the baby.

To that end, First Candle (www.firstcandle.org), with a grant from the Heinz Family Philanthropies, has initiated a new US initiative – **KICKS count!** They have also joined forces with Finger Lakes Productions International to secure celebrity spokespersons and produce high quality radio public service announcements (PSAs) to deliver important information to expectant parents on counting baby’s movement.

Their message is: **Counting your baby's kicks during your last trimester is a simple, free and effective way to help monitor your baby's health. Many experts now agree that it may also help reduce the risk of stillbirth.**

Thousands of Kicks Count brochures have been made available to doctors, midwives, and parents who wish to better understand this method of counting movement toward the end of pregnancy with the goal of hopefully reducing stillbirth. The guidelines suggest paying attention to movement since, “What your baby is telling you with its kicks (movements) is important!” It goes on to say that there are reasons to call your doctor immediately, “If your baby kicks less and less in the course of a day, or you don't feel any kicks on any given day…” The brochure suggests that, “…kick counting is being recognized as the first proactive strategy that may reduce the risk of stillbirth.” For more information on this initiative, to download a brochure or a Kicks Count chart (a tool to help keep track of the movement), visit http://www.firstcandle.org/kickscount/index.html

An Iowa nonprofit, Health Birth Day, has a statewide Count the Kicks campaign also. They encourage people to visit www.countthekicks.org to learn more.

**Newly Introduced 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](http://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](http://zip4.usps.com/zip4/welcome.jsp). You will then be able link directly to your Representative's website.

- Visit [www.senate.gov](http://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.

**OCTOBER AWARENESS MONTH EVENTS**

Though we know most of these activities have already occurred, we hope these events inspire you for future programming and give you a sense of the worldwide efforts that are made each year to promote October as Pregnancy and Infant Loss Awareness Month and October 15th as Int’l Pregnancy and Infant Loss Day.

**Australia**

Adelaide: Sunday, October 18, 10 am, Memorial Walk, Pinky Flat, Torrens River, “Take the steps our babies could not take…”, SANDS Pauline@sandssa.org

Brisbane: Sunday, October 11, 9 am, Walk to Remember and Memorial Service, New Farm Park
SANDS nsi00@bigpond.net.au

Sydney: Saturday, October 10, 7-11:30 pm, Charity Gala Dinner, Courtside Function & Event Centre, Rod Laver Drive, Sydney Olympic Park, Tickets $100.
Dinner, dancing, candle-lighting service, prizes, auctions, and raffles. Bears of Hope

**England**

St Austell: Carlyon Bay Hotel, Carlyon Bay, St Austell, Cornwall. Thursday 15th October 6.30-8pm
Informal drop-in/meet and mingle. Candle Lighting at 7pm Refreshments available and support from experienced bereavement support workers available.
More info: [www.forgetmenotcharity.org](http://www.forgetmenotcharity.org)

More info: [www.babylossawarenessconcert.kk5.org](http://www.babylossawarenessconcert.kk5.org)

Surrey: Under Tungate Arch, Guildford Town Centre. Thursday 15th October 7pm Candle Lighting
More info: Surrey Sands

**Ireland**

Belfast: Belfast Castle. Sunday 11th October, 4pm release Balloon Release
For more info: Organised by Life After Loss [www.lifeafterloss.org.uk](http://www.lifeafterloss.org.uk)

**Scotland**

Edinburgh: Saughton Winter Gardens, Edinburgh EH11 3BQ Sunday 4th October at 1.30pm
In Memory of Our Beautiful Babies: Balloon Release
More info: Contact Angie 07760 196321
aadcc@btinternet.com

Edinburgh: The Sanctuary, The Royal Infirmary of Edinburgh, Little France Thursday 15th October 6.30pm – 7.30pm Candle Lighting at 7pm a short introduction (words and music) prior to this and light refreshments to be served after.
More info: In conjunction with SIMBA and The Hospital Spiritual & Pastoral Care Team
Sandy Young (Hospital) 0131 242 1990 or Sara Fitzsimmons (SIMBA) 07917 054802
Inverness: Falcon Square, Inverness Thursday 15th October 7pm Candle Lighting
More info: Highland Sands

Italy
CiaoLapo Onlus, charity for grief support after perinatal death is organizing several activities in Italy. Among them:
• Oct 10-11th - National meeting in Milan
• Oct 15th - Local meetings all around Italy with candlelight ceremonies (wave of light at 7pm) and balloon release
• Oct 18th - National meeting in Bologna, in the "Garden of Angels"
Further information in the website www.babyloss.info

U.S.
Many activities occurred throughout the country. Many are listed on the www.pregnancyandinfantloss.com site. Here area a sampling of a few—

Bellingham, WA, Remembrance Walk & Ceremony, Sunday, October 11th from 4:30 - 7:30pm at the Fairhaven Village Green. Registration begins at the event at 3:45 pm. The event included a memorial walk to the Taylor Dock and a ceremonial scattering of rose petals on the bay. There was music, poetry, sharing and community building, plus participants had an opportunity for a meditative labyrinth walk at the Fairhaven Village Green. The event is co-sponsored by Mending BabyLoss and Laughing Flower Labyrinth Co.
To commemorate and honor the life of children who died before or after birth. Whether the loss is recent or was years ago, all are warmly invited to the healing Mass celebrated by Bishop Lee Piche. Babies' names were entered into the Book of Life. The Mass is co-sponsored by Nativity parish and by God's Children, a ministry of the Archdiocesan Office for Marriage, Family and Life. For more information, please call 651-291-4498.

Saratoga Springs, NY: Saturday, October 17, 2009, Angel Names Association’s (ANA) hosted its annual Memorial Walk at Saratoga Spa State Park
A day of celebration, the annual Memorial Walk invited friends and remembered their loved ones with a walk to remember and honor babies who have died too soon. At this event, families who have experienced miscarriage walk alongside those who have suffered the tragedies of stillbirth and infant deaths who died years, and even decades, ago. The Memorial Walk supports bereaved families, raise awareness about infant death and ANA’s role in the community, and provide people an opportunity to contribute to ANA’s programs. More than $2,000 in raffle items and prizes for the top three fundraisers of the day! http://www.firstgiving.com/14144

A Love Song

The mention of my child’s name may bring tears to my eyes but it never fails to bring music to my ears. If you really are my friend please, don’t keep me from hearing the beautiful music. It soothes my broken heart and fills my soul with love.

by Nancy Williams from Awakening from Grief by John E. Welshon

RECENT STILLBIRTH RESEARCH UPDATE

The Placenta, Cord, and Cord Accidents
Ruth C Fretts MD, MPH, Chair-ISA Scientific Committee

The evaluation of the placental and cord function is an evolving area of research. Some of the difficulties of studying the cord and cord accidents are related to the way stillbirths are studied and classified. One reason for classifying a stillbirth is to access the recurrence risk and to identify prevention strategies. Unfortunately, many stillbirths have not been thoroughly evaluated. The most important aspects of the stillbirth evaluation include examination of baby, cord, and placenta together.

In the past, clinicians and parents may have had a sense of relief when after a stillbirth, an abnormality of the cord is noted—Meaning to most people that the death was truly an “accident” and there was no one is to blame. This assumption is too simplistic, however.
The opinion of whether or not a placental or cord problem resulted in a stillbirth depends not only on the findings at birth and but also the degree of pathology present. In life, there is always a range of conditions. Cord loops and knots are very compatible with a normal pregnancy outcome. Some mild cord and placental abnormalities might be tolerated by a well grown baby but not by a baby who is small and already shows signs of stress. As pathology increases, however, so is the likelihood that the condition can cause a less than optimal outcome and fetal death. The “level of evidence” to attribute a condition as a cause of death is up for debate and because of this the number of stillbirths that are classified as “unexplained”, related to “placental dysfunction” or “cord accidents” is quite variable. Obviously, more systematic research is required. This research update is specially focused on cord accidents and placental pathology.

Importantly, there is also an international effort to clarify a classification system that can help further our knowledge. In the Journal of Obstetrics and Gynecology, Reddy and colleagues reported the results of an Executive Summary of the National Institute of Child Health and Human Development on the Stillbirth classification, developing an International Consensus for Research.

For comments or further additions to this research update please email info@stillbirthalliance.org.

Cord obstruction, signs of severe, IUGR (growth restriction), and nuchal cord (around the neck 4 times) resulting in heart decelerations, baby delivered early but alive.

2. Placental histologic criteria for umbilical blood flow restriction in unexplained stillbirth, Mana Parast, MD, PhD, Crum, Boyd, Brigham and Women’s Hospital and Harvard Medical School, Human Pathology, Vol. 39, Issue 6, pages 948-953, 2008.
Summary: “Fatal hypoxic injury due to restriction of umbilical blood flow (‘cord accident’) may be causal in a subset of unexplained late pregnancy stillbirths. Minimal histologic criteria suggestive of cord accident were defined as a vascular ectasia and thrombosis within the umbilical cord, chorionic plate, and/or stem villi…Thus, we find nonacute cord compression implicated in over half of “unexplained” third-trimester stillbirth.”

Summary: “The incidence of placenta and umbilical cord abnormalities is high in abnormal course of the delivery. Although the detection rate of umbilical cord abnormalities is steadily increasing with the improvement of ultrasound technology, and the fact that ultrasound scanning can distinguish umbilical cord conditions, this information has not exerted much impact on the management of labor to date. Prenatal detection of umbilical cord abnormalities can reduce the number of emergency cesarean sections and intrauterine fetal deaths. In this review, the authors describe the ultrasound diagnosis and management of major umbilical cord abnormalities, including abnormalities of cord insertion site (velamentous and marginal cord insertion), hypercoiled cord and nuchal cord, considering the current knowledge on physiologic and pathologic aspects of each umbilical cord abnormality.”

4. Does low blood pressure increase the risk of stillbirth? Erick Hodgson, MD and E. Norwitz, MD, PhD.,Chief of Maternal Fetal Medicine. Yale University School of Medicine, Contemporary Ob/Gyn, October 2006.
Key point: “Despite conventional wisdom, low blood pressure (hypotension defined as a maximum diastolic blood pressure of less than 65 mm Hg) in the third trimester may not be reassuring observation. Indeed, recent studies suggest that it may be a risk factor for stillbirth. However, these data should be regarded as preliminary…”

This summary was the result of an international meeting where experts reviewed the strengths and weaknesses of our current and varied classification systems. Ideally a classification system would include information on maternal conditions and risk factors, fetal conditions and placental and cord pathology. A strategy of including this information and grating the severity of the conditions would help identify patterns and prevention strategies. This of course relies on a comprehensive stillbirth evaluation.

6. Diverse placental pathologies are the main causes of fetal death; Korteweg et al., Obstetrics & Gynecology. 114(4):809-817, October 2009.
The authors studied 750 couples with singleton intrauterine fetal death after 20 weeks of gestation. They found the main causes of stillbirth varied by gestational age . At lower gestational age, placental and unknown were the most dominant causes of death (34.8% and 41.7%, respectively); at higher gestational age, the relative importance of an unknown cause decreased and a placental cause increased (16.5% and 77.6%) (P<.001). They concluded that most fetal deaths were caused by a variety of placental pathologies. These were related to gestational age, and their clinical manifestations varied during pregnancy.
RECENT STILLBIRTH PUBLICATIONS

Health in South Africa
The Lancet Series
Excerpt: The extensive research and analysis conducted for the Lancet “Health in South Africa” Series provides a detailed assessment of the country’s health status and health system. Written by a group of South African researchers, physicians, public health specialists, and care providers the Series presents an overview of the burden of disease in South Africa and identify priority interventions and actions. This Series culminates in a call for action for the South African Government, for universities, training institutions, health councils, researchers, and civil society. Everyone has a part to play and we must all work together to strengthen the health care system in South Africa - strong leadership and stewardship are critical. Click here to access the full articles.

Saving the lives of South Africa’s mothers, babies, and children: can the health system deliver?

Achieving the health Millennium Development Goals for South Africa: challenges and priorities

Gray R, Bonellie S R, Chalmers J, Greer I, Jarvis S, Kurinczuk J J, Williams C.
Smoking is known to increase the risk of stillbirth and infant death. Smoking is also associated with higher levels of socio-economic deprivation. This study examines the effect of smoking during pregnancy on the social inequalities gap in stillbirth and infant death in a cohort of Scottish hospitals over a ten-year period. It was found that stillbirth and infant death were more common in deprived groups and that smoking during pregnancy accounted for over a third of the social inequality in stillbirths and around a third of the inequality in infant deaths. Although tackling smoking during pregnancy is a major priority for reducing stillbirth and infant death, other measures to improve the social circumstances, social support, and health of mothers and infants are needed. Click here to read full article.

BJOG International reviews.
BJOG special issue 2009, 116 (s1).
Over 99% of women who die from pregnancy-related causes occur in the developing world. This special issue of BJOG: An International Journal of Obstetrics & Gynaecology focuses on women’s health in low-resource settings. It includes topical reviews and discussions surrounding health services and quality of care, as well as a “How to…” series including information on providing technical assistance, searching the internet for evidence-based care, and teaching. Click here to access all the full articles.

Ensuring effective Essential Obstetric Care in resource poor settings (p 41-47)
EJ Kongnyuy, JJ Hofman, N van den Broek.

Quality of care for maternal and newborn health: the neglected agenda (p 18-21)
NR van den Broek, WJ Graham

ISA WELCOMES NEW MEMBERS

In the last few months ISA welcomed three new member organisations: Angel Whispers Baby Loss Support Program from Canada, Evelyn Rose Foundation and the Star Legacy Foundation both from the US.

Angel Whispers Baby Loss Support Program is ISA’s first Canadian organisation and exists to provide caring, confidential support services to families who have experienced baby loss, as well as their caregivers.

Evelyn Rose Foundation (Associate Member) is a new organisation focused on providing a high standard of care for families, providing memory bags to hospitals and providing high quality resources to families.

Star Legacy Foundation is a non-profit organisation committed to supporting research to prevent stillbirth.

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.
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; Shereeke Ilse (US) co-chairs Parent Advisory Committee; Stephanie Fukui (Japan); Carron Millard (Antigua); Belinda Jennings (Australia)

Parent Advisory Committee
Co-Chairs: Liz Conway and Shereeke Ilse
Members: Jillian Cassidy, Line Christoffersen, Vicki Culling, Mairie Cregan, Sue Hale, Claudia and Alfredo Ravaldi

Scientific Advisory Committee
Co-Chairs: Ruth C Fretts, M.D., MPH and Dr Jan Jaap H.M. Erwich, M.D., PhD
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Members: Vicki Flenady, Stephanie Fukui, Grace Guyon, Suzanne Pullen

Fundraising Committee
Chair: Neal Long
Members: Carolyn Bray, Marion Currie, Vicki Flenady, Stephanie Fukui, Ron Ryzeck, Marian Sokol

2010 Australian Conference Committee
Chairs: Vicki Flenady and Leanne Raven.

Public Awareness and Health Promotion Committee
Chair: Janet Scott
Members: Vicki Flenady, Emma McLeod

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)

Canada
Angel Whispers Baby Loss Support Program

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

Italy
Ciao Lapo Onlus

Japan
SIDA 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
SIDA and Kids New Zealand

Norway
Norwegian SIDS and Stillbirth Society
Norwegian Society of Perinatal Medicine
Perinatal Research Center

Spain
Umanamita

Sweden
Swedish National Infant Fund (Spadbarnefonden)

UK
National Perinatal Epidemiology Unit
Royal College of Obstetricians and Gynaecologists
SANDS (Stillbirth and Neonatal Death Society)

USA
1st Breath
Angel Names Association (Associate Member)
A Place to Remember (Associate member)
A Small Victory (Associate Member)
Evelyn Rose Foundation (Associate Member)
Evie’s Network
First Candle/SIDS Alliance
Hygeia Foundation
MEND (Mommies Enduring Neonatal Death)
National Stillbirth Society (NSS)
Neo-Fight, Inc.
Global Alliance to Prevent Prematurity and Stillbirth (GAPPS) (Associate Member)
Star Legacy Foundation
Still Angels (Associate Member)

Vietnam
The Institute for Reproductive and Family Health (RaFH)
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, Stephanie Fukui, and Anais Gschwind.