



ISA Newsletter

2015 ISSUE 2

DECEMBER 2015

INSIDE THIS ISSUE:

ISA Stillbirth Workshop in Georgia	4
Notes from Vietnam	6
ISA at GMNH Conference	7
Sustainable Development Goals: Stillbirth Missing	8
Global Strategy lacks Stillbirth goals	9
2016 ISA/ISPID Conference	11
Vancouver IM-PROVE workshop	13
Update from ISA Chair	14

Please donate to ISA this holiday season; every contribution makes a difference! (p.15)



Lancet Stillbirth Series Launch!

ISA has teamed up once again with many top global researchers, policy-makers and practitioners for a new landmark Lancet series: Ending Preventable Stillbirths. The new series will be launched **January 19, 2016**, just a few months after the launch of the post-2015 Sustainable Development Goals (SDGs) and the Global Strategy for Women's, Children's, and Adolescents' Health, the global platform to support rapid implementation of the health-related SDGs.

THE LANCET

The new series encompasses five papers:

- (1) Stillbirths: Progress and unfinished business;
- (2) Stillbirths: Rates, risk factors and acceleration toward 2030;
- (3) Stillbirth: Economic and psychosocial consequences;
- (4) Stillbirths: Recall to Action in high-income countries; and
- (5) Stillbirths: Seizing the opportunity to end preventable deaths by 2030.

Several invited commentaries will be published in the Lancet and a companion series in

BMC Pregnancy & Childbirth. This launch is a follow-up to the first Lancet Series on Stillbirths in 2011 and calls for an elimination of preventable stillbirths, among other goals.

Despite progress, stillbirth still is often not even acknowledged, still not counted in the statistics, and reducing stillbirth is often excluded from international goals for maternal and child health care.

The ISA website will have a link to the launch and the Lancet series on January 19th, 2016.

Vancouver ISA Conference a Success

On October 2, 2015, Still Life Canada hosted the 2015 International Stillbirth Alliance conference in Vancouver, BC, Canada. 78 participants attended--40% bereaved families and 60% health care professionals and researchers.

The conference program included a variety of evi-

dence based topics on new directions in research on stillbirth prevention, and best practices for bereavement care following a stillbirth. Dr. Lynn Farrales from Still Life Canada shared community-based participatory research she has conducted with bereaved parents, and members of ISA reflected on

stillbirth as a local and global issue. Panelists also discussed care in the pregnancy following stillbirth
(continued next page)



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

Vancouver ISA Conference a Success



(continued from page 1)

and the impact of stillbirth on health care providers.

The day following the conference, the clinical IM-PROVE workshop (Improving Perinatal mortality Review and Outcomes Via Education) was offered for the first time in British Columbia further enhancing the knowledge translation regarding best practices following a stillbirth.

The conference was planned by a small, dedicated group of bereaved parents who put in over

2000 volunteer hours to ensure conference success (see photo below). Participant feedback from the conference indicated tremendous satisfaction:

"It was nice to see people coming together to make change."

--Bereaved Parent

"This was my first time here and it was so good! I thought I knew about stillbirth but I am much better informed now. Thank you!"

--Health Care Provider

"Excellent on both points [quality and applicability of conference]! The day flew by too fast! The Call to Action exercise was excellent! To share ideas will build capacity!"

--Health Care Provider

"I attended the recent stillbirth conference in Vancouver and it was one of the most moving and informative days I have spent learning in a long time."

--Vancouver Midwifery leader

<http://still-lifecanada.ca/01/>

Right: Questions after a panel discussion. At podium, from left: Claire Storey, Dr. Alexander Heazall, Dr. David Ellwood, Dr. Dimitrios Siassakos (all from ISA). Audience members standing: Dr. J.J. Erwich, center(ISA) and Dr. Lynn Farrales, right (Still Life Canada)



Left: Artwork in memory of their children, created by parent members of Still Life Canada

Vancouver ISA Conference a Success

Right: Still Life Canada conference organizers, from left:
Dr. Lynn Farrales,
Peter Muyzers,
SLC President
Jaime Ascher,
John Nanson,
Colleen McCain,
and Lora Boshoff



Above: Katherine Gold (of ISA) presenting on the impact of stillbirth on providers.

Right: a full conference schedule.

Conference at a Glance		ISA2015
Day 1 - Friday, October 2, 2015		
08:00 - 08:20 am	Breakfast & Registration	
08:30 - 09:00 am	Stillbirth: a Local and Global Health Issue	Jan Christilaw, Jaime Ascher and Claire Storey
09:00 - 09:45 am	The Local and Global Impact of Stillbirth	David Ellwood, K.S. Joseph, Melanie Basso, Lily Lee, Cheryl Davies
09:45 - 10:10 am	Morning Break	
10:10 - 11:40 am	New Directions in Stillbirth Prevention	Alexander Heazell, David Ellwood, Dimitrios Siassakos
11:40 - 12:40 pm	Lunch	
12:40 - 12:45 pm	Introduction to Afternoon Session	
12:45 - 02:45 pm	Care After Stillbirth: Raising the Bar	Lynn Farrales, Lora Boshoff, John Nanson, Claire Storey, Dimitrios Siassakos, Katherine Gold
02:45 - 03:15 pm	Considerations in Pregnancy After Stillbirth	Alexander Heazell, David Ellwood, Dena Bloomenthal
03:15 - 03:45 pm	Afternoon Break	
03:45 - 04:45 pm	Local and Global Calls to Action	
04:45 - 05:00 pm	Closing Remarks	Jaime Ascher, Alexander Heazell
05:00 - 07:00 pm	Reception	
07:00 - 08:00 pm	ISA AGM	

Stillbirth Workshop in Tbilisi, Georgia



By Professor
David
Ellwood



It was at one of the recent ISA/ISPID meetings in Vietnam (2013) that **Vicki Flenady** (former ISA Chair and current board member) and I first met two amazing women from Georgia who were keen to share with us their own experiences of introducing bereavement care for women in their country.

Dr. Natia Sharabidze, an obstetrician in private practice, and a bereaved parent, represented a group called the **'Women's Rehabilitation Association'** (WRA) which was started in 2008. Since 2012, WRA has been trying to improve care for women in a country which has a relatively high stillbirth rate.

Georgia has a population of about 3.75 million and is an emerging economy, having been a Soviet Republic until 1991, and then civil unrest and economic crisis throughout the 1990s, and then suffered the turmoil of civil war in 2008.

We renewed our acquaintance in Amsterdam last year and then eventually, after much planning, myself, and **Professor Jan Jaap Erwich** (ISA Board, member of Scientific Advisory Committee) travelled to Tbilisi in June of this year to help to run a workshop on stillbirth. We were provided with some data beforehand but this represented the first attempt to produce any meaningful

profile of perinatal outcome in Georgia. It appears that the stillbirth rate is more than double that experienced in my own country (Australia) and although we did not see any formally classified data it appears that late gestation stillbirth and fetal growth restriction are significant



problems.

One very obvious factor to a visitor is the high rate of smoking, which was quite confronting coming from a country in which smoking is becoming (almost) outlawed. National data are not easy to come by but estimates are that the rate of smoking is >50%, and one doctor told us it was probably closer to 70% and this high rate translates into a very high rate of smoking in pregnancy. Smoking cessation programs would surely make a big impact in reducing stillbirth?

All the obstetricians in the country were invited to the workshop which covered a wide range of topics with local speakers, and both myself and JJ contributing talks on the global burden of stillbirth, audit, classification, contributing factors and managing decreased fetal movements.

*In 2013, the
Women's
Rehabilitation
Association
became a
member of ISA*



Women's
Rehabilitation
Association

Stillbirth Workshop in Tbilisi, Georgia

(continued from page 4)

There were over a hundred in attendance on the day, and although I don't have a breakdown my impression is that it was predominantly medical, with a small number of parents, nurses, and at least one psychologist from Lithuania (who also worked in Georgia) who was providing bereavement counseling and was very keen to learn about how things are done elsewhere. From my understanding the WRA does not receive any government support and relies entirely on private donations for all of its activities.

The photo below shows us at the end of the workshop, on the back verandah of the Hotel Old Tbilisi. Satisfied with a job well done, having raised the profile of stillbirth in Georgia and formed some lasting relationships, but then guess what happened next? It started to rain, and while we had a fantastic meal and watched traditional Georgian dancing, the river rose and eventually burst its banks the following morning, flooding the city zoo and allowing a lot of wild animals to escape. But fortunately by that time I was on a plane home and the rest of the story will have to be told by those that stayed behind.

Let's hope we can catch up with Natia and her friends in Uruguay next year and perhaps hear about the progress being made in Georgia to reduce both smoking and stillbirth rates, and also improve the care for women after perinatal loss.

Below: Dr. David Ellwood presenting in Tbilisi, Georgia



Left: Dr. David Ellwood (2nd from right) and Dr. Jan Jaap Erwich, (3rd from right) both of ISA, with colleagues, at their hotel in Tbilisi, Georgia

Notes from the Field - - Vietnam

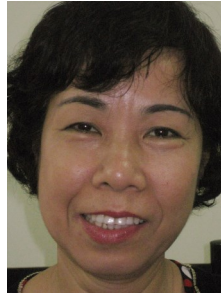
From the Institute for
Reproductive and Family Health
Hanoi, Vietnam



*The Institute
for
Reproductive
and Family
Health was the
local host of
the 2013 ISA
International
Conference*



**Professor Nguyen Thi Hoai Duc, RaFH
Founder and Director (left) and Ms. Dang
thi Nghia, RaFH Midwife (right)**



In Vietnam, stillbirth, perinatal, and neonatal deaths are given little attention in health care systems despite important social concerns for the quality of life for infants and families. According to the World Health Organization (WHO), the rate of newborn death in Vietnam is 3rd in the Asia-Pacific region, preceded only by the Philippines and Indonesia. That means for every 1000 newborn babies, there are 15-16 deaths. Half of these occur in the first 24 hours of life and 75% within the first week after delivery.

Although Vietnam has demonstrated significant achievements in maternal and newborn care, remote and mountainous regions as well as ethnic minority areas continue to have the highest maternal mortality and neonatal death rates. For example, in Dien Bien, there is one maternal death per 148 deliveries, in Lai Chau it is one per 218, and in Cao Bang, one per 242.

Among pregnant mothers who die, 65% receive no prenatal care, 22% visited a physician just once in pregnancy, and only 13% had two or more visits.

Stillbirth is particularly neglected and unreported; therefore no accurate numbers are available, even in national reports or studies by health professionals. Many of these stillbirth cases are preventable, but this requires a focused effort to improve the quality of antenatal care services. In Vietnam, many obstetricians and midwives do not focus on perinatal care and there is little technology available to ensure fetal well-being. Research on stillbirth is also neglected. Autopsies are virtually never used to determine cause of a stillbirth, and since many women never present for prenatal care or delivery, the true rate of stillbirth may be under-reported.

Stillbirth is a deeply traumatic and emotional event for mothers, fathers, and other family relatives. The attitudes and behaviors of health professionals after a stillbirth are often nonchalant, emphasizing the importance of education around family experiences and the impact of stillbirth on bereaved parents.

There is a huge need to increase research and medical education around stillbirth and bereavement care in Vietnam. Prioritizing antenatal care and availability of technology to assess fetal well-being are essential components in reducing stillbirths and improving maternal health care services in our country.

Email: info@rafh-vietnam.org.vn

Website: www.rafh-vietnam.org.vn

ISA Represented at Global

Maternal and Newborn Health Conference in Mexico



From Left: Betsy McCallon, Executive Director, White Ribbon Alliance; Dr. Rakesh Kumar, Joint Secretary, RMNCH-A, Ministry of Health and Family Welfare, Government of India, Jessica Ruidiaz, Founder of the Fundación Era en Abril and ISA Board member; Mrs. H.E. Toyin Saraki, Founder and President, Wellbeing Foundation

Clr. Jessica Ruidiaz, a member of the board, represented ISA at the Global Conference on Maternal and Newborn Health, held in Mexico City from October 18-21. The conference was co-chaired by individuals from the Harvard T.H. Chan School of Public Health, USAID, and Save the Children, and ISA was pleased to participate as it gave us an opportunity to advocate for the inclusion of stillbirths within the maternal, newborn, and child health continuum.

Jessica was part of the panel: "Ending 6 Million Deaths at Birth: Counting stillbirths as a marker for quality care for women and newborns." The title of her talk was "Intrauterine death and Latin American culture: How have parent groups help to end the stigma?"

Nearly 200 people attended this lively session, and Jessica helped articulate the impact of these deaths on families. Later in the conference, Richard Horton, the Editor of the Lancet quoted from Jessica's speech: "A child is irreplaceable. The pain of the death lasts a lifetime."

<https://www.globalmnh2015.org/>

Right: a packed room at the panel session.





*Effective
care in
facilities for
women and
babies at
birth could
prevent
530,000*

Sustainable Development Goals:

No targets for Stillbirth

In September 2015, the United Nations held the Sustainable Development Summit in New York City and launched the **Sustainable Development Goals** (SDGs).

The event was important for both what it did include and what it did not. Despite much behind-the-scenes efforts by groups (including ISA) who advocate for stillbirth preven-

tion and targeted reductions in stillbirths in future years, the **SDGs ended up NOT including a global target for reducing stillbirth** rates.

This was a significant disappointment since the SDGs seek to reduce maternal mortality and infant deaths and ISA and others have long noted that stillbirths are on the same

continuum in terms of causes and risk factors.

However, ISA organizations submitted many comments in favor of SDG stillbirth goals and we will continue to push to have stillbirths addressed globally.

<http://www.un.org/sustainabledevelopment/summit/>

Upcoming International Stillbirth Events

- January 19, 2016: Global Launch of the Lancet: Ending Preventable Stillbirths series. Main launch in London with others around the world. ISA is a key player in the launch.
- January 2016: WHO Executive Board meets to discuss implementation plans for the Global Strategy; this is the framework for the health-related sustainable development goals (SDGs); **ISA is seeking champions to make floor statements advocating for specific goals for stillbirth reduction which currently are not in the SDGs.**
- May 2016: World Health Assembly in Geneva, Switzerland. These annual meetings are often attended by National Health Ministers, and policy is frequently decided for WHO and for many individual countries. There is usually a concurrent meeting of civil society groups with many opportunities to participate.
- September 2016: ISA and ISPID (International Society for the Prevention of Infant Deaths) will co-host the 2016 annual conference on Stillbirth, SIDS, and Baby Survival in Uruguay.
- September 2016: General Assembly Meeting of ISA, Uruguay; open to all member organizations. (See page 11)

*Effective care
in facilities
for women
and babies at
birth could
prevent
530,000
stillbirths.*

Global Strategy for Women's, Children's, and Adolescents' Health 2016-2030

The goal of the Global Strategy for Women's, Children's and Adolescents' Health, 2016-2030 is to end preventable deaths among all women, children and adolescents, to greatly improve their health and well-being, and to bring about change for a sustainable future.

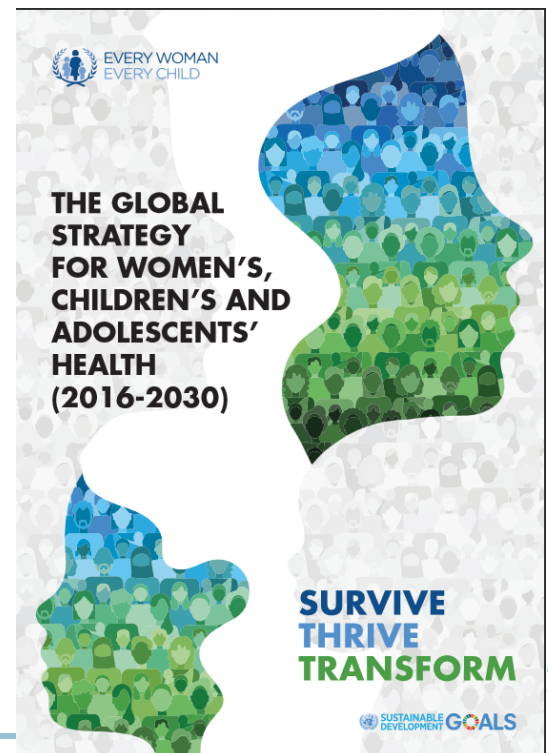
This updated global strategy (the previous was 2010-2015) was announced in September in New York City

The Global Strategy includes goals related to reducing maternal, newborn, and under-five mortality but sadly has **no specific goals for reducing stillbirth.**

However, the report does note that effective care in facilities for women and babies at birth could prevent 530,000 stillbirths by 2020.

The report also suggests that high-impact health system investments and high-impact health interventions could prevent 32 million stillbirths by 2013.

Despite the limited mention of stillbirth in the Global Strategy, ISA is actively engaged in advocating for greater inclusion of stillbirth in plans for implementation of the strategy.



We can no longer remain
silent about **stillbirths**

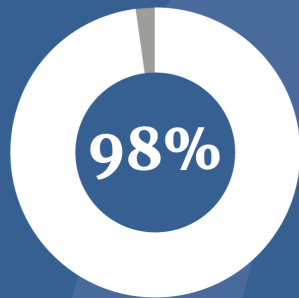
At least **2.6 million**
babies are **stillborn** each year

(1.2 million of those babies begin
labour **alive** and **die before birth**)

That means that every day

7,300 women

suffer the loss of their babies in the last
3 months of pregnancy



98% of all stillbirths happen in
low & middle income countries...

...but intervention at the critical time
around birth would result in a
triple return on investment
preventing maternal & newborn deaths,
as well as stillbirths



We need to:

- **count stillbirths around the world**
- **break the taboo around stillbirths**
- **ask policymakers to act & invest in the issue**

Save the Date! 2016 ISA Conference in Uruguay



We are happy to announce the **2016 International Conference on Stillbirth, SIDS and Baby Survival!**

The conference will be held at the Radisson Hotel in Montevideo, Uruguay and is scheduled for September 8th, 9th and 10th (pre-conference meetings and opening welcome reception on Sept 7th), 2016

This Conference is jointly organized by the Uruguayan Society of Pediatrics (SUP), the Argentine Society of Pediatrics (SAP), era en Abril, the International Stillbirth Alliance (ISA) and the International Society for the Study and Prevention of Perinatal and Infant Death (ISPID).

The goal of this conference is to raise awareness about actions that can reduce the incidence of stillbirths, sudden unexplained infant deaths, and SIDS and improve the care of bereaved families. The Conference will emphasize the importance of research on a regional and

international level and is geared toward researchers, physicians, nurses, public health professionals, counselors, parents and community members. The organizers wish to extend a special welcome to bereaved families to attend this conference; we value the contributions and experiences of families and cannot overemphasize the extent to which parent voices can make a difference in stillbirth and infant death.

We look forward to seeing you in Montevideo!

September

7-10, 2016

**Montevideo,
Uruguay**



Reserva la Fecha!

2016 Congreso de ISA en Uruguay

Nos es grato anunciar el **Congreso Internacional sobre la Muerte Intrauterina, el Síndrome de Muerte Súbita del Lactante, y Supervivencia Infantil 2016**. El congreso se llevará a cabo en el Hotel Radisson en Montevideo, Uruguay y está programado por los días 8, 9, y 10 de septiembre del 2016 (actividades precongreso y la recepción de apertura se desarrollarán el día 7 de septiembre).

Este congreso está organizado conjuntamente por la Sociedad Uruguaya del Pediatría (SUP), la Sociedad Argentina de Pediatría (SAP), la

International Stillbirth Alliance (ISA) y la International Society for the Study and Prevention of Perinatal and Infant Death (ISPID).

El objetivo de este congreso es crear concientización de las acciones que pueden disminuir el riesgo del Síndrome de Muerte Súbita del Lactante y de Muerte Intrauterina, y mejorar el cuidado de las familias desconsoladas. El congreso hará hincapié en la importancia de la investigación al nivel regional y nacional y está dirigido a investigadores, médicos, enfermeros, profesionales de la salud pública, consejeros, padres y miembros

de la comunidad. Los organizadores desean extender una bienvenida especial a las familias en duelo a asistir a este congreso; valoramos los aportes y experiencias de las familias y no podemos exagerar la diferencia que pueden hacer las voces de los padres en la investigación de la muerte intrauterina y la muerte súbita del lactante.

¡Esperamos contar con su presencia en Montevideo!

We Need Your Help!!

Needed:
ISA Member Organizations to host an event
promoting the Launch of the new
Lancet series on stillbirth!



By Susannah Leisher, MSc, MA

Help spread the word about the new Lancet series on stillbirths, set for launch on January 19th. Events could be on January 19, to link with the main launch in London, but could also be any time afterward that works for your group.

THE LANCET

You could issue a press release to your local media, organize a discussion of the series with a group of parents, write an article for your local paper, **issue a series of tweets**, hold a reception, or even organize a mini-conference. Or you could join an event being held near you (a list of events will be posted on the ISA website).

ISA is happy to help if you have questions on what to do or how to do it. Please let us know if you are planning an event. We look forward to hearing from you!

ISA has also prepared a "**Launch Toolkit**" that will help organizations wishing to host a launch even. The kit includes "how-to" guides on how to write a press release and speak with the media, and more. For information, please contact info@stillbirthalliance.org

Launch events are now being planned or considered in many places around the world, including:

Europe: London (main event), Birmingham, Bristol, Ireland, Spain, Oslo, the Netherlands, and Geneva

North America: New York City, Seattle, Atlanta, San Francisco, Vancouver and Toronto

South America: Buenos Aires, Montevideo

Asia and Pacific: Brisbane, Manila, Beijing

Africa: Pretoria, Dar es Salaam

We are developing a brief ISA summary of the Lancet series which we are trying to get translated into a variety of languages to increase the ability to share across the world. While we have found translators for some languages, we **still need volunteers who can help us translate!** Please contact:

info@stillbirthalliance.org

ISA Board

- Dr. Alexander Heazell (Chair)
- Claire Storey (Vice-Chair)
- Assoc Prof Vicki Flenady
- Jillian Cassidy
- Prof Jan Jaap Erwich
- Prof Christine East
- Dr. Dimitrios Siassakos
- Susannah Leisher
- Jessica Ruidiaz
- Dr. Katherine Gold

ISA Newsletter, Dec. 2015, Issue 2. Editor: Dr. Katherine Gold

Vancouver IMPROVE

(Improving Perinatal Mortality Review & Outcomes Via Education)

By Professor Alison Kent



On Saturday October 3rd, 2015, the day after the successful ISA meeting in Vancouver we held an international IMPROVE course with 23 attendees. Thanks to the

organisational capabilities of Jamie Ascher and Lynn Farrales of Still Life Canada and Eszter Katona at the Mater Research Institute in Queensland, the event was a great success.

The IMPROVE course is a SCORPIO (Structured, Clinical, Objective Referenced, Problem-based, Integrated and Organized) style educational program that has 6 stations. The stations cover the following components relating to perinatal mortality: autopsy consent, autopsy and placental pathology, investigation of a perinatal death, examination of a deceased baby, classification of perinatal deaths and bereavement care. Each inter-

active station lasts 30 minutes.



Above: Presentation by Diana Stubbs, Liason Midwife, Department of Health, Victoria, Australia

Great thanks to all the educators who gave their time on the day:

Prof. David Ellwood, Queensland, Australia

Dr. Peter Scott, Australian Capital Territory, Australia

RM Diana Stubbs, Victoria Australia

Prof. Jan Jaap Erwich, Groningen, Holland

Prof. Alison Kent, Australian Capital Territory, Australia

The course is taught across Australia and has been adapted for use internationally in Vietnam, Holland and Fiji. The course was well received in Vancouver and sparked keen interest for more availability across Canada and the United States which is our next goal.



Vancouver IMPROVE Attendees from around the world

Update from the ISA Chair



international
stillbirth alliance



Dr. Alexander
Heazell

**Stillbirths
have declined
only 15% in
the last two
decades.**

Greetings!

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

We have had a busy year, although much of the effort has yet to bear fruit. This year we developed a database of stillbirth and infant death research with our friends at ISPID (International Society for the Study and Prevention of Perinatal and Infant Death) which will allow researchers to register their studies and should help promote collaboration.

Many board members have been involved in developing and writing material for the new Lancet Stillbirth series which will be paired with another series of papers in BMC Pregnancy and Childbirth. A global launch is planned for January 19th, 2016.

We will need as many members and member organizations as possible to use this opportunity to get stillbirth on the radar of caregivers, researchers, and policy-makers.

In addition to our website, we have expanded our Facebook and Twitter accounts to publicise the work that we do and engage with parents and professionals.

Finally, we have begun making arrangements for 2016 conference in Montevideo, Uruguay which we be in September. I hope that you are able to join us there to present your exciting work, learn about new scientific advances, and meet others who care about preventing stillbirth.

With very best wishes, Alex

Join ISA on Social Media!

Please "Like" us on Facebook!



And Follow Us on Twitter!
@ISASTillbirth





international
stillbirth alliance

Support the fight against stillbirth
this holiday season!

**Please Donate to the
International Stillbirth Alliance**

We're on the Web!
<http://stillbirthalliance.org>

Or email us at:
info@stillbirthalliance.org

Stillbirth affects millions of families worldwide. The International Stillbirth Alliance (ISA), established in 2002, is a volunteer-led consortium of leading stillbirth scientists and researchers, healthcare professionals, and bereaved parents, with nearly 60 member organizations on six continents. We work at a regional and global level to raise awareness and promote research and collaboration for the prevention of stillbirth and improvement of bereavement care worldwide.

Support the fight against stillbirth this holiday season!

Please Donate to the International Stillbirth Alliance



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

Despite this modest background, ISA has been able to promote research, advocacy, and bereavement care on a global level for families who experience stillbirth. We could not do this without your support.

If you are a bereaved parent or family member, consider a donation in honor of your baby, to help other families around the world avoid the tragedy of stillbirth. You can also add a memorial message for your child on our website.

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

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

ISA is tax-exempt under section 501(c)3 of the U.S. Internal Revenue Code and all gifts are tax deductible.

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