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## A note from the Chair...



It is my pleasure and privilege to include a message to those working with ISA organizations and others working in many ways to address the all too often hidden tragedy of stillbirth around the world. My message focuses on [The Lancet's StillbirthSeries1-6](#); a huge step on the path to address stillbirth.

*The Lancet's* Stillbirth Series, launched last week, delivers what many have searched and hoped for over many years; a tangible means by which to reduce the number of these deaths. The launch of *The Lancet's* six-paper stillbirth series heralds a *brand new day* for many who have worked tirelessly to bring attention to this human tragedy. The Lancet editors begin with a commentary bringing stillbirth *out from the shadows*<sup>1</sup> to be faced and addressed alongside other major public health problems. Anyone touched by the birth of a baby who is stillborn, understands the profound effect this loss has on everyone; mothers, fathers, and family and also care providers. It is almost with a sense of relief that we see that this commentary includes a photo of parents with their stillborn baby clearly illustrating the enormity of this loss. This series gives hope that the *invisibility of stillbirth*, which has held back progress for so long, is now over. Paper one<sup>1</sup> further highlights the tragedy by presenting the experience of stillbirth in communities around the world; many are hidden losses, grieved in silence.

I would like to thank and to congratulate *The Lancet* on publishing the Stillbirth Series, the Gates Foundation for their support and the Lancet Series Steering Committee<sup>2</sup> for their commitment which made this series a reality. I would also like to acknowledge the work of ISA member organisations and individuals whose dedication and commitment to raising awareness of stillbirth contributed to the decision by *The Lancet* to produce the series.

I pay tribute to the three mothers of stillborn babies who, together with a few health care professionals, founded ISA. Their vision was to create an organization that would combine the knowledge of healthcare professionals with the passion of families in order to advance stillbirth research, medical care, and bereavement services. That vision has become a reality and *The Lancet's* Stillbirth Series provides an opportunity for ISA to extend this work with global partners to make a real difference reaching all families throughout the world to address the disparity that exists for the world's poorest families.

Through annual conferences that combine bereavement care, clinical practice and research in stillbirth prevention, ISA brings people together from all backgrounds to share knowledge and foster collaboration. The ISA conferences in 2011 ([Antigua and Barbuda hosted by SANDS](#)) and 2012 (US hosted by First Candle) hold promise of bringing people together to advance the change that is urgently needed in low and high income country settings through focussing on **the call to action in The Lancet's stillbirth series**<sup>4</sup>.

Lastly, I would like to acknowledge the ISA Parent and Scientific committees for their continued dedication in all ISA activities and give a special thanks to the ISA Awareness and Communications committee for this newsletter and their contribution to the successful launch of *The Lancet's* stillbirth series. I would also like to thank Maddie Elder for providing support *with a smile* in the ISA secretariat and the Mater Medical Research Institute, Brisbane Australia who provide a home and support for the ISA secretariat.

I hope to see you at a future ISA Conference!  
Warm wishes to all  
Vicki Flenady  
ISA Chair, Co-Chair of the Lancet's Stillbirth Series Communications Committee  
[www.stillbirthalliance.org](http://www.stillbirthalliance.org)

1 Mullen Z, Horton R. Bringing stillbirths out of the shadows. *The Lancet*.  
2 Frøen FJ, Cacciatore J, Jokhio AH, et al. Stillbirth: Why they matter. *Lancet*. Available online, 14<sup>th</sup> April, 2011.  
3 Lawn JE, Blencowe H, Pattinson R, et al. Stillbirths: Where, when, why? *Lancet*. Available online, 14th April, 2011.  
4 Bhutta ZA, Yakoob MY, Lawn JE, et al. What will it take to reduce the burden of stillbirths in developing countries? *Lancet*. Available online, 14th April, 2011.  
5 Pattinson R. Stillbirths: how can health systems deliver? . *Lancet*. Available online, 14th April, 2011.  
6 Flenady V, Middleton P, Smith G, et al. Stillbirth: The way forward in high income countries. *Lancet*. Available online, 14th April, 2011.  
7 Goldenberg RL, McClure EM, Bhutta ZA, et al. Stillbirths: The vision for 2020. *Lancet*. Available online, 14th April, 2011.  
Published online April 14, 2011 DOI:10.1016/S0140-6736(11)60098-6.

## Resources

[The Lancet's Stillbirth Series](#) is available online for free, with the Executive Summary translated in [English](#) and [Italian](#). French and Spanish translations will be available shortly.

[Download](#) Partnership for Maternal, Newborn, and Child Health, International Stillbirth Alliance, Save the Children and First Candle Press Release – [Download](#) WHO Press Release

[Listen](#) to the Australian Science Media Centre Media Briefing - [Listen](#) to the UK Science Media Centre Media Briefing

[Download](#) PMNCH Knowledge Summary: Make Stillbirths Count - [Download](#) National, regional and worldwide estimates of stillbirth in 2009 with trends since 1995. WHO Policy Brief - [Download](#) map: 2008 Global Stillbirth Rate - [Download](#) map: 2009 Global Stillbirth Rate - [Download](#) White Ribbon Alliance Atlas of Birth: Losing Lives at Birth

## Stop Press

The primary media launch was held at London's Science Media Centre revealing the truth surrounding global stillbirths.

The Lancet's Stillbirth Series was made public, freely accessible and hit the world tabloids, television stations, internet news sites, radio and magazines the very next day - 14th April 2011.

### Launches

London by Lancet, with SANDS UK on behalf of ISA, Save the Children and others

New York hosted by UNICEF, UNFPA and First Candle on behalf of ISA

Hobart, hosted by ISA, ANZSA and the Australian Science Media Centre

Geneva, led by WHO at the UN Palais de Nations

Cape Town, South Africa with MRC, Save the Children and ISA working with local government officials and professionals and parents

Florence, Italy hosted by Ciao Lapo Onlus, Florence University & ISA

### India

All events were met by interested journalists and the response and interest at each media event has been astounding

The International Stillbirth Alliance has proudly been associated with each of these successful media launches. To connect to the world's leading news items please scroll down...

## Dr. Frederik Frøen walks us on the road to *The Lancet's Stillbirth Series*



### When did the original idea of a Lancet Series come up; what sparked it?

Lunchtime, September 30<sup>th</sup>, 2007 – sparked by a walk in the park." Dr. Frederik Frøen laughs, "Too brief? Well, the long version is that having stillbirths on the global health agenda was an essential goal for us already set at the founding meeting of ISA. Why was there no attention to such a huge burden? As soon as we were ready for our first ISA Conference in Washington DC in 2005 we invited the World Health Organization, and Dr. Jelka Zupan told the audience of an invisible burden around the globe. I think that presentation was important for ISA as an organization as it helped everyone in ISA see more clearly just how impossible it would be to address stillbirths without a global view. For the 2007 conference the Director of the WHO Department for Making Pregnancy Safer, Dr. Monir Islam, held a passionate talk of the global injustices in stillbirth. As Chair of ISA at the time, I grabbed him at the first break and suggested WHO and ISA should collaborate to develop a global plan for stillbirth prevention. "Yes!" he said, before I had completed my sentence, and during a short walk in the park we agreed that our goal should be a series of papers for the Lancet. I would have settled for a WHO publication, but Monir insisted on Lancet" Dr. Frøen recounts with a smile. "I remember thinking that this brief meeting with Monir had been an achievement for ISA, but if I knew how much work it would be, I would have known that the step of alliance with WHO was less than a fraction of an achievement!"

### How was the work and the team organized?

"Well, it is now 2011, so as you can see it has been a long journey," Dr. Frøen says. "In 2007 and 2008, I travelled on numerous occasions to Geneva to meet with Monir and his team at the WHO. We established groups to write four reviews: Why and how to count stillbirths globally, and how to prevent stillbirths before delivery, stillbirths during delivery, and stillbirths by infections. We managed to have these ready for brief presentations at the 2008 ISA Conference in Oslo, however, it proved to be difficult to dedicate sufficient resources in the WHO to complete all of them at the level of comprehensiveness and scientific rigor that we knew would be needed. Because Dr. Richard Horton, Editor in Chief of the Lancet was aware of our work, Monir and I decided to send the papers to The Lancet with the suggestion of making a Stillbirth Series, while acknowledging that a couple of papers were *only drafts*". Dr. Frøen pauses. "That was hugely frustrating... A Lancet series could bring the awareness for stillbirth that so many deeply needed, and what ISA worked for - and parts of our submission were considered to be *only drafts*. I was really uncomfortable about that. If the manuscripts were insufficient to make Richard Horton and the Lancet editors see the significance of stillbirth, I would have failed a significant opportunity really badly", says Dr. Frøen.

### How did Lancet respond?

Impressively" Dr. Frøen says and smiles again. "I was impressed! We were summoned to London to meet with the editors and reviewers. Richard Horton and our managing editor Zoë Mullan were very positive, informed and interested in the cause and had obviously decided to make this happen. Lancet had called upon some of the key authors of their neonatal mortality series, among them Joy Lawn and Zulfiqar Bhutta, to review the drafts and provide advice for a stillbirth series. The meeting was really more than just a boost to the project – *it was a revival!* The course was clearly set, and with direct guidance on what Lancet expected from the series in terms of content, the pieces began to fit together. A Steering Committee was formed with Joy and Zulfi adding Vicki Flenady from ISA, as well as Robert Pattinson, Robert Goldenberg, Monir and I who were already at work on the series. Zoë too was almost like a member of the Steering Committee and guided us through the entire process. Writing a series for the Lancet in terms of science and experience this was a boost for us, but an additional boost was received from within the group. Anyone who has been in a room with Joy knows the turbo-version of human kind, and her energy has been invaluable for the Steering Committee. Working with a Steering Committee from five continents makes obvious challenges for communication. Nonetheless, it has been a great group to work with."

### What was the most important factor to succeed?

"People!" Dr. Frøen exclaims with no hesitation. "It has been such a great experience to meet so many dedicated and extraordinary people during the development of the series – and certainly several whose immediate enthusiasm for the cause were absolutely crucial for this series to be a success. All the co-authors, of course, and all the wonderful people you find in the endless lists of acknowledgements in the papers – I can't even start listing all their efforts and achievements. It seems quite straight forward – you just do a few surveys to see what people are thinking, count all stillbirths, find out what can be done and how it should be done, calculate how many can be saved and what it would cost, make a plan, suggest some actions, get some people to prioritize essential research for the future, and write it up. But I can assure you that many people have dedicated considerable time to make this happen!"

### You are the lead author of the first paper called "Stillbirths: Why they matter" – what information did you think needed covering? Isn't it obvious that stillbirths matter?

"Unfortunately, no, that's not obvious to all. We had included parts of this discussion as introductions to the first drafts, but during the discussions in London, we also presented to **The Lancet** how little recognition there is of stillbirth in many cultures, and how widespread the *lack of support for affected women* seems to be. We also discussed encounters with health professionals and global charities who openly said that they found no reason to prevent stillbirths – these were simply the result of natural selection of babies that were never meant to survive, or who felt that a stillbirth was such a minor loss for women in poor countries – they just got a new baby! It was Richard Horton who said this clearly – "if you cannot present a first paper to convince every reader that stillbirths matter, then there is no need for papers to explain how to prevent them." So we added this first paper to the series to report not only how stillbirths have been invisible on the global health agenda, but also to report how stillbirths are perceived around the globe. This was important to us, as many of those with power to act and change conditions for pregnant women and those affected by stillbirth have had no data and evidence on the additional burden many societies place on families affected by stillbirth."

### What are you hoping the result will be from publishing this research? What's next?

*I hope people will read the series.* It sounds a bit simplistic, but I believe it has a powerful humane message. It is easy to think that the most important thing to do is to *mobilize powerful people to act* – make money available for prevention, ensure governments and international agencies put stillbirth on the agenda, have professional organizations promote optimal prevention. But in the case of stillbirths, *everyone can help. Every individual and community can help end the invisibility of stillbirths.* The stigma and marginalization of affected families can end without government money or aid. Awareness and information can help every pregnant woman make the best choices for herself and her baby" says Dr. Frøen, and adds: "Hopefully, many people will think: *What can I do?*"

## Stillbirth in the News

Almost 1000 news items related to stillbirths hit the media within the first week of *The Lancet's* Stillbirth Series being published. Click on the following links to connect to some of these news items:

[ABC](#)  
[Al Jazeera](#)  
[BBC](#)  
[Fox News](#)  
[Guardian](#)  
[Reuters](#)  
[SKY News](#)  
[Top News, United Arab Emirates](#)

[Australia](#)  
[The Australian](#)  
[ABC](#)  
[Sydney Morning Herald](#)  
[Perth Now](#)

[Bangladesh](#)  
[Financial Express](#)

[Botswana](#)  
[Mmegi Online](#)

[Brazil](#)  
[Estado](#)  
[Epoca](#)

[Bolivia](#)  
[FMBolivia](#)

[Canada](#)  
[The Globe and Mail](#)

[Finland](#)  
[Helsinki Times](#)

[Germany](#)  
[Spiegel Online](#)

[India](#)  
[The Hindu](#)  
[The Times of India](#)

[Italy](#)  
[Di Firenze](#)  
[SaVona News](#)

[Jamaica](#)  
[Jamaica Observer](#)

[Mexico](#)  
[El Universal](#)

[New Zealand](#)  
[NZ Herald](#)

*Floating in and out of faith,  
Disconnected,  
I try to feel you, my baby,  
But find myself absorbed instead  
In my own sorrow at losing you  
You tore my world in two  
As earthquakes do*

*... I am shaped by your absence, haunted by the detail of you...*

*Except for the few birth photographs... the birth and death certificates we have locked in our safe, the small grave on a hill near our home, there is little physical evidence that our daughter ever existed. Yet...the entire landscape of all our lives has fundamentally changed.*

*Nothing can be as it was before.*

*"Invisible Earthquake" expresses the traumatic dimensions to the stillbirth experience as well as the transformative and self-discovery & self-empowerment potential this shattering experience can provide the opportunity for. More in "Stillbirth Matters II".*

Excerpts taken with the author's kind permission from author of "Invisible Earthquake. A woman's journal through stillbirth" by [Malika Ndlovu](#). ISBN 978-0-9802729-3-2

## Stillbirths: the invisible public health problem

*Dr Flavia Bustreo*  
Assistant Director-General, Family and Community Health  
World Health Organization.

Working together with researchers from academic institutions, the [World Health Organization](#) (WHO) has developed the first comprehensive, global set of stillbirth estimates by country. Published in *The Lancet* as part of a series on stillbirths, these new estimates show that, worldwide, some 2.6 million third-trimester stillbirths occur every year. Despite these large numbers, stillbirths have been relatively overlooked, and they are not included in the Millennium Development Goals for improving maternal health and reducing child mortality.



Stillbirths often go unrecorded, and are therefore not seen as a major health problem. Yet, stillbirth is a heartbreaking loss for women and families. We need to acknowledge these losses and do everything we can to prevent them.

Almost half of all stillbirths happen when the woman is in labour, and are directly related to the lack of care at this critical time for mothers and babies. Stillbirth rates are much higher in countries where women have less access to good-quality pregnancy and childbirth care.

Most stillbirths are avoidable -- evidenced by the low stillbirth rates in developed countries, in contrast to those in regions such as sub-Saharan Africa, which are more than nine times higher. Increased data and expanded use of this data are vital to improve understanding of the burden and magnitude of stillbirths and for prioritizing actions to prevent them. But data alone will not solve the problem without the implementation of policies to prevent stillbirths.

1. Improving access to well-known interventions for maternal and newborn health would reduce the number of stillbirths. These include: Better family planning to encourage birth spacing and planned pregnancies.
2. Skilled attendants at birth, particularly midwives and physicians, and the availability of emergency obstetric care for caesarean section, if needed.
3. Better antenatal care services, including:
  - detection and treatment of syphilis;
  - malaria prevention using insecticide-treated bed nets and drugs; and
  - detection and management of hypertension, diabetes and fetal growth restriction
4. Routine induction at 41 weeks of pregnancy, when exact dates are known.

Comprehensive efforts should be made to strengthen the capacity of health services to provide such care. To accelerate progress in this area, WHO is firmly committed to supporting the implementation of the *Global Strategy for Women's and Children's Health* launched by the UN Secretary-General in September 2010. This initiative has drawn commitments from countries, donors and stakeholders to improving access to reproductive, maternal and child health services. If these commitments are met, not only could the lives of 16 million newborns and mothers be saved by 2015, but millions of stillbirths could also be prevented.

*Photograph supplied by WHO/L. Taylor*

## Cost saving strategies to prevent stillbirths

New analysis suggests that the world's 2.65 million third trimester stillbirths could be halved by 2015 at a cost of only \$2.32 per person per year in the 68 highest burden countries. These same interventions are already being promoted to reduce maternal and neonatal deaths, and, indeed, almost 1.5 million newborns and around 201,000 women would be saved with the same interventions".

[Bhutta ZA, Yakoob MY, Lawn JE, et al. What will it take to reduce the burden of stillbirths in developing countries? \*Lancet\*. Available online, 14th April, 2011.](#)

[Nigeria Vanguard](#)

[Pakistan The News](#)

[Uganda Daily Monitor](#)

[UK Daily Mail](#)  
[BBC Mirror](#)  
[The Independent](#)  
[Herald Scotland](#)  
[Wales Online](#)

[USA Voice of America](#)  
[Washington Post](#)  
[LA Times](#)  
[The Atlantic](#)  
[Boston Globe](#)  
[Chicago Sun Times](#)

[Paraguay Ultimahora](#)

[South Africa Times Live](#)  
[Business Day](#)  
[News 24](#)  
[City Press](#)

[Blogs: The Economist](#)  
[The New Scientist](#)  
[TIME](#)  
[Marie Claire UK](#)

[Bill and Melinda Gates Foundation Blogs:](#)

[Family Health: Key to Addressing Stillbirths](#) - Posted by Gary Darmstadt

[Breaking the Silence Around Stillbirths](#) - Posted by Melinda French Gates

[Stillbirths: Time to Count This Daily](#)  
[Reality for Families Around Around the World](#) - Posted by Joy Lawn

[Why Should Stillbirth Matter More?](#) - Posted by Frederik Froen

[The Connection Between Stillbirth, Maternal, and Newborn Health](#) - Posted by Bob Pattinson

## Guide to an Effective Response

by Dr Joy Lawn

Co-Chair, Lancet's Stillbirth Series Communications Committee

Lead Author, Paper 2

Director, Evidence and Policy. Saving Newborn Lives/Save the Children



This newsletter comes to you immediately following launches for *The Lancet's* Stillbirth Series. This is a moment when the huge, hidden tragedy of stillbirth has the best chance to date of moving from the

shadows towards more attention and action on the global stage. *The Lancet's* Neonatal series in 2005 was a landmark in bringing 4 million newborn deaths out of the shadows, and we now have that same hope for **stillbirths**.

Each day more than 7,200 babies are stillborn - 2.6 million a year. Death just when a parent expects to welcome a new life. Each one is an individual story of a family devastated by the loss of their child. The loss is especially felt for women, who may be marginalized and even be blamed for the loss. Yet these millions of stillbirths occur uncounted each year and are not reflected in global policy. Until now, United Nations (UN) data have not included stillbirths. Global policy targets such as the Millennium Development Goals (MDGs), omit stillbirths. Yet even in the process of developing this series, change has started. When WHO asked countries for their **stillbirth** data for the first ever time, the response was overwhelming. Countries are counting their **stillbirths** and by starting this dialogue, WHO and others can help countries to count stillbirths better and most importantly to *use the data* in their countries to *prioritise action and be accountable for reducing stillbirth*.

This series represents the work of 69 authors from over 50 organizations and 18 countries, with the analysis on numbers and lives saved drawing on over 5 years of extensive reviews and analysis. Many organizations, some of which have not traditionally focused on stillbirths, have come together with a common purpose to work together for change. **International Stillbirth Alliance** (ISA) and many partners have played key roles, and ISA especially brings *the power of parents* - a voice that has brought change in some higher income countries and yet a voice that is virtually unheard in low income settings. 98% of stillbirths happen for families in low and middle income countries while over 75% in South Asia and Sub Saharan Africa. These families also need recognition, need a voice, need to know that steps are being taken to avoid other such deaths.

The series has six papers, two articles, and eight linked commentaries which together provide the most comprehensive overview of stillbirth around the world to date, demonstrating how stillbirths have been overlooked by the global public health community, providing new data and time trends for 193 countries, and importantly offering solutions including solutions for the poorest families. Our new analysis suggests that the world's 2.65 million third trimester stillbirths could be halved by 2015 at a cost of only \$2.32 per person per year in the 68 highest burden countries. These same interventions are already being promoted to reduce maternal and neonatal deaths, and, indeed, almost 1.5 million newborns and around 201,000 women *would be saved with the same interventions*.

BUT a series is only a set of papers - even if it is *The Lancet!* Every page of the series has data and stories -



and used for action. The building blocks for change. Yet change will come only if the words are read, shared window for media attention is usually days, although with repackaging on local numbers this may last longer. *The real goal is policy and program action* and the window for maximizing change is months, or at most a year or two, before this is old news. Policymakers have a short attention span and *we have attention now and need to use it well*. What can our community do?

### 1. Know and use the data

*Read the papers:* *The Lancet* has generously made the papers and executive summary (8 pages) free on line for all the world not just subscribers. [www.lancet.com/series/stillbirth](http://www.lancet.com/series/stillbirth)  
The *headline messages* in the executive summary and *key messages* in each paper give the main points clearly.

*Know your numbers:* at least know the global number of stillbirths, and your local (national) number. Numbers are easier to understand than rates. Noting that in high-income settings the definition may differ from the WHO definition ( $\geq 1000$  g or  $\geq 28$  weeks gestation). For example in the USA using the WHO definition would report around 15,000 stillbirths a year for 2009 but the CDC 20 week definition reports 27,500 in 2009. If everyone is using different numbers then momentum will be compromised.

*Consider a national Factsheet* - a one pager, at most 2 pages with a report card of numbers, rates, rankings and *key issues to address*.

### 2. Get the news out

*Organize local or national events*, inviting media and professional partners and parents to discuss what your community or country can do to prevent stillbirth, to better support parents. Contact your local print and other media to get the local story out highlighting parent's personal stories.

### 3. Maximise the use of the data for use in policy and programs

*Help disseminate the papers* and adapt summaries for your community or country. Adapt the series Powerpoints to have a local flavor. Consider *translations* - some ISA members have been remarkable in helping this. *Sponsor* print copies to reach key audiences. The International Confederation of Midwives Congress in South Africa in June 2011 is a key opportunity to engage with midwives who are the lynchpin for care at birth. Funds are needed to reach 4000 at the congress with messages on their role in preventing stillbirth.

*Many thanks* are due. This series would not have been possible without partnership and thanks go to Vicki in her leadership role at **ISA** in drawing in the strengths of ISA. I also especially want to highlight Dr Lale Say and her team at WHO working nights and weekends with us on the **stillbirth** rate estimates. Dr Hannah Blencowe and Prof Cousens for giving up 6 months of their lives to run and re run models, and the Lives Saved Tool team including Neff Walker, Ingrid Friberg and Kate Kerber and leadership in extensive reviews By Professor Bhutta of Aga Khan University for extra ordinary work over a 3 year period to set up the stillbirth module in LiST. You can download the software free from [here](#). Funding from The Bill & Melinda Gates Foundation has been crucial and has approved grants to a number of teams including **Saving Newborn Lives/Save the Children**, **GAPPS** and **ISA**.

*The biggest thanks go to women and families around the world who have experienced a stillbirth and are working to reduce stillbirth* - let us extend our efforts to those affected in low and middle income countries. Their voices have not been part of the global dialogue - let us use this data in the series and draw in those family stories and know that change really can happen if we work together.

## Partners in dissemination

[The Lancet](#)

[Bill and Melinda Gates Foundation](#)

[Engender Health](#)

[GAPPS](#)

[Healthy Newborn Network](#)

[ISA](#)

[ANZSA](#)

[Maternal Health Task Force](#)

[Save the Children](#)

[UNICEF](#)

[UNFPA](#)

[White Ribbon Alliance](#)

[WHO](#)

[WHO SEARO](#)

[WHO PMNCH](#)

[CiaoLapo](#)

[First Candle](#)

[Norwegian Institute of Public Health](#)

[SANDS Australia](#)

[Sands New Zealand](#)

[Sands United Kingdom](#)

[SIDS and Kids](#)

[South African Medical Research Council](#)

[The Aga Khan University](#)

[Drexel University College Medical School](#)

[London School of Hygiene and Tropical Medicine](#)

[Mater Medical Research Institute](#)

[RTI International](#)

## A Mother's Voice

By Melanie Young of Breaker Bay, Wellington, New Zealand

Five and a half years ago, when I was ten days overdue and planning home birth, our perfect baby daughter Amelie, died as I went into labour.

Looking back, it has been the hardest thing my family has had to live Through...I hope it is the hardest thing we ever have to go through.



When I was in labour and Amelie's heart beat could not be found, I thought it was the cruelest joke to play on anyone. Amelie was especially wanted and loved and so meant to be. I could not believe that she had died ensuring that day of labour I held out an irrational belief of her being born and miraculously - alive. My heart and body ached for her. I wanted to grow her. My milk flowed. And if I could have - without hurting anyone else - somehow stolen a baby, I would have.

In the days and weeks that followed I remember the exhaustion of grief. The paralysing numbness that made me become physically stuck – standing by the kitchen bench I could not move to do what I had set out to do. Trying to make a cup of tea would take for what seemed like ages. It really was a time when others needed to help and fortunately they did. I am eternally grateful for the nourishing food that arrived every day until we were able to feed ourselves again. Good food and sleep were essential for the energy required to face the grief. I felt intuitively, right from the start, that I did not want the grief to beat me, or destroy our lives. At first I was thrown around by violent emotions of loss and sadness. By talking to a SANDS (New Zealand) volunteer as well as seeing an excellent grief counsellor, I became a bit stronger again reaching the point where I actually *wanted to face the grief*. It took time. Facing the grief and *looking right at the worst bits, the very saddest memories of our loss*, helped me regain my power and not live a life half-in-fear. I wanted to be able to love my future babies fully.

Another mum who lost her baby a year earlier said that *the grief is still there but that life grows around it*. Eventually, I became more practiced at *moving in and out of the grief*. Now life has grown more and more around the grief, especially since we have been *blessed with two more beautiful healthy children*.

Being a positive person, I have tried to find the 'silver lining' of losing Amelie. That silver lining has been hard to find, as there were just so many negatives that resulted from her loss. Initially I felt that her death could only be justified if she was the last baby to die needlessly. But sadly, inevitably, this was not the case.

At times I thought the pain of the grief would kill me but it hasn't. Most of the time, I am able to live a happy, healthy and fulfilled life now.

Here's to Amelie, our darling first daughter who would have been six later this year. Here's to remembering all our babies who did not get the chance to grow.

## Evidence-based interventions to reduce stillbirths

The Lancet's Stillbirth Series has established that the five big causes for stillbirth are:

1. Childbirth complications
2. Maternal infections in pregnancy
3. Maternal disorders, especially hypertension and diabetes
4. Fetal growth restriction
5. Congenital abnormalities

Effective evidence-based interventions have been established as a guideline showing a reduction in stillbirths as well as maternal and neonatal deaths.

*The Lancet's* Stillbirth Series identifies interventions for during the planning stages of pregnancy and for advanced and specific antenatal care. For more information please visit:

[Pattinson R. Stillbirths: how can health systems deliver? Lancet. Online April 14, 2011.](#)

## From the chair of ISA Scientific Advisory Committee (SAC).



Jan Jaap Erwich  
ISA SAC Chair

In this newsletter the publication of the Lancet series stands central. Rightly so, as others describe so passionately. One of the main perspectives for the future is of course the research agenda as Eckhart Buchmann points out for developing countries. Does that mean that developed countries can sit back? Of course not. The team of ISA's SAC carries a global responsibility of facilitating research on stillbirth. Whether it is basic science into how a placenta delivers nutrition to a developing child and why it sometimes doesn't, or setting up effective ways in finding the cause for a stillbirth or suggesting best practises for prevention of stillbirths and caring for bereaved parents. It is my conviction that this boost of information will receive proper attention and it is our task to disseminate the knowledge and put it into action. Global cooperation is a challenge, within an organisation like ISA it is the standard.

ISA would like to thank our members:

ISA extends whole-hearted appreciation to the ISA member organisations who assisted ISA and the authors with whole-hearted commitment:

ANZSA  
Ciao Lapo Onlus  
GAPPS  
First Candle  
Norwegian  
Institute of Public Health  
SANDS Australia  
Sands New Zealand  
Sands UK  
SIDS and Kids

Become a member organisation by registering your organisation with the [International Stillbirth Alliance](#)

ISA 2011 CONFERENCE

ISA invites you to attend the ISA 2011 Conference held in Antigua Barbuda in November this year. For more information, please visit [here](#). We hope to see you there!

ISA 2012 CONFERENCE

The ISA 2012 conference, hosted by First Candle will be held in Washington DC in October 2012. Watch this space for further details.

## Finding Out Research Priorities for Stillbirths in Developing Countries

Professor Eckhart Buchmann,  
Co-author, *The Lancet Stillbirth Series*

The **Lancet Stillbirth Series** had, among its many objectives, the *defining of research priorities*. The two papers on health systems and interventions in low and middle income countries are specifically concerned with delivery and development of interventions that could prevent stillbirths. Each of these papers is expected to provide a list of research priorities, based on evidence of research gaps. Such a list allows interested researchers and funders to identify priority areas for research into stillbirth interventions. To achieve this, we chose the CHNRI (best pronounced 'Chinree') method, developed by the Child Health and Nutrition Research Initiative of the Global Forum for Health Research<sup>1</sup>. The method, now accepted by the World Health Organization and other bodies, involves four steps:



1. Compiling a list with a large number of potential research questions by a process of consultation and discussion based on evidence of research gaps
2. Selecting an independent, heterogeneous and globally representative group of experts on the topic of interest (in our case stillbirths), and sending out the list to the experts
3. Scoring of the questions in the list by the experts, each working alone, using a systematic subdivision of themes and
4. Statistical analysis and dissemination of the results to stakeholders and the global research community.

The method gives robust and stable lists of research priority rankings, but depends on a sample size of at least about 20 scorers for each list.

### Compiling a list of research questions

Fortunately, interest in stillbirths has grown in recent years, and discussions of research gaps for prevention of stillbirths were not difficult to find. A research priority-setting exercise had recently been done by GAPPS (Global Alliance for the Prevention of Prematurity and Stillbirth), and the results were available to us. BMC Pregnancy and Childbirth<sup>2</sup>, and the International Journal of Gynaecology and Obstetrics<sup>3</sup>, had recently run series which provided useful analyses of knowledge around stillbirth prevention. We also reviewed the Cochrane database for evidence, or the lack thereof, of effectiveness of health care interventions in preventing stillbirths. And so, **The Lancet Stillbirth Series** group produced a list of 52 research questions (27 on delivery and 25 on development) for low-income country settings, and another list of 45 questions (15 on delivery and 30 on development) for middle-income settings. 'Delivery' refers to health policy or systems that promote or allow proven health interventions to be used, and 'development' is the application or improvement of proven interventions in the setting of interest.

### Selecting experts on stillbirth prevention

From our networks and contacts around the world, and through various organisations such as GAPPS and the **International Stillbirth Alliance** (ISA), we assembled two potential teams, one for low-income countries and one for middle-income countries, consisting mainly of obstetricians, from Africa, Asia, South America and the Middle East. We sent emails to these experts, asking their help in scoring the list of research questions we had compiled. The emails and questions were also translated into Spanish for the South American colleagues. *The scoring task was not small*. Scorers were warned that it would take about two hours to score all the questions. It proved a challenge to get the scorers, all highly effective and busy people, to make time to attend to the questions. Eventually, after many months and numerous reminders, 22 experts from low-income countries and 19 from middle-income countries completed the scoring, described below.

### Scoring of the research questions

In line with the CHNRI method, each question was scored in five themes, each with three sub-themes, with the scorers awarding points to each sub-theme. The five themes for each question, with sub-themes, were:

1. Answerability of question (well-defined, answerable, ethical);
2. Effectiveness of intervention (efficacious, effective, quality of evidence);
3. Deliverability of intervention (deliverable, affordable, sustainable);
4. Expected reduction of stillbirths (5-10%, 10-20%, >20%); and
5. Equity (underprivileged affected by stillbirth, intervention that can help all affected, improving equity in stillbirth burden).

### Analysis and dissemination

The completed lists of scored questions were analysed at the Mater Institute in Australia. Weightings were applied to the five question themes, with answerability and reduction of stillbirths being accorded the largest weightings. The results of the whole exercise were released for the first time at the **ISA Conference in Sydney in October 2010**, in the form of a stakeholder meeting. A summary of the results appeared for the first time in print in **The Lancet Stillbirth Series**, with the full lists of research questions in *webtables for on-line users*.

### What of the results?

Since the results appear in **The Lancet Stillbirth Series**, it would be a waste of space to repeat them here in detail. *The clear message from this exercise is that research to prevent stillbirths should be focused* (not necessarily in any order) on:

1. How best to train? – midwives, doctors, drills;
2. How best to get maternity services and communities closer to each other?
3. How best to manage labour and to use a simplified partogram? and
4. How best to make antenatal care effective?

Finding the answers to these questions should take us a long way towards reducing the burden and pain of stillbirths, *wherever we are*.

### References

1. Rudan I, Gibson J, Kapiriri L, et al. Setting priorities in global child health research investments: assessment of principles and practice. *Croat Med J* 2007;48:595-604.
2. Goldenberg RL, McClure EM, Belizan JM. Commentary: reducing the world's stillbirths. *BMC Pregnancy Childbirth* 2009;9(suppl 1):S1.
3. Hofmeyr GJ, Haws RA, Bergstrom S, et al. Obstetric care in low-resource settings: what, who and how to overcome challenges to scale up? *Int J Gynecol Obstet* 2009;107(suppl 1):S21-45.

Photograph supplied by South African Research Medical Council

## Launch Photos

Included here is a snapshot of launches in Florence, Italy and Cape Town, South Africa. To access footage from the launch in London please visit [here](#).



Alfredo Vannacci Vice President of CiaoLapo and member of ISA presents *The Lancet's* Stillbirth Series to an audience of journalists, parents, medical professionals and politicians



Journalists, parents, medical professionals and politicians meet in Florence, Italy to learn more about stillbirth



April 14<sup>th</sup> 2011 marked a special day for many bereaved parents in Italy and around the world. Vice President of CiaoLapo Claudia Ravaldi stands with a group of CiaoLapo bereaved parents.



A panel of experts spoke about the Lancet's Stillbirth Series in Cape Town, South Africa last Friday.



The Australian panel in Hobart speak to journalist across the country and in New Zealand about *The Lancet's* Stillbirth Series

## CONTACT US

Please contact the [International Stillbirth Alliance](#) if you have any enquiries or feedback. Your query will be treated with utmost confidentiality and responded to as promptly as possible by either the ISA Parent Awareness Committee or ISA's Scientific Committee.

ISA also invites you to memorialise and remember your precious baby through the [ISA World Circle of Loved and Remembered Babies](#). You might consider sharing your experience or opinion. Consider joining a stillbirth blog or join the ISA Twitter and Facebook accounts.

## SPECIAL THANKS

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If you would like to contribute to Stillbirth Matters II please contact Karen at [karen.davy@vodamail.co.za](mailto:karen.davy@vodamail.co.za)



ISA Secretariat  
C/- Mater Medical Research Institute  
Level 2, Quarters Building, Annerley Rd, Wolloongabba, QLD, Australia, 4101  
[www.stillbirthalliance.org](http://www.stillbirthalliance.org)  
[www.stillbirthalliance.org/lancetseries](http://www.stillbirthalliance.org/lancetseries)  
[info@stillbirthalliance.org](mailto:info@stillbirthalliance.org)