

Jason Hyde with his son Sherman, stillborn on
26th June 2009, at 37 and a half weeks gestation

Spotlight on Sands

**News Bulletin: Issue 5
November 2012**

Introduction

Welcome to our latest issue of Spotlight on Sands, bringing you up-to-date on all our campaigning news.

I am pleased to report that, since our last news bulletin, the momentum has continued to build across all areas of Sands' work resulting in many positive steps forward.

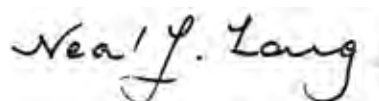
We believe strongly in the urgent need for research into stillbirth causes and prevention and thanks to the wonderful support of our many fundraisers, we are delighted to be able to fund three new research studies starting this autumn. You can read more inside about the details of these new projects and how they will potentially unlock some of the answers.

We continue to develop our relationships with all the UK governments. Following the Cabinet reshuffle in England in September, we were sorry to see Anne Milton MP leave the Department of Health. Anne took a strong personal interest in stillbirths and neonatal deaths,

supported a number of key events for Sands, and most recently gave her ministerial backing for the joint DH/Sands stillbirth prevention workshop in March this year. We are however delighted to welcome Dr Daniel Poulter MP to his new role of Parliamentary Under Secretary of State for Health. We look forward to working with him and his team to ensure that the key issues raised in our *Preventing Babies' Deaths* report are now addressed through the five small expert working groups which resulted from the workshop in March.

We are also delighted at the progress being made by the Scottish and Welsh governments, who are already tackling many of the issues head-on; full details are on page 6.

Thank you for taking the time to read about our work, and for your continued support in keeping the individual tragedies of so many babies' deaths in the spotlight.



Neal Long, Chief Executive, Sands

Contents

- 2** *Preventing Babies' Deaths* report: progress
- 3** Sands Campaigning Voices group
- 4** Stillbirth research projects
- 5** MBRRACE / Bereaved parents survey
- 6** International and devolved governments

Diary Date

***Royal College of Midwives
Annual Conference 2012.***

Tuesday 13th and
Wednesday 14th November.
Brighton Centre, Brighton.

*Visit the Sands exhibition
stand at this essential
event for all midwives and
everyone with an interest
in maternity services.*

Preventing Babies' Deaths report: Progress

Our report *Preventing Babies' Deaths: what needs to be done* launched at the start of the year and highlighted the shocking scale of baby deaths in the UK. 17 babies are stillborn or die shortly after birth every day, with stillbirth being the largest contributor to child deaths under the age of five years.

The report described the devastating impact these deaths have on parents and their families, and outlined the areas where we believe progress can be made that could save hundreds of babies' lives.



Shortly after the report launch Sands and the Department of Health were pleased to bring together a select group of key experts and professional bodies in March for the first-ever national workshop in England to focus on stillbirth prevention.

During the day, stakeholders discussed the wide-range of issues raised in our report and agreed to form five small expert working groups to tackle individual issues relating to the reduction of perinatal mortality. These include:

- ▶ A group, led by Sands, will identify standards that enable robust perinatal review, dissemination of learning and audit of change.
- ▶ A group, led by the DH, will identify the key dataset indicators that ought to be collected in order to improve detection of risk of stillbirth.
- ▶ A group, led by Sands, will identify key public health messages that all those delivering public health will need to be aware of in order to reduce the risk of stillbirth.

▶ A group, led by the DH, will develop and agree the information/tools that Clinical Commissioning Groups will need to build stillbirth prevention into the commissioning of maternity services.

▶ A group collaborative of the Royal College of Midwives and the Royal College of Obstetricians and Gynaecologists, will develop combined guidance to ensure that stillbirth risk, including fetal movement and prolonged pregnancy, is more prominently featured in midwifery and obstetric training curricula.

The expert groups have now begun to set specific objectives, and will meet regularly to measure progress against these objectives. Sands and the Department of Health met in October to discuss the workstreams of each group, and to look at details of the public health messaging which is likely to be the first workstream to be disseminated into the public arena. We will post news updates on our website as they become available.

We have also been working with a wide range of stakeholders to make progress in other areas of concern raised in our report and are pleased to update you on some specific activities that are underway.

Parent power: Sands Campaigning Voices group

We are continually grateful to all the bereaved parents and families who support Sands in so many ways.

Our Sands Campaigning Voices group brings together people keen to push for change at a local and national level. The group receives regular ebulletins from the charity,

highlighting any areas of concern or interest that they may be able to raise with their local MPs.

As a result of this local campaigning, many MPs are actively supporting Sands at constituency and government level. Some have raised questions in the House or written to the Health Minister;

others have visited local Sands groups, local maternity units or helped with local publicity.

To get involved or find out about our campaigns email:
campaigns@uk-sands.org



Helen Cooper with her nephew Daniel. Her own daughter Daisy was stillborn at 25 weeks.

Helen Cooper joined Sands Blackpool and Preston group in October 2011. Her daughter Daisy was stillborn at 25 weeks two years earlier.

"Losing a baby had never happened to anyone I knew and I just didn't know how to handle the overwhelming grief, so rather than face it head on I chose to ignore it," says Helen. "Two years later, I had a breakdown. That's when I found Blackpool and Preston Sands, who gave me the comfort and support to

Case study: Blackpool and Preston Sands

be able to speak about my experience and acknowledge my daughter, and eventually to mark her third birthday. I have just completed and passed my Sands Befriender training and I now run the local group with another lady."

"Losing a baby had never happened to anyone I knew and I just didn't know how to handle the overwhelming grief"

Helen was so shocked by the stillbirth statistics – 17 babies dying every day – that she decided to join the Sands Campaigning Voices group to raise awareness and press for action to be taken to reduce the number of baby deaths. One of her first actions was to contact her local MP, Gordon Marsden MP for Blackpool South. She emailed Gordon a copy of the Preventing Babies' Deaths report and proposed

a meeting to discuss her personal experience, the work of the local group, and the broader issues. "The meeting went very well," explains Helen. "Gordon was very keen to know what he could do for Sands, especially in parliament. He agreed to write to the Minister, and also to our local hospital to confirm how important the role of the Bereavement Support Officer within the maternity ward is to parents that have lost a baby. Our group covers quite a few local wards across Blackpool and Preston and we are hoping to lobby some more local MPs and get them on board too.

"I do this in Daisy's memory, it's all about her. I can't change that she isn't here but if I can do something to help others then that's a fitting tribute to my beautiful girl."



The need for research and new interventions

Background

Our report called for government research funding bodies to fund projects which expressly look at the causes and prevention of unexplained stillbirth. A third of stillborn babies are perfectly formed and born at gestations when they might safely be delivered. But routine antenatal care is failing to detect far too many babies who need help. New reliable, diagnostic tests are urgently needed. Stillbirth is where cot death was 30 years ago. There is still so much to be done.

Progress

Sands continues to lobby government for research funding and we are in communication with the main government research funding bodies. In the meantime, the Sands-funded Stillbirth Clinical Studies Group has made its recommendations about the next round of research that Sands will fund, and we are pleased to announce that we will be funding the following projects:

▶ A study to determine whether a new scanning approach (routine ultrasound scans at 28 and 36 weeks plus utero-placental Doppler scan) could predict which babies are SGA (small for gestational age) and therefore be used as a way to predict stillbirth. It is known that stillbirth is associated with SGA but currently there is no effective way of predicting SGA babies. The results from this study would potentially help to

answer the question about increasing and improving use of scans, which could possibly lead to changes in routine care.

▶ A study to inform better care for parents who experience the death of a baby and better training for healthcare professionals. Though there is considerable anecdotal opinion about what makes good bereavement care, there is very little research evidence to guide practice. This study aims to fill that gap by interviewing bereaved parents and holding focus groups with health professionals about their experiences of bereavement care and making recommendations on how care and training can be improved.

▶ A study aiming to develop a standardised approach to collecting perinatal post mortem data, develop an evidence base for what post

mortem investigations are useful and to identify future targeted research studies. We are concerned that there is a lack of research investigating the causes of stillbirth, but one barrier to research is the poor quality of data from post mortems. At present perinatal post mortem data is reported and stored in different ways by different pathologists, with great variation in what investigations are done, what data is collected and in what format. Standardising the recording of perinatal post mortem results is the first step to improving the use of post mortem data in researching the causes, and therefore prevention, of stillbirth. Improving the quality of post mortem also has implications for improving the information for parents after their baby's death, and for improving the process of seeking post mortem consent.

Although we are excited about these new projects, the level of funding – and potential impact – is still very small. We need significant amounts of money for large-scale research projects, and we will continue to campaign for this. Please email campaigns@uk-sands.org if you would like to get involved and support our Research Funding Campaign, or would like to make a donation towards research.

Understanding how many babies die and why?



Our report called for the Clinical Outcome Review Programme Maternal and Newborn Health which was stalled in April 2011 to be resumed in April 2012. Good data and audit are essential to advance understanding of why babies die and to improve care. But key health policy work for collecting national perinatal data was suspended in April 2011. As a result we the UK has possibly two years of incomplete data on babies who have died.

Progress

As of April this year MBRRACE-UK (Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries) took over work previously undertaken by CMACE (Centre for Maternal and Child Enquiries). Sands is very pleased to be involved as a stakeholder in the new collaboration to continue the national programme of work investigating maternal deaths, stillbirths and infant deaths including confidential case reviews.

The aims of MBRRACE-UK, which includes investigators from Oxford, London, Leicester, Liverpool and Birmingham Universities, are to provide robust information to support the delivery of safe, equitable, high quality, patient-centred maternal, newborn and infant health services. By being part of this collaborative, Sands is able to provide the family perspective on issues relating to improving perinatal care.

To find out more go to: www.npeu.ox.ac.uk/mbrrace-uk

Caring for bereaved parents

Our report called for better care for parents after the death of a baby, including the development and implementation of a Bereavement Care Pathway, outlining minimum standards of care for bereaved families.

Progress

Working with Sands and the baby charity Bliss, researchers at the National Perinatal Epidemiology Unit (NPEU) at the University of Oxford are carrying out the first national survey ever conducted of bereaved parents. Funded by the Department of Health the study will survey the maternity care experience of parents who have recently had a stillborn baby or a baby who has died neonatally (in the first four weeks of life) in England.

The results will provide up-to-date information about care, and parents' experience and perceptions of that care, and will be used to help improve maternity services for women and families who experience such a loss. The Office for National Statistics (ONS) is using birth and death registration records to select women to take part in the survey and is mailing letters and questionnaires to women. The first invitations to take part were sent in October this year. These will be followed by invitations to another group of women in February 2013.

For more information please see the study website:
www.npeu.ox.ac.uk/listeningtoparents



International stillbirth prevention initiatives

Our involvement with the International Stillbirth Alliance (www.stillbirthalliance.org) and the team who authored the Lancet Stillbirth Series, goes back many years. The annual ISA meeting which we attended in October is an opportunity to get up-to-date with the latest international research and share the campaigning work we do in the UK with parent organisations in other

countries. Next year's meeting will be in Vietnam and in 2014, when the hosts will be Holland, we hope to encourage many UK-based clinicians, researchers and parents to attend.

Sands is co-funding a meeting of international experts in placental research in Manchester in January 2013. Sixty per cent of stillbirths remain

unexplained but placental causes are believed to play a role in many of these deaths. This groups aims to collaborate and develop new avenues of research and work in this area.



Scotland

The Scottish Stillbirth Working Group, chaired by Scottish Government Senior Medical Officer Catherine Calderwood, is continuing to focus attention and action on stillbirth reduction. The multi-disciplinary group of experts is looking at improving standards across Scotland for detection of poor fetal growth, managing reported decreased fetal movements, reviewing perinatal deaths and caring for parents after a baby has died. The group is also looking at public health messaging in relation to stillbirth risk factors, in particular smoking.

Sands and the Scottish Stillbirth Working Group plan to host a Stillbirth Seminar, a one-day training seminar for Scottish obstetricians and midwives, in June 2013.



Wales

The Welsh Maternity Collaborative, part of the 1000 Lives plus initiative, has taken up stillbirth as its new work programme. An expert working group, modelled on the Scottish Stillbirth Working Group, has convened and begun work on key priorities for reducing perinatal mortality. The first stillbirth training day for maternity professionals from

every Welsh Health Board took place in October, and Sands was invited to talk about what parents want health professionals to do.

In June the Welsh Government Health and Social Care Committee, chaired by Mark Drakeford AM, held a one-day National Inquiry into Stillbirth, taking evidence from experts in obstetrics, research and public health. Sands was called to give evidence about priorities for stillbirth prevention in Wales. The full Inquiry can be viewed at www.senedd.assemblywales.org. The Committee is due to report its findings this autumn.

About Sands

Sands, the stillbirth and neonatal death charity, was founded in 1978 by a small group of bereaved parents devastated by the death of their babies, and by the total lack of acknowledgement and understanding of the significance and impact of their loss.

Sands today operates throughout the UK and focuses on three main areas of work:

- ▶ We support anyone affected by the death of a baby
- ▶ We work in partnership with health professionals to try to ensure that bereaved parents and families receive the best possible bereavement care
- ▶ We promote and fund research that could help to reduce the loss of babies' lives

If you would like any further information or to make a donation please contact us or visit our website.

Contact Sands:

3rd Floor, 28 Portland Place, London, W1B 1LY

t: 020 7436 7940

f: 020 7436 3715

e: info@uk-sands.org

w: www.uk-sands.org

Support:

t: 020 7436 5881

e: helpline@uk-sands.org

Newsletter sign-up:

e: newsletter@uk-sands.org



Stillbirth & neonatal death charity