

Caroline and Jon Morgan with baby Anabelle,
stillborn at 32 weeks.

Spotlight on Sands

**News Bulletin: Issue 6
April 2013**

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

We have had an incredibly busy start to the year. Our well-established relationship with the Department of Health in England continues to develop. I was particularly encouraged to attend two of the recent 'Stillbirth task and finish' working group meetings on Standardised Perinatal Mortality Review and Public Health Messaging respectively, which highlighted how stakeholder collaboration can really drive our agenda forward.

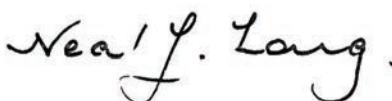
In Scotland, we are delighted to be part of the excellent Scottish Stillbirth Group, led by Dr Catherine Calderwood. Dr Calderwood has been instrumental in supporting various national initiatives in stillbirth prevention in Scotland, which includes the new research study on decreased fetal movements to which Sands is contributing funding. I would also like to congratulate Dr Calderwood on her recent appointment as the National Clinical Director for Maternity and Women's

Health at NHS England and look forward to working with her in this capacity in the future.

In Wales, we are glad to see the recommendations of the Health and Social Care Committee's autumn Inquiry into Stillbirths, which broadly reflect the actions Sands called for in giving evidence. We will continue to work closely with the Welsh Stillbirth Group to support their implementation.

The vital funds raised by individual fundraisers through the Why17? Campaign we launched in 2009/10 in each of the UK countries, have enabled Sands to invest just under £500,000 in eight projects over the last three years. In the coming year we will do all that we can to increase the funding committed to research to ensure that fewer babies die and that there are fewer bereaved parents and families to support.

Thank you for taking the time to read about our work, and for your ongoing support.



Neal Long, Chief Executive, Sands

Contents

- 2 Department of Health 'Stillbirth task and finish' groups
- 3 Welsh Assembly stillbirth inquiry
- 4 Research and prevention
- 5 Post mortem consent package
- 6 Sands Campaigning Voices group

Diary Date

Scottish Stillbirth Seminar

Friday 14 June 2013

9.30am - 4.30pm

Royal College of Physicians
of Edinburgh

This seminar organised by Healthier Scotland and Sands is primarily aimed at professional leads, senior clinicians and decision makers.

To register your interest please go to www.surveymonkey.com/s/SSS2013-06-14

Working with the Department of Health

We continue to work closely with the Department of Health in England and are pleased to bring you further updates from the multi-disciplinary 'Stillbirth task and finish groups', which emerged from the Sands Stillbirth Workshop co-hosted with the Department of Health in March 2012.

Raising awareness: developing stillbirth public health messages

Sands has long argued that awareness alone can act as a preventative measure in stillbirth reduction. So many bereaved parents tell us of their shock at how common stillbirth is and yet how little they knew of the risks until the unthinkable happened to them. The challenge is how to communicate difficult messages about potential risks, including that of stillbirth, to pregnant women when pregnancy is largely seen as a 'normal' and happy event. The Stillbirth Public Health Messaging group's aim therefore is

to identify what messages are useful to parents and health professionals in understanding stillbirth risk and how to convey these messages effectively and sensitively, empowering mums-to-be to understand their own risk profile in order to take care of themselves and their babies.

Public Health Minister Dr Daniel Poulter MP hosted the group's first meeting in January inviting representatives from obstetrics and midwifery in Scotland and Wales as well as the RCM, RCOG, RCGP, Public Health England, the Health Visitors Association, the Stillbirth Clinical

Study Group, MBRRACE-UK and Sands. The group had a useful discussion to draw up a list of proposed public health messages relating to stillbirth. The Sands team was inspired by the level of engagement and commitment of everyone involved. Sands and the Department of Health now plan to test these messages with relevant audiences, before looking at ways to disseminate them through new and existing information platforms for pregnant women.

Cataloguing and recognising stillbirth risk: data collection

The Stillbirth Workshop last March established that data is key to cataloguing and recognising stillbirth risk. The Stillbirth Data Items group was formed and met last November for the first time. It includes representation from the RCOG, RCM, RCPCH, the Stillbirth Clinical Study Group, MBRRACE-UK and Sands. The remit of the group is to define all relevant stillbirth risks, to ascertain whether this data is kept on existing data sets, and to work out how it might be enhanced to improve detection of at-risk women in the future.

Lesson-learning: perinatal review

When a baby dies, robust perinatal mortality review is essential to learning lessons about the death in order to understand whether avoidable factors were missed and how care might be improved in the future. But there is currently wide variation in both the methods and quality of review around the country.

The Perinatal Mortality Review group, representing Royal colleges, professional bodies and parents, aims to look at principles and standards of review so that the deaths of babies from 22 weeks'

gestation to 4 weeks of life are all reviewed in a thorough and systematic way and lessons are learned both locally and nationally.

The group met for the first time in Birmingham in January to look at existing formats for perinatal mortality review and to discuss and agree the principles for review going forward. These have been established by the group and we are currently looking to NHS England for support to progress this work further.



Welsh Assembly calls for action on stillbirths

In February, the National Assembly for Wales's Health and Social Care Committee published its eagerly-awaited report on stillbirths, which outlined that the Welsh Government could and should do more to reduce the rate of stillbirth in Wales.

The Committee's recommendations came after a one-day inquiry last year. Sands provided evidence which examined the awareness, implementation and effectiveness of current guidance and recommendations across the different sectors with regard to stillbirth prevention, and where potential improvements could be made.

The report concluded that there was not one single remedy to end the problem, and made nine recommendations to the Welsh Government including that they:

- ▶ take an active lead – via the recently established National Stillbirth Working Group – in developing key public health messages as a matter of priority;
- ▶ work with professional bodies and health boards in Wales to ensure that all expectant parents

receive adequate information from clinicians and midwives about stillbirth and its associated risks; and,

- ▶ commission, through the national Institute for Social Care and Health Research's Clinical Research Centre, a comprehensive piece of work on the underlying cause of stillbirth.

This comprehensive report is a significant step forward to improving care for all parents and babies in Wales and we urge the Welsh Government to lose no time in actioning its nine vital recommendations. Sands will continue to work closely with the National Stillbirth Working Group in Wales and other key stakeholders to keep the issues top of the political agenda.

For the full recommendations visit www.senedd.assemblywales.org (Search: stillbirth inquiry)

▶ There are four babies stillborn in Wales every week.

▶ In 2011, 150 Welsh babies were stillborn.

▶ Stillbirth rates have barely changed since the early 1990s.

▶ The stillbirth rate in Wales – and likewise across the UK – remains higher than in most other European countries.



Alexander and big sister Anabelle -
"Anabelle remains a huge part of our family and isn't something we will ever get over."

A parent story

Caroline and Jonathan Morgan, from Newport in Wales, welcome the recommendations of the report. Their first child Anabelle was stillborn at 32 weeks, in June 2010. "Up until 31 weeks, we had an uneventful pregnancy," explains Caroline. "But the week before, I was taken to hospital with threatened pre-term labour. However I was treated to stop the labour happening and they did scans and everything was fine."

"The next week I noticed she had stopped moving. We went to the hospital and we were told that she had died. What had happened before was just a horrible coincidence. Her death was unexplained - we were offered a post mortem but were told there was no guarantee there would be any answers."

The couple have since had their second child, Alexander, and feel strongly that parents should be given information during pregnancy about stillbirth and the possible risk factors. Above all, they believe it is vital to raise awareness about stillbirth, and the huge and tragic impact of a baby's death. "There are no words that can really convey the enormity of losing a child," Caroline reflects. "So often I find myself overwhelmed with the forever. That she will always be dead. My baby."

Research and prevention

Fetal movement awareness study: AFFIRM

Sands is contributing £50,000 towards a £350,000 study on fetal movement awareness run by Professor Jane Norman at the Medical Research Council's Centre for Maternal and Fetal Health in Edinburgh. The AFFIRM study aims to discover whether promoting increased awareness of decreased fetal movements reduces stillbirth. The study is due to begin in June and will be run over three years in maternity units in Scotland, Ireland, Wales and possibly regions of England. It will include information for mums-to-be and a care package for health professionals.

The odds of stillbirth fell by 30% after the introduction of a similar package of care

in Norway in 2006 but the efficacy of this intervention (and possible adverse effects and implications for service delivery) have not been tested in a randomised trial.

Professor Norman says: "I am very grateful to Sands for their generous support of the AFFIRM study. The trial team and I are very excited about the possibility of showing that a relatively straightforward intervention could have a significant impact on rates of stillbirth."

The study is being funded primarily by Scotland's Chief Scientist's Office as well as Sands and Tommy's. Researchers aim to publish findings by 2016.



'Listening to Parents' survey

The National Perinatal Epidemiology Unit (NPEU) at the University of Oxford has selected a second cohort of bereaved parents to survey for their 'Listening to Parents' study.

This survey, funded by the Department of Health in England and developed with input from Sands and Bliss, is the first time that bereaved parents have been asked in detail about their experience of maternity care in a national survey. The results will provide up-to-date information about care and will be used to help improve maternity services for women and families who experience such a loss.

For more information visit www.npeu.ox.ac.uk/listeningtoparents

Stillbirth and the placenta: international meeting in Manchester

It is well recognised that placental problems and fetal growth restriction (FGR) play a significant role in causing many of the unexplained stillbirths which account for over half of all perinatal deaths. Yet there is a chronic lack of research into what is going wrong or how to stop it happening.

In January 2013 Professor Colin Sibley and Dr Alexander Heazell (Maternal and Fetal Health Research Centre, Manchester University) and Professor Gordon Smith (Cambridge University), organised and hosted a two day international workshop to share knowledge about placental dysfunction, growth restriction and stillbirth and find ways to collaborate in the future.

Delegates from the UK, Europe and the US agreed a series of joint actions to take forward: to agree international standardised approaches to placental investigations in order to improve the data available for research; to work on improved predictive antenatal screening tools based on markers of placental dysfunction; and to review methods for identifying FGR.

Sands was delighted to support this extremely constructive initiative, co-sponsored with Tommy's and Visit Manchester, and looks forward to reconvening with the group in 2015 to assess progress.

Visit www.uk-sands.org/research for updates on all our research initiatives.

Post mortem consent package

We are delighted to have launched the Sands *Post mortem consent package*, developed to provide information and guidance about post mortems for health professionals seeking consent, and for bereaved parents whose baby has died before, during or shortly after birth.

Every year in the UK over 6,500 babies die just before, during, or soon after birth and a post mortem examination is the single most useful investigation in providing information for parents about why their baby died. However, perinatal post mortem rates in the UK are low, leaving many parents with unanswered questions. There are a range of factors for these low rates including:

- ▶ many health professionals underestimate the value of a perinatal post mortem and so may not discuss a post mortem with parents.

- ▶ understandably many find this discussion very difficult. They also worry that they will add to parents' distress.
- ▶ some are deterred by the long, complicated and detailed consent forms currently in use in their hospitals.
- ▶ in some places, the task of discussing post mortem with parents is given to inexperienced staff who have had no preparation or training for this difficult discussion.

In order to help overcome some of these issues the Sands *Post mortem consent package*, developed in association with the Human Tissue

Authority (HTA), aims to support both health professionals and parents in discussing the option of a post mortem when a baby has died. It has been developed over the last two years in consultation with a wide range of health professionals and bereaved parents across the United Kingdom. The package includes; a new *Post mortem consent form*, a *Guide for consent takers*, and a support booklet for parents: *Deciding about a post mortem: Information for parents*.

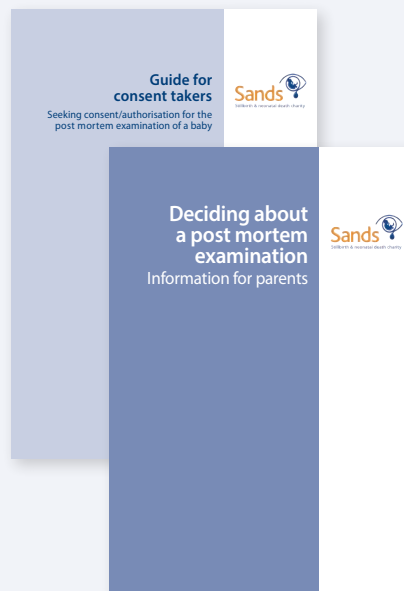
The package has been sent out to all maternity units, and we have been overwhelmed by the hugely positive response.

"For the first time I've been able to take consent with some dignity." Midwife

Get involved!
We need parent campaigners and MPs to encourage uptake of the Sands *Post mortem consent package* in local maternity units.

We are proud to have developed this excellent package, and want to ensure that maternity units have received it and are using it. If you would like to help us spread the word and encourage uptake of the *Post mortem consent package* by getting in touch with your local unit, we can provide you with a template letter and background leaflet.

Contact Tara MacDowel,
Campaigns and Public Affairs
Lead for more information:
campaigns@uk-sands.org



Find out more

The complete package for health professionals can be ordered from www.uk-sands.org/shop or downloaded from the Human Tissue Authority website: www.hta.gov.uk/licensingandinspections/sectorspecificinformation/postmortem/perinatalpostmortem.cfm

The *Information for parents* booklet is also available to order from www.uk-sands.org/shop

"When you have a baby who dies it seems that there's nothing positive, and you just have to try to find something that might be positive. For us, it was that we got an answer about why, but also, knowing that somebody else may gain from that." Bereaved mum

Get involved!

Join our campaign calling for more funding for research into the causes and prevention of stillbirth

Although we are pleased with the level of commitment to stillbirth prevention being shown by governments across the UK, we still believe that funding for research will be the key to making a real difference. Sands is concerned that there remains insufficient research into what is causing so many babies to be stillborn each day. While Sands campaigning has increased focus on this research challenge, the size of studies and levels of funding continue to be insufficient to make a real impact on these deaths, with the majority of maternity related studies having broad remits that encompass many other aspects of care.

We need government-funded research bodies to direct significant amounts of money towards large-scale stillbirth research projects, and for the research community as a whole to focus on this issue.

We want parent campaigners to raise these issues with their local MP, and parliamentarians to raise the issues with the Minister and in the House.

Please email campaigns@uk-sands.org if you would like to get involved and support our Research Funding Campaign.

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 our charity e-newsletter, 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.

About Sands

Sands supports anyone affected by the death of a baby and promotes research to reduce the loss of babies' lives.

To keep up-to-date with all the latest news from Sands, please sign up to receive our regular e-newsletter, by visiting our website or emailing newsletter@uk-sands.org

If you'd like support or want to find a local Sands group please contact us or visit our website.

If you would like to get involved or make a donation, please contact:

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