

Claire and Dan Ashley whose daughter Ruby was stillborn.

Spotlight on Sands

**News Bulletin: Issue 7
November 2013**

Introduction

Welcome to our latest issue of *Spotlight on Sands*, bringing you up-to-date on our recent activities.

As we near the end of 2013, I am hugely proud of our achievements this year.

As well as providing invaluable support to bereaved families via our helpline, leaflets and booklets, and through our 104 groups across the UK, we have seen major successes across other areas of our work. These include developing the *Sands Post mortem consent package*, training 600 health professionals through our Guidelines Training Programme and representing bereaved parents on Government Stillbirth Working Groups in England, Scotland and Wales to develop strategies for preventing avoidable deaths.

In recent months we jointly hosted the fifth annual Uncertainty and Loss in Maternity and Neonatal Care conference alongside Bliss and the Royal College of Midwives.

The event was a huge success with over 200 health professionals in attendance.

We launched our first fundraising appeal for Baby Loss Awareness Week to help fund research into stillbirth and neonatal death.

We also unveiled our new website www.uk-sands.org. As well as being a fully comprehensive source of information, our site is now optimised for a wide range of devices including mobile phones and tablets enabling people to access this information whenever or wherever they need it. We think it is a great improvement and hope you agree.

I would like to take this opportunity to thank you for your invaluable support and to express my gratitude towards the entire team at Sands for their hard work and commitment.

Kate Anker

Kate Anker, Chair of Trustees, Sands

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Diary Date

Royal College of Midwives Annual Conference 2013
Wednesday 13th and Thursday 14th November, International Centre in Telford, West Midlands

Visit our stand, no. 31, to discuss our latest recommendations for improving the care for parents whose baby dies before, during or shortly after birth.

Department of Health Task and Finish Groups

Stillbirth Public Health Group

With increased recognition that many stillbirths are potentially preventable, we have spent the past year working closely with the Department of Health to establish a stillbirth prevention work programme. Our Stillbirth Public Health Task and Finish Group, including representatives from the RCM, RCOG, RCGP, Public Health England, DH (England, Scotland and Wales), key clinicians and other leading baby charities, met

earlier in the year to begin drawing up a common set of public health messages to raise awareness and reduce the risk of stillbirth.

We are now pleased to be taking this programme to the next stage: assessing how these public health messages would be received by the intended audience. Sands is working with a specialist research agency to run a series of focus groups with

pregnant women and midwives, exploring their general awareness and understanding about stillbirth - how often it happens and what risks are associated with or directly cause stillbirth - and how best to share information about these potentially sensitive issues.

Results from the focus groups will be reported in early 2014.

Perinatal Mortality Review Group

When a baby dies, robust perinatal mortality review is essential for learning lessons about what happened, to understand whether avoidable factors were missed and how care might be improved in the future. However, the methods and quality of review vary widely around the country. The Department of Health and Sands Perinatal Mortality Review Task and Finish Group aims to look at the 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 can be learned locally and nationally.

The Group, representing the Royal Colleges and professional bodies as well as parents, met for the first time in January 2013. A smaller subgroup has met to benchmark existing review tools. Once the work is complete, the Group will be looking to NHS England for their support in

producing an audit tool for maternity units that examines what happened prior to a baby's death. The existing *Sands Audit Tool for maternity services: Caring for parents whose baby has died* looks at the quality of care provided to bereaved parents. We hope the new audit tool will be available next year and that the two can be used alongside each other.

For more information please email research@uk-sands.org.

Our new website launches

We are thrilled to have launched our brand new website www.uk-sands.org. Over the past 2 years, we have seen the number of people accessing our site from mobiles or tablet devices increase dramatically to the extent that mobile users now form nearly half of our online visitors.

We therefore believe it is crucial that people have optimal access to our site wherever they are and whatever device they are using, and our new site has been designed with their needs in mind. The new website launch is the first step in Sands' digital development plan and additional features and functionalities will be updated and added over the coming months to further enhance visitor experience.



Working with devolved governments



Scotland

The Scottish Stillbirth Working Group, set up in 2011 after Sands

launched our *Saving Babies Lives* report and petitioned the Parliament, has been busy continuing work in Scotland to reduce stillbirths.

- ▶ The first Scottish Stillbirth Seminar was held on 14th June 2013 hosted by the Scottish Government. Over 200 delegates attended including: policy makers, clinicians, lead midwives, registrars and some student midwives. There were many eminent speakers on a variety of topics and it culminated in a Question Time style session chaired by Sally Magnusson from BBC Scotland.
- ▶ The Scottish Stillbirth Working Group, which Sands has been part of since it was set up in 2011, now includes representation from the Maternity Care Quality Improvement Collaborative (MCQIC), part of the Scottish Patient Safety Programme, launched earlier this year to improve outcomes and reduce inequalities in outcomes in maternity settings in Scotland. A key objective of MCQIC is to reduce the avoidable proportion of stillbirths and the neonatal mortality rate by 15% by December 2015. With this in mind a working group on smoking cessation is aiming to introduce carbon dioxide monitoring at antenatal care appointments.
- ▶ A subgroup dedicated to bereavement care has formed reporting into the Scottish Stillbirth Working Group. It is gathering information from directors of nursing, heads of midwifery and deaneries in order to better understand bereavement care services in Scotland. It is also considering hosting an event around service development for bereavement care.



Wales

The Welsh Initiative for Stillbirth Reduction (WISR) group has been

- responding to recommendations outlined in the report *One-day inquiry into stillbirths in Wales (February 2013)*, published by the National Assembly for Wales' Health and Social Care Committee.
- ▶ Improving monitoring of babies in the womb by standardising how fetal movements are monitored, as well as improving measurements of a baby's growth during pregnancy. Wales is also participating in the AFFIRM fetal movement study.
 - ▶ Trying to increase post mortem consent by reducing the waiting time for parents, especially those who live in rural locations far from the pathology centres.
 - ▶ Joining in the Sands working groups looking at public health information and audit of perinatal deaths.
 - ▶ Examining how Wales looks after women whose pregnancies go beyond 42 week's gestation.



Northern Ireland

In March 2010, the Sands Why17?

campaign launched in Ireland, with an event at the Northern Ireland Assembly and an Ireland-specific media campaign.

- ▶ We joined forces with Bliss and TinyLife charities for an event at the Northern Ireland Assembly, issuing a briefing to government, *Every Baby Matters*, which called for the prevention of stillbirth and neonatal death and world class support for premature and sick babies and their families.
- ▶ Since that time, our Northern Ireland Network has continued to build and strengthen relationships with Assembly Members.
- ▶ In July 2013, Sands was invited to be a member of a new Assembly group, the Northern Ireland Child-Loss Working Group, which has a remit to look at all child deaths from miscarriage up to 1 year of age, including preventable stillbirth. Sands will provide parent input to the working group and we are delighted to have this opportunity to share our expertise and knowledge, as well as the experiences of bereaved parents.

Our Sands Post mortem consent package has been updated with *Learning Outcomes for Consent Taker Training* to improve and standardise training across the UK. Our aim is for all countries to improve the consent process for bereaved parents and professionals and increase the uptake of post mortems, the single most useful investigation in providing information about cause of death.

More information can be found at www.uk-sands.org/Professionals



AFFIRM study update

The AFFIRM study into fetal movement, which Sands is part funding, has now had uptake from all units in Scotland, many perinatal units in Ireland and nine in Wales via the Sands-supported Welsh Initiative for Stillbirth Reduction (WISR). Sands has played an important role in bringing more regions on board - our stillbirth symposium at the British Maternal and Fetal Medicine Society (BMFMS) conference in April generated interest from English regions.

The AFFIRM study aims to discover whether promoting increased awareness of decreased fetal movements reduces stillbirth. While routine kick counting is not advised, the AFFIRM study aims to understand the significance of improving awareness of fetal movements.

The study proposes a package of care that includes written information for women about the importance of DFM and the need to promptly report DFM to their midwives; education for clinicians about the importance of DFM; and better management of women presenting to hospital with DFM, including the identification of placental insufficiency, with timely delivery in confirmed cases.

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.

More details of the study can be found at www.uk-sands.org/Research



Asian Outreach project

Sands recognises the urgent need to reach out to black and minority ethnic communities. To ensure our services are truly accessible to all and achieve our aim of supporting anyone affected by the death of a baby, we have been undertaking a 6 month Asian Outreach research project.

The project is exploring the different bereavement support needs of Asian communities and the individuals within them, and the barriers they face in accessing the support we currently offer.

We will then identify relevant ways of working with others to reach out across Asian communities and consider how these can be built into our future support plans.

Uncertainty and Loss in Maternity and Neonatal Care conference 2013

The fifth annual Uncertainty and Loss in Maternity and Neonatal Care conference jointly hosted by Bliss, the RCM and Sands, took place in London in September.

Delegates listened to a range of respected speakers including clinicians, researchers, a senior mortuary manager, bereaved parents, and the director of national charity, ARC (Antenatal Results and Choices). The conference was chaired by Jane van Zyl, Deputy Chief Executive, Sands (pictured).

The varied programme was packed with insights about best practice when responding to critical illness in babies and how to provide the best possible care to parents who are facing uncertainty, loss and bereavement. Recurring themes

included the need for effective communication, collaborative working, continuity of care and further research in order to reduce stillbirth and neonatal death rates and to improve the care of bereaved parents.



The New NHS

We have been engaging with the new NHS and importantly with the Strategic Clinical Networks (SCNs). There are 12 new Maternity Clinical Networks in England covering 12 regions of the country.

The networks will be setting national and local priorities for maternity care and have invited us to be part of that process. We attended the national meeting in September and contributed information to individual network launch days

during that month. We hope the SCNs will provide a channel for creating awareness of stillbirth and highlighting quality of care issues on all aspects of care and services, from antenatal care to bereavement care and post mortem services.

NHS England survey

NHS England recently commissioned Sands to carry out a short survey among bereaved parents on the Friends and Family Test (FFT), which is a single-question survey asking patients whether they would recommend the NHS service they have received to friends and family who need similar treatment or care. The FFT was initially conducted among inpatients and patients discharged from A&E and from 1st October 2013, the test was introduced to those who use a hospital's maternity services.

NHS England wants to find out whether it would be acceptable to use a version of the test with parents who have had a miscarriage, stillbirth or neonatal death. They also asked us to find a form of words that would be acceptable. We devised an online survey to gather feedback and received an excellent level of response from bereaved parents.

Our report has now been provided to NHS England and we shall update you on the outcome in our next issue.



Parent perspective

In 2012 bereaved parent Laura Mongiovi, whose son Alfonso died shortly after birth in 2006, set out on her mission to help others by setting up a local Sands group in Wolverhampton.

Alfonso was born via an emergency C-section with a very faint pulse, he died 22 minutes later having lost too much blood.

'Alfonso was my first baby and when he died my world fell apart,' says Laura. 'At that time, there was nowhere to turn locally for support, as the nearest Sands group was in Birmingham. I knew that I had to do something to help other parents going through the same devastating experience of losing a baby.'

Today, more than 6 years later, as Chair of Wolverhampton Sands she, along with other group members, has proved how essential this is to her local area.

Care and support services have improved dramatically with helpline support and monthly meetings.

'I wish there'd been something like this for me. Seeing how supported the parents can feel makes me think that I could have taken steps forward a lot faster than I did. Running this group has been cathartic and I can see how far I've come. When I meet these parents I'm reminded of that early pain.'

'My aim is for them to see that life does move forward, albeit very slowly, with the right support.'

'The work that Sands does in terms of research and prevention is so important. If headway can be made into why so many babies die in this day and age and how these deaths may be prevented, then parents in the future may be spared the agony of losing their baby.'



Bereaved parent Laura Mongiovi and her daughter Sophia

There are 104 local Sands Groups within our UK-wide network. They offer emotional support and help to bereaved families. Many groups also work closely with hospitals in their area, and get involved in local and national campaigning to call for action to reduce the numbers of babies dying.

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 www.uk-sands.org

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

Fundraising:

t: 0845 6520 448

e: fundraising@uk-sands.org

www.uk-sands.org/Get-involved

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

Support:

t: 020 7436 5881

e: helpline@uk-sands.org

www.uk-sands.org/Support

For all other enquiries, contact Sands head office:

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Sands 
Stillbirth & neonatal death charity