

Sands research update

Sands supports a number of research projects that aim to reduce stillbirths in the UK. As well as supporting some studies financially, we also input to the study design from the mother's or family's perspective, and support researchers' applications to major funding bodies. Studies we currently support include:

- ▶ a study run from Cambridge University, which is building evidence to show how ultrasound scanning in the third trimester might be better used to detect more babies at risk of stillbirth
- ▶ AFFIRM, a study running across Scotland, England, Wales and Ireland looking at the impact of following a specific pathway of care in maternity units for responding to women who say their baby's movements have reduced
- ▶ STRIDER, which is investigating whether the medication sildenafil (better known as Viagra) can improve blood flow through the placenta to help babies with severe growth restriction (identified between 22 and 29 weeks of pregnancy)
- ▶ a study led from Great Ormond Street Hospital, which is collecting information from over 1,000 post mortems of stillborn babies. The study will identify the most helpful tests and will also develop a way for pathologists to record information consistently which will, in turn, help with further research.

For more information about all the research in which Sands is involved, visit www.uk-sands.org/Research

Setting priorities for stillbirth research

Sands is part of the steering group of the Stillbirth Priority Setting Partnership (PSP) working to produce a 'top ten' of unanswered questions around stillbirth. Through an online survey, the Stillbirth PSP is asking bereaved parents, health professionals, researchers and anyone else affected by stillbirth to submit what they think are the most important questions for stillbirth research. These can relate to any aspect of prevention, management and bereavement care.

The Stillbirth PSP will then look to see if they've been answered by research already carried out. Those that haven't will be collected together and those people who took part in the initial survey will be asked to prioritise them to give a top 10-15 of the most important questions.

The simple online survey is open to individuals, groups and organisations and can be found at www.stillbirthpsp.org.uk until 12 July 2014. The priority list of unanswered questions is expected to be published in May 2015.

This work, which is being coordinated by Dr Alexander Heazell at Manchester University and the James Lind Alliance, presents an exciting opportunity to highlight the unknowns in research related to all aspects of stillbirth and to improve access to funding for key projects. We urge you to take part.

The steering group of the Stillbirth PSP includes representatives from other parent charities, the Royal Colleges and professional groups. Further information is available at www.stillbirthpsp.org.uk

NHS England examines support available following loss in pregnancy

A new report titled *A review of support available for loss in early and later pregnancy* has been launched by NHS England. Sands' Groups Manager, Judith Abela, attended the report launch and was given the opportunity to talk to the audience about the work of Sands, along with the Miscarriage Association. The report focuses on:

- ▶ what support currently exists for women and families across England who experience loss at less than 24 weeks gestation
- ▶ what support exists for women and families across England who experience loss at greater than 24 weeks gestation
- ▶ what support exists for stillbirth, pre- and post-delivery, identifies the key charities involved in this and determines what they offer
- ▶ identifying areas of good practice, soft intelligence and stories from women with experience of loss.

It is hoped the report's findings will lead to ongoing improvements in care. To read the full report, visit: www.nhs.uk/resource-search/publications/pregnancy-loss.aspx

Parent perspective

Chair of Huddersfield Sands, Rachael Brann, set up her local group in 2012, 4 years after her baby died.

In 2009, Rachael's waters broke when she was 22 weeks pregnant and she was put on bed rest. Five days later, she went into labour naturally but it was found that baby Mason had died in the womb. He was born weighing 1 pound 2 oz.

"When Baby Mason died there wasn't a local Sands group near me. I had to travel to attend meetings and this made me realise that setting up a group in Huddersfield was vital to all those affected by the death of a baby in my local area."

The death of a baby is a devastating and life changing experience, and it is vital that good-quality support is available."



Photo from left to right: Barry Sheerman MP; Rachael Brann; midwives Sarah Hall and Sara Balmforth; Head of Midwifery, Anne Marie Henshaw; parent and member of Sands, Jo Grace.

Rachael's drive to support others recently culminated in Huddersfield Sands being able to fund the refurbishment of a bereavement suite at the Calderdale Royal Hospital, after spending more than a year collecting donations, including £4,000 from local bereaved parents.

The group worked closely with hospital staff in order to refurbish one of the rooms on the maternity unit and turn it into a dedicated bereavement room. It is hoped the separate suite with facilities for parents both during labour and afterwards will go some way to helping parents and families at a most devastating time. The 'Little Footprints' suite was officially opened in February 2014 by Huddersfield's local MP Barry Sheerman; a supporter of the local group.

Mr Sheerman said: *"I'm honoured to have been asked to open this suite by Huddersfield Sands. The charity carries out such a great job supporting and caring for parents at such a distressing time and I'm happy to help out in any way I can."*

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



Harriet and her baby sister Beatrice who died shortly after birth

Five years ago Sands launched its *Saving Babies' Lives* report in the House of Commons and subsequently in the Welsh Assembly, in the Scottish Parliament, and in the Northern Ireland Assembly. In the foreword to that report I wrote:

"The overriding message from Sands and the thousands of parents who are supporting the Why 17? Campaign is that the deaths of 17 babies a day in the UK is totally unacceptable. What we want to see is a real, collaborative commitment to address these individual tragedies as a matter of urgency and priority."

Five years on, the question is: are we making progress? The answer is yes. An unstoppable momentum is building, based on a real national and political commitment in each of the four UK Governments.

Reducing stillbirths is now a priority for each of the 12 Strategic Clinical Networks in England and we are delighted to be working with them. In 2012, the stillbirth rate dropped to its lowest recorded rate in England (4.81/1000) for 20 years, but this is still unacceptably high.

The Northern Ireland Maternal and Infant Loss group is focusing on reducing stillbirths and perinatal deaths as part of its strategic work programme. In Scotland, the numbers and rates of stillbirths and perinatal deaths in 2012 were the lowest ever recorded. While the Welsh Initiative for Stillbirth Reduction (WISR) is sharing best practice and driving improvements across Wales through Local Health Board 'champions'.

The professional bodies are also working strategically to reduce babies' deaths. In March this year, the Royal College of Obstetricians and Gynaecologists launched its initiative to reduce stillbirths, called 'Every Baby Counts'.

The momentum is building, but there is still much to do to ensure our collective goal of fewer deaths and fewer bereaved parents to support. With your continuing help we can make that a reality.

Neal J. Long.
Neal Long, Chief Executive, Sands

Sands
Stillbirth & neonatal death charity

Spotlight on Sands

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Diary Date
International Stillbirth Alliance Conference 2014
18 – 21 September 2014, Royal Tropical Institute, Amsterdam, the Netherlands.

Please join us there or help to spread the word among your local healthcare professionals about the conference.

Tackling the low awareness of stillbirth

Awareness of stillbirth and its causes is low. We know this from our work with bereaved parents, and focus groups of non-pregnant mums and pregnant women have now confirmed it. The groups, organised for the Public Health Task and Finish Group (see end), were the first step to developing effective public health information to help women reduce their risk of stillbirth.

The focus groups were clear. Women want stillbirth messages presented as part of a wider ‘safer pregnancy’ package as they feel they are already getting a lot of information about health and pregnancy. And women want practical information about what they can do to reduce their risk.

In early May, Sands brought together other charity groups, representatives from the Royal College of Midwives, the Royal College of Obstetricians and Gynaecologists and the Scottish Stillbirth Subgroup, as well as organisations and midwives at the front line of communicating with women, to agree the priority messages and how they fit with ‘a safer pregnancy’.

Wording around lifestyle, attending antenatal appointments, reporting concerns and reducing risk of infection will now be developed and tested on women over the next couple of months, as will designs and formats. Once agreed by health professionals, charities and public health experts, the final messages and products should be available in early 2015. We will keep you updated on progress.



The Public Health Task and Finish Group is a Sands-led group of experts brought together following the Sands/Department of Health national workshop to reduce stillbirth

International Stillbirth Alliance Conference 2014

Sands is delighted to be a sponsor of this year’s ISA conference entitled *The 2014 International Conference on Stillbirth, SIDS and Baby Survival*, taking place in Amsterdam, the Netherlands, 18–21 September. This hugely important conference brings together experts from all over the globe who are working to reduce stillbirths.

The conference provides a great opportunity to share big ideas and small changes, exchange views and evidence about what works well, and meet and hear from health professionals, parents and researchers from different countries.

- This year, the main themes are:
- ▶ breaking down the barriers and transfer of knowledge and experiences of parents
 - ▶ identifying preventive and risk factors for perinatal, neonatal and post-neonatal death
 - ▶ online parent support groups moving forward: how to achieve infant death reduction.

Reduced attendance fees are available for parents, nurses and students.

Please consider joining us there, or help to spread the word among your local healthcare professionals about the conference. More information on the programme can be found at www.babysurvival2014.nl

The Growth Assessment Protocol (GAP) Programme



How to identify a baby in trouble during pregnancy is a key challenge for those working to reduce stillbirth. A slowing of baby’s growth is a sign that something is wrong, and a ‘growth-restricted’ baby (a baby who is smaller than they should be for their gestation) has a greatly increased risk of stillbirth or perinatal death. But important though it is to track and monitor the baby’s growth, midwives face this task armed with only a tape measure and a growth chart. Research is under way to find more reliable and accurate ways of monitoring growth, but in the meantime, efforts have been made to make the best use of the tape measure method.

The GAP Programme from the Perinatal Institute, a national non-for-profit organisation, is being adopted by a growing number of trusts and health boards across the UK in efforts to improve the detection of babies with poor growth.

The Programme trains and supports health staff to make consistent and reliable tape measurements of the fundal height (the distance from the top of the uterus to the top of the pubic bone, which is used to assess the baby’s growth; a short film by the MAMA Academy shows how to take an accurate measurement, <http://youtu.be/kCDHn1Imr0>).

The measurements are plotted on a ‘customised’ growth chart for that baby, which is matched to certain characteristics of the mum (height, for example). So a baby who is expected to be small because mum is small has its growth plotted on chart where the lines for expected growth are set for smaller babies. Some babies are flagged up for further checks using the customised charts when they would have been seen as ‘normal’ on the general one-size-fits-all chart, while other healthy babies who might have been considered small on the general chart are ‘normal’ on the customised charts.

Better training, heightened awareness of the importance of these measurements and a consistent approach to taking and recording the measurements should make it possible to identify more babies at risk of perinatal death (stillbirth or death soon after birth). These are early days for the GAP Programme, but there are some encouraging results in the regions of the UK where it is being used. As with all new ways of working, the collection of data, information and experience with the Programme over a longer period of time will give us a clearer overall picture of the effect of the GAP Programme on the numbers of babies dying.

Results of NHS England survey

Readers may recall that in the November issue of *Spotlight on Sands* we highlighted how NHS England had commissioned Sands to carry out a survey among bereaved parents about its Friends and Family Test (FFT).

The FFT asks patients whether they would recommend the NHS service they have received to friends or family who need similar treatment or care, and NHS England wanted to know whether it would be acceptable to use a version of this test with parents who had had a miscarriage, stillbirth or neonatal death.

We received a fantastic level of responses from parents to our survey, and we are delighted to say that as a result of this feedback, NHS England issued clarification about the test to healthcare providers. The clarification stated that parent responses to the Sands survey strongly suggested that the standard FFT question, its timing and method of delivery, are not appropriate for recently bereaved parents, and informed providers that they are not required to offer FFT questionnaires to bereaved parents, but that they have flexibility, on a case-by-case basis, to exercise discretion, and avoid causing unnecessary, additional distress to families in hugely difficult circumstances.

NHS England is continuing to look at this issue, recognising that it is ‘vitaly important’ to hear the views and experiences of affected women, whilst simultaneously ensuring that such feedback is handled sensitively.

Listening to Parents

“I felt my consultant was too busy to care. Consultant simply said if you lose it you lose it. Nothing you can do. Very insensitive.”

“Doctors, midwives and hospital staff were extremely gentle with us and all decisions made were without pressure.”

Listening to Parents, an in-depth survey of women’s and their partners’ experiences of care when their baby was stillborn or died shortly after death, has highlighted huge gaps in care and provision. While some of the 720 parents who responded said their care was sensitive and supportive care, others did not.

Around two-thirds of parents whose baby died before labour suspected something was wrong, but around half of these parents felt their concerns weren’t listened to or taken seriously when they contacted a health professional.

Too many bereaved women stayed in rooms within earshot of newborn babies and women in labour (more than half in the case of mothers of stillborn babies).

When women returned home, some reported that the health professionals who visited them were clearly uncomfortable handling their situation. And many were not given information about how to cope with breast milk production or contacts for counselling.

The report will inform improvements to Department of Health policy that must be made to avoid the postcode lottery of bereavement and postnatal care. Sands is using learning points from the survey to inform its training programmes for health professionals and is joining its voice with other charities to campaign for better care for all parents.

Sands launches new and updated support booklets

We have created and updated a number of key support booklets since the last issue of *Spotlight on Sands*. *Saying goodbye to your baby*, a vital booklet for parents designed to help them through the first hours, days and weeks after losing their baby, has been updated with the latest information and guidance. *Supporting children when a baby has died* and *For family and friends* have both been expanded from 4-page leaflets to detailed booklets. And *Sexual relationships after the death of a baby* has been created to address what is a sensitive and often hard to talk about subject.

All our booklets are available for free. They can be downloaded from our website (www.uk-sands.org/Resources) or ordered from our online shop (<http://shop-sands.org/shop/>) or by calling 0845 6520 448.



The full report from the study, which was carried out by a team from the National Perinatal Epidemiology Unit at Oxford University and published in April 2014, can be found at www.npeu.ox.ac.uk/listeningtoparents.

The team contacted all women who’d registered a stillbirth or neonatal death in England between 1 Jan and 31 March 2012 or 1 June and 31 August 2012 for the survey, and 720 women felt able to complete and return the study questionnaire.

