

Issue 3 June 2011

Spotlight on Sands

Parliamentary Bulletin

Introduction

Welcome to issue 3 of *Spotlight on Sands* our parliamentary bulletin, bringing you the latest news and updates on the charity's campaigns. This issue coincides with our annual June Awareness Month where we aim to improve awareness of stillbirth and neonatal death, and raise vital funds towards Sands important work.

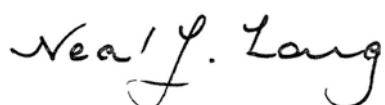
The issue of stillbirth made headlines in April after the publication of the Lancet medical journal's Series on Stillbirth. Research found that the UK has one of the worst stillbirth records among similar high-income nations. You can read details on the Series on pages 2 to 4, along with our recommendations for change.

We have also been closely monitoring developments in the NHS. We would like to add our voices to those questioning the processes of local commissioning of maternity services through GP consortia. We are concerned that maternity services will become

increasingly 'lost' among the many local health care priorities, and that service provision may become variable. The threat of reducing resources, given existing constraints on midwives and lack of truly 24-hour obstetric cover, is very worrying when stillbirth rates are already too high.

While we continue to respond to government consultations and enquiries where relevant, we have also joined forces with influential women's magazine *Grazia* to launch a new campaign calling for government to fund research into what is causing stillbirths and potential screening techniques to identify at-risk babies. Thousands have already signed our petition, which we will be presenting to Government before the Summer Recess.

Thank you for taking the time to read about our work.



Neal Long, Chief Executive, Sands

Contents

- 2 The Lancet Series on Stillbirth
- 3 Scottish Stillbirth Sub Group Sands Audit Tool
- 4 Reasons for high stillbirth rates Recommendations for improvement
- 5 Grazia/Sands joint campaign Westminster event: November 2011
- 6 Sands parliamentarians

Diary Date

Sands Parliamentary Briefing 2011

Wednesday,
30 November,
4 to 6pm.

The Terrace Pavilion,
House of Commons.

See page 5 for more details.



Stillbirth & neonatal death charity

The Lancet Series on Stillbirth

"11 babies dying every day is a national scandal which has persisted for far too long in this country." Neal Long, Chief Executive, Sands

In April, The Lancet medical journal published their Series on Stillbirth which revealed that the UK has one of the worst stillbirth records among high-income nations. Sands contributed the Parent Commentary to the Series and over 350 media outlets covered the story in the UK alone.

The UK's stillbirth rate (for deaths in the third trimester) in 2009 was 3.5 stillbirths per 1,000 births ranking only 33rd out of 35 high-income countries. This places us amongst the most poorly performing countries in the developed world, with higher rates in only France and Austria.

The Lancet Series analysis of stillbirths in high-income nations (Paper 5)



Jason Hyde hand-in-hand with his stillborn son, Sherman

shows that while countries such as Norway, Australia and The Netherlands have seen significant reductions in their stillbirth rates over the last ten years, in the UK stillbirths are at the same levels they were a decade ago.

The Series highlights the fact that stillbirth rates vary between countries

with similar populations, demonstrating that stillbirths are not 'just one of those things'. Many stillbirths are due to preventable factors and it is possible to take action and avoid the deaths of many babies.

Why is this not happening in the UK?

"Our son Matthew was stillborn at 38 weeks, no complications, no issues, no explanation. My life changed forever that day. The Lancet research raises some fundamental questions, not least why there is so little being done about the fact that 11 babies are dying every single day here in the UK." Steve Hale, bereaved Dad

Key facts

- ▶ 11 babies are stillborn every day in the UK. This means over 4000 babies die every year leaving thousands of Mums and Dads, their families and friends devastated by the death of their babies.
- ▶ A significant proportion of these deaths are potentially preventable.
- ▶ While infant and neonatal mortality has declined in the UK, the stillbirth rate has remained largely unchanged over the past ten years, and even increased in 2009 to 5.2 stillbirths per 1,000 births (from 5.1 in 2008). (NB this rate is for 24+ weeks gestation deaths)
- ▶ Stillbirths are 10 times more common than cot death.
- ▶ 90% of babies who are stillborn do not have any serious abnormality and a third of stillbirths have no obvious cause, meaning the baby was otherwise perfect. Most stillborn babies die at gestations when they might have survived if they had been delivered in time.

The Lancet medical journal's Series on Stillbirth provides the most comprehensive assessment to date of the global stillbirth situation. To access the Series please go to www.thelancet.com/series/stillbirth

Scottish Stillbirth Sub Group

Stillbirth rates in Scotland appear to be significantly higher than in the rest of the UK. Following our campaigning activity in Scotland, the Scottish Government has taken action to look at stillbirths and what can be done to bring the rates down.

The new Scottish Stillbirth Sub Group, working under the umbrella of NHS Scotland's Maternity Services Action Group (MSAG), aims to identify priority areas for action and to provide advice and leadership in implementing policy

changes. Sands has representation on this Group.

Led by Dr Catherine Calderwood, Senior Medical Officer Women and Children's Health, Scotland, the Sub Group's first meeting took place in the spring. It identified a number of areas of focus, including perinatal review processes; a pathway for care after a perinatal death; education for clinicians, and a detailed examination of the data on perinatal deaths.

The Sands team believe that the group has the potential not only to drive through change in Scotland, but could act as a template for action elsewhere in the UK, and will be suggesting this to the relevant officials over the coming months.

How MPs can help?

► Write to the Secretary of State for Health to recommend similar working groups are set up in England, Wales and Northern Ireland.

The Sands Audit Tool for maternity services

Launched in March 2011, the *Sands Audit Tool for maternity services: Caring for parents whose baby has died*, has been developed to help those responsible for commissioning and providing maternity services to assess the quality of care they provide to bereaved parents, and identify any improvements that are needed. It aims to help maternity services managers and staff ensure that bereavement care services and processes in place at any given hospital are as good as they possibly can be.

The Tool is accredited by the Royal College of Midwives and offers recommendations on changes that could improve care. Whilst we recognise that there are costs associated with such changes, we are urging maternity units and commissioning bodies to see bereavement care not as an add-on service but as a front-line service.



The way parents are cared for at this time can have a long-lasting emotional impact. All Heads of Midwifery, Trusts and Health Boards have now received a copy of the Audit Tool and it can be downloaded at www.uk-sands.org. Sands has also recommended that maternity units involve local Sands support groups in providing feedback on the care parents have received

and any recommendations for improvements.

How MPs can help?

► Write to your local maternity unit to ask if they are using the Audit Tool and if they have identified any changes needed, or what challenges they face to implement change.

Why are UK stillbirth rates high?

- ▶ **Lack of awareness about stillbirth and risk factors, and little targeted action to reduce rates.**
- ▶ **No accurate ways to detect babies at risk of unexplained stillbirths – which are the majority of stillbirths.**
- ▶ **Sub-optimal maternity care, which contributes to over half of otherwise unexplained stillbirths.**
- ▶ **Over-stretched and under-resourced maternity units, making it hard for staff to deliver safe care.**
- ▶ **No standardised review of stillbirths, meaning lessons are not learned and practice does not change.**
- ▶ **Lack of understanding about inequalities in stillbirth rates amongst ethnic minority and socially deprived groups.**

Stillbirths must be a key public health priority. Sands wants to see:

1. Increased awareness of stillbirth risk:

- ▶ Women need to be informed about risk factors such as obesity, smoking, alcohol consumption and being an older Mum (over 35 years of age), so they can make informed decisions in relation to pregnancy.
- ▶ Women need better information about warning signs that their baby may not be thriving, such as fetal movements slowing down, so they have the confidence to seek help quickly if they think something is not right.
- ▶ Healthcare staff need appropriate training so they are fully aware of the risk factors and warning signs for stillbirth and know how to respond.

2. Lessons to be learnt when a baby dies:

- ▶ We need far more rigorous investigations into stillbirths in the UK so lessons can be better learnt. Several high-income countries, such as Norway, Australia and The Netherlands are seeing significant

reductions in their stillbirth rates, helped by information from detailed audit of every stillbirth.

- ▶ We want an analysis of best practice for stillbirth review in the UK, and national guidance to make the review process more effective in finding answers about what contributed to a baby's death.
- ▶ Reviews must be carried out to find out the clinical cause of each baby's death, and also to identify changes in practice that could reduce future deaths. Accountability is required to ensure recommendations are implemented and sustained.
- ▶ Specialised perinatal post mortem services need to be more accessible – there are not enough specialist pathologists in all areas, and the costs of ordering a post mortem are inhibiting when budgets are tight.

3. Properly funded and resourced maternity care:

- ▶ We need properly funded and resourced maternity services that provide the highest levels of care

with safety as the first priority. This should be a truly 24 hour, 7 days a week level of service and care.

- ▶ Antenatal care must be accessible and able to meet the needs of the UK's increasingly complex maternal population.

4. Funds committed for research:

- ▶ We need research to find ways to screen pregnancies more accurately so that vulnerable babies can be delivered early and safely.
- ▶ We need to find out why otherwise healthy babies are dying. One in 3 stillbirths are related to placental dysfunction and a third of stillbirths remain unexplained.
- ▶ We need research to understand the role ethnicity and social deprivation play in increasing the risks of stillbirth and what the most effective ways of tackling inequalities are.

"The majority of stillbirths in the UK could be prevented if we had better means of detecting babies at risk. This Lancet series outlines the scope of the problem and the priorities for research." Professor Gordon Smith, Head of Department of Obstetrics and Gynaecology, Cambridge University and Chair of the RCOG's Stillbirth Clinical Study Group

Lancet findings spark widespread media coverage...

Sands was alarmed at the Lancet findings, and these feelings were mirrored across the UK, with unprecedented media interest in the story.

The Sands team worked tirelessly to provide dozens of media outlets with background information about stillbirth. Parents bravely told of the true 'human impact' of their babies' deaths.

We featured:

- ▶ On 7 TV programmes including BBC, Sky and ITN news
- ▶ On 15 radio stations, including the Today programme on BBC Radio 4
- ▶ In more than 20 national newspaper stories, both in print and online
- ▶ In more than 300 regional newspaper stories online, and 25 in print
- ▶ In 4 stories in health publications, print and online



Baby Maisie Hughes

The amount of publicity highlights how many people really care about these issues, and the extent of public support for urgent action to improve the situation in the UK.

...and prompt joint campaign with *Grazia* magazine

As a direct result from the Lancet series we were approached by *Grazia* magazine.

They were appalled by the statistics and wanted to join forces with us to call on government for more research into what's causing babies to die, and to develop new ways of screening pregnancies. We launched a joint

petition in the 23 May issue of *Grazia*, and within just one week we had over 7,500 signatures.

GRAZIA

How MPs can help?

- ▶ Make your constituents aware of the petition and encourage them to sign online or download a paper version. Contact tara.macdowel@uk-sands.org for more information.

Sands returns to the House of Commons

It is over two years since Sands launched the acclaimed *Saving Babies' Lives Report, 2009* at a parliamentary event in Westminster. The launch sparked huge media and political interest in the issues, and acted as a springboard for many of our campaigning activities.

We are pleased to announce that we will be returning to Westminster on 30th November 2011 for an event in the House of Commons, kindly

hosted by Dr Daniel Poulter MP. Not only will the event provide Sands parents a forum to meet with their local MPs, but it will also see the launch of a follow-on report providing an up-to-date picture of progress made and issues that still need addressing.

Invitations will be sent out in the autumn, but in the meantime if you would like to register your interest in attending this event, please contact tara.macdowel@uk-sands.org.



Support us as a Sands Parliamentarian

The Sands Parliamentarians Group is an informal group of MPs, MSPs, AMs, MLAs and Peers who are committed to supporting the issues that are of concern to Sands, because they are the issues that matter to the bereaved families we represent.

The group will help us to raise the profile of our *Why17? campaign* at a national policy level, to stimulate debate and encourage collaboration to create a national strategy to reduce the number of stillbirths and neonatal deaths.

For more information on becoming a Sands Parliamentarian, or how to support our *Why17? campaign* contact:

Tara MacDowel, Campaigns and Policy, Sands
tara.macdowel@uk-sands.org 0208 973 3691

Katie Duff, Communications Manager, Sands
katie.duff@uk-sands.org 0845 6520 442

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 is a national charity, with nearly 100 support groups across the UK, focusing 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 care
- ▶ We promote and fund research that could help to reduce the loss of babies' lives

Helpline: 020 7436 5881

Office: 020 7436 7940

Web: www.uk-sands.org

Web: www.why17.org

Email: info@uk-sands.org

Charity registration number 299679