

Spotlight on Sands

Issue 10
May 2015

*Mark Goodridge with daughter Alyssa,
stillborn at two weeks before her due date*

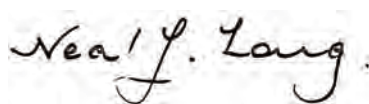
This issue brings the welcome news from the Office for National Statistics that the UK stillbirth rate in 2013 was the lowest recorded since 1992, and that the rate of neonatal deaths has also decreased.

Sands has played a key role in raising awareness of the UK's unacceptably high stillbirth rate, and reducing neonatal mortality and stillbirths are now priority areas for NHS England. Initiatives in Scotland, following Sands' 2009 report *Saving Babies' Lives*, have resulted in the most consistent fall in the stillbirth rate across the UK.

Whilst this news is positive, we know that much more still needs to be done. A number of the measures we called for in our *Preventing Babies' Deaths* report are not yet in place.

The report of the Morecambe Bay Investigation reflects many of our own recommendations, echoing our own call for the rigorous investigation of baby deaths to inform changes in care, and the need to involve the family in the process.

Sands is widely acknowledged and respected for our input into policy and direct research into preventing stillbirth and neonatal death. But the UK stillbirth rate is historically one of the worst in the developed world, and we want to see the UK rate fall further. None of the work to help achieve this could continue without our supporters and fundraisers. In this edition we highlight the vital work of our many fundraisers, giving some behind-the-scenes insight into their efforts. It also reaches you in time for Sands Awareness Month throughout June - visit www.uk-sands.org for information and how to get involved. We look forward to seeing you at the events, and thank you for your continued support.



Neal Long, Chief Executive, Sands

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Diary Date

June is Sands Awareness Month
– with events across the UK

**Sands Remembrance Service
and Garden Open Day**
13 June

**7th Joint Conference of Sands,
Bliss and Royal College of
Midwives** 17 September

Visit www.uk-sands.org for more
information about these and many
other events and how to get involved
in Sands Awareness Month.



Government figures show decline in rate of stillbirth and neonatal death

Data from the Office for National Statistics (ONS) published in March this year revealed that the rates for stillbirths are the lowest since 1992. The 2013 figures show a fall in the UK stillbirth rate to 4.6 stillbirths to every 1,000 births.

This positive change is after over a decade of stagnation in the UK stillbirth rate, which is historically one of the worst in the developed world.

The rate of neonatal deaths also decreased in 2013 to 2.7 per 1,000 live births.

While Sands welcomes the beginnings of a downward trend in recent years, we know much more can be done to bring rates down. We want to see the UK stillbirth rate fall further, to no more than 3 per 1,000 births as has been achieved in other countries.

So what is behind the fall in the rates? There are likely to be a number of reasons. Sands' *Why17?* campaign, launched in 2008, significantly raised awareness of the high number of babies dying every day in the UK, not just among the public but also among health professionals and policy makers.

Our reports *Saving Babies' Lives* and *Preventing Babies' Deaths* highlighted the changes needed at a national level.

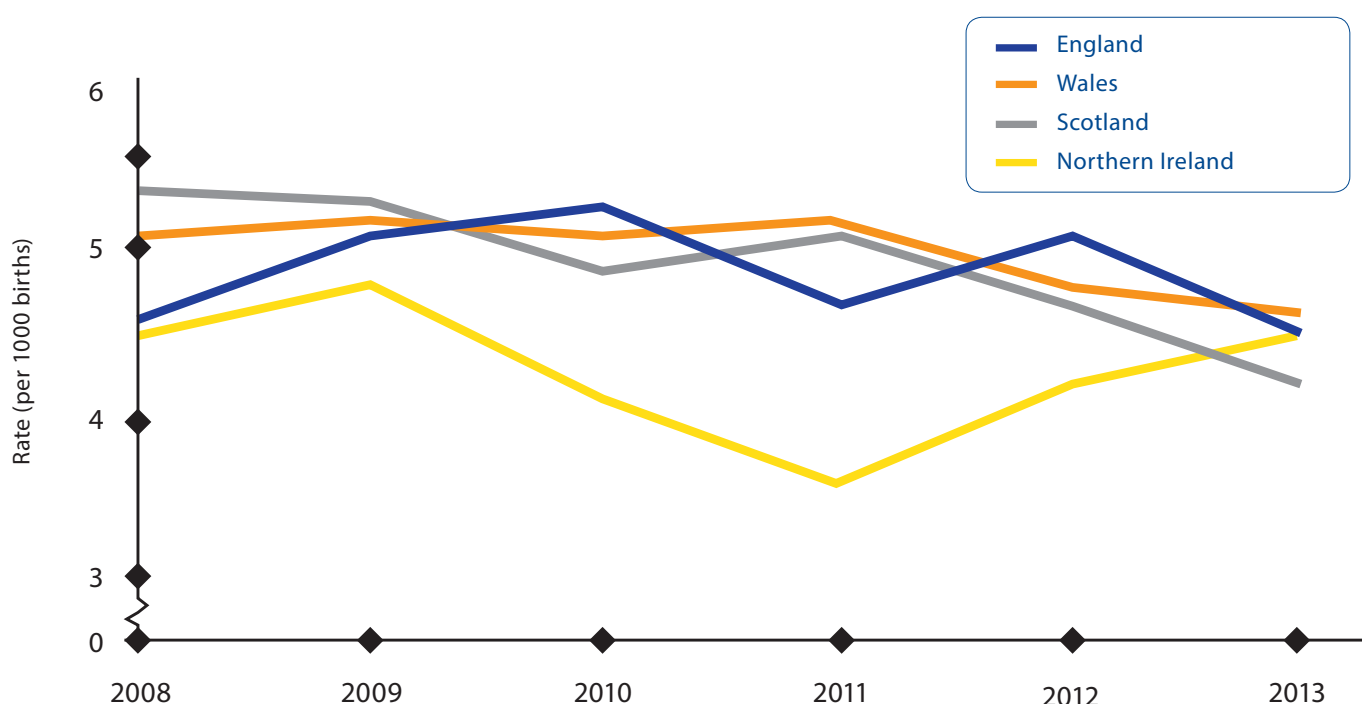
Scotland and Wales established expert working groups to look at ways to reduce the numbers of babies dying.

NHS England set stillbirth reduction as a priority for the NHS, and Sands' work with the Department of Health means stillbirth risk is now included in health information for pregnant women and their partners.

Northern Ireland has established a steering group to look at all baby and infant loss, from miscarriage to infants under one year of age.

While we welcome the focus on reducing the rates, there is still much more that can be done to prevent all avoidable deaths before, during, or shortly after, labour and birth.

Sands is continuing to press for important changes to policy and practice and to support new, pioneering research.



Morecambe Bay inquiry highlights serious failings in maternity care

March saw the publication of the Kirkup report, detailing the investigation into maternity and neonatal services at the University Hospitals of Morecambe Bay NHS Foundation Trust from January 2004 to June 2013.

It catalogues 20 instances of significant failures of care that may have contributed to the deaths of three mothers and 16 babies, finding that different clinical care in these cases would have been expected to prevent the death of one mother and 11 of the babies. Systemic failures were found on all levels, from the maternity unit, to the Trust's management, to the health regulators.

Sands particularly supports the report's recommendation that clear standards for open and honest reporting must be developed. We have long called for all baby deaths to be rigorously and objectively investigated so that lessons from poor care, where it exists, can be learnt and mistakes not repeated. To be effective, this process has to be open and honest and must always include the parents' perspective of events. All maternity services can learn from the report so that tragic deaths such as these can be avoided in the future.

Sands will continue to support efforts to establish high-quality investigations into all baby deaths and to ensure that parents' voices are always heard.

Sands part of re-launched National Stillbirth Working Group for Wales

Sands is delighted to be part of the new National Stillbirth Working Group for Wales (NSWG), which since its launch in January meets each month to share experience and drive progress.

Sands has been able to update the group on our ongoing work to develop safer pregnancy advice about reducing the risk of stillbirth, as well as on our progress in developing a standardised approach to perinatal review.

We're also advising on steps to improve information about post mortems, recommending that the NSWG looks at bereavement care in Wales.

The previous Working Group (known as WISR – the Welsh Initiative for Stillbirth Reduction) was part of a three-year programme to improve the experience and outcomes for women, babies and their families using maternity services in Wales. Progress had been made in key areas, including that highlighted by the inquiry into stillbirths in Wales by the National Assembly for Wales' Health and Social Care Committee.

The NSWG, chaired by Dr Jean White (Chief Nursing Officer/Nurse Director for Wales), will continue the WISR work. Each of the nine Welsh health boards is represented, alongside representatives from Public Health Wales, the Welsh Government and Antenatal Screening Wales.

The Sands baby sculpture in the Sands Garden at the National Memorial Arboretum, near Litchfield, Staffordshire.

*This year's Remembrance Service will take place on
Saturday 13 June.*



Improving bereavement care – Sands launches new training for doulas

The Sands bereavement care training programme has now been expanded to include a workshop for doulas.

Pregnancy loss and the death of a baby: Sands training for doulas launched in Hull in March, receiving high praise from the attendees, with 100% stating they felt more confident in communicating sensitively and effectively with bereaved parents and their families.



Doulas said:

“A brilliant opportunity, amazing support, and a privilege to be part of and offered the training. It has made a huge difference to my support.”

“The real-life story of Romina was emotional, inspirational and thought provoking. All information will be useful within my role.”

**The training will be available throughout the UK.
View more at www.uk-sands.org/professional-training,
Contact Sands at training.professionals@uk-sands.org
or on 020 7436 7940.**

New online learning for midwives launched

Sands and Child Bereavement UK have co-authored an e-module training course, *One chance to get it right: bereavement care*, to better prepare midwives for supporting parents when a baby dies.

Funded by the charity Abigail's Footsteps, the course provides three and a half hours of learning and reflective exercises and is accessed through the Royal College of Midwives' i-learn platform.

The course will develop awareness, knowledge and understanding of the importance of providing parent-led, sensitive and empathic care for parents whose baby dies before, during, or shortly after birth. It is intended to complement rather than replace face-to-face training.

Find out more at www.ilearn.rcm.org.uk

Sands Groups funding important research

Sands Groups are essential to meeting all three of our aims: providing support, improving bereavement care, and promoting and funding research. You may be aware that Groups support anyone affected by the death of a baby and work locally to improve bereavement care, but importantly they also take part in research and prevention projects and provide funding to enable this vital work to continue.

Fundraisers are at the heart of our work, and Sands Groups accomplish an incredible amount of fundraising each year.

Over recent months several Groups have made significant contributions

to funding three important projects - the AFFIRM study into the impact of awareness of decreased fetal movement on stillbirth, MiNESS (*Midlands and North of England Stillbirth Study*), and a project researching the economic, societal and human costs of stillbirth, to be published in the *Lancet* medical journal.

Information on these projects can be found at www.uk-sands.org.

Collectively, Sands Groups from Cardiff and Newport, Dumfries and Galloway, Fife, Glasgow, Hull and East Yorkshire, Teesside and the Northern Ireland network, have donated an amazing total of £62,000.

We are extremely grateful for all this generous support which has helped to ensure that both the AFFIRM study and the *Lancet* report have been fully funded. There will be further opportunities for Groups to support pioneering research projects later in 2015.



Cardiff and Newport Sands presenting a cheque for £10,000 at the Welsh Network Day.

Case study: One fundraiser's story

Sands relies on the generosity of fundraisers and supporters to continue our work to support bereaved families and improve the care they receive, as well as fund vital research to prevent more families suffering the death of their baby.

This loss is devastating not just for parents, but is felt by grandparents, siblings, other family members, as well as friends and work colleagues. It also touches the lives of the health professionals that have cared for the parents and babies that have died.

Gethin Hine's elder brother Aled was stillborn in the 1980s. On 26 April he joined Team Sands to run this year's Virgin Money London Marathon, in memory of his brother and to raise funds and awareness of Sands.

Gethin, 25, explains the significance of Sands to his family:

"My parents are long-time Sands members and the support of the charity was very important to them after my brother sadly passed before his birth.

"It means a great deal to me to support the charity by running the race to raise funds and awareness for this cause."

Gethin, a tax advisor from Stafford, trained five times a week for the event, getting up early before work each morning to run. His dedication was rewarded with a fantastic Marathon time of 3 hours, 17 minutes 33 seconds. He says, *"The best part was definitely the atmosphere on Tower Bridge. And the worst was the last 6 miles!"*

Gethin's incredible achievement has raised over £3,000 for Sands.

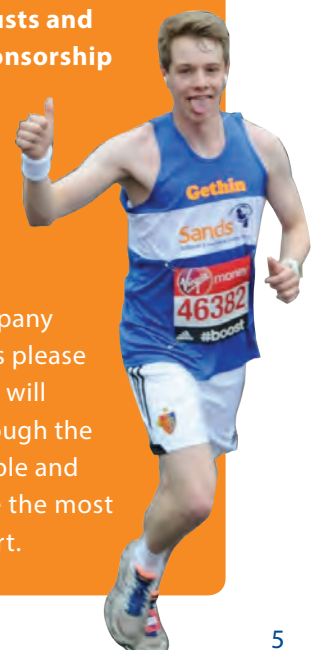
Be a fundraiser

If you would like to do something to raise money for Sands this year visit www.uk-sands.org for ideas on how to get involved.

Our fundraising team will be delighted to hear from you.

Charitable trusts and corporate sponsorship

If you are affiliated with a charitable trust or would like to find out how your company can help Sands please contact us. We will guide you through the options available and help you make the most of your support.



Parent Perspective

On Easter Sunday, Lyndsey, John, and daughters Lucy and Sophie marked what would have been the tenth birthday of baby Kirsty by laying flowers on her grave near their home in Aberdeen. Kirsty was born on 5 April 2005 and died at only 33 hours old the following day, after complications during labour.

"It was heart-breaking. I'm amazed we managed to find the strength, but I suppose we had little choice."

"You hear about things like this happening to other people, but you never think it's going to happen to you. To be honest, I was blissfully ignorant to the fact that there would be any complications, let alone that you could go full term and then lose the baby."



Lyndsey, John and baby Kirsty



Baby Kirsty Spiers

When a few months later Lyndsey discovered she was pregnant again the news was both happy and terrifying. But a healthy Lucy – now eight – arrived the following June. Sadly three miscarriages followed, until Sophie, now two, was born in March 2013. They love nothing more than being a family.

"We think of Kirsty every day. She will always be part of the family. I may only have two children, but I think of myself as a mother of three."

Lyndsey recently became a Sands befriender – a volunteer who supports bereaved families – and has raised hundreds of pounds for Sands to help others affected by the death of a baby.

"It's the best way to keep Kirsty's memory alive. Losing a child was the worst thing that could have happened to us, but thankfully we got through it."

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

 facebook.com/sandscharity

 [@SandsUK](https://twitter.com/SandsUK)

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