

Spotlight on Sands

**Issue 12
June 2016**

*Michelle Yale with her twin baby boys
Jake and Alfie Taylor*



This issue arrives in the midst of Sands awareness month, held in June of each

year. While families of course remember their babies all year round, this month offers more opportunities to come together in activities and events ranging from quiet reflection at our annual Sands Garden Day on 11 June through to fundraising events in different parts of the country.

It is also a powerful way of helping us to promote the importance of campaigning and raising awareness as a means of achieving our collective goal of reducing the number of babies who die before, during or soon after birth.

We also discuss the latest MBRRACE-UK perinatal mortality surveillance report. The report follows the 2015 announcement of a national ambition to halve the rate of baby deaths in the UK by 2030 and importantly outlines changes in policy and practice that could potentially work towards that goal. Sands has worked closely with the Department of Health for a number of years on one of these

recommendations, the standardised process of review when a baby dies, and it is encouraging that we are now very close to seeing this piece of work completed.

However, as the January 2016 publication of the second *Lancet* series, Ending Preventable Stillbirths, highlighted, the wider effects of a stillbirth on parents, families, health staff and society remain largely unrecognised. More awareness of the unacceptably high rates of babies' deaths and the socio-economic effects of stillbirth will help to maintain pressure on the government to meet its target.

Together with our wonderful volunteers, supporters and fundraisers we will keep campaigning to ensure steps are taken to allow government pledges to become a reality. Every bit of progress made to date has been thanks to your ongoing support and we are forever grateful for your commitment.

Judith Abela
Acting Chief Executive, Sands

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Diary Date

June is Sands Awareness Month – with events across the UK

15 September
8th Joint Conference of Sands, Bliss and Royal College of Midwives

9-15 October *Babyloss Awareness Week*

15 October *Wave of Light 7pm*

9 December *Lights of Love*

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

MBRRACE-UK Perinatal Mortality Surveillance Report 2014

The MBRRACE-UK Perinatal Mortality Surveillance Report for deaths in 2014 was published on 17 May 2016 at a launch event at the Royal College of Obstetricians and Gynaecologists attended by more than 250 delegates.

It shows that, in 2014, as in 2013, 15 babies died every day before, during or within four weeks of birth.

The poorest women, and women with a Black or Asian ethnic background, continue to have an

increased risk that their baby will die. There also continues to be stark variation in rates across the country, from 4.9 to 7.1 deaths per 1,000 births.

The MBRRACE-UK report calls for all units in the UK to use a standardised process of review when a baby dies to learn lessons and improve future care.

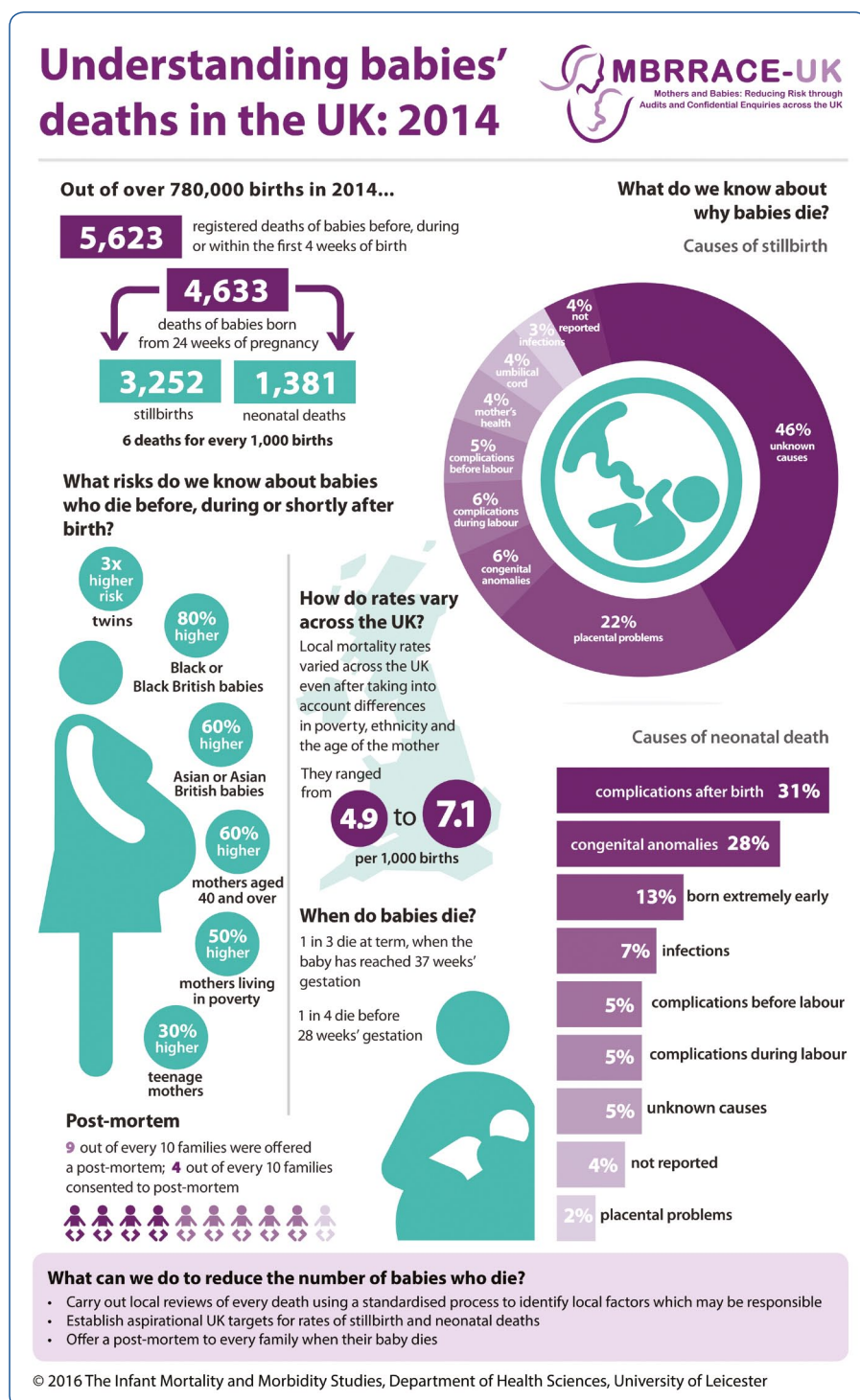
It also calls on all healthcare and policy leads in each UK country to set national targets for stillbirth and neonatal death rates against which their maternity services can be measured.

Sands is working with the Department of Health to develop a standardised tool for reviewing deaths which will be ready by March 2017.

Despite committing to an ambition to halving stillbirth and neonatal deaths by 2030, the government has committed limited funds to achieving this: £1 million towards training and £2 million towards equipment which has been divided among 90 English NHS trusts.

This financial injection, Sands argues, is not enough. *"A significant fall in the rates of stillbirth and neonatal death will not succeed without a clearer strategy, supported by adequate funding,"* said Judith Abela, Sands Acting Chief Executive.

"Without this the existing inequalities cited by the MBRRACE-UK report will persist and avoidable deaths will continue to happen."



Sands research funding: update

Supporting research to help reduce the number of babies dying is one of Sands' three main aims. Thanks to our amazing supporters, we have proudly funded high-quality studies over the last few years. And we want to continue and grow this support.

We are now establishing an annual funding programme, with a procedure for selecting studies that, as with our previous funding decisions, takes account of the recommendations of experts.

Applications for research funding will have initial expert assessment, with those making the first 'cut' being sent for independent review by further researchers. Our Perinatal Expert Panel, chaired by Professor Gordon Smith

(Cambridge University), will then take all opinions into account, judge the applications against specific criteria, and make funding recommendations to the Sands' trustees. Throughout the selection process, we will ask: 'is this study likely to make a difference' and 'does this study represent good value for Sands' money?'

By taking advice from the top researchers and clinicians working in the area of obstetric and perinatal care, we are confident that Sands will continue to fund research that will make a difference.

We're delighted to have the support of so many of the UK's experts in perinatal deaths, and we thank them for their generous time and advice.

The Lancet 2016: Ending Preventable Stillbirths

The ground-breaking 2011 *Lancet* series of papers on stillbirth made headlines around the world. In the UK, most attention focused on the message that the UK's stillbirth rate was far higher than that of similar countries.

Sands' own Janet Scott wrote one of the comment papers in the series, describing the grief of families when a baby dies, and we incorporated messages from the papers in our own campaigning.



Mark Bell with his baby son Rory Bell

January 2016 saw the publication of the second *Lancet* series, Ending Preventable Stillbirths. Once again, the articles highlighted some stark contrasts. In the Netherlands, for example, the rate of stillbirths has been falling by 6.8% per year since 2000, whereas the UK's rate has fallen by only 1.4% per year over the same time period.

The series also included Dr Alex Heazell and colleagues' evaluation of the impact of stillbirth. This work, funded by Sands, shows that the wider effects of a stillbirth on parents, families, health staff and society remain largely unrecognised, reflecting the 'silent grief' of stillbirth and the failure to capture information about the ongoing impact of a baby's death in society.

Dr Heazell called on the global community to lift the taboo on stillbirth and collect the information needed to inform strategies, local services and practices to prevent stillbirth, and interventions to reduce the negative effects of stillbirth.

Calling for an end to preventable stillbirths by 2030, the 2016 *Lancet* series says stillbirths remain 'hidden in the worldwide agenda.' Through our work at Sands, we will continue to raise awareness of stillbirths and the effects on parents and families, and to support those affected.

Scottish student midwife training initiative

Thanks to funding from the Scottish Government and the Sands Scottish Network, Sands launched a project to train all first and third year student midwives in Scotland in bereavement care.

This academic year we will have reached all first year students attending the three universities in Scotland offering the undergraduate midwifery degree. This amounts to 164 first year students from Napier

University, Edinburgh, the University of the West of Scotland and Robert Gordon University in Aberdeen.

We have also trained all third year midwifery students from Napier University, Edinburgh and the University of the West of Scotland – 112 in total.

We hope to see this become an annual programme of training for all first and third year students.

"It was very powerful and gave me good grounding on how to help and support families."

1st year student midwife

"Excellent day and a great addition to the curriculum."

3rd year student midwife

"Very well run and informative. Would highly recommend all student midwives should get this."

3rd year student midwife



Upcoming bereavement care training dates

Accredited by the Royal College of Midwives, our one-day workshops help healthcare professionals confidently provide high-quality, sensitive care to parents who experience the death of a baby.

- ▶ 10 June 2016, Cardiff
- ▶ 23 September 2016, Birmingham
- ▶ 12 October 2016, Antrim
- ▶ 14 October 2016, London
- ▶ 26 October 2016, Inverness
- ▶ 7 February 2017, Bristol

Book now at
www.uk-sands.org/professional-training



New edition of Sands Guidelines - coming soon...

The 4th edition of our indispensable publication *Pregnancy Loss and the Death of a Baby: Guidelines for Professionals* is due to be published in September 2016 and will be available in print and online.

Since the first edition was published in 1991, the Sands Guidelines have been widely recognised as an essential benchmark for good practice when caring for parents whose baby dies during pregnancy, at birth, or afterwards.



Take part in your ultimate challenge for Sands

Nearly everybody has a bucket list of ambitions and challenges they would like to complete in their lifetime.

Why not achieve your dreams AND support Sands at the same time? Whether you wish to walk the Great Wall of China, complete a Three Peaks Challenge here in the UK, jump from an aeroplane or keep your feet firmly on the ground with walks or runs, we're here to help you realise your goal. Our fundraising team can help source places on local, national and international charity challenge

events, help you organise your own event and offer advice on fundraising ideas, supporting you every step of the way.



Please contact us by calling **0845 6520 448** or emailing **fundraising@uk-sands.org**

Case study: one fundraiser's story

At Sands we rely on the generosity of fundraisers and supporters to continue our vital work. Our dedicated fundraising team is there to support and motivate every step of the way. Each fundraiser's motivation and experience is unique. Here's Tom's story...



Tom running the London Marathon 2016

Want to get involved?

Here are some dates for your diary...

- ▶ 11 September 2016: London to Brighton Cycle
- ▶ 9 – 15 October 2016: Baby Loss Awareness week
- ▶ 15 October 2016: International Wave of Light
- ▶ 16 October 2016: Great Birmingham Run
- ▶ 23 October 2016: Great South Run
- ▶ July – October 2016: Big Fun Run series across the UK
- ▶ July – October 2016: Dog Jog series across the UK
- ▶ August – September 2016: Tough Mudder events

Tom Stock's daughter Millie was stillborn in August 2015. Running the marathon gave Tom the opportunity to raise funds to ensure other families will get the help they need for as long as they need it.

"Having a stillborn baby is very isolating. The initial support from Sands meant we were able to make the most of our short time together as a family to create memories when we did not have the ability to think for ourselves. We are incredibly proud of Millie who will always be the first member of our family."

"I really enjoyed the marathon, 22 miles flew by as I enjoyed running down the familiar streets. The crowd were amazing, cheering us and shouting the names of our charities."

"It got tougher after 22 miles and I started to feel drained. Somehow in the last mile I found a boost of energy - the end was near as the markers counted down the distance!"

"Afterwards I felt tired but so proud of my achievement. Now I can say I've run the London marathon!"

"People were really touched that I was running in Millie's memory. That really struck a chord and I received some very generous donations from friends, family, colleagues and strangers raising over £5,200."

Since completing the marathon Tom has helped Sands become 'Charity of the Year' for his employer haysmacintyre. Thank you Tom for your incredible support in Millie's memory.

Parent perspective

Lisa and Stefan's first child Max James Goodyear Loveless was stillborn at term on 27 August 2013.

Up until 32 weeks, Lisa had been enjoying a textbook pregnancy when she noticed she wasn't feeling as much movement as before and her midwife said she was measuring small. She was referred to a consultant who concluded that as Lisa was petite herself it was understandable, so no further scans or checks were scheduled. Lisa visited the hospital on two further occasions to report reduced movements, but was sent home both times. During her next visit her fears were confirmed. *"I already knew but hearing the actual words that Max's heart had sadly stopped*



Max James Goodyear Loveless

beating was truly devastating. It was like someone had pressed pause on our lives and it took us some time to really come to terms with and deal with the events which followed."

The post mortem revealed that although Max had some growth issues, no conclusive cause for his death was found. It was Lisa's sister who recommended Sands, where she found the online forum to be an invaluable source of support.

"This enabled me to reach out to other bereaved parents who were experiencing the same sad and isolating journey of trying to piece our lives back together after receiving such harrowing news. This played a pivotal role in giving me the motivation to turn my own situation into a positive and although we were faced with further miscarriages after the loss of Max, we finally welcomed our rainbow baby, Rosie, in December 2014."

As a Fine Wine Office Manager for Berry Bros. & Rudd, Lisa played an

instrumental part in her employer choosing Sands as their Charity of the Year in March 2014 for three years. Her colleagues have been a fantastic support, from presenting about Sands on Lisa's behalf whilst she was on maternity leave, to organising many exciting fundraising events; marathons, cake sales and fundraising dinners to name just a few.

"I cannot be more thankful for the support and generosity of my colleagues at Berry Bros & Rudd. It's such an honour to work alongside people who embraced my situation and wanted to help raise awareness of Sands in loving memory of our son, Max. Our main aim was to generate funds for research so that other families do not ever have to face what we did and we've surpassed any expectation we had. Thank you to my company and to Sands for ensuring that Max's memory will live on."

We would like to thank Lisa and everyone at Berry Bros. & Rudd for their incredible support.

About Sands

Sands supports anyone affected by the death of a baby, works to improve bereavement care, and promotes vital research to save 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:

Victoria Charity Centre

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