

Country Launches

June 2009: Welsh Assembly Launch

In June 2009 we took the *Why17?* campaign to the Welsh Assembly, and published a Welsh insert to the *Saving Babies' Lives Report 2009* highlighting some of the issues specific to Wales surrounding stillbirth and neonatal deaths.

A seven day journey across Wales by hundreds of Mums and Dads, their families and friends, to raise awareness of the 300 babies dying every year in Wales culminated in a launch at the Senedd, hosted by Kirsty Williams AM. Hundreds of parents also signed a petition, calling upon the National Assembly for Wales to urge the Welsh Assembly Government to:

- take note of the new *Saving Babies' Lives Report 2009*, published by Sands in support of its *Why17?* campaign
- develop a strategy for reducing levels of stillbirths and neonatal deaths in Wales
- fund further research to improve understanding of why stillbirths and neonatal deaths happen
- develop gold standard antenatal care provision in all NHS Trusts in Wales and

- work with Sands to improve public awareness of these issues.

Sands also met with several key Welsh officials, including Welsh Minister for Health and Social Services, Edwina Hart.

Outcomes

The campaign made headline news across all major Welsh media outlets including BBC Wales TV news and *Western Daily Mail*, *South Wales Evening Post* and many other local newspapers and radio stations. Several Assembly Members publicly pledged their support for the campaign.

Our petition attracted hundreds of signatures from supporters, including over 800 signatures via the Welsh Assembly website.

The petition was subsequently considered by the Petitions Committee who wrote to the Minister for Health and Social Services to raise our concerns. Her response guaranteed that she would “be taking forward a number of issues...raised” and instructed officials to “continue to work with Sands to establish what



Culmination of the Welsh journey, outside the Senedd

further can be done to ensure that services for mothers and babies are further improved”.

After the launch, a Welsh Liberal Democrat debate on neonatal services debated many of the issues in our report resulting in an amended motion being agreed which included a call on the Welsh Assembly Government to raise awareness of stillbirth and neonatal death as a key public health issue.

As a result of our activities in Wales, Sands was invited to work with the Welsh National Specialty Advisory Group in Obstetrics and Gynaecology to improve care for bereaved parents and develop greater understanding and review of stillbirths.

Facts

- ▶ 177 babies were stillborn during 2007 in Wales – that’s one baby in every 200.
- ▶ 115 babies died within four weeks of their birth in 2007 in Wales - 84 of those within the first seven days of their lives.
- ▶ The stillbirth rate in Wales has not changed significantly in 15 years. Risk factors for stillbirth including obesity, social deprivation, teenage pregnancies and older mothers are high or increasing in parts of Wales.



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, the stillbirth and neonatal death charity, 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
taramacdowel@btinternet.com 0208 973 3691

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

Sands, the stillbirth and neonatal death charity, was established by bereaved parents in 1978 and obtained charity status in 1981. Sands core aims are to:

- ▶ Support anyone affected by the death of a baby.
- ▶ To work in partnership with health professionals to improve the quality of care and services offered to bereaved families.
- ▶ To promote research and changes in practice that could help to reduce the loss of babies' lives.

Sands is a national organisation with over 100 regional support groups across the UK.

Helpline: 020 7436 5881

Office: 020 7436 7940

Web: www.uk-sands.org

Web: www.why17.org

E mail: info@uk-sands.org

Charity registration number 299679



Spotlight on Sands

Parliamentary Bulletin

Introduction

Welcome to the first issue of Spotlight on Sands, our new parliamentary bulletin. We have been working hard over the last twelve months to raise awareness of stillbirth and neonatal deaths at government level, and have had considerable success in focusing attention on what could be done to save babies' lives.

This bulletin brings you up to date with our recent political activities and campaigns, as well as highlighting forthcoming events. We are grateful to all parliamentarians who support our work, and hope to see many more of you coming on board as Sands Parliamentarians during 2010.

Neal Long, Chief Executive, Sands

Contents

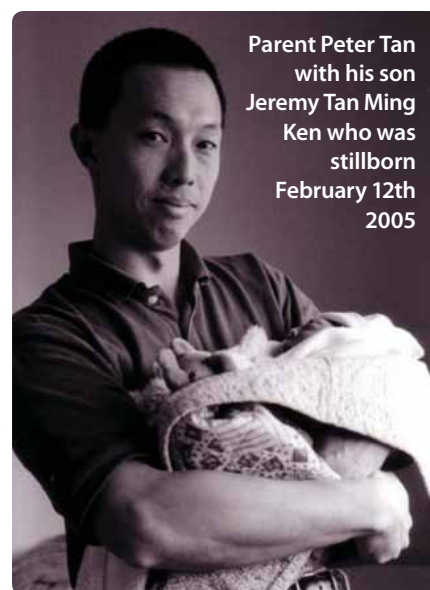
- 2 *Saving Babies' Lives Report 2009*
- 2 Westminster launch
- 3 Wales launch
- 4 Scotland launch
- 4 Northern Ireland launch
- 5 NICE guidance: Seeing and Holding
- 5 Research collaborations
- 6 Become a Sands Parliamentarian

Facts

- ▶ 17 babies die every day in the UK either just before or soon after they are born. Every hour and a half a family is devastated by the tragic stillbirth or neonatal death of their baby.
- ▶ 6,500 babies die every year, yet awareness of this level of loss is still extremely low.
- ▶ One baby in every 200 births is stillborn. Stillbirth in the UK is 10 times more common than cot death, and the rates have not changed significantly in the past ten years.
- ▶ Over half of stillbirths are 'unexplained', leaving parents asking why their otherwise perfectly healthy baby has died.

Sands *Why17?* campaign asks WHY, in spite of medical advances, do 17 babies die every day in the UK?

We want to see a clear acknowledgement of the seriousness and extent of the problem and a real, collaborative commitment to address these individual tragedies as a matter of urgency and priority.



Parent Peter Tan
with his son
Jeremy Tan Ming
Ken who was
stillborn
February 12th
2005



Why17?

campaign

March 2009: Sands in Westminster

We launched our *Why17? campaign* in Westminster in March, starting with a series of meetings with key officials to discuss the issues we care passionately about, as outlined in the *Saving Babies' Lives Report 2009*.

We were pleased to meet with Ann Keen MP, Parliamentary Under Secretary for Health Services, members of the Health Select Committee and the All Party Group on Maternity, and the National Clinical Director at the Department of Health, Dr Sheila Shribman, as well as representatives from the Partnerships for Children, Family and Maternity Division. This meeting programme led up to our *Why17? campaign* parliamentary launch at the House of Commons in March 2009, hosted by Anne Milton MP. The support we received was unprecedented; 64 cross-party MPs attended, along with several high-profile peers. Over 200 Sands parents across

the country also approached MPs to draw their attention to the new report, and the event, which undoubtedly helped the turn-out on the day.

Outcomes

The launch event resulted in the *Saving Babies' Lives Report 2009* making headline news on BBC Breakfast television as well as Radio 4's news agenda-setting Today programme and almost a dozen BBC regional morning radio broadcasts. During the day we were also featured on GMTV and ITN news.

MPs engaged with the campaign in numerous ways: 85 signed up to our Early Day Motion (911), around 50 pledged their support through local press releases, and dozens became Sands Parliamentarians (see page 6). Many also met with local constituents who had suffered a stillbirth or neonatal death; some subsequently visited their



L to R: Speakers Dame Joan Higgins, Chair of the NHS Litigation Authority, Sands CEO Neal Long, Anne Milton MP and parent Steve Hale.

local maternity unit and wrote to the Health Secretary.

Health minister Ann Keen MP agreed to hold a national Stillbirth Workshop, hosted jointly by Sands and the Department of Health.

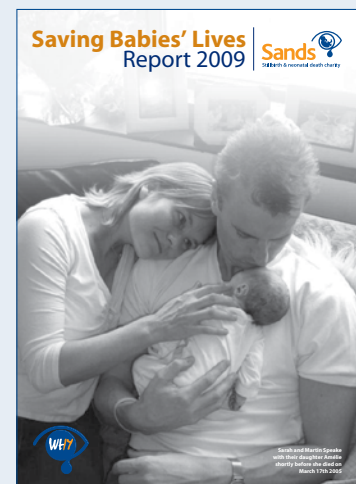
The meeting, due to take place in 2010, aims to bring together key people at a national level to discuss the way forward in reducing stillbirths, with a view to forming a national, government-backed strategy. Though the focus will be on the English health service, the discussions will be relevant nationally.

Saving Babies' Lives Report 2009

In March 2009, we published a new report outlining the key issues surrounding stillbirth and neonatal deaths, and calling for government to address these through:

- ▶ Increased awareness of how many stillbirths and neonatal deaths there are in the UK.
- ▶ Recognition at the highest levels that these baby deaths are a national problem and that a proportion of these deaths might be avoided with improved care and funding for research.
- ▶ Collaboration with other interested parties to create a national strategy to reduce the number of stillbirths and neonatal deaths across the UK and to specifically look at:

- properly valuing each and every baby's life
- improving antenatal care by developing a culture of continual risk assessment within maternity service provision in order to identify pregnancies which may be at risk, even among low-risk mothers
- recruiting and training more midwives to ensure the highest levels of care
- better overall resourcing of antenatal and neonatal services to provide a truly 24 hour, 7 days a week level of service and care
- comprehensive and standardised review of all deaths and improved perinatal pathology services
- more funding for research.



The publication of the *Saving Babies' Lives Report 2009* was the launch pad for the *Why17? campaign* and a twelve month drive to raise awareness of the issues in Westminster and the devolved governments of Scotland, Wales and Northern Ireland.

November 2009: Taking the campaign to Scotland

The *Why17?* campaign was launched in the Scottish Parliament in November, at an event hosted by Ken Macintosh MSP.

Mr Macintosh is the local MSP of Sands parent, Susan Lynagh, who also spoke at the event and whose book *Born Asleep* movingly tells of the continuing impact of the stillbirth of her daughter Amy in 2002 and how she began a search for answers from politicians and health officials.

Sands launched a petition calling on the Scottish Government to address the key issues raised in the *Saving Babies' Lives Report 2009*. We also published a Scottish insert to this report highlighting issues specific to Scotland and met with key Scottish government officials.

March 2010: Northern Ireland Assembly

This month we are excited to end our tour of the UK governments at an event in the Northern Ireland Assembly in Stormont on Tuesday 23rd March. We have joined forces with TinyLife and Bliss; together the three charities have more than 80 years combined experience supporting families whose babies are born premature or sick, or who have died. We are publishing a new briefing paper *Every Baby Matters* for Northern Ireland.

We are meeting with key members of the Health Select Committee, as well as Department of Health officials, and will bring you updates on these meetings in our next bulletin.

Outcomes

Our petition attracted 888 online signatures and as a result the Scottish Petitions Committee agreed to write to the Scottish Government, Royal College of Midwives, Royal College of Obstetricians and Gynaecologists, Centre for Maternal and Child Enquiries, Royal College of Pathologists and Cruse Bereavement Care Scotland seeking responses to the points raised. The issues raised in the petition are currently being considered by the Maternity Services Action Group.

The Scottish Government agreed to funding of £20,000 to ensure maternity staff across Scotland are given specialist education and training so that they will be better equipped to support bereaved parents. Public Health Minister Shona Robison announced the funding at the event, saying:



Shona Robison MSP at our launch event

"Every baby lost to stillbirth represents a tragedy for their parents and family. Proper support from maternity staff at this desperately sad time can make an important difference, which is why we have asked Sands to look at how this support can be improved. Our investment of £20,000 over two years will enable Sands to share their experience with health boards, and identify where staff need education or training to improve their care for parents after a stillbirth."

The Minister has also undertaken to support a joint meeting with Sands and key experts in Scotland to discuss how to work to reduce the high levels of stillbirth.

Facts

- ▶ Every day in Scotland a baby dies.
- ▶ Almost 500 babies die every year in Scotland before or just after their birth.
- ▶ In 2008, 325 babies were stillborn – that's one in every 200 births.
- ▶ The stillbirth rate in Scotland has not changed significantly in 20 years.
- ▶ In 2008, 168 babies died within four weeks of their birth; the majority of those within the first seven days.
- ▶ Scotland has one of the highest perinatal mortality rates in Europe.



Other News

Seeing and Holding Campaign: Sands questions NICE guidance

In December 2009 we launched a campaign to ensure that bereaved parents continue to be offered choice about seeing and holding their baby after death.

Current guidance, Clinical Guideline 45: Antenatal and postnatal mental health, issued by NICE (National Institute for Health and Clinical Excellence) to midwifery units on caring for bereaved parents may be open to misinterpretation.

Sands is concerned that the recommendations on seeing and holding a baby after he or she has died could imply that choice is being removed from parents over whether they do see and hold their baby after

death. We met the Deputy Chief Executive of NICE in January to outline our concerns, and as a result NICE agreed to clarify the intended meaning of the recommendation on seeing and holding a stillborn baby. In line with regular practice, they will revisit the guideline when it is next due to be updated and review any new evidence at that time.

We have also been assured that the charity will be included as a stakeholder in future discussions about this issue.

Keep updated by visiting www.nice.org.uk.



Sands highlights the need for research

Research is desperately needed if we are to understand why so many babies die before or soon after their birth.

Some causes of stillbirth, such as pre-eclampsia and preterm labour are known and there is research going on into these areas. However, much more work is needed, especially into the more than 50% of stillbirths which are unexplained.

Sands has made some important advances in the last twelve months. In association with the National Reproductive Health Research Network (NRHRN) which coordinates the prioritisation of research in women's health through one portal, we have established a new Clinical Studies Group (CSG) on Stillbirth. This new CSG is chaired by Professor

Gordon Smith, Professor of Obstetrics & Gynaecology at Cambridge University, and will provide the primary route through which new ideas for clinical trials and other well designed studies are developed in the field of stillbirth.

We have also teamed up with Wellbeing of Women (WoW), a charity that already has over 40 years of experience in funding research into reproductive health. WoW works in close partnership with the The Royal College of Obstetricians and Gynaecologists (RCOG) and their Research Advisory Committee is drawn from RCOG members including leading experts in fetal and maternal health.

Through WoW we called for applications in research into the causes or prevention of stillbirth. We are delighted that Sands has agreed to

fund two proposals starting in 2010. The first will look at the risks to and the treatment of pregnant women with obstetric cholestasis. The second will investigate whether the heart defect, cardiac arrhythmia, could be a cause of unexplained stillbirths.

Sands has recently been invited to join the Cochrane Pregnancy and Childbirth Group of Stakeholders. The Cochrane group is internationally recognised for carrying out systematic reviews of research into the effectiveness of clinical interventions in antenatal and postnatal care. The Stakeholder group has helped to prioritise topics for future reviews, and Sands input has ensured a number of topics important to stillbirth, such as decreased fetal movements and post term induction of labour, will be included.