

# Network Newsletter

Issue 6, October 2017

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## Dates for the diary

- ▶ **4 November** Sands AGM, Solihull
- ▶ **18-19 November** Part 1 Befriender Training, Antrim
- ▶ **8 December** Lights of Love
- ▶ **June 2018** Sands Awareness Month
- ▶ **2 June** Sands Garden Event, Lichfield
- ▶ **9-15 October** Baby Loss Awareness Week
- ▶ **15 October** Wave of Light 7pm



UK turns pink and blue (page 6) – Marischal College in Aberdeen.

## *Presentatio magnifica!*

Four muggles at JK Rowling's old school won £250 for Sands for a presentation about the charity in July. Harry Dymock (below right) and his friends, Ryan, Megan and Lucy, from Wydean School in Sedbury, won a share of £1,000 that was up for grabs as part of *First Give's* schools partnership, using video and PowerPoint presentations, in the JK Rowling Library at the school. The team were amazing and, despite being up against difficult competition, were awarded the runner-up prize by a panel of judges; there was not a dry eye in the house.

Harry is big brother to Lily and he wanted to do something in her memory. Harry contacted Welsh Network Coordinator, Heatherjane Coombs, for information on the charity and had recently climbed *Pen Y Fan* in memory of his sister. Harry's mum, Sam Knight, a befriender at Cardiff & Newport Sands, is very proud of him. She pointed out how important it is that we allow siblings to be able to talk about their brothers or sisters, as they can often struggle in silence.

*Harry (far right) and friends, aged 12, at the JK Rowling Library in their school, successfully bidding for prize money for Sands.*



## Letter from Clea

It is great to be able to write to you at the end of one of our most successful Baby Loss Awareness Weeks ever. By working with over 40 other baby loss charities we both raised awareness and called for improvements in bereavement care.

Our reach extended from the thousands who joined the global Wave of Light, to the politicians who took part in debates. We worked across the country to draw attention to the issue of baby loss by lighting up over 40 public buildings pink and blue, securing national media interest, and running more than 50 remembrance ceremonies in local communities.

Taken together with the success of our #15babiesaday initiative during awareness month, and our presence on government-led panels across the four nations, 2017 has marked a real step forward in our aim of pushing baby loss higher up the national agenda. You can read more about this impact throughout this newsletter.

Together with this external work, we have been strengthening Sands



Clea at the APPG reception in the House of Commons. Photo: Jennifer Moyes

internally and, as a part of this, memory boxes are now free of charge to all who need them (p.5). Helping to fund this national work, 21 Groups are now operating within the new financial model, and in these areas we are now also funding bereavement care training.

As more groups move into the new model next year, we will continue to ensure that all bereaved parents and families everywhere benefit from the work we do. I am enormously grateful to the early adopters who are blazing a trail for everyone else.

I hope to see as many of you as possible at the Sands' Conference in Solihull on 4<sup>th</sup> November. As you will have seen from other communications, we would like to explore how we can make even more of a difference for parents now and into the future. Exploring whether a merger with The Lullaby Trust would allow us to do this is a conversation that we all need to have together – only when everyone has been heard will we be in a position to make the right decision for bereaved parents and for Sands.

*Clea*

## Welsh Network garden

Sands' Welsh Network is a step closer to funding a Welsh Sands memorial garden following a £5,000 grant from the Institute of Cemetery and Crematorium Management (ICCM). The donation, from Colwyn Bay Crematorium, is also being used to purchase a letterbox to be placed at the crematorium for parents and siblings to post their loved ones a letter.

Did you know . . . Sands has benefitted from a number of grants from the ICCM scheme? It is worth approaching your local crematorium to find out how your group can apply for a grant from the ICCM, or ask your Network Coordinator for some advice.

## Fire walk raises £14,000



23 brave people walked twice over hot coals to fundraise for Sands NI in September. The fire walk was a great success with the final total looking like it will be around £14,000. The funds raised will be used to help fund memory boxes and bereavement suite projects.

The event was the first Northern Ireland Network's joint fundraising event and was the idea of Chris, a dad at Antrim Sands; Claire, an Antrim Sands' befriender, took up the idea and organised the event. Thanks to everyone who took part, especially Chris and Claire.

## Fundraising fun



Extraordinary fundraising activities have been taking place across the country; here is a snapshot of just a few.

Valley Sands were very fortunate to be picked as the Mayor's Charity of the Year in 2016-2017 and received the wonderful amount of £2,559. Numerous events and bucket collections were held over the year. The Mayor chose the charity as it is close to his heart, following a loss he had had a number of years ago. The group have made a donation towards a statue for the local baby area in the crematorium.

Two supporters of Hastings & East Sussex Sands walked 96 miles in seven days, from Glasgow to Fort William in Scotland. Luke Brooks and John Brooks walked in memory of their daughter and granddaughter, Evie.

Father and son team, Joe and Paul Molloy, drove 400 miles in a tractor, from Mizen Point in Cork to Malin Head in Donegal, to raise funds for Sands NI and another charity. The boys' tractor challenge took just two days. The final total raised stands at an astounding £25,000.

Brighton & Worthing Sands organised an 11-mile sponsored walk from Worthing to Brighton in June. Committee members and volunteers had a great time despite the windy, rainy weather conditions. All monies raised will go towards buying new equipment to support bereaved parents at Brighton and Worthing hospitals.

Cornwall Sands are Truro Sainsbury's Charity of the Year and the group had an awareness table at the store, along with arranging a tombola.

Swindon Sands raised £500 through attending a 'Because Grease Monkeys' car enthusiast fundraising event in April.



Left: Hastings and East Sussex supporters walk from Glasgow to Fort William. Above: Worthing to Brighton sponsored walk. Below left: Swindon car enthusiast event. Below right: Sands NI tractor challenge.



The sun was shining brightly and many car enthusiasts and general public came to show their support. The money raised was split between Swindon Sands and another charity, *Cots 4 Tots*.



Even small events can help raise awareness; some Lincoln Sands volunteers held a Tea and Toast morning at RAF Cranwell, raising £50, which will help pay towards training befrienders.

## Groups working together



Families from two Sands groups in Exeter and South Devon got together at the World of Country Life in Exmouth at the end of May. Children were able to chat and play together, as did the adults; a great way to network, give each other support and keep the kids busy too. If you've got another Sands group close by, why not team up on some

fundraising or raising awareness – many hands make light work.

Meanwhile, East Kent, West Kent & Medway, and Tunbridge Wells Sands groups worked together to place memorial benches at four local cemeteries. There are a further three planned, subject to new developments at those cemeteries/crematoria.

# #15babiesaday success



Sands volunteers across the UK poignantly drew attention to baby loss during Awareness Month, by participating in the #15babiesaday initiative. Pictures of babygros on washing lines were spread across national and local news in June, and especially social media; the images moved many to tears, and certainly raised awareness of baby loss in a unique way.

Our tweets about #15babiesaday were retweeted over 3,000 times, there were over 5,000 shares on Facebook and our videos were viewed over 35,800 times.

We are very grateful to all Sands groups and volunteers, as well as Sands staff, who held events and took photos, often in front of well-known local landmarks such as the London Eye, the Angel of the North and up Ben Nevis, to name but a few. There were a wide variety of awareness events, including duck races, flower drops and sponsored walks. They climbed mountains in Wales, Scotland and Northern Ireland (*Pen Y Fan*, Ben Nevis and the Mournes).



#15babiesaday washing lines around the UK during Sands Awareness Month. Clockwise from top left: London Eye, Angel of the North, Aberdeen Sands, Enniskillen Castle, Cardiff sky line, Derby Sands, Bristol Sands, Castell Coch.

Working together with SANDS Lothians, the washing line was taken to the Scottish Parliament where a number of MSPs supported us.

Thank you for your dedication and giving up your time to work with this successful initiative; we really couldn't have done it without you! We'd like to thank groups and volunteers for their help in Sands Awareness Month in: Aberdeen, Antrim, Ayrshire, Banff & Buchan, Belfast, Birmingham, Bradford, Brighton & Worthing, Bristol, Cardiff & Newport, Cheshire East,

Chesterfield, Coleraine, Cookstown, Cornwall, Coventry, Derby, Derry, Durham & Wearside, East Kent, East Lincs, Enniskillen, Exeter, Farnborough, Fife, Forth Valley, Glasgow, Huddersfield & Halifax, Hull & East Yorkshire, King's Lynn, Newry, Norfolk, North Down, North Manchester, Omagh, Oxfordshire, Peterborough & Stamford, Portadown, Scarborough, Sheffield, Shetland, South West London, Southampton, Surrey, Swindon (incl. Devizes), Tayside, Teesside, Wakefield, West Berkshire, West Herts & Bucks, West Kent & Medway, Winchester, York, and many more besides!



## 23 staff funded at conference

An incredible 23 midwives, NICU nurses, doctors and chaplains were funded by Hull and East Yorkshire Sands to attend the 9<sup>th</sup> Sands/ Bliss/RCM Joint Annual Conference *Transforming Loss: Meeting the needs of parents* in Birmingham in September.

Eszti Pontone, Treasurer of the group, said, "The feedback from the day, which cost our group over £3,000, was absolutely incredible and showed it was money extremely well spent. All those who attended came back wanting to actively improve local bereavement care."



Other Sands groups have also funded health professionals to attend the conference; this is

something your group may like to discuss with your local hospital staff and fundraise for.

## Cuddle cot for hospice

The Welsh Network recently gave a cuddle cot to the children's hospice, *Ty Hafan*, in Penarth, after fundraiser Neil Clarke raised over £6,000. Heatherjane Coombs, Welsh Network Coordinator, knew that Neil wanted to use some of the funds on a cuddle cot, but none of the hospitals had needed one. Heatherjane attended a local crematorium's bereavement services open day, and discussed with Emma from *Ty Hafan* how a few neonatal babies were being transferred from the hospital to the

hospice. The hospice were delighted to receive the cuddle cot from Neil, his colleague and Heatherjane.



## Free memory boxes

Sands memory boxes are now free to everyone, as of 1<sup>st</sup> October 2017. Sands groups can continue to use the direct link: <https://www.sands.org.uk/node/1739> to order memory boxes free of charge (including postage), whilst families, healthcare professionals and hospital staff can order them directly from the Sands website.

We are encouraging hospitals to continue to liaise with their local Sands group about the fantastic support you can offer whilst hopefully reducing the need for you to store or order memory boxes on behalf of hospitals.

In addition to making the boxes free, we have put out an online survey asking for feedback on Sands

memory boxes from bereaved parents, families and anyone involved in supporting those whose baby has died. By the end of September, we had had over 1,200 responses from bereaved parents.

As an important source of support for bereaved parents, we want to ensure that it is accessible and available to all families who might need one and is made up of items that offer opportunities to make and keep those precious memories of their baby. The survey asks questions about the appearance, contents, quality and ordering process for the memory boxes. The survey is open until 31<sup>st</sup> October and we'd love to hear your thoughts: <https://www.surveymonkey.co.uk/r/SandsMemoryBoxSurvey>.

## Fun day raises over £4,400



Shetland Sands' first major fundraiser brought in a staggering £4,420 from a fun day in June. For a group that's been running less than two years, this is quite an achievement.

The funds raised will help keep the group running, as they often need to take ferries and drive long distances to run support meetings. The group are also hoping to fund essential packs for families who are shipped off Shetland to the main land to receive urgent care, with little notice or resources.

Marie Manson, Chair of Shetland Sands said, "Thanks to everyone who baked, donated raffle prizes and who helped on the day. And thanks to everyone who came to our fun day – this money will help us provide the support and care to anyone who has gone through the loss of a baby. We'd also like to thank our sponsors: the Adenia, the Antares, EMN Plant and Aurora marine, plus Shetland Dairies provided the milk."

# UK turns pink and blue for Baby Loss Awareness Week



Over 40 huge buildings across the UK were lit up pink and blue for Baby Loss Awareness Week in October. Sands, along with nearly 50 other participating charities and support organisations, led the 16<sup>th</sup> Awareness Week, which culminated with the Wave of Light on 15<sup>th</sup> October, at 7pm.

Several buildings in Aberdeen turned pink and blue, including Marischal College, Robert Gordon's University and HMT theatre. In Wales, Cardiff City Hall was lit up for the week, along with Ice Arena, Wales. There was a bucket collection for Sands at the Wales v Ireland football game, raising over £1,000. In England, Blackpool Tower and Arches were lit up, along with

Banbury Cross in Oxfordshire. In Northern Ireland, Belfast City Hall was lit up, along with several other city and town hall buildings.

There were over 50 global Wave of Light events across the UK (see right). In addition, small events were organised across the UK to allow parents, families and friends to come together to light candles and share this special time together. There was a candlelit walk in North London, a memory walk in Nottingham, a lantern walk organised by West Kent and Medway Sands, a candlelit vigil in Bristol, a candle give-away in Shetland, a flowers on the lake event in Birmingham, plus many more events across the country.

There were global Wave of Light events in: Aldershot, Ashford, Banbury, Belfast, Blackpool, Boroughbridge, Bristol, Canvey Island, Cardiff, Carshalton, Chesterfield, Colchester, Coventry, Cramlington, Devizes, Douglas, Dudley, Edinburgh, Exmouth, Glasgow, Gosport, Greenhithe, Guildford, Harrogate, Hastings, Hemel Hempstead, Huddersfield, Hull, Isle of Wight, Keighley, Leeds, Leicester, Liverpool, Ludlow, Middlesbrough, Newburgh, Norwich, Oban, Oldbury, Peterborough, Plymouth, Portadown, Portsmouth, Reading, Rochester, Sheffield, Shetland, Solihull, Southampton, Swindon, Tewkesbury, Thatcham, Thurso, Truro, Whitburn, Woking, Worcester, Wrexham, Wythenshawe, York.

*Top left: the Kelpies in Falkirk turned pink and blue. Top right: Blackpool Tower. Below, clockwise from left: Sheffield City Hall, Gateshead Millenium Bridge, Cardiff City Hall, Huddersfield & Halifax and Wakefield Sands, Armagh Palace, Chesterfield Wave of Light.*



## Prime Minister talks about Sands in PMQs

Prime Minister Theresa May spoke of funding to Sands during Prime Minister's Questions on Wednesday 11<sup>th</sup> October.

Antoinette Sandbach MP asked the Prime Minister if she would thank and acknowledge parents, charities and health care professionals on their hard work to develop the new National Bereavement Care Pathway. Ms. Sandbach said, "The Conservative government has launched 11 pilot projects in a National Bereavement Care Pathway. This ground-breaking pathway supports parents who have lost a child starting from conception to the age of one. Can I ask the Prime Minister to congratulate the parents, the charities and the healthcare professionals that worked so hard to develop this project, and to make sure that this is rolled out on a wider level once the lessons from the project have been learned?"

The Prime Minister said, "Well, I'm very happy to join my Right Honourable Friend in congratulating all those who have worked so hard on this issue, which of course brings such distress, sadly to too many people including, I know, members of this House. I'm sure that everybody will want to join me in marking Baby Loss Awareness Week. There was a debate yesterday and I would pay tribute to those from across the House who spoke very movingly about their own experience, and I'm happy that my Right Honourable Friend has welcomed the pilot and launch of the National Bereavement Care Pathway this week."

"The Department of Health is also providing funding to Sands – the stillbirth and neonatal death charity – to work with other baby loss charities and royal colleges to improve the quality of bereavement care in the NHS. We do expect for this to be rolled out nationally in 2018. As my Right Honourable Friend says it's important I think to do a pilot project so we can learn from that as we come to the national rollout."



Above: Antoinette Sandbach MP, Dr Clea Harmer (Sands CE), Nicola Housden (Jude Brady Foundation) and Will Quince MP at the APPG Baby Loss reception in the House of Commons. Below: The opulent Jubilee Room. Emma Kedge, Surrey Sands Chair (below right) shared her experience. Photos: Jennifer Moyes

The All Party Parliamentary Group on Baby Loss hosted a reception and remembrance event for BLAW in the House of Commons's Jubilee Room, also on 11<sup>th</sup> October. Speakers at the event included Justin Madders MP (Shadow Health Minister), Philip Dunne MP (Minister of State for Health), Dr Clea Harmer (Sands CE), Will Quince MP and Antoinette Sandbach MP. Emma Kedge, Surrey Sands Chair, shared her experience of bereavement care.

Clea said, "It is long overdue that the NHS makes the provision of excellent bereavement care mandatory across the UK. Despite claims that it is a priority, there is still a shortage of dedicated bereavement rooms and too few health care professionals are getting the essential training they need. We believe every parent should be offered the bereavement support they need, when they need it, for as long as they need it. One way to make this happen is for a National

Bereavement Care Pathway to be included in the Government's Mandate to NHS England, and to ensure a similar approach is taken across the UK."

There was a backbench debate on baby loss in Westminster on 10<sup>th</sup> October. In addition, there was a BLAW event at the Scottish Parliament, to which many of the Scottish Sands groups went along. There was also a service held at the Welsh Assembly.

This week is an important opportunity to help make the world more aware of the devastating impact of baby loss and the work of each of the charities, particularly Sands. Instigated by a group of bereaved parents, the week gives families an opportunity to remember their babies by purchasing and wearing a specially-designed enamel ribbon pin or by lighting a candle as part of the global Wave of Light.



## Butterflies and mud

Blackpool and Preston Sands have been going to extremes, with a butterfly release in July followed by a tough mudder in September.

The group's 4<sup>th</sup> annual butterfly release, at Lytham Crematorium baby garden, gave bereaved families the chance to set butterflies free in memory of their babies. Beautiful wild flowers fill the garden and a massive oak tree provides a focal point and some shade. Families have their babies' names engraved on leaves hung on a tree sculpture within the garden.

Claire Maxwell, Chair of the group, said, "The butterflies hung around with us for a little while before fluttering off into the beds of wild flowers. There are butterfly houses around the garden too, so hopefully some will have set up home."

Meanwhile Lydia and Paul Collins, along with #teamtheo, braved the Tough Mudder North West. They raised money and awareness of the group. From the photographs, it looks like they all had a fantastic time and got extremely muddy.



## AGM and Sands' conference

The AGM and Sands' conference is on Saturday 4<sup>th</sup> November in Solihull, West Midlands. This year's theme of *Working with Others* provides an opportunity to share good news, progress and good practice across the charity. Guest speakers will include Prof. Alex Heazell, Senior Clinical Lecturer in Obstetrics at Manchester University. We hope to see many of you there.



## Who's who



Sands' new Director of Bereavement Support and Volunteering, Jen Coates, is responsible for our bereavement support provision; the helpline, the forum, networks, and volunteering. Jen, who has been with Sands just under two months, says, "I've had a really enjoyable time over the last few weeks, meeting some of the extraordinary teams of volunteers and staff across Sands. I feel extremely privileged to have joined an organisation with such a phenomenal reputation and one so keen to continue growing and developing the range and quality of support we provide."

Jen has followed Sands' work for many years, since unexpectedly caring for bereaved parents as a student nurse, and working in children's hospices, but first encountered the charity as a teenager 30 years ago when her little brother died, and Sands

supported her father and step-mother. Jen comes to us from Macmillan Cancer Support.

"I know many of you have asked for more clarity and structure for the various volunteer roles and I'm working with Richard and Gail to develop this, as a priority. I'm also working closely with the other directors to make sure people who volunteer their time for Sands have a variety of options and can move between roles, as their interests or time change. I want us to offer everyone a positive, high-quality, supportive experience volunteering for Sands. I'm particularly interested in your thoughts around volunteer roles and structure; if you'd like to be involved in this work, please let me know."

Jen is keen to meet as many of you as possible and to work with all of us to continue to develop our support for all parents, along with the crucial awareness work with hospitals. Jen has attended Network days in Birmingham and Cardiff, and hopes to attend the Northern Ireland day too.

Jen says, "Please do get in touch with thoughts, ideas or just to say hello: [jen.coates@sands.org.uk](mailto:jen.coates@sands.org.uk). I am in the London office Monday to Thursday and work from home in Suffolk on Fridays. When I'm not working, I might be found cycling between tea and cake stops in Suffolk, or playing inept football with my son."

## Happy 30<sup>th</sup> Oxfordshire!



To celebrate Oxfordshire Sands' 30-year anniversary, the group had a stall at Bloxham Steam Rally in June. They gave away free cake and had a children's colouring competition, whilst raising awareness of Sands and the work of the group. Congratulations Oxfordshire Sands on all your hard work and dedication over the years!

## Local hero award in West London

West London Sands Chair, Lynn Lacey, has been given a special local hero award for her dedication and hard work volunteering for Sands. The Mayor of Hounslow, Cllr Ajmer Grewal, presented the award at a ceremony in the presence of the Deputy Lord Lieutenant, Maria Pedro, Chair of Hounslow Council, Cllr Steve Curran, and Chiswick Cllr, John Todd.



Lynn said, "I am thrilled to have been given this award, which reflects the hard work of others too on the West London Sands committee, all giving their time to help other bereaved parents and to promote better care for parents in the local hospitals."

Lynn has put in a tremendous amount of effort, ensuring that

the support groups run regularly, and she is also in close liaison with all the major local hospitals to improve their services to bereaved parents.

Councillor Todd was aware of West London Sands through his wife, Ruth, who has volunteered for the charity for some years.

## Belfast half marathon



Lots of Sands NI Network parents, families and friends ran the Belfast half marathon on Sunday 17<sup>th</sup> September. Ciara from Enniskillen and a team of friends ran in memory of their babies. Stephen Tuff ran in memory of his son, Charlie. Susan Boyd ran in memory of her niece, Eve Murray, and Eugene Rooney ran for three causes, including Sands NI.

Eugene said, "I ran the half marathon in support of Sands NI and two other charities close to my heart. It was great to see people supporting such a great cause. Sands NI has supported so many in their time of need, it's time I gave something back."



## Meet the MP

East Kent Sands met Damian Green MP, First Secretary of State, in September when they attended the Ashford Volunteer Fair. They presented him with a copy of Sands' Impact Report.

## Over 500 people supported by groups

52 Sands groups supported 292 people at support groups across the country in September, initial findings from our recent survey show.

We asked groups to let us know how many people attended their support meetings in September, as well as how many people befrienders in the group supported separate to those support meetings.

We had 47 befrienders respond to the befriending survey, and they supported 226 people outside of support meetings in September, with many befrienders supporting by text, calls and emails. In total, we know that 518 people were

directly supported by our amazing Sands volunteers. We discovered that 24 of those groups have a closed Facebook group which is administered by a Sands volunteer. Our reach on social media is huge, with 2,676 parents registered as members of these closed groups.

Thank you very much to those of you who completed the surveys. We know that this might be the tip of the iceberg, and would love all groups to participate next year so we can develop a fuller picture of the people we support. We know we reach many more people, and currently estimate we are reaching over 900 people a month via Sands groups.

## Climbing a mountain

In June, over 120 men, women and children from the Welsh Network carried the #15babiesaday washing line to the top of the highest mountain in South Wales, *Pen Y Fan*. Over £2,500 was raised, which will go towards setting up a Welsh Sands garden.

Strangers walked together, sharing the stories of their babies as they set off; the support and encouragement was awe-inspiring. People finished as friends, having shared more than one amazing journey. A huge thanks to the sponsors, everyone who took part, and Cardiff & Newport Sands for arranging, delivering and sorting the t-shirts.

Linsey Morgans, Cardiff & Newport Sands, said, "We did the walk in memory of our son Morgan Simmonds and all the other babies gone too soon. Despite walking *Pen-y-Fan* many times before, it was particularly emotional for us this time, seeing how many friends and families turned out to walk in memory of our boy and all the other angel babies. A beautiful day."



## Research fund – round two

We're delighted that our 17/18 research funding round kicked off on 2<sup>nd</sup> October 2017; UK-based researchers can send Sands their ideas for research projects that will improve bereavement care, help identify babies at risk and/or improve their chances of survival. All applications must come from individuals based in academic centres in the UK (i.e. their email ends with .ac.uk). Applications will then go through our lengthy process of review, which sees the number of applications whittled down until Sands Board of Trustees finally makes its decisions about which to fund next year.

The first selection round resulted in four outstanding projects being funded:

- improving health professionals' communication with parents faced with difficult decisions on the neonatal unit.
- why stillbirth is more common in women living in poorer areas of the country.
- what happens to babies who are resuscitated at birth, but still have no heartbeat after 10 minutes.
- pulling together different studies' results to help doctors predict a woman's individual risk that her baby will die before or soon after birth, and the best way of helping to reduce that risk.

These studies go to the heart of Sands' work. Without generous donations to the Research Fund from groups, donors and fundraisers, they're unlikely to have gone ahead.

During our funding process, we take advice from experts – our esteemed Perinatal Expert Panel, chaired by Professor Gordon Smith of Cambridge University, and a host of independent researchers whose specialist knowledge means they can offer invaluable opinions about the quality of individual applications. It's a complex process that involves a lot of hard work by all concerned, but it means that we can be sure that we're funding the best research.

Visit our website at [www.sands.org.uk/our-work/research/apply-research-funding](http://www.sands.org.uk/our-work/research/apply-research-funding). If you'd like more information on the funding process or the research Sands funds or supports, please email [research@sands.org.uk](mailto:research@sands.org.uk).

## Radio award



Hastings and East Sussex Sands were awarded the *More Radio* Charity of the Year Award in July. The Group were recognised for all of the hard work they have done in the local area supporting bereaved parents.

The group have gone from strength to strength since starting in April 2016; as well as their support meetings, the group have worked closely with the Conquest Hospital and the bereavement suite now has two beautiful cuddle cots, handmade by the Darvill community, and funded by the Conquest hospital's league of friends. The group have also just held their second successful charity ball.

## Five new groups launched



In a busy few months, five new groups have launched across England. In the North West, Stockport Sands started their support meetings in June. The group recently provided bedding for the bereavement suite at Stepping Hill Hospital, as well as sponsoring two midwives from Macclesfield Hospital to attend the Sands/Bliss/RCM conference in September.

Meanwhile, Bolton Sands have been running support meetings since July. Their local branch of Sainsbury's nominated the group as their Charity of the Year and kindly gave them a meeting room free of charge. The group raised £335 from a recent bag pack at the store, raising awareness of the group. Thanks to all staff and volunteers for making it a fun weekend.

Sheffield Sands held their first meeting in September, and over 20 people attended. This is an area that was very much in need of support. The group are lucky enough to have a large committee of 12 people, and already have four trained befrienders. The group held a #15babiesaday event in June, to help raise awareness of the group.

Cambridgeshire Sands held their first support meeting in October, in an area which was in much need of support, as the nearest Sands groups were at least an hour and a half drive away, and Cambridge has



*Clockwise from top left: Stockport Sands with Sheryl McMahon (left) NW Network Coordinator, Sheffield Sands at their #15babiesaday event, Bolton Sands with Sheryl McMahon, Cambridgeshire Sands with Rose Abrehart (right) East Network Coordinator, Portsmouth & Chichester Sands with Joanna Lamb (right) SE Network Coordinator.*



a very large maternity unit. Eight committee members attended their Part One New Groups Training in June. The group has raised considerable funds; the Chair's firm raised funds for the group to the tune of £2,500, plus they've held several cake sales.

Portsmouth & Chichester Sands has re-formed out of two groups (Portsmouth Sands and Chichester Sands), and are hoping to start support meetings very soon. They had great things arranged for Baby Loss Awareness Week: the group arranged for the enormous Spinnaker Tower in Portsmouth Harbour to be lit up pink and blue.

## Hosted IT package for groups

We have started to offer email addresses to some groups using the 'groupname@sands.org.uk' format. We are also rolling out on a test basis a free hosted-website package, which some groups are trialling for us, in which a group's website is hosted via the Sands main website. We will provide you with a template and some set content, and other sections your group can adapt to suit local needs. We will soon be rolling out the websites more widely; please let your Network Coordinator know when you are interested.

These steps, which groups have requested for years, will tighten up our branding to increase our impact, while giving us more security over our IT infra-structure. It will also be paid for centrally, moving the costs away from the groups, so is a key element of the new financial model.

## Four directors

Our new team of directors is supporting Clea to implement Sands' strategic objectives. Danyanne Quemper continues to lead our Finance and Resources department, and has been key in developing the new financial model. Jen Coates, Bereavement Support and

Volunteering, wants to strengthen the volunteering structure in Sands. Kate Mulley, Research, Education, and Policy, will be working to increase our lobbying power. Dan Brett-Schneider, Fundraising and Communications, is focussed on developing our profile and fundraising platforms.

## Lights of Love 2017

On Friday 8<sup>th</sup> December Lights of Love services across the UK will give bereaved families a shared moment to remember their babies. The services are accessible to all and non-denominational; many are held in churches, but they can be held at other venues.

Services this year will be held in: Cardiff, Durham, Enniskillen, Epsom, Exeter, Farnborough, Guernsey, London, Nottingham, Portadown, Sheffield, Stirling, Swindon; other locations to be confirmed (keep an eye on our website). In addition, many Sands groups hold similar services throughout December.

A bereaved dad said, “Just writing this message brings a warm feeling to me and how special the evening always is. I am very grateful that you provide this service. It is a time I can just forget about the rest of the world and focus on my daughter.”

Since 2000, Lights of Love services have been held every December, offering anyone affected by the death of a baby the opportunity to spend time remembering their baby, and meet with others in a peaceful atmosphere. There is candle-lighting, readings, hymns and carols, as well as a Christmas tree on which you can hang a hand-written message.

Erica Stewart, Sands Bereavement Support and Awareness Specialist, said, “This annual Sands event brings bereaved parents and families together to remember their babies at what is often a difficult time of year. We do hope to see you there for what is always a very special and moving evening.”

One bereaved mother said, “Thank you so much for providing a service that has meant the world to us and given us a reason to celebrate Christmas along with our late baby, even if only in spirit.”

If you are holding a Lights of Love service this year, and haven't been in touch, or would like to organise one in 2018, please contact Erica for a chat: [erica.stewart@sands.org.uk](mailto:erica.stewart@sands.org.uk) or call 0203 897 3469.



Families hang personal tags for their babies on the Christmas tree at the Lights of Love service in London in 2016. Photo: Paulina Sobczak Photography.

## International Stillbirth Alliance in Cork

370 delegates from 26 different countries attended the International Stillbirth Alliance (ISA) conference in Cork, Ireland at the end of September. A team of nine Sands staff and Sands NI volunteers, including Clea Harmer, Sands Chief Executive, attended a variety of research presentations and workshops, including a stillbirth prevention workshop for clinicians and an art workshop for parents to express their grief through images.



Sands' Kate Mulley, Director of Research, Education and Policy, and Senior Research officer, Laura Price, at the ISA in September.

The conference gave us an opportunity to re-connect with established researchers and bereavement specialists from around the world, and to meet and share our expertise and experience with health professionals and other charities. We showcased [www.saferpregnancy.org.uk](http://www.saferpregnancy.org.uk), and received many compliments on our new pregnancy website.

Much of the research 'buzz' was around the latest findings on the effect of sleep position in pregnancy. MiNESS, the study part-funded by Sands that has looked at this and due to be published shortly, will translate directly into advice for pregnant women. Other speakers described their research into the placenta and risk factors for perinatal death. There was much discussion about the evidence underpinning care

and support for parents. The impact of a baby's death on health professionals was a focus of discussion and presentation, with research showing that some obstetricians and midwives leave their profession because of the longlasting effects.

It was a worthwhile weekend; Sands forged stronger links with our good friends *Feileacain* in Ireland and there are plans to work together on more cross-border projects in the future. Delegates attended a very special and moving remembrance service on Saturday evening at St Finn Barre's Cathedral, followed by an evening of food, music and Irish dancing.

In June 2018, the ISA moves to Glasgow and we recommend that you go along.

## Two new baby gardens

Two new baby memorial gardens have been opened in Birmingham and Chesterfield, thanks to the hard work of dedicated Sands volunteers.

### *Heartlands Hospital, Birmingham*

A new baby remembrance garden at Heartlands Hospital in Birmingham was opened during Sands Awareness Month, with fundraising by Solihull Sands. The group paid for two chairs in the garden.

Clea Harmer, Sands Chief Executive, who opened the garden, said, "It was an enormous privilege to be invited to open the new baby memorial garden at Heartlands Hospital, and to have the chance to recognise both the vision and the hard work that had gone into creating it. The beautiful garden has been designed with so much care and love, and will provide a tranquil and special place where families can remember their babies and be with their babies, and find the support that this will give them."

At the opening on 29<sup>th</sup> June 2017, bereaved parents read poems and wrote their baby's names on a butterfly to hang in a tree or on a pebble to place in the garden. Solihull Sands committee members Liz Boobyer, Catherine Greenway, and Stephanie McCrea, Birmingham Sands Chair Ann-Marie Millward, and West Network Coordinator Nathalya Kennedy were all in attendance.

The space where the garden now stands was found by a bereaved family, who were looking for an outside space to spend time with their baby when their baby had died. It is the only green space on the hospital site, and it is just behind the maternity unit.

The local bereavement midwife, Clare Beesley, led the project, and local charities, including Solihull Sands and the Lily-Mae Foundation, were involved in the designing and funding of the garden.

### *Staveley Baby Memorial Garden*

Meanwhile, in Derbyshire, Staveley Baby Memorial Garden was opened on 17<sup>th</sup> September 2017; the third baby memorial garden created by Chesterfield Sands. The group worked with staff from Chesterfield Borough Council's bereavement services, to create the garden in the children's area of Staveley Cemetery.



*Clockwise from top left: Staveley baby garden memorial, butterflies hung by parents at Heartlands Hospital, Clare Beesley (bereavement midwife) at the Heartlands garden opening, Chesterfield Sands committee at Staveley baby memorial garden opening.*



Nicky Whelan, Chair of Chesterfield Sands, said, "We are so excited to have opened the garden following on from the success of the Never Land Garden at Chesterfield Crematorium and Boythorpe Baby Garden in Boythorpe Cemetery. I know that our new garden at Staveley will help many more local families."

The garden was opened by Patricia Willerton and Margaret Tickner, of Crowder and Alderson Funeral Directors, who have always been very supportive of Chesterfield Sands. The event included a balloon release, after which families stayed and enjoyed a picnic whilst listening to singer Chloe Boulby.

## Visitors from the East

Sands was visited by two volunteers from *Light in Hands*, a new Russian charity looking to introduce the idea of good bereavement care and support to their country. Over the course of a few days, the delegates attended a bereavement care training session and met members of several staff teams.

Ekaterina Nemenok and Dmitri Feshin told us how the perinatal death rate in Russia is still incredibly high compared to the West. We also learned how Russians see bereavement support in a slightly different way – the charity focusses on providing psychological support, and had not yet encountered the idea of peer support. They were interested to hear of our volunteer-led structure, and what we have been able to achieve with it.

*Light in Hands* now know about Baby Loss Awareness Week and the global Wave of Light, so look out for them in the future. They are looking to expand across Russia in the coming years, and we intend to keep in touch. You can learn more at [www.lightinhands.ru](http://www.lightinhands.ru) – with a bit of help from google translate.

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## Network days

We got so much out of the latest round of Network days. We discussed getting better at planning local projects, demonstrating their impact, then using those impact measures to make the case for similar projects elsewhere in the country. We talked about streamlining internal communications to increase our shared impact via social media; and supporting hard-to-reach communities, linking with other organisations to make those crucial connections.

Most importantly, we were all inspired to hear about the amazing work taking place in each other's groups, and to hear from Clea about how our work fits into the national picture of change. Send your ideas for next year to: [lorna.delayahu@sands.org.uk](mailto:lorna.delayahu@sands.org.uk).



*From left to right: Helen Butlin (Bereavement Support Services Manager), Jen Coates (Director, Bereavement Support and Volunteering), Ekaterina Nemenok & Dmitri Feshin (Light in Hands), and Clea Harmer (Chief Executive).*

## New perinatal mortality review tool

A free, online tool, aimed at saving future lives and giving parents much-needed answers, will be rolled out to health professionals across the UK, by the end of this year. Sands is a member of the Perinatal Mortality Review Tool (PMRT) collaboration that is developing and establishing a national standardised web-tool, building on the work of the DH/Sands-led expert group that was tasked with improving the quality of hospital-level lesson learning after a baby's death.

Crucially, the new review process includes the principle that parents are informed and involved in review, which we know from both parents and research has not been the case until now. As the only people who are present for the whole pregnancy and tragic death, parents' perspectives could lead to vital links being made, that would otherwise be missed.

Healthcare professionals will be able to use this tool to help them review a baby's death, so that all aspects of clinical care are considered and families get as much information as possible about events leading up to their baby's death. The tool will provide a means for hospitals to learn from what happens in every case,



and save future lives by developing action points to improve care when a death has been potentially avoidable.

While not all deaths can be prevented, we know from research that up to 6 out of 10 stillbirths occurring before birth, around a baby's due date, are potentially avoidable. Sands has been calling for improved understanding of events around a baby's death since 2012. Too often after the death of a baby, families go home without the fullest picture possible about their care and the circumstances leading up to their baby's death.

While it still needs to be informed by on-going research about communications with parents, the new PMRT will give parents the opportunity to give their views of events leading up to their baby's death. It aims to ensure their questions are answered and the review's conclusions are fed back to them. For more information about the PMRT go to: [www.npeu.ox.ac.uk/pmrt](http://www.npeu.ox.ac.uk/pmrt).