

# **Network Newsletter**

Issue 7, February 2018

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#### Sands is 40!

This June, we'll be galvanising ourselves across the country to mark our charity's  $40^{th}$  anniversary and launching a campaign to 'break the silence' and empower everyone to talk about baby loss as part of Sands Awareness Month. We want to encourage everyone to feel confident in knowing what to say and do if someone they know has experienced a stillbirth or neonatal death. We will be keeping you informed as our plans develop so that all our volunteers know how they can get involved.

Sands will be marking its 40<sup>th</sup> anniversary starting in the third week of June and, as an integral part of the celebrations, we'd love to hear from you! Share your thoughts and ideas about how you would like to get involved by completing this short survey https://www.surveymonkey.co.uk/r/Sands4 Oth. It will enable us to offer you support and necessary materials and/or toolkits in time for the celebrations.



Durham & Wearside Sands' team warming up after their very cold dip in the North Sea on Boxing Day.

## **Boxing Day dip**

Durham & Wearside Sands volunteers braved a dip in the freezing North Sea on Boxing Day morning, whilst the rest of us were enjoying our warm firesides. These hardy Sands supporters ran into the sea at Seaburn Beach and raised £1,500 for Sands. The dip is an annual event held by Sunderland Lions and in 2017 226 dippers from a variety of charities raised over £18,000 for their causes.

Kayleigh Beckham said, "We all really enjoyed it and are planning on doing it again this year. It felt amazing doing it for our group in memory of our beautiful babies."

## **Dates for the diary**

- ▶ 17-18 March Part 1 BFT, Cambridge
- ▶ 21-22 April Part 1 BFT, Exeter
- ▶ 12-13 May Part 1 BFT, Cardiff
- ▶ June Sands Awareness Month
- **2 June** Sands Garden Event, Lichfield
- ▶ 7-9 June ISA Conference, Glasgow
- ▶ 9-10 June Part 1 BFT, Leeds
- ▶ 25-26 June Part 1 BFT, London
- ▶ 8-9 September Part 1 BFT, Scotland
- ▶ 6-7 October Part 1 BFT, Manchester
- ▶ 9-15 October Baby Loss Awareness Week
- ▶ 15 October Wave of Light, 7pm
- ▶ 17 November Sands conference, Scotland
- ▶ 24-25 November Part 1 BFT, Birmingham

#### **Timeline**

We are keen to build up an historical timeline of the growth of Sands over the last 40 years. Would you help us to capture your group's timeline?

Please email communications@sands.org.uk and your Network Coordinator (subject: *Sands timeline*) with important dates, such as: year your group started offering support; year major event happened (such as held ball, bereavement suite opened, memorial garden opened) and so on.

In addition, if you have any photos of events that your group has organised, for example opening of a bereavement suite at a local hospital, first remembrance event, longest serving volunteer or fundraising activity, please share those with us too.

#### Letter from Clea

It has been great to talk to so many of you about the potential merger with the Lullaby Trust, and I want to thank everyone who has attended the Talking Together meetings, the webinars, and all those who have emailed or filled in the survey. I know how much Sands means to all of us and how important it is to make the right decision, which is why it has been key to hear your thoughts and ideas.

In many ways, it is fitting that we are having this conversation in our  $40^{th}$  year; reflecting back on how much has been achieved over the

end of March to decide in principle
whether a merger is the right way
forward for Sands.

I am enormously grateful to all of
you for the time, energy and
are commitment that you give to Sands

Clea

thank you.

# Special stillbirth edition

The medical journal BJOG: An International Journal of Obstetrics and Gynaecology published a special Stillbirth edition in December 2017, bringing together recently published research on stillbirth with a range of commentaries and new articles. Importantly, the Stillbirth issue is groundbreaking in its efforts to reach a wider audience.

In their editorial, guest lay editors, Lindsey Wimmer and Claire Storey, write about how research isn't just for the health professionals. They said, "Parents know that there is room for improvement in all areas of stillbirth, including risk identification, prevention, economic and financial impact, psychosocial care, social support, and more. This issue tells us that stillborn babies should and do matter to the healthcare community and to society."

To underwrite the journal's commitment to making research accessible, they have published a series of plain English summaries of papers that appear in the journal issue.

#### Sands conference

last 40 years, but also looking

forward to the next 40 years and

thinking about the difference we

Being able to share your thoughts

about a merger with the Board will

be crucial when they meet at the

- you are what makes Sands the

amazing organisation it is,

would like to make during that time.

The Sands conference will be held on 17<sup>th</sup> November 2018 in Scotland. It is aimed at all our volunteers, members, and anyone interested in the charity. This year, the AGM of Sands members will be held the evening before, so the whole of the Saturday will be given over to our conference, which is for everyone. The day is made special by those who are able to make it, and we want as many of you to attend as possible.

Last year's event included a presentation from Professor Alex Heazell, who is a leading figure in research into stillbirth. It was also the starting point of the merger

Sands conference in Solihull in November 2017 had a variety of presentations and speakers, including Professor Alex Heazell (below left) and Clea Harmer, Sands Chief Executive (below right).





# ISA conference in Glasgow

An international conference about perinatal death will take place in Glasgow from 7<sup>th</sup>\_9<sup>th</sup> June 2018. Organised by the International Stillbirth Alliance (ISA), it will bring together researchers and parents from across the world to share knowledge, experiences and models of how to bring about change.

This year's conference gives UK parents and families the opportunity to hear first-hand about international stillbirth and neonatal death research and best practice in bereavement care. You can find out more and register for the conference at: www.ispid-isa.org/2018.

discussion; the first opportunity for those of us who care about Sands to think about it and share our feelings.

The agenda for this year's event is not yet set, and we will be asking you to help us plan parts of the day as we get closer to it. It is your day, and we want you to be there. Look out for more details soon.





#### Tractor road run

Tractors took to the roads in Lockerbie on 18<sup>th</sup> February to raise funds for Dumfries & Galloway Sands' projects. Fundraisers Graeme Murray and Sheila Jackson organised the charity road run and encouraged local tractor owners to get out on the road with a minimum £10 donation per tractor.

There was a prize for the best turned out tractor, as well as a raffle with prizes from some local businesses. So far the event has raised £4,900 for Sands.

Graeme said, "The death of a baby is a devastating experience and unfortunately suffered by my family when my niece, Bethany, was stillborn in December 2013. In the darkest days following Bethany's death, Dumfries & Galloway Sands were a lifeline for Ali and Kenny."

## Fundraising round up

A fantastic £11,000 was raised for Sands by four men from Helping Hands in Northern Ireland by selflessly going without food all day on Christmas Day.

A staggering £15,008 was awarded to Portsmouth & Chichester Sands by former Mayor of Havant, Councillor Faith Ponsonby, in November 2017. The group will put some of the money towards refurbishment of the bereavement suite at Queen Alexandra Hospital in Portsmouth.

West Berkshire Sands have started fundraising for a baby memorial garden, as there is not one in their area, to give bereaved families a space dedicated to their babies. The group held a Christmas craft fair, and are planning a quiz night and a summer craft fair. They have been planning a garden for a long time and were recently given the go ahead by Thatcham Town Council following a public consultation. The group said, "It is fundamental for families to keep the memory of their babies alive and having this space will enable our families to do just that."

In Norfolk, the local group accepted a £463 cheque from Mary Goldsmith and colleagues at Ansabac Ipswich to be used for IT equipment at Norfolk Sands. Any excess will go towards memory boxes.



Above: Tractors take to the roads in Lockerbie for Sands.

Below left: Sands NI Christmas Day Fast Team handing over £11,000 cheque. Below right: Portsmouth & Chichester Sands accepting a cheque for £15,008 from the former Mayor of Havant.



Horsham & District Sands received a cheque of £1,335 from local funeral directors, Dandelion Farewells. The funds will go



towards Sands ongoing research projects and may be used for the future refurbishment of the suite at East Surrey Hospital.

#### Halloween fun



King's Lynn Sands held their second Halloween Party in 2017, which encouraged siblings and bereaved parents to come together for peer support and to raise funds for Sands.

## Hospital refurbishments

Groups around the country are busy helping local hospitals refurbish bereavement suites and rooms. Aberdeen Sands recently funded refurbishment of rooms on Rubislaw Ward at Aberdeen Maternity Hospital. Fiona Donald and Sandra Stephen from the group met up with Myra Kinnaird, Ward Manager, in early February and handed in items to the ward. A plaque has been placed on the entry to the rooms.

Sandra Stephen from the group said, "The feedback we have had regarding the refurbishment has been positive and it's all thanks to those who fundraise for us and enable us to fund such projects."

West London Sands funded a smart new sofa bed for Hillingdon hospital's bereavement room, meaning that dads, or other friends or family, will be able to stay overnight in comfort. The group have future plans to create a teaand coffee-making area for the room. The group currently work with six hospitals.

Lynn Lacey, Chair of the group, said, "Hillingdon doesn't have a dedicated bereavement room, but we are working with staff there to improve the room that they use for the birth of precious stillborn babies. Thanks to the fundraising efforts of our West London parents."

A wonderful £2,365 was donated to Farnborough Sands by Take the Lead Services. The funds will go towards the refurbishment of the Rowan Suites at Frimley Hospital. The Rowan Suite has been designed to provide a peaceful, calming environment where parents can grieve. Take the Lead Services said, "We feel privileged to be able to help in such a way."

The bereavement suite in the maternity unit at Stevenage's Lister Hospital has also recently been refurbished, thanks to funds donated to Sands by Darcie's Wish and Albie's Football Challenge. The room has been redecorated and an en-suite bathroom added.



Above: Hannah Kate, community midwife, helping to decorate the room in Aberdeen. Below from top: Frimley Hospital rooms; bereavement suite at Lister Hospital; sofa bed at Hillingdon Hospital.







If your local hospital wants assistance with setting up a bereavement suite or room, please speak to your Network Coordinator about setting up a project plan, fundraising for the project, and so on.

# New interpreter training

In January, 39 delegates attended brand new bereavement care training for interpreters trialled by Sands NI at Belfast City Hospital. Claire Hamilton, Head of Interpreter Services NI, said, "The workshops were a valuable learning experience for all who attended."

Two pilot workshops and a launch workshop included material tailor-made for interpreters and were delivered by Sophia Cross, one of Sands' Improving Bereavement Care Trainers. Fintan's mummy, Annie, shared his story and Theo's mummy, Laura, shared his story on Theo's second birthday. It is now hoped that these workshops can be rolled out across the UK.

One of the interpreters commented, "I could never imagine how quickly I would use the knowledge gained from the Sands training. I'm just out of an appointment where I had to break bad news during a routine antenatal scan. I found the course extremely helpful. I was able to break the bad news in a professional manner and managed my own feelings as well. I cannot thank you enough for this course."

## North West work together for cuddle cot

Sands groups across the North West of England joined forces to donate £1,570 to buy a cuddle cot for the Bridgewater Community Healthcare NHS Foundation Trust. In January, Sheryl McMahon, Sands North West Network Coordinator, went along to the hospital to present the staff with the new cuddle cot.

Julie McIntosh, Midwifery
Community Coordinator at the
Trust, said, "I approached Sands to
ask for their help to buy a new
cuddle cot. Currently, women can
have an extended stay in hospital
with their baby, but there is no
provision in our area to allow them
to choose to be at home with their
baby and family. A cuddle cot will
allow ... more families the chance
to take their baby home and to
grieve in their own way and at their
own pace."



Sheryl McMahon (right), North West Network Coordinator, handing over the cuddle cot to Julie McIntosh, Midwifery Community Coordinator.

## Sands-funded Midwifery Fellow

Sands has just helped the Royal College of Obstetricians and Gynaecologists (RCOG) appoint a Sands-funded Midwifery Fellow, who will work with hospitals to improve their reviews and learning, to support the RCOG's Each Baby Counts work. Each Baby Counts aims to cut by half, by 2020, the number of babies who die or are seriously brain injured because of something that happens during labour. The Sands Midwifery Fellow, who is due to be in post in March, is an experienced midwife passionate about safety and investigation, and about parents having the opportunity to take part in reviews.



Royal College of Obstetricians and Gynaecologists

#### More cuddle cots



Southampton Sands' Abigail Hooper and fundraiser Kate Gibson, donating a cuddle cot to a local funeral directors.

Several other Sands groups have also funded cuddle cots.
Southampton Sands donated one to a local funeral directors in December 2017. The majority of the funds were raised by a sponsored head shave by Kate Gibson, a member of the group, in memory of her grandson, Benjamin.

Chester Sands funded a cuddle cot for the neonatal unit at

Countess of Chester Hospital, which was delivered in December 2017. Monies were generously donated by a local couple who requested donations in lieu of wedding gifts.

East Cumbria Sands purchased a cuddle cot for Cumberland Infirmary using funds from a substantial donation from the Institute of Cemetery and Crematorium Management.

## Elvis is in the building

Elvis was all shook up whilst singing at Gwynedd Sands' charity evening in November, raising £608, which will go towards purchasing items for the maternity unit at Ysbyty Gwnedd in Bangor. 75 people attended the evening at Bangor Football Club, organised by the group, with help from the staff of the Bangor branch of Santander selling raffle tickets. Tina from the group said, "I sang my heart out, even though he was before my time." And Llinos said, "An awesome evening!"

Elvis (Wynne Roberts) gave his time for free. Wynne is a big charity organiser and was short listed for the Welsh Award for Pride of Britain for his charity work.

Also, local fundraisers walked 60 miles in 24 hours to raise sponsorship for Sands. Gareth and Christine Griffiths, with friend Islwyn Owen and sister Eirys, raised £1,180, which they hope will be of help in the future for other families.

## Community star award win

Elena Coleman from Brighton and Worthing Sands won an Argus Community Star Award in January for her tireless fundraising, having raised over £4,000 towards the group's running costs. Local newspaper *The Argus* hold annual Community Star Awards that recognise the outstanding achievements of adults, children and organisations across Sussex.

Local TV presenter, Fred Dineage, gave out the awards at a ceremony held at the Dome in Brighton. As Elena was unable to attend the ceremony, committee members Jess and Candice collected the award on her behalf. Candice said, "We were thrilled for Elena to win. It was a very humbling event with some amazing people making contributions to the community. Jess and I collected the award, then suddenly the microphone was in front of me! So I had a great chance to say how Sands gives vital support to families ... it's so important that families have someone to talk to."



Elvis raised the roof with Gwynedd Sands' volunteers Elfed, Nia, Llinos and Tina at their charity evening. Nia said, "Elvis was in full swing performing all his greatest hits over the decades."

#### Who's who



Sands' new Scottish Network Coordinator, Christopher Somerville, who started in January 2018, is responsible for working with all Scottish groups and volunteers.

Christopher says, "It's great to be on board with Sands. I'm hugely impressed by the sheer number of people who have sent me a quick welcome email – it's great to be made to feel so much part of the team before I've done anything to earn it. I'm very excited to get to know you all better, and learn more about the charity and the great work you do."

Christopher and his family live in Edinburgh, but he is originally from a dairy farm in rural Northern Ireland. He has worked in the homeless sector, and for seven years managed the *FareShare* C & SE Scotland food redistribution service, which has huge volunteer involvement, redistributing seven tonnes of food a week from the food industry to around 100 charities in Scotland.

Christopher says, "I'm so impressed to see the Sands groups creating connections for those who suddenly feel very alone. I'm really excited to be learning more about it and play a small part in helping it to happen."

"I know that the charity is in a time of change and I appreciate the frustrations, concerns, difficulties and big successes that can bring. I've been through changes in charity structure and come out the other side. I look forward to working with the Scottish Network, seeing what ideas and ambitions they have to better support more bereaved parents and reduce mortality rates across the nation."

## Success with grants and funding

Two groups in the South West have successfully become a local business' charity of the year thanks to support given by Sands Corporate and Trusts Fundraising team. Patrick High, Corporate and Trusts Fundraising Officer, and Susy Gould-Obiora, Senior Corporate and Trusts Fundraiser, helped submit a proposal to Tozers, a firm of South West based solicitors, who hope to raise at least £10,000 through various activities. The firm will be supporting not only Exeter Sands and South Devon Sands, but also Sands nationally.

If you are thinking of applying for local charity of the year partnerships or for funding from local trusts and foundations, then Susy and Patrick can help you. They are both based at Sands main office in London and part of their role is to support local groups and volunteers with their corporate and trust fundraising.

Patrick said, "Do let us know what specific projects you need funding for and we can offer you guidance and support with your fundraising. Along with the initial application process we can also support you in the stewardship, ensuring we maximise the full potential of any partnership."





Bristol Sands' third ceramic painting event in November 2017 was their busiest yet, supporting 12 bereaved families. Christmas baubles were painted, as well as plates, mugs, butterflies and candleholders. The group funded £10 per family and provided refreshments and plenty of cake. Feedback was very positive and the group intend to run another event in 2018.

Abbie, befriender, said, "It was another relaxed occasion when we could chat with others and remember our babies, channelling our love and creative talents into making something beautiful to remember them by."



Susy Gould-Obiora (second left) and Jo Anderson (third left) from Sands with the team from Tozers.

If you have questions about making a grant application, or you need support with funders, then please contact:

patrick.high@sands.org.uk, 0203 897 3432 or susy.gould-obiora@sands.org.uk, 0203 897 3444.

## White blankets please

Our army of dedicated blanket knitters send us over hundreds of white blankets every year for Sands memory boxes; thank you so much! During 2016-17 we distributed approximately 1400 Sands memory boxes.

If you, or someone you know, would like to knit or crochet white blankets for Sands the pattern is here:

https://www.sands.org.uk/getinvolved/volunteer-sands/knitsands. If you aren't a knitter or crocheter then you can still help by donating white double knitting wool. Please post blankets and/or wool to: SANDS MEMORY BOX BLANKETS, Sands Fundraising, PO Box 243, Boston, PE21 1EU.

Our Knitting Ambassador, Pat Poole, who recently spoke at the Sands Conference, is happy to help with any queries about knitting or crocheting for Sands. Please email us at: shop@sands.org.uk.



Frequently, we also receive angel pockets, booties, hats and coats, in an array of beautiful colours. Whilst these are lovely, and have been knitted with such love, care and attention, we do not have an easy route to distribute them. Our advice would be that if you want to knit/make such items, then please contact your local hospital, either the labour ward, SCBU or NICU, who may like to take such items. This would save you postage costs shipping them to us, and would mean that the items are used locally. We want to make sure that all items that you create with such love and attention go directly to those who need them.

### Remembering at Christmas



Bereaved parents and families remembered their loved ones at 16 Sands Lights of Love services across the UK in December 2017: Cardiff, Derry, Durham, Enniskillen, Epsom, Exeter, Farnborough, Guernsey, Huddersfield, London, Norwich, Nottingham, Omagh, Portadown, Stirling and Swindon. Thank you to all volunteers, readers, musicians, singers and anyone else that helped make these services so special.

In addition, many groups held other services and events across the UK. Oxfordshire Sands held their annual remembrance service in Oxford, where wooden stars with quotes on







were given to families as a gift. Families wrote their babies' names on stars, which they hung on the tree, and lit candles in their memory. A parent said, "It was hard, but comforting, to hear all the poems and readings. It was lovely to put our babies' names on stars on the trees, and to get a lovely Christmas decoration too. We are so glad we went."

Dumfries & Galloway Sands held two services: the first was a family service with Troqueer School Choir providing beautiful singing, and the second service had Dumfries Male Voice Choir take part. In Prestwick, Ayrshire Sands' Bauble Service was attended by 350 people and had a candle procession by the children.

Lights of Love services across the UK:
Clockwise from top left:
Cardiff candles; tree with tags in
Guernsey; Ayrshire bauble service;
family members lighting candles in
Wales; presents bought for children
in Portadown; Durham & Wearside
candle arrangement;
Dumfries Male Voice Choir;
wooden star gift at
Oxfordshire service.



Fife Sands held their service in Kirkcaldy, with wooden dove ornaments for their tree, on which families wrote messages for their babies.

Other services and events were attended or held by Sands groups in: Aberdeen, Banff & Buchan, Bedfordshire, Blackpool and Preston, Chesterfield, Hastings & East Sussex, Sheffield, Shetland, Tayside, and more besides.





#### Christmas tree festivals

Some groups took part in local Christmas Tree Festivals, including in Bristol, Hull and on the Isle of Wight. In Bristol's Treefest, thousands of visitors saw the group's tree adorned with the names and dates of their babies. Charlotte. Abbie and Kaeti from the committee worked together to decorate a tree at the event, where about 80 local charities and organisations displayed trees in a church. Charlotte Coombs from the group said, "We thought that this was both a public act of remembrance for our parents, but would also get a very heart-breaking message across to those who came to view the tree who knew nothing about Sands."

The 21<sup>st</sup> Brighstone Christmas Tree Festival on the Isle of Wight saw over 200 trees displayed at seven locations in and around the town, decorated by a wide variety of charities, organisations, schools, community groups and clubs. Isle of Wight Sands took part for the first time this year, raising £100 for Sands, and decorated their tree with hand-crafted snowflakes and angels as well as over 25 stockings, beautifully cross-stitched with the name of a baby no longer with us and a personalised design, made by committee member Holly and her mum. Ellen from the group said, "They were so beautiful and seeing them hung together on the tree really brought home the importance of these little ones short lives to everyone who saw them."





Sands groups decorated Christmas trees to raise awareness at tree festivals around the country. Above: Hull and East Yorkshire Sands with their tree decorated with hearts.



Above: Bristol Sands' decorated tree at their local Treefest.

Below left: Isle of Wight Sands' tree at Brighstone Christmas Tree Festival. Below: handmade cross-stitched stockings.



## **Support at Christmas**



Some groups held special Christmas support groups. Southampton Sands held a Christmas drop-in event, with ornaments available to decorate with babies' names, as well as festive punch, mince pies and chat. Visitors hung the ornaments on a special Christmas tree before taking them home to decorate their own trees or their babies' resting places. Newcastle Sands made Christmas baubles, including felt baubles. In Stockport, the group had a light buffet and the opportunity to remember each of their children in a gentle environment, and provided personalised gifts for parents.



## Help protect wildlife

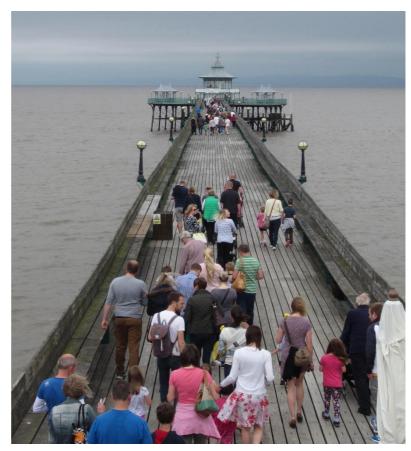
Remembrance events and opportunities to mark our children's special days are important to many of us. We've come up with some ideas for things you can do to remember and celebrate together — and in a way that doesn't harm wildlife:

- Blow bubbles into the breeze
- Float flowers on the water
- Paint a stone and leave it somewhere special
- Create a piece of art
- Make a decoration or bauble
- Wind spinners or fly kites
- Write your messages in chalk
- Decorate a tea-light holder
- Throw wild flower bombs
- Plant bulbs or insect-friendly plants
- Plant a tree
- Transform an unwanted space: vacant lots, roundabouts and verges could use a little of your love. Watch new life grow from between the cracks!

When planning such an event, please consider the impact on wildlife and the environment, by thinking of eco-friendly ways to mark the occasion. Please have a chat with your Network Coordinator to come up with ideas.

In the past, some Sands Groups have organised balloon releases as a way of marking parents' bereavements and raising awareness. Even so-called biodegradable balloons can take months to degrade, and are still harmful to the environment and wildlife. While much of the balloon might disintegrate over time, the knot and some of the latex remains long after you said your goodbyes, while their strings entangle wildlife. In addition, Helium used in balloons is a depleting resource. We've had a group in the past that has been targeted by an environmental group to prevent their balloon release from taking place, which was very upsetting for bereaved parents and families. In addition, some local councils have started introducing by-laws against balloon releases. Chinese lanterns are also best avoided, as they have caused fires in the past.

Butterfly releases can also be problematic; if they are released at the wrong time of year and in an unsuitable location the butterflies can perish quickly. Dove releases are also best avoided; we need to be mindful of their care and safety. Whilst it is a significant symbolic gesture,



Bristol Sands flower drop at Clevedon Pier to remember their babies.

the doves are only part of the event for a minute, before flying off. Many birds will not survive post-release: doves live in flocks, mate for life and do not fare well as solitary birds. If they do not meet up with another flock of doves, their survival rates are low.

## Remembering Baby exhibition

An art exhibition in Sheffield in December, entitled 'Remembering Baby', explored parents' and healthcare professionals' experiences following the death of a baby. Ashleigh Corker and Sheryl McMahon from Sands attended the exhibition. Ashleigh said, "I found the exhibition to be incredibly powerful and was especially moved by the artwork created by parents."

The exhibition was part of a wider project entitled 'End of or Start of Life', which was led by a research team based at the University of Sheffield, working with artists Hugh Turvey and Justin Wiggan. Local bereaved families took part in a 'lasting impressions' workshop in 2016, and some of the artwork that



they created was on display. The exhibition was also held in London in November 2017.

The team behind the exhibition have applied for more funds, and are hoping to have further exhibitions in 2018. To find out more visit:

www.rememberingbaby.co.uk.

## One year later ...

After starting up over a year ago, three new Sands groups are going from strength to strength. Wakefield and District Sands and Monmouthshire Sands both had their Part Two New Groups Training in January 2018. Both groups are part of the first wave of the new financial model.

In Wakefield, the group met up with Ashleigh Corker, Sands North East Network Coordinator, and discussed their plans for the next year, which include a memorial garden in the area and supporting study days.

Monmouthshire Sands met up with Heatherjane Coombs, Sands Welsh Network Coordinator. The group have joined forces with neighbouring Powys Sands to work towards providing a bereavement room at Hereford Hospital, along with a few other charities. The group are keen to find more volunteers to bolster their committee, so if you would like to help run the group please email heatherjane.coombs@sands.org.uk.

A third group, Peterborough & Stamford Sands had their training in November 2017, with Rose Abrehart, Sands East Network Coordinator. As well as their monthly support meetings at Peterborough football stadium, the group are moving forward with



Groups attending their Part Two New Groups Training.

Above: Sally, Sarah, Rachel and Helen from Wakefield & District Sands with Ashleigh Corker. Below left: Karen and Sally from Monmouthshire Sands.

Below right: Lucy, Sally and Amy from Peterborough & Stamford Sands.



their project to improve the memorial garden and are organising a photography workshop for midwives. They have also found a church in Peterborough to light up in BLAW 2018. A large Peterborough employer, BGL Group, has offered volunteer time to the group.



#### **Research fund**

The shortlist has been drawn up for the 2018 Sands Research Fund, and successful applicants have now been invited to send in a full proposal. These will be reviewed by external researchers and then considered by our Perinatal Expert Panel, with final decisions made by trustees in June.

## New commitment from government

Jeremy Hunt has brought forward the target date for the government's 'halve it' campaign, committing to halving the rates of stillbirths, neonatal and maternal deaths, and brain injuries that happen during or soon after birth by 2025 - five years earlier than first stated. Speaking at the launch of the latest MBRRACE-UK report in November, the Secretary of State for Health in England announced a new maternity strategy along with the new commitment. This is welcome news, and Sands will be working hard to ensure this ambition is achieved.

Under the new plans, babies who died or were seriously brain injured because of something that happened during birth will be referred to the Healthcare Safety Investigation Branch, the new NHS safety investigator, for independent review.

Janet Scott, Sands Research and Prevention Lead, said, "Sands has long emphasised to politicians and the NHS that high-quality review and subsequent learning is key to reducing avoidable deaths, and we continue to work as members of the Perinatal Mortality Review Tool team to help develop these processes. We met with Keith Conradi, Chief Investigator at HSIB, in early 2017, and will be meeting with the lead investigator on the maternity work in coming weeks."

Sands is also working with other charities and politicians to follow up Mr Hunt's suggestion that coroners should be able to investigate stillbirths. We have sought the views of parents and those who have experience of the coronial system, and have fed this into discussions.

## National Bereavement Care Pathway launched

The National Bereavement Care Pathway (NBCP) for pregnancy and baby loss is now live in 11 sites across England, and will be launched in a further 20 sites in April 2018.

The full list of pilot sites is: Chelsea & Westminster (London); Heart of England (Birmingham); Hull; Ipswich; Liverpool Women's; Medway (Gillingham); North Devon (Barnstaple); Queen's (Romford); Walsall; West Middlesex; Wirral; York. The sites have been using guidance notes and pathway documentation, based on national good practice, produced by the NBCP Core Group and its partners since the wave 1 launch in October 2017.

Marc Harder, NBCP Project Lead, said, "We are beginning to gather feedback from the pilot sites, and will be reviewing and refining the documentation in February and March ahead of the wave 2 launch in April. The wave 2 sites will be announced later in February."

We are also delighted to announce that the NBCP in Scotland will be running from April onwards, thanks to £94,000 funding from the Scottish Government.

On 15<sup>th</sup> December 2017, three staff members from Sands (Laura Price, Phil Simon and Marc Harder) and three colleagues from NHS England ran a half marathon (13.1 miles) around London, to raise awareness of the NBCP, stopping at the offices of many of the Core Group partners along the way for refreshment, encouragement and a photo.

Marc said, "We wanted to do something challenging to raise awareness of the National Bereavement Care Pathway. This was a fun way of doing so and I'm really grateful to those who supported us along the way – mirroring the great collaborative work which has taken place during 2017."

Alongside the programme, an independent evaluation is being carried out by Fiveways Research, surveying parents and professionals to establish the impact and effectiveness of the pathway, ahead of what we hope to be a national roll out towards the end of the year.

For further details contact Marc Harder, NBCP Project Lead: marc.harder@sands.org.uk.



Sands and NHS England staff members ran a half marathon around London to raise awareness of the new NBCP (from left to right): Lisa Ramsey (NHS), Marc Harder (Sands), Phil Simon (Sands), Cat Wilson (NHS), Laura Price (Sands) and Kath Evans (NHS).

# Still Born documentary

Berkshire Sands' members and Erica Stewart, Sands
Bereavement Support and
Awareness Specialist, have been involved in a 15-minute *Still Born* documentary, conducted by a group of third-year students from the University of Westminster.

The documentary explores the issue of baby loss in the UK, aiming to promote awareness and to convey the impact of such loss on families, how they cope with life after loss and the type of support that is available. The students were honoured to be let into the lives of families through the making of this documentary. You can see the documentary here: https://www.youtube.com/embe d/iHO5\_yMHZzY?rel=0.

The documentary makers said, "Sands and Berkshire Sands group have been a great help to us as a crew, but more importantly to hundreds of families across the country."

## **60 Minute** Makeover



Jayne from Hastings & East
Sussex Sands had a surprise visit
from Peter Andre and Linda
Barker who gave her house a
60 Minute Makeover. Jayne was
nominated by her sister, husband
and friends to say thank you and
give her a treat. They honoured
the time she spends looking after
her mum, the Hastings & East
Sussex Sands group and her local
school fundraising team, as well
as being mum, a wife and dealing
with her own grief after the death
of her baby, Jessie.

Jayne said she is "... feeling very grateful that people will hear the name Sands on television and will know that support is available for anyone affected by the death of a baby."

## £60,000 cheque

An enormous £60,000 cheque was presented to Clea by the Northern Ireland Network Chair, Tommy Ferguson, on behalf of the Northern Ireland Network steering committee (NISC), at their Network Day in Templepatrick in November.

Andrew McCreery, the Treasurer, said, "In Northern Ireland, we decided that it was best to send these funds to UK Sands as they are leading on so many valuable projects: influencing governments, research, etc. We are all working together to one cause. Whether we save a baby's life in England or in Belfast, we don't want any parent to suffer. We want to save babies' lives everywhere."

The NI Network has not yet moved into the new financial model, but it takes very seriously the idea of sharing resources to make a difference. The steering committee reviewed their budget and plans alongside their income and expenditure over the year and identified the surplus they had available, which they asked to release into general funds to be spent achieving the charity's objectives across the UK.



Tommy Ferguson, Sands NI Chair, handing over a large cheque for £60,000 to Clea Harmer, Sands Chief Executive, and Steven Guy, Sands NI Network Coordinator.

Steven Guy, Sands NI Network Coordinator said, "The £60,000 is surplus funds left over after the Network had allocated funds for core costs, projects, etc. Some of the funds were raised from a tractor drive and a fire walk." "The NISC decided a few years' ago to send any surplus funds to UK Sands at the end of each financial year. This is the fourth cheque we have presented in the last few years, bringing the total to around £150,000."

## Sands online community

The Sands online community had an astonishing 1389 new users in 2017, with over 700 posts per month. Recently, we updated the look and functionality of this source of 24/7 bereavement support and we hope that this will encourage more people to benefit from this supportive online community.

A bereaved mum said, "Sands has helped me complete my grieving by having a forum who have welcomed me and allowed me to talk about [my son, born in 1972] and given me an opportunity to help the newly bereaved. In those far off dark days you never mentioned babies gone too soon as that was taboo. Thank you the wonderful people running this site."

The online community provides essential support for parents at a time when they can feel no one understands them, and no one is around. It can be accessed here: https://sands.community/login. The new software is mobile-device friendly. It has a registration process, to ensure that users are genuine; we ask for your email address, user name and confirmation

that you agree to our community guidelines and terms of use. It takes approximately 24 hours to activate a new account. Some bereaved parents read the experiences of others without necessarily posting themselves and others use it as a safe, supportive online space to talk about their baby and their grief. It is moderated by Sands staff to ensure that all posts are appropriate and adhere to our guidelines.

Currently, the online community is aimed at those who are over 16, but we are looking at developing pages where younger people can access support.

If you would like to contribute or comment on the new-look online community, please email your thoughts to Helen Butlin, Bereavement Support Services Manager: helen.butlin@sands.org.uk.

#### **AMRC**



Sands has now been approved as a member of the Association of Medical Research Charities (AMRC), the national membership organisation of leading medical and health research charities, after showing that we have a rigorous process for selecting and funding research. Laura Price said, "We passed with flying colours!"

Membership gives us networking and training opportunities, and means that funded research is eligible for additional support from the Government. There's more information here: www.amrc.org.uk.