



# The Lullaby Trust Impact Report 2018-19

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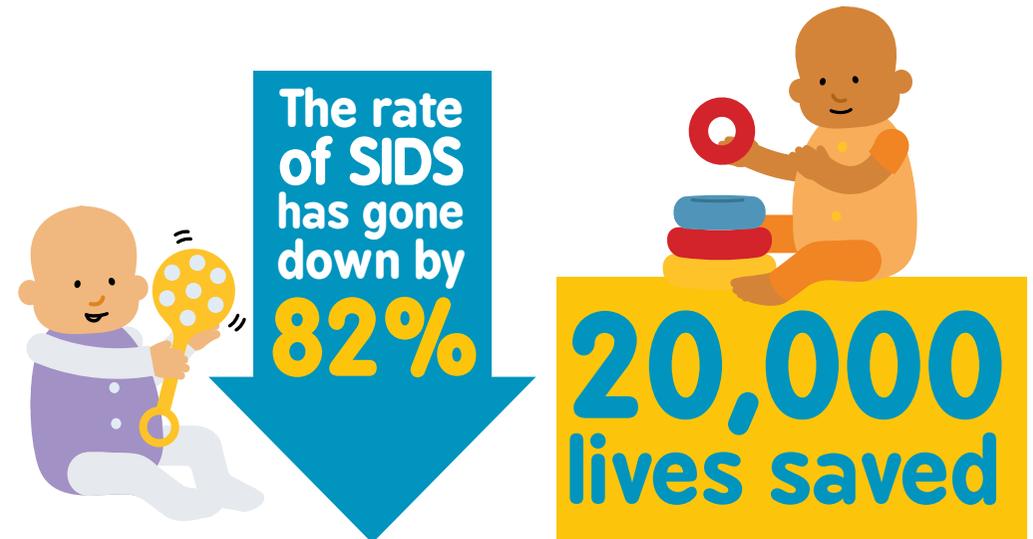
## Who we are

The Lullaby Trust is a charity that saves babies' lives and supports bereaved families. Around 4 babies a week still die from sudden infant death syndrome (SIDS) and we are committed to bringing that number down to zero.

Through educating parents on how they can reduce the risk of SIDS and investing over **£12million** in research, we have played a key role in reducing the number of babies who die from SIDS by **82%**, saving the lives of more than **20,000** babies.

Each year we train thousands of health professionals to support parents in sleeping their baby safely. We campaign tirelessly to raise awareness of SIDS and ensure our life saving advice reaches all parents.

The Lullaby Trust supports bereaved families, through our helpline and befriending scheme. Our work with the NHS to provide a Care of Next Infant Programme (CONI) offers a lifeline to bereaved families expecting a new baby.



# Our year in numbers

**149,891**

leaflets on safer sleep advice were sent out to parents and professionals working with families

**2,220**

parents and professionals contacted us for information on safer sleep

**1 million**

visits to our website. That's a 56% increase on last year



**Over 17 million**

people were reached with safer sleep advice during our Safer Sleep Week campaign

We provided

**4,500**

professionals with safer sleep advice

**7.9 million**

 people reached on Facebook

**813**

bereaved families contacted us for direct support and 258 professionals contacted us for support on behalf of a family they were working with

**598**

adults and 449 children attended our free days out for bereaved families

**87 families**

were allocated a befriender to offer peer-to-peer support during the year



## Saving lives through expert advice

Our safer sleep advice gives parents simple steps they can follow to reduce the risk of SIDS. In 2019 we reached more parents than ever before with information that could save their baby's life.

We trained **4,500** health professionals in safer sleep advice that they can pass on directly to new and expectant parents. Our team of regional staff have been involved with several local projects to train healthcare professionals during the year.

We distributed **149,891** leaflets, had over **a million** visits to our website and reached **7.9 million** people on Facebook.

We have developed new resources for parents and health professionals with Public Health England, Unicef UK Baby Friendly Initiative and Basis and will continue to promote our new messages and resources to ensure all professionals are clear on safer sleep advice.

In March 2019, we ran our fifth and most successful annual awareness raising campaign; Safer Sleep Week,

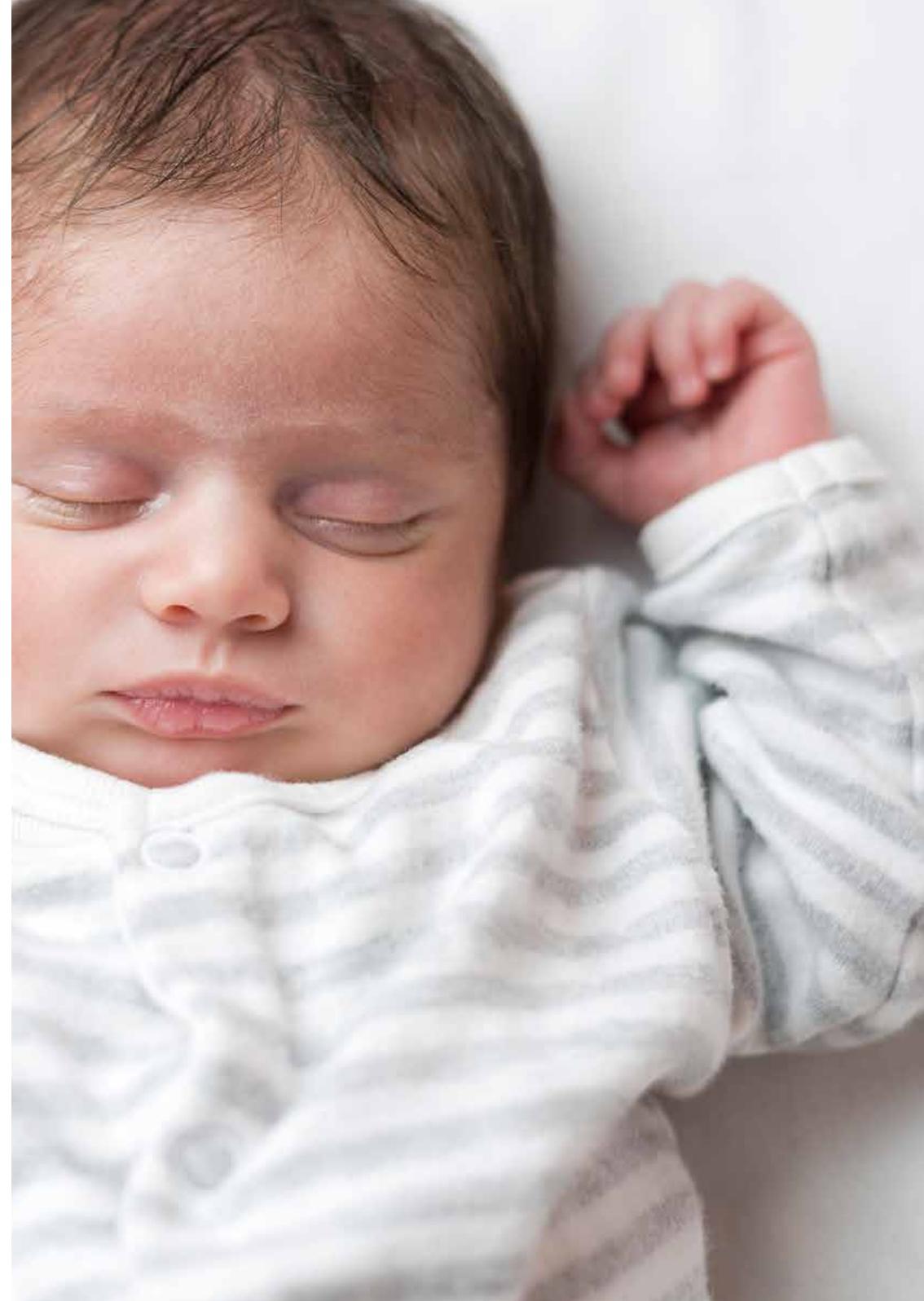
# 4,500

trained health professionals

with the support of Public Health England. We reached over 17 million people through website, social media, email, printed publications and media coverage. During the campaign we appeared more than 650 times in the media including slots on ITV news, Sky News and BBC Breakfast.

We have worked hard to secure regular coverage in the media. Over the past year we have issued news stories and statements on a variety of subjects from baby boxes to the impact of celebrity influencers on parental behaviour. We have achieved hundreds of pieces of media coverage in the local and national press, and on television and radio, which have given us the opportunity to reach millions of people with our safer sleep messages.

We reached over  
**17 million**  
people through  
**Safer Sleep Week**  
our annual awareness  
raising campaign



# Robert's Story

**Bereaved father Robert Weeks sadly knows only too well the importance of raising awareness of SIDS and safer sleep.**

On the 3rd January 2012 our lives changed forever when our beautiful daughter Sophia died suddenly and unexpectedly. She was just about to turn twelve weeks old.

We have still never had an explanation for why our healthy and 'normal' daughter died. We were one of 221 families that year whose child died for no apparent reason and with no cause found, even after a post-mortem was held.

I think the work that The Lullaby Trust does to raise awareness of safer sleep for babies is absolutely vital. Every new parent should be made aware of this information if it will prevent other families from going through what we have been through.



# Empowering young parents



Babies born to mums under 20, in the UK, are five times more likely to die of SIDS than those born to older parents. The Lullaby Trust's young parent project Little Lullaby provided advice and support to young mums and dads delivered through their peers.

Little Lullaby provided a community to reduce the isolation often experienced by young parents. Our young parents produced thousands of blogs and videos, sharing their experiences and advice and regularly took part in takeovers of our social media channels. By the end of the project our social media reach had exceeded 3.5 million.

Unfortunately, our second round of funding from National Lottery Community Fund came to an end and we were unable to secure alternative funding. As a result, the project came to an end in March 2019.

Though the project has ended we are very proud of all that has been achieved during its four years. 39 young parents were trained as ambassadors delivering safer sleep advice to their peers. Of the last

cohort, 90% said they had gained new skills as a result of the training. We worked with health professionals to help improve young parents' engagement with health services. As a result, 93% of professionals said they felt better equipped to support young parents to adopt safer sleep practices.

We have learned a great deal from our work with these inspiring young people and will continue the legacy by ensuring our activities and messages are inclusive of and relevant to young parents. The Young Parent Panel, an advisory body of young parents, remains active.

**87%**  
of young parents  
who completed our survey  
said they felt  
less isolated  
or had made new friends  
through their connection  
to Little Lullaby.



# Leigh's story

**Young mum Leigh trained as a Little Lullaby ambassador, delivering talks on safer sleep to other young parents and talks to health professionals on working with young parents. She is now a member of our Young Parent Panel.**

☺ At first, I wasn't sure I wanted to do the course but then I went along and they explained things more. I got interested because it's things that I didn't even know, like I didn't even know about sudden infant death syndrome. I didn't know how common it could be and what you could do to reduce the risks and I found it really interesting.

I learned to become more confident; before Little Lullaby I wouldn't get up and talk and then I was able to get up in front of loads of groups of people. When I did my first safer sleep talk I was really scared at first, I didn't know how it was going to be. But then Charlene the project manager was there as well and she didn't put you on the spot- she helped you if you didn't know what you needed to say. Afterwards I couldn't stop talking about it, I was so happy that I did it.

It helps you as well because then you're learning about other situations that you wouldn't find yourself in usually. It felt like I was helping other young parents that didn't have that support, which I also didn't have but was able to give to them.

I think Little Lullaby would help a lot more people if they continued and it's sad that some young people won't get the chance that I was given. But then I can still pass on those messages about SIDS and safer sleep to young people myself. ☺



# Understanding SIDS and how to prevent it

It can be very hard for parents if no medical or other explanation has been found as to why their child died. We are committed to finding out more about SIDS; why it happens and how it can be prevented.

Since our formation, The Lullaby Trust has invested more than £12 million in research. This research has saved lives and made a significant contribution to the decline in SIDS rates by allowing us to share wider knowledge on how to reduce the risk.

We are currently funding a three-year long research project at Great Ormond Street Hospital to investigate whether there is a link between certain combinations of infection-causing bacteria and sudden infant death.

We are also contributing to a wider research trial to support and incentivise pregnant women to give up smoking. If no women smoked during pregnancy we estimate SIDS deaths would fall by a third.

We continue to be involved in projects, which will allow us to further our knowledge of SIDS, and have joined the stakeholder group convened by the University of Bristol to help develop the first ever national child mortality database. The National Child Mortality Database will collect information about all children in England who die before their 18th birthday. The collection, analysis and public reporting of information from all child deaths across England will aid learning to reduce preventable child mortality. We are also involved in the development of the National registry for unexpected deaths in childhood.

**If no women smoked during pregnancy, we estimate SIDS deaths would fall by a third**



# £12 million invested in research

# Jemma's story

*Jemma's daughter Ruby, sadly died suddenly and without explanation in 2002. 17 years later Jemma still struggles with not knowing why she died.*

☺ Ruby was a happy placid baby, she had just cut her first tooth and was enjoying solids. Ruby was described as pristine, which she really was. She had beautiful blonde hair and blue eyes. She was just perfect.



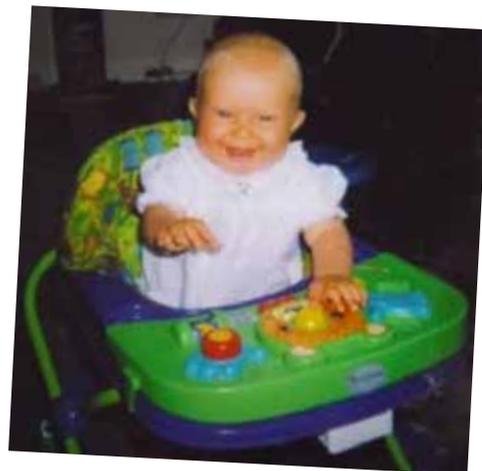
One morning in August 2002, I woke up with her beside me in bed. She was warm and floppy. I picked her up and started screaming. My friend Julie then rushed in and took Ruby off me.

Julie told me to leave the room and she started to do baby CPR. It was really distressing; I wanted to be in

the same room as my baby. When the paramedics arrived they took Ruby off to the hospital and I followed as quickly as I could.

As I got to the hospital I could see the nurse waiting outside and straight away I knew that Ruby was dead.

Waiting for the cause of death seemed to take forever. I also had to go to an inquest. The inquest was not a nice experience. I had to leave when they spoke about the post-mortem as I didn't want to be present for that. I know what happens and I really didn't want to hear all the details.



The outcome of the inquest was 'unascertained'. To this day it still makes me feel numb to have no reason at all for Ruby's death. I thought cot death only happened to babies under three months until Ruby passed. Cot death doesn't really get spoken about until it happens to you or someone you know.

I saw a paediatrician after the inquest who went through the post mortem with me. He said that the results should have read SIDS, but I said it's still the same: we don't know why she died.

I first learned about The Lullaby Trust when I was given a card with the details of the charity's bereavement support line at the hospital. It took me a few days until I decided to get in touch. I still have that card somewhere. The Lullaby Trust provided me with a Befriender which was a great help.

I visited Ruby's grave as often as I could. My son chose the spot for her to be buried.

I'm booked to do an abseil down the Mittal Orbit in London on what would be Ruby's 18th birthday in January 2020. My mum and sister have both done parachute jumps in her honour and I've done the women's 5k challenge with my niece, as well as doing Miles in Memory and a sponsored push over the years, all to raise money for The Lullaby Trust.



I have good and bad days but I've learned to live with Ruby's passing. She stays with me in my heart. I find talking about her keeps her memory alive and although it can be upsetting it gives me some comfort. ☺

# Supporting bereaved families

The Lullaby Trust offers support to bereaved parents and family members over the phone or through social media and email. We also support anyone who has been affected by the death of a baby such as friends of the family or professionals involved in the care of the baby.

All bereaved families who contact us are offered support from a Befriender. Befrienders are trained volunteers who are themselves bereaved parents, grandparents and siblings. They offer personal support for as long as needed. This year we have been awarded a grant from the National Lottery Community Fund to expand our befriending service. This has enabled us to recruit more Befrienders and offer more training and support to those undertaking this vital role.

Our support service is available whether people are newly bereaved or the bereavement was many years ago. During the year, we had **1,071** contacts looking for bereavement

support, **439** of whom were contacting us for the first time.

Parents who have suffered a sudden and unexpected death of a baby often feel anxious when they have another baby. Working with the NHS, we run a national health-visitor led service for bereaved parents, Care of Next Infant (CONI) programme.

The CONI programme provides extra support for bereaved families, during pregnancy and after birth, to help reduce anxiety and allow them to enjoy the first year of their baby's life. The programme offers regular contact with a health visitor, symptom diaries, weight charts and movement monitors and the support of a paediatrician. Thanks to generous funding provided by the partnership with Teddy's Wish, we are able to deliver free CONI Co-ordinator training to health visitors. This will open up training to areas of the country that might not have previously been able to afford it and allow more families access to the vital support offered by the CONI programme.

We are also in the process of forming a partnership with Nimans who produce the Snuza monitor, a small wearable movement monitor for babies. Nimans plan to donate 300 monitors to the CONI scheme, which will allow us to gift monitors to many parents rather than loan the more expensive monitors.

We offer every bereaved parent, the offer of a free family day out once a year. They are held throughout the country at various venues, and allow families to spend time with their children, to remember their baby who died, and to access face to face information and support. Last year we held **8** days, which were attended by **598** adults and **449** children.

During the year, we had

**1,071**

contacts looking for bereavement support



# Holly's story

“ As supporters of this amazing charity, we were invited to their annual family day recently. This year we were lucky enough to have a free day as a family and access to face to face support at Lightwater Valley and the opportunity to meet other loss parents.

We have had a very difficult year. I had no idea having a rainbow baby was going to feel the way it did. It drastically had an impact on our toddler Beau's behaviour, which has made life very difficult and I have to say I was nervous about going to a theme park with a toddler. I worried I wouldn't get a chance to talk to

anyone from the charity and it would be a stressful day.

I have to say the day couldn't have gone better. We had an absolutely lovely day. It was the first time in ages I had felt close to Beau after he had been pushing me away recently and only wanting his Daddy. It was a joy to see him so happy too. For the first time in a long time I felt content and happy with life and this day out couldn't have come at a better time. It allowed me to actually feel positive about the future.

When we lost our daughter Silver and even when she was alive and unwell,

me and my husband Fabian proved we could in fact work well in difficult situations together and support each other through difficulties. This dwindled a bit over time as the stress of regular life came back to the forefront and suddenly it was not practical to dwell on our grief and be all consumed every day. This day out together showed us that we can actually still support each other really well and gave us a boost in confidence for a much happier future as a family with two living children.

Over the lunchtime period we also got to meet up with the charity and speak with some of their befrienders. It felt incredibly cathartic to talk to other people that had lost babies too and be able to openly speak about how we are coping and say Silver's name. It was nice just to have someone so animatedly asking questions about Silver and not shying away or avoiding the topic. I enjoyed being able to talk about her, without feeling I was making people uncomfortable.

Not only this but Beau was included too and we got to make origami butterflies. This enabled us to have the opportunity to speak easily, whilst he was entertained and I am hoping over the years if they



continue doing these events that Beau will eventually be able to talk about his sister and how he feels too.

I know to some people a day out may seem a trivial thing but grief is isolating and naturally depressing. We all need a break from reality, the chance to talk about how we feel and we need the opportunity to smile



again without feeling guilty. Different people will benefit in different ways from these events. Some may have had no support and desperately needed to talk to someone who understands. Others maybe just needed that reason to leave the house for the first time.

I didn't realise until the day came just how much I really needed a family day. A day where we could just focus on enjoying each other's company and an opportunity to smile for the first time in a long time. With Silver's anniversaries coming up and the anniversary of our miscarriage the following day, I have been very emotional recently. This retreat was a much needed break with a much needed opportunity to talk about how I had been feeling. ☺



## Working together to improve bereavement care

The Lullaby Trust has taken an active role in working with other charities to highlight the high level of infant mortality in the UK and the need for better bereavement care for families. During the year we were involved in some large collaborative projects with other organisations.

Over the last 3 years we have worked closely with Sands, Bliss, Miscarriage Association, Antenatal Results and Choices on the National Bereavement Care Pathway. The NBCP, which has the support of the Department of Health, has been developed to improve the quality of bereavement care for parents and families at all stages of pregnancy and baby loss up to 12 months. This is done through a set of guidelines to help professionals support families whose baby dies. During the year, we celebrated the extension of the project to a further 21 hospitals.

An independent evaluation of hospitals where the NBCP has been implemented, published in May 2019, provides evidence that the NBCP has improved the bereavement care received by parents after the loss of a baby and increased confidence

and empowered staff to provide consistently good bereavement care

We continue to provide the secretariat of the All Party Parliamentary Group on Baby Loss in Parliament. During the year, one of the Co-Chairs, Will Quince MP, stepped down, having been appointed to a ministerial role. Antoinette Sandbach MP became the Chair at this time. We thank both of them for their dedicated work to highlight the issues around baby loss, and look forward to the next year. We are also part of the Baby Loss Alliance, a group of charities leading Baby Loss Awareness Week. The Baby Loss Awareness Week debate in parliament was again a key focus of the Week.

**The National Bereavement Care Pathway to improve the care of bereaved parents was rolled out to a further 21 hospitals this year**

# Looking forward: Our Future Plans

## **Promoting our safer sleep message**

by continuing to build on the number of people we engage via our social media channels and website and to build on our training of health professionals. We hope to continue to build on our trusted reputation amongst health professionals to ensure our advice is passed to parents when it is most relevant.

**Supporting research** by involving ourselves in projects that allow us to further our knowledge of SIDS, such as the development of the first ever national child mortality database. This will aid learning on SIDS deaths and how we can prevent them. We are also involved in the development of the National registry for unexpected deaths in childhood.

## **Supporting bereaved families**

by expanding our services to support more families who have lost a baby during the neonatal stage. New partnerships have allowed us to expand our CONI service and we will be able gift free SnuzA breathing monitors to families.

## **Working to reduce wider infant**

**mortality** by collaborating with the other leading pregnancy loss and infant death charities across the UK, to campaign for change to help us reduce preventable infant mortality and improve services for bereaved families.

**Engaging with young parents** by continuing the legacy of Little Lullaby, which allowed us to open a dialogue and work closely with young mums and dads.

Our Young Parent Panel will continue to guide us and ensure young parents are represented and that we are reaching them with information and advice that is relevant. We continue to provide guidance to health professionals on working effectively with young parents.



# Your support saves lives

A huge thank you to our supporters whose generosity, dedication and feats of endurance and bravery have allowed us to continue saving lives and supporting families. You are all amazing.

Special thanks go to comedy writer, performer and best-selling author, Adam Kay who generously supported The Lullaby Trust throughout his sell-out theatre tour of This is Going to Hurt Live. Collections held at each performance have so far raised over **£100,000**. We're also delighted to welcome Adam as an official Ambassador for The Lullaby Trust.

**56** runners took part in the London marathon, their hard work and training raised an incredible **£136,000**. Also thanks to all those who donated to the Big Give Challenge raising **£70,000** for our support services for bereaved families.

Thank you to everyone who has requested donations to The Lullaby Trust for their birthdays through the new Facebook birthday fundraisers, helping us to raise an incredible **£37,532**.

We were also delighted to secure funding from the National Lottery Community Fund Reaching Communities for **£87,754** over 2 years and 3 months to invest in our Befriender programme.

One of the many highlights from our active Community supporters was the Children's Portrait Awards 2018; The Lullaby Trust was chosen for a second year as the beneficiary and received a generous donation of **£6,080**.

Whether you took on a challenge, baked a cake, organised or attended an event, or made a donation of any amount, you made a difference to families in the UK.

# 56

marathon runners covered a combined distance of over

# 1456

miles.



# Jessica's Story

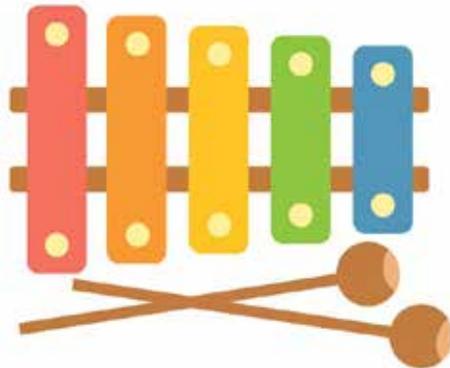
“ When I became pregnant with my second child in 2012 I just knew she was a little girl. She was born at 33 weeks by c-section. We called her Millie Grace. She was tiny, just 3lb 4oz and the most beautiful little thing I had ever seen. She spent 2 weeks in Neonatal. Our son Jayden, who was 3 at the time, loved stroking her hand and holding her. Over the next few weeks she grew bigger and was getting stronger each day. But when she was 5 weeks and 6 days old we had a restless day and we all went to bed early.

I fell asleep with her in our bed and before my eyes opened I already knew, I felt like a part of my body had gone. The next few hours were a blur and those hours turned into weeks; I did not sleep, eat or even talk. I could not accept that she had gone before her due date. One morning my little boy walked over to me and said “Mummy can you take me to school”, I did not just lose my daughter but my family had lost me. From that day I said to myself that I would never stop saying Millie's name and I would celebrate her short life. She gave me the strength to carry on. She changed our lives.

Each year we hold a Mile in Memory event to remember our beautiful little girl. It's an emotional day with tears, smiles and laughter, a day full of love. Our first walk, family and close friends, 20 people attended. This year, our most recent walk we had around 70 people. Over the last few years we have raised £6,135 for The Lullaby Trust.

I will continue to support The Lullaby Trust for awareness, but also so no other parent has to feel alone.

Millie Grace where I go you go. ”



# Thank You

## Companies, Trusts and Foundations who have supported us in 2018/2019 include:

- Adint Charitable Trust
- BBC Children in Need
- Candis Magazine
- Cascade Productions International Ltd
- Dandia Charitable Trust
- Eve Sleep
- God My Silent Partner Foundation
- Global Make Some Noise
- Greenery
- Gwyneth Forrester Trust
- Iliffe Family Charitable Trust
- JE Posnansky Charitable Trust
- Kiddy
- Magri Developments Limited
- Masonic Charitable Foundation
- Medical Air Technology
- Moba
- Morrisons Foundation
- National Lottery Community Fund

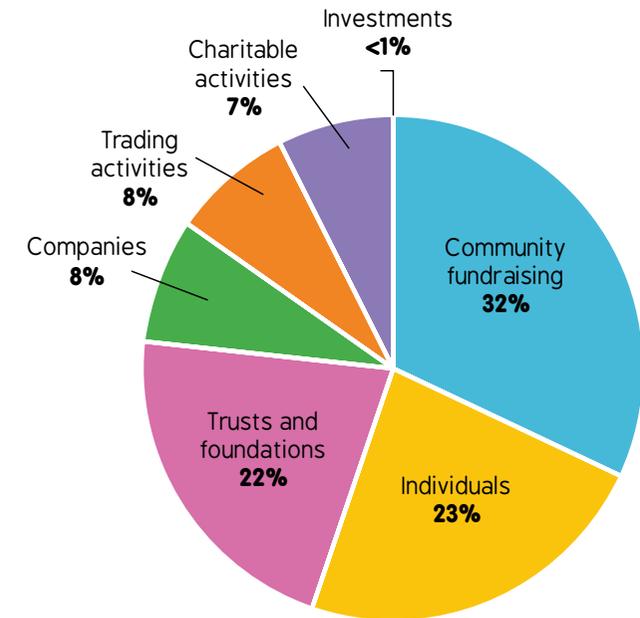


- Pilkington Charities' Fund
- Postcode Community Trust
- Sandhu Charitable Foundation
- Sandra Charitable Trust
- Teddy's Wish
- The Gro Company as part of Mayborn Group Ltd
- The Kristina Martin Charitable Trust
- The Motcomb Street Traders Association
- The Schuh Trust
- The Swire Charitable Trust
- Walton Wagner
- White and Case
- Yorkshire Children's Hospital Fund

# Income

## Where our money came from

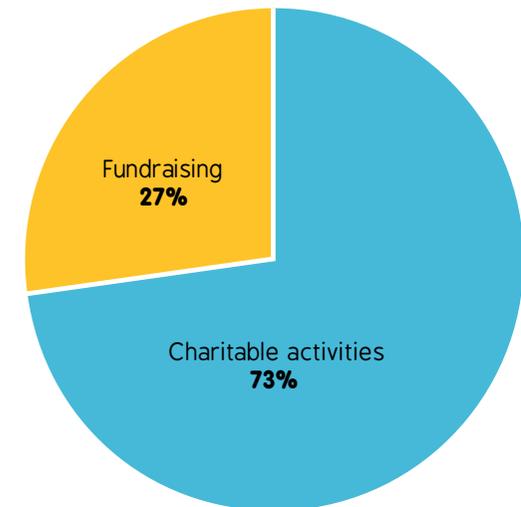
Thanks to the incredible generosity of our supporters we generated net income of **£1.65m** in 2018/2019.



# Expenditure

## How we spent our money

This year we spent **£1.55m** (excluding the direct costs of our trading activities). For every pound we spent, **73p** was spent on our charitable work and **27p** was invested into raising funds to continue our work.



Financial information has been extracted from the full Annual Report and Consolidated Financial Statements which were approved by the Board of Trustees on 3 December 2019. These summary statements have not been separately audited.



[www.lullabytrust.org.uk](http://www.lullabytrust.org.uk)

[office@lullabytrust.org.uk](mailto:office@lullabytrust.org.uk)

**020 7802 3200**

Audley House, 13 Palace St,  
Westminster, London,  
SW1E 5HX

The Lullaby Trust is a registered charity (262191) and a company limited by guarantee in England and Wales (01000824)