The Lullaby Trust Impact Report 2017-18

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Contents

Who we are	3
Our year in numbers	4
Keeping babies safer while they sleep	6
Loren's Story	8
Empowering young parents	10
Stephanie's story	12
Looking for answers	14
Supporting bereaved families	16
Cat's story	18
Our new Baby Check app to support parents	20
Looking forward: Our future plans	21
Maggie's story	22
Campaigning for change	23
Lilly's story	24
Your support saves lives	26
Income	28
Thank you	29

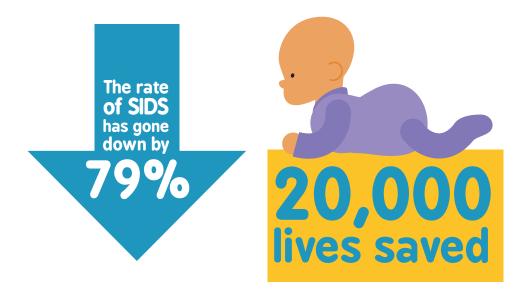
Who we are

The Lullaby Trust is a charity that saves babies' lives and supports bereaved families. Around 5 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 \pounds 12million in research, we have played a key role in reducing the number of babies who die from SIDS by 79% over the last 30 years, 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 young parent project Little Lullaby reached over 36,000 young people via workshops and our website



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





young parents trained as Little Lullaby ambassadors to provide peer-to-peer safer sleep talks to other young parents



227

Our year in numbers

199,637 Ieaflets on safer sleep advice were sent out to parents and professionals working with families



1,960

parents and professionals

contacted us for information

on safer sleep



Keeping babies safer while they sleep

In 2018 we continued our work to reach as many parents as possible with our life saving advice on how to reduce the risk of SIDS.

We trained **5,000** 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 **199,637** leaflets, had **687,369** visits to our website and reached **4,619,752** people on Facebook.

In March 2018 we ran our fourth annual awareness raising campaign Safer Sleep Week with the support of Public Health England. We reached close to **4 million** people through website, social media, email and printed publications. We also appeared more than **250** times in the media including slots on ITV news and BBC's Victoria Derbyshire.









Loren's Story

I am hoping one day, all parents know how to reduce the risk so parents don't have to experience the loss that I did.

I was 18 when I fell pregnant; I was going to college training to be a hairdresser. I remember feeling really sick one day and one of my friends joked I might be pregnant. Little did we know I was!

I felt totally in shock. My family took a few months to accept it, but as my due date got closer, they started to show their excitement. It was hard watching my friends go out and on holidays – but being able to eat what I want and not worry about the calories, feeling his kicks and seeing the scans made up for it.

Archie was born by emergency C-section in July 2012. He had blonde hair and loved to pout. He was amazing – worth all the sickness, pains and nights in. I was given a print out about antenatal care and we come home 3 days later.

The health visitor told me about SIDS at our first visit. The word made me feel sick but she reassured me it was rare so I quickly put it to the back of my mind and told myself it would never happen to families like mine. Archie was bottle fed and didn't have a dummy. We shared a bed as I didn't drink, smoke or take drugs. Archie was gorgeous and he knew it, he loved the mirror, he could drink milk for England and was a little chunk with skinny legs and big feet. His favourite game was flying like superman, he started to smile, did the cutest laugh for the first time and his favourite thing was his bouncer. When he was 6 weeks and 4 days old we said goodnight to him for the last time.

The following morning he was taken to hospital and they told me it was SIDS. I found some information and support on The Lullaby Trust website. The hospital provided great aftercare and was very supportive while my family and I helped each other to grieve.

When I found out I was pregnant again, I got loads of help from my midwife, she was brilliant and put me in touch with the Care of Next Infant (CONI) programme that provided advice and equipment to put my mind at ease. When my son was born, it was the scariest but happiest time of my life. He's now 2 and I still keep him wrapped up in cotton wool, like we all do. Now I know the dangers I would never share a bed with him.

Now, 3 years later, I am fighting to get clearer, more informative support and guidelines on safer sleeping, spreading awareness of sudden infant death syndrome and teaching parents the things about safer sleep that no print out or leaflet could tell you. I am hoping one day, all parents know how to reduce the risk so parents don't have to experience the loss that I did. I'm also currently part of the Young Parents Panel for The Lullaby Trust. The panel helps the charity to reach as many young parents as possible by telling them what appeals to us. I have started a petition in Liverpool for better education and more accessible guidelines around SIDS. I tell everyone with children to follow the guidelines and tick every box, because one little change could save your baby's life.



Empowering young parents

Babies born to mums under 20, in the UK, are still three times more likely to die of SIDS than those born to older parents. Backed by The Big Lottery Fund, The Lullaby Trust's young parent project Little Lullaby, provides advice and support to young mums and dads delivered through their peers.

Guided by our Young Parent Panel Little Lullaby provides a community to reduce the isolation often experienced by young parents who face a range of challenges unique to their age and may lack a support network. Young parents share their parenting experiences and advice on our website and social media channels through blogging, posting, takeovers and conversation.

Almost all our content comes directly from young parents aimed at other young mums and dads. Little Lullaby aims to challenge stereotypes and give young parents a voice by sharing the positive aspects of young parenting and to empower young parents to achieve their full potential.



Parents under 25 are less likely to engage with antenatal services so we provide training and a range of resources for health professionals to be able to work more effectively with young parents. We also train young parents to deliver safer sleep information to other young parents.

This year 23 young parents trained as Little Lullaby ambassadors, to teach other young parents about safer sleep through peer-to-peer safer sleep talks.





Stephanie's story

Losing my niece inspired me to become a young parent ambassador

It was my little cousin's fourth birthday. I'd spent the day with my family, laughing, playing and celebrating, just like any other family get-together.

The same day, I started to get contractions. I was so excited! I thought 'Oh my God! My little boy is going to be here anytime now! How amazing!' At 10.42pm the next day, I welcomed little Joshua into the world.

My little boy's father and I weren't on good terms at this point, so when I went to the delivery room, he wasn't present. I called him once I'd given birth to tell him the news. At first he was really excited but I could tell down the phone that he was uneasy, something was distracting him. 'I need to tell you something,' he said just before we ended the phone call.



He came to the hospital, ready to meet our son, but I could see that something wasn't right. He just stood there, completely still. Slowly, he told me the news: our niece had passed away. At that moment, my world came crashing down.

I didn't believe him at first, I just kept shaking and saying 'You're lying! Why would you say such a sick joke?' He reassured me that everything was going to be okay. My heart just bled for her.

I picked up my phone and went through my photos before I found the last image I had of her, taken just two weeks before, and I burst into tears It was heartbreaking. On the day I was meant to be celebrating a new life entering the world, I found myself mourning for the loss of this gorgeous little girl. She was only three months old. She was supposed to be Joshua's little partner in crime, his best friend. I was so looking forward to seeing them grow up together, but now she was gone. Later, we learned that she had died from sudden infant death syndrome (SIDS) or 'cot death' as some people call it. I had heard of SIDS before, but I had never really been told about it in depth.

Losing my niece is what inspired me to become a young parent ambassador. I want to make sure that all young parents are aware of the risks of SIDS and the simple things mums and dads can do to reduce the risk of it occurring. I want to make sure no other families experience the heartbreak my family has.



Looking for answers

Since its formation, The Lullaby Trust has invested £12 million in research to try and find out more about the causes and prevention of sudden infant death. This research has led to the development of safer sleep practices that can be followed to reduce the risk of SIDS such as sleeping a baby on its back. However, we still don't know what causes SIDS and are determined to keep going until we find out.

Thanks to money raised by our 2017 Big Give appeal we are 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 currently 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.

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£12 million in research

Supporting bereaved families

The Lullaby Trust offers support for parents and family members over the phone and via social media and email. All bereaved families who contact us are offered support from a Befriender. Befrienders are trained volunteers who are themselves bereaved parents, grandparents and other relatives. They offer personal support for as long as needed. Many people find it an enormous comfort to talk to someone who understands what they are going through. During 2017-18 we allocated **119** families a Befriender.

Our support service is available whether people are newly bereaved or the bereavement was many years ago. During the year, we had **1,011** contacts looking for bereavement support, **370** of whom were contacting us for the first time. We distributed **3,434** bereavement support leaflets.

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.

We offer every bereaved parent who has given us their details, 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 **7** days, which were attended by over **339** adults and **285** children.

We have supported the families of more than 570 babies in 2018 alone



Cat's Story

On 7th February 2016 our healthy baby boy came into the world. Ezio was perfect in every way and we felt our little family was complete. Life was hard adjusting to a newborn as first time parents but we were loving every minute.

At 2.30am on 10th March our lives changed forever. We woke to find Ezio unresponsive. Immediately I started CPR and an ambulance reached us in record time but despite the best efforts of the paramedics and hospital team our baby boy gained his wings.

Prior to this, SIDS had never crossed my mind. I'd read about safer sleep in passing but not given much thought to it; I just didn't think it would ever affect us.

The next few months were dark, sad times. Then in November we found out we were expecting again. Obviously we were overjoyed but also filled with fear about how we could keep this little person safe.

Thankfully we had received information from The Lullaby Trust, following Ezio's death, about the CONI scheme. When Arno was born we were equipped with an apnoea monitor. The steady click with each breath Arno took was a huge source of comfort and through the scheme we were provided with extra support from our health visitor.

Unfortunately I became unwell with postnatal depression and my mental health gradually deteriorated in the months following Arno's birth. I was wracked with guilt for not keeping my oldest baby safe. For not reading the safer sleep advice I so diligently trawled prior to Arno's birth.

I had started to run as a means of self-healing and one day a post came up on social media about completing a half-marathon for The Lullaby Trust. It inspired me to sign-up and this year I completed four half marathons raising funds in memory of my little boy.

The work the Lullaby Trust does is invaluable and for so many families it is a spark of light in the darkness that follows the loss of a beloved child. I feel truly privileged to be able to contribute in any small way to their endeavours.



Maggie's story

My son Nicholas died 15 December 1983. He was 14 weeks old. I had a good pregnancy and delivery. A week before he died he had a bad cold and our GP prescribed antibiotics. We found him face up at the other end of his cot under a blanket. He must have struggled because in those days we put babies face down and he hadn't started moving yet. I thought he had suffocated but the post-mortem had reported otherwise. It was a typical cot death.

I had great support from day one. My GP provided me with a therapist at the surgery. I put my trust in him and he was a great support. I also had a wonderful Befriender at The Lullaby Trust (known then as FSID) called June Reed. She was at the other end of a phone when needed. We remained in contact for years but sadly she had become quite ill and passed away. I will never forget her kindness. I chose to become a Befriender because it actually chose me. When I received a letter from the Lullaby Trust asking if I would be interested I thought it would be a good idea and I could help other families as I had been helped. I have been a Befriender for 6 months now and feeling more confident and have more of an understanding of how it all works. I look forward to hopefully befriending other mums in the future.



Campaigning for change

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. This has included meetings with MPs and Ministers to lobby for improvements to healthcare for families and babies.

Over the last two years we have worked on the development of the National Bereavement Care Pathway in collaboration with Sands, Bliss, Miscarriage Association, Antenatal Results and Choices. The pathway is now being piloted in a number of NHS Trusts to ensure that all bereaved parents, receive the same high quality of bereavement care following the death of their baby. Our Chief Executive continues to co-chair the national Smoking in Pregnancy Challenge Group, which has helped to secure a new commitment from the Department of Health to reduce the numbers of women smoking in pregnancy from **10.7% to below 6% by 2022.**

As a result of our expertise and trusted brand, we have managed to secure regular coverage in the media. During the past year, we have issued statements on a variety of subjects ranging from the impact of air pollution on infants to baby boxes.



Over the last year we have achieved several hundred pieces of media coverage in the local and national press, on television and on the radio.

Our new Baby Check app to support parents

The Lullaby Trust has developed Baby Check in collaboration with Birmingham Community Healthcare NHS Foundation Trust; a free app that helps parents make an informed decision about whether their baby needs medical attention. The app gives parents simple checks to perform if their baby seems unwell. The app then calculates a score that lets them know whether their baby needs to see a doctor and how urgently.

After a successful pilot The Lullaby Trust launched a new and improved version of the app this summer. Baby Check was first developed as a result of a research project led by child health experts who analysed the signs and symptoms of illness in over 1,000 babies under 6 months of age. The 19 signs and symptoms now used in Baby Check were found to give the most accurate assessment.

Now a certified medical device, the Baby Check app has been welcomed by health care professionals. The Royal College of Paediatrics and Child Health said of the app.

"Having a baby can be an extremely anxious time for parents so any device that can help put their mind at ease may be incredibly useful – it could also help ease pressure on hospital services which we know are under immense strain"

The app can be downloaded for free from Google Play and the App Store. In 2018 the app was downloaded **24,848** times.





Looking forward: Our Future Plans

Promoting our safer sleep message

by ensuring our advice reaches as many people as possible via our social media channels and website and that we are answering the questions people ask about SIDS and safer sleep. We plan to build on our training services enabling us to train more health professionals in supporting parents to sleep their baby more safely.

Funding research by using the results of our "Global Action and Prioritisation of Sudden infant death (GAPS)" project (which established new global priorities for tackling sudden unexpected death in infancy) to identify relevant projects that could help us reduce SIDS still further over the next 10 years.

Supporting bereaved families

by making improvements to our bereavement support services such as providing extra training to our volunteer Befrienders. We are also expanding our bereavement services to support more families who have lost a baby during the neonatal stage.

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

working to securing the future of our work with young mums and dads when funding for Little Lullaby ends in Spring 2019.

Our Young Parent Panel will continue to guide us and ensure young mums and dads are represented and their voices heard.



Your support saves lives

A big thank you to our supporters whose incredible generosity has allowed us to continue our work saving babies' lives and ensuring that bereaved families receive the support they need.

Special thanks goes to the **58** runners who took on the London marathon, training hard and braving the sweltering heat to raise over **£128,000**. Also to all of you, who donated to the Big Give Challenge raising **£80,000** for SIDS research.

We were fortunate that Global Radio chose to support The Lullaby Trust through their annual charity appeal, Global Make Some Noise raising a phenomenal **£84,000** in donations from Global Radio listeners.

We were also delighted to be chosen as one of the benefiting charities for the 2018 HQR London Ball which raised an amazing **£42,000** for The Lullaby Trust.

Whether you ran, swam, cycled, jumped, baked up a storm or hosted an event we couldn't do what we do without you!









Lilly's Story

My beautiful daughter Bria Lily was born on the 11th November 2013, two weeks early and a perfect 8lb with gorgeous thick curly dark hair. She was perfect.

She was walking and talking by 10 months old and she amazed me every day with how confident and clever she was and I was so blessed to have had 14 beautiful months with her.

The 28th January 2015 was the day my heart was broken when I went to wake Bria up. It was later than she would usually wake up but she'd had a slight cold which had disrupted her usual routine as she'd been coughing through the night so I thought she was probably more tired than usual. As I opened her bedroom door I felt this overwhelming sense that something was wrong and it was. She was face down in her cot and cold. An image I will never be able to forget. My beautiful daughter, my best friend had gone. I never imagined that sudden infant death could happen once she was over 1 year old.

After Bria died I remember feeling so lost, helpless and alone and I rang The Lullaby Trust after reading about the charity online and I spoke to a lovely befriender who didn't try to pry or push, she just listened and it was comforting to know I wasn't the only person who had been through what I have.

Since her tragic death I've done everything I can to keep her memory alive and last year when I realised that The Lullaby Trust Bake it for Babies campaign was running during what would have been her 4th birthday, I decided it would be perfect to hold a bake sale in her memory.

I held 'Bria's Bake It For Babies Fundraising Fun Day' and thankfully the whole local community got together to help me by generously donating prizes and their services. I had a bouncy castle, tombola, Mega raffle, a huge bake sale, children's games like guess the name of the elephant, how many sweets are in the jar, face painting and glitter make up, a meet a greet with princess characters and loads more activities to keep children entertained. I started organising and promoting really early for the event; I used Facebook as my main platform to promote and keep everyone up to date and printed hundreds of posters and put them up around in work places and anywhere that would let me put up a poster. Bria's special Bake it for Babies fundraising day was a huge success on the day raising over £2,259.15 in Bria's memory for The Lullaby Trust, a charity that is very close to my heart.



27

Thank You

To our corporate partners who have helped to fund our work this year Gro, Moba, Kiddy

Companies, Trusts and Foundations who have supported us in 2017/2018:

Bump PR Charles S French Charitable Trust Childwick Trust Dandia Charitable Trust Dennis Curry Charitable Trust Douglas and Gordon Esmee Fairbairn Foundation Eve Sleep **Eveson Charitable Trust** Experian Fowler Smith and Jones Trust Garfield Weston Foundation Global's Make Some Noise Grosvenor Estates HQR London Charitable Foundation Identica J E Posnansky Charitable Trust Kiddy Lord Austin Trust Masonic Charitable Foundation May Gibson Charitable Trust Moba **Morrisons Foundation**

Nationwide

Oliver Wyman



Quilter Cheviot R S Brownless Charitable Trust Sandra Charitable Trust Sir Jules Thorn Charitable Trust Souter Charitable Trust Springfields Medical Research and Charity Trust Fund (Bnfl)

Teddy's Wish The Borrows Charitable Trust The Big Lottery Fund (Reaching Communities)

The Ernest Kleinwort Charitable Trust The Frederick And Phyllis Cann Trust The Fulmer Charitable Trust

The Gro Company

The Hasluck Charitable Trust

The Joseph Strong Frazer Trust

The J W Bankes Charitable Settlement

The Lower Green Foundation

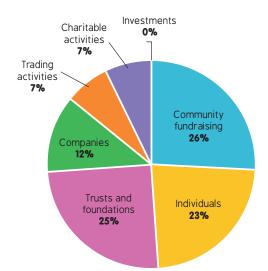
The Manchester Guardian Society Charitable Trust

The Motcomb Street Traders Association The Swire Charitable Trust UKH Foundation Vandervell Foundation White and Case Yorkshire Children's Hospital Fund 12 Yard Productions

Financial Overview

Our sources of income

Thanks to the incredible generosity of our supporters we generated income of **£1.6m** in 2018. If we include only the net profit from trading activities (such as selling merchandise and putting on special events) the total amount raised is **£1.58m**.



How we spent our money

This year we spent **£1.73m** (excluding the direct costs of our trading activities). For every **£1** we received, we spent **81p** on our charitable work.

Financial information has been

Fundraising 27% Charitable activities 73%

extracted from the full Annual Report and Consolidated Financial Statements which were approved by the Board of Trustees on 4 December 2018. These summary statements have not been separately audited.