



The Lullaby Trust Impact Report 2019-20

Contents

Who we are	3
Our year in numbers	4
Saving lives through expert advice	6
Naomi's Story	8
Empowering young parents	10
Kevin's story	12
Understanding SIDS and how to prevent it	14
Beth's Story	16
Supporting bereaved families	18
Jennifer's Story	20
Working together to improve bereavement care	23
Looking forward: Our future plans	24
Your support saves lives	26
Anna's story	28
Thank you	30
Income and expenditure	31

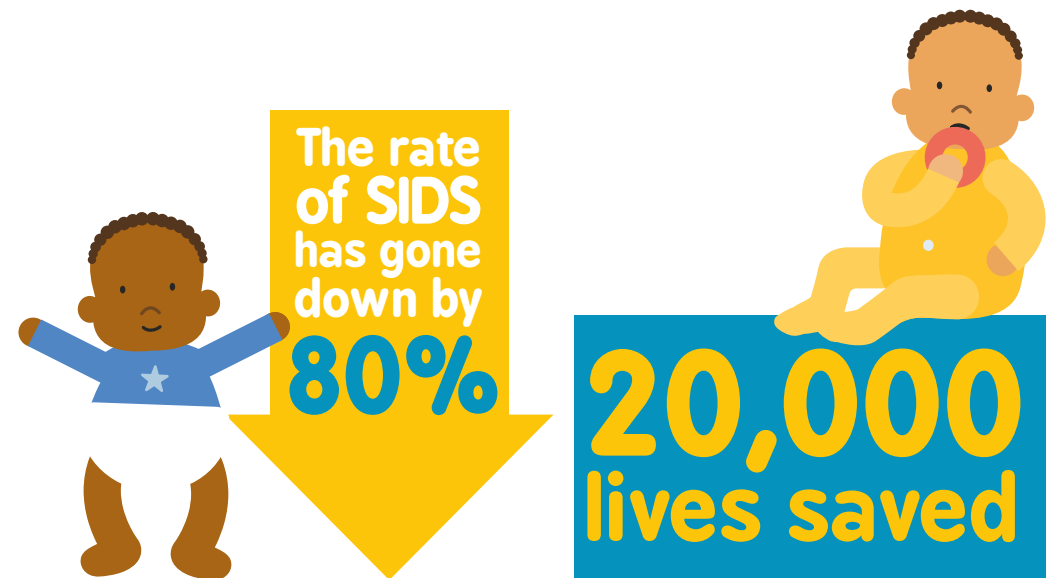
Who we are

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 **80%**, 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

125,647

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

We provided

2,000

professionals with safer sleep advice



3,020

parents and professionals contacted us for information on safer sleep

14.5 million

 people reached on Facebook

767

bereaved families contacted us for direct support and 379 professionals contacted us for support on behalf of a family they were working with

1.7 million

visits to our website. That's a 63% increase on last year



Over **5 million**

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



74 families

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

Saving lives through expert advice

Awareness of safer sleep advice has led to an 80% drop in the rate of SIDS deaths since 1991. In 2020 we continued to grow our profile and our online following, allowing us to reach many more parents with our safer sleep advice.

We trained **2,000** professionals in safer sleep advice that they can pass on directly to new and expectant parents. The COVID-19 crisis placed the NHS under enormous strain leaving new and expectant parents, particularly the most vulnerable, with less information and guidance around safer sleep and baby care. Demand for information was higher than ever with our 'Coronavirus and caring for your baby' information page being viewed over **174,000** times.

Getting information to parents in the most accessible way became a priority. Funding from the London Community Response Fund allowed us to create a series of animations covering the key questions and areas of concern that come up repeatedly on our information line and social media channels. One of the animations covering the main points of safer sleep is text free and silent to ensure the advice is available for parents who don't speak English or struggle with reading.

2,000
trained health professionals

In March 2020, we ran our sixth annual awareness raising campaign; Safer Sleep Week, with the support of Public Health England. We reached millions of people through website, social media, email, digital resources and media coverage. Though news of COVID-19 being declared a global pandemic dominated the media, we still secured some high profile coverage including a spot on BBC's Victoria Derbyshire.

We re-launched our Instagram feed in June allowing us to reach a wider audience. We have almost doubled our following to around 19K followers over 5 months and plan to continue building on this. Our reach on Facebook also continues to grow.

We reached over
14.5 million
people on Facebook
in 2019-2020



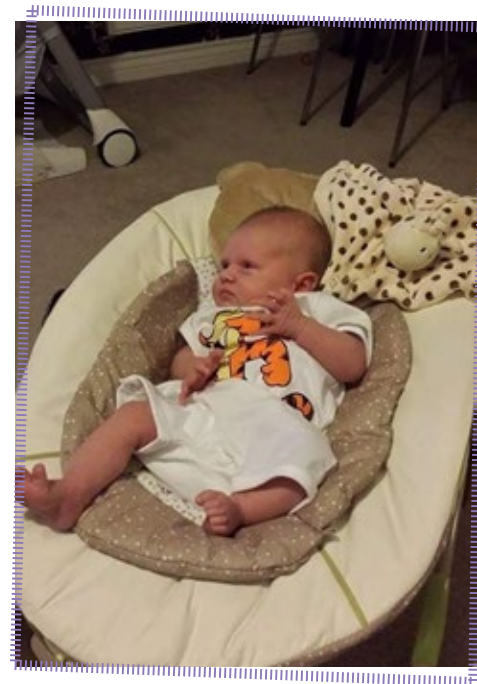
Naomi's Story

Bereaved mother Naomi sadly understands only too well the importance of safer sleep awareness.

My first daughter Madaline was born 26 September 2014. She was perfect and healthy.

But on 22 October, only a few weeks later, at 5.30am in the morning, I woke to the sound of my ex-partner screaming for me to call an ambulance.

The emergency services arrived but they couldn't save Madaline. They said it was an unexplained death.

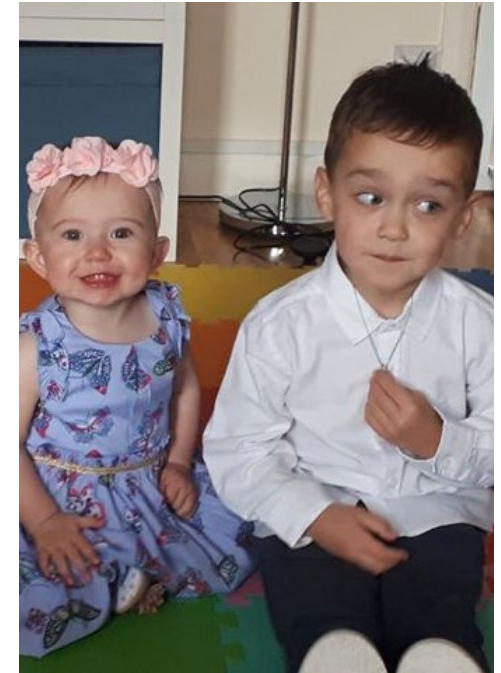


In January 2015 I found out I was pregnant again. Shocked and scared I did a lot of research and found out about The Lullaby Trust's CONI programme online.

I got in touch and was pointed in the direction of my local CONI lead. CONI wasn't very well known in my local area at the time and a lot of people asked me what it was and why I was on it. There needs to be more awareness because it is so helpful and put me at ease, especially the weekly visits.

I was given The Lullaby Trust's safer sleep for babies booklets, which were really helpful and put my mind at ease when my second baby arrived.

As a bereaved mum I think it's very important that all families know the safest ways to sleep their baby. This knowledge can help parents stop worrying that something will happen to their baby in the night. Having access to safer sleep information definitely helped me sleep a little bit better.



My other children are one and four years old now and getting on very well. My four year old is at the age where he is asking more and I struggle to know how to answer him.

We go to visit Madaline at the cemetery, we bring her flowers and I have lots of pictures of her up around the house.

Empowering young parents

According to the latest figures, the SIDS rate was 4 times higher amongst mums under 20 compared to all other age groups.

The Lullaby Trust's young parent project, Little Lullaby, relaunched this year and provides advice and support to young mums and dads delivered through their peers.

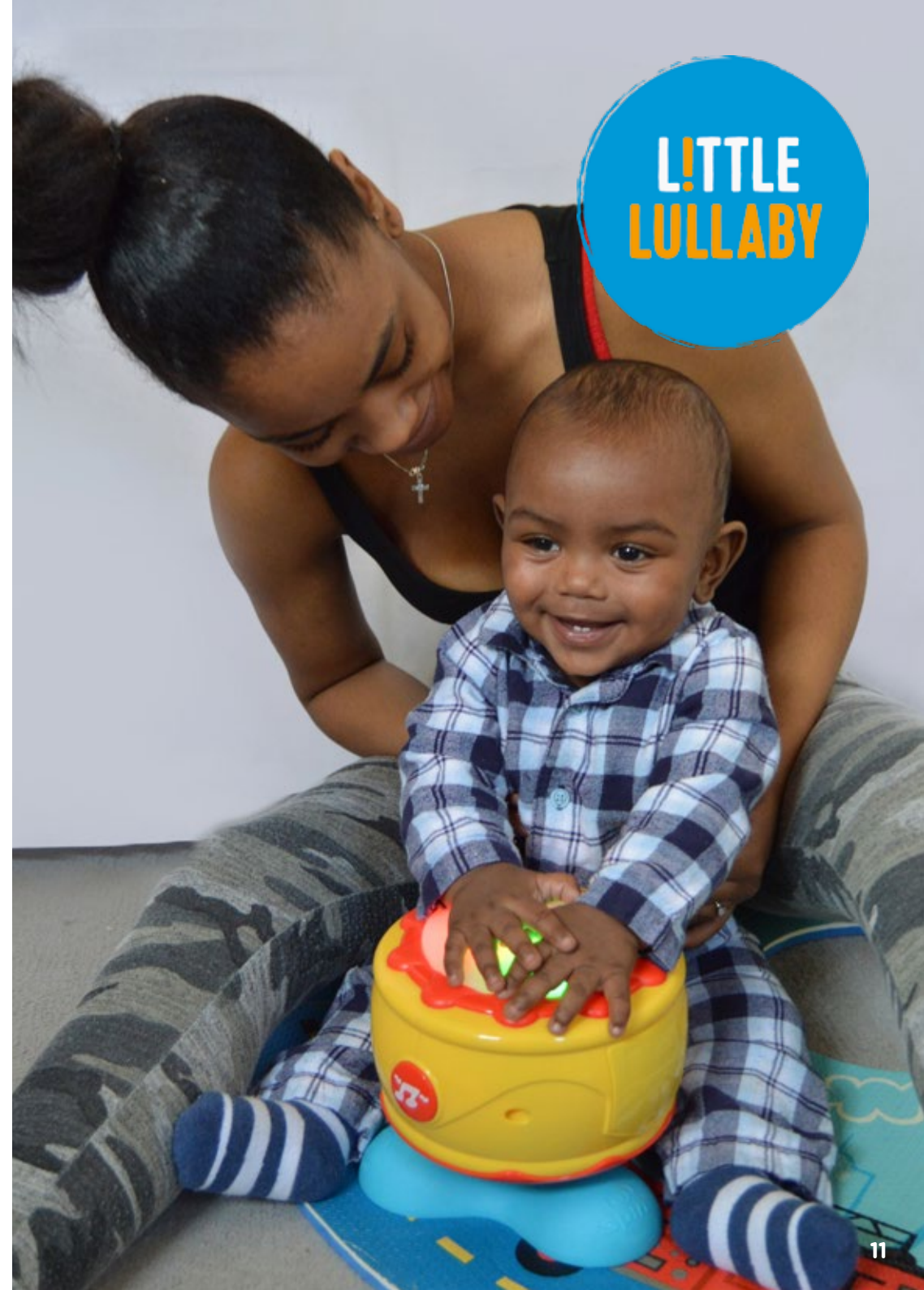
Little Lullaby aims to reduce the isolation often experienced by young parents and made worse by the COVID-19 pandemic restrictions. Our young parents produce blogs and videos, sharing their experiences and advice. When the project ended in early 2019 our social media reach had exceeded **3.5 million** and we had shared hundreds of young parent stories. With the help of our dedicated Young Parent Panel and volunteers we are now re-building our reach and engagement.

Parents under 25 are less likely to engage with antenatal services so we provide a range of resources for health professionals to be able to work more effectively with young parents.

Our Young Parent Panel

is made up of **15 parents** under the age of **25** who provide advice and steer the direction of **Little Lullaby**

**L!TTLE
LULLABY**



Kevin's story

Young dad Kevin gives his insight on the importance of fellowship for young dads and connecting with other young parents

“ From my experience I found that my friends changed and for me it's not bad to change friends. Sometimes you need to be around people who are in similar situations that are actually influencing you, helping you and showing you that there is a better way as well. So if for example, you are a young parent and you don't surround yourself by young parents and you are going through all these battles on your own. Then who else can you lean on and talk to? And I think for me that's important. The power of network, you cannot miss that, I call it fellowship. It's important to have fellowship with the right people.

Being around young parents in a similar situation will help you do much within your own experiences and it takes the pressure off as well. The minute you have a conversation with another young parent and you find that they are going through similar issues, they may have dealt with it slightly differently, it just helps, it gives you an insight.

Sometimes they don't even have to tell you what to do but just in the conversation you are having with your peers in similar situations you find a way. I'm quite fortunate to have some really good friends who are out there doing really well for themselves. I call them inspiring young mums and dads. ”



Understanding SIDS and how to prevent it

It is particularly difficult 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 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 participate in projects, which will allow the furthering of knowledge about SIDS, and are involved with a group that has developed the first ever national child mortality database. The National Child Mortality Database collects 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 sudden unexpected death in infancy (SUDI) registry.

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Jennifer's story

Jennifer, whose daughter Jessica Rose died of SIDS aged 10 months hopes one day an answer will be found.

“ Jessica Rose was born in March 2014, just two years younger than her big brother Jack. We couldn't believe how lucky we were to have a baby girl, “one of each” was more than we'd dared to hope for and we felt like we had the world in our arms when she arrived to complete our family.

I had a completely normal pregnancy, a relatively quick and straightforward delivery and Jessica thrived and met her milestones just like her big brother had done before her. I felt so relaxed second time around, as I knew what I was doing this time!

When Jessica was 10 months old I returned to work part time. She started to attend the same nursery as Jack and from experience, I knew to expect a few months of sickness as she shared germs with the other children.

One Wednesday evening I finished work and went to collect Jessica to find she had just fallen ill as I arrived. I took her home and she wasn't interested in her milk, or anything to eat so I decided to run her a bath to relax her and get her to bed so she could rest.

Jessica was always a light sleeper, she would often wake during the night and cry for a moment before going back to sleep, sometimes my husband or I would go in to comfort her if she needed reassurance. At around 5am she woke and cried, she shared a room with Jack so James went in to give her a cuddle and settle her down. I heard her give her usual murmurs and go back to sleep, James came back to bed and we all settled down again.



At 6am Jack leapt out of bed as he does every morning, full of energy and running across the room! I jumped up quickly and pulled their bedroom door shut, relieved that he hadn't woken Jessica as being poorly she would need her rest. We went downstairs, made a cup of tea and watched the Thomas the Tank Engine DVD Jack had received for his birthday a couple of weeks earlier.

James went upstairs to brush his teeth and get ready for work. When he reached for his toothbrush he knocked over the pot containing the brushes and it clattered into the sink. Concerned that he didn't hear Jessica stir following the loud noise he went to check on her. On opening the bedroom door he found her face down in her cot and unresponsive. James rushed downstairs with her whilst calling my name and I ran to the door, to find him stood with her in his arms, her face and body were limp, we were terrified.

James passed her to me and made the 999 call, as he gave our details to the operator I carried her to the hallway and laid her down flat on the carpet, taking her out of her sleeping bag and opening her mouth to check her airways, I couldn't find any obstructions but she wasn't breathing. At that point James took over and started to give CPR on the instructions of the emergency operator whilst we waited for the ambulance to come.



I called my Mum and asked her to come straight away to look after Jack. Whilst we waited for the ambulance I clutched Jack close and sobbed “please come, please come and fix it”. When the ambulance arrived we rushed to the hospital and they took her to the resus room. They started to hook our tiny baby up to numerous cables and monitors and worked.

They said we could watch but we went to the relative's room to wait, I knew deep down what the outcome would be. After a while we were called back in and the doctors explained that they were having no success and they called the time of death whilst we were in the room. It was like watching a TV show, it was so surreal.



It took 8 months to receive the results of Jessica's post mortem, which delivered the expected verdict of SIDS. Although not having a reason for her death was hard to deal with, we knew we had done nothing wrong and followed all the safe sleep guidelines. Maybe one day an answer will be found, which is why we choose to support Lullaby with monthly donations and are helping with the latest research scheme.

Six months after that morning, we fell pregnant again and in March 2016 we welcomed another beautiful little girl into our family, Juliet Joy. Whilst losing Jessica has been our worst nightmare, in many ways it has made us stronger. We no longer worry about the small things, we do what makes us happy and we don't for one moment take what we have for granted.

We will always have 3 children, just one isn't here with us at home, however she is firmly tucked inside our hearts and will forever be a part of our family. ☺☺

Afterwards we weren't allowed to go home. We handed over our house keys to the police who had to be involved as it was a sudden death of a child. When we did go back we found them searching and photographing the whole house. They took some of Jessie's things away in evidence bags, it was so upsetting, all we wanted was to be alone to process the shock of what had just happened.

Very soon after Jessica died we were given details of the Lullaby Trust and a local bereavement charity called the Bluebell Foundation. Knowing that Lullaby was there was such a comfort, I would often read stories and information on the website whilst I tried to process what could have happened to our little girl.

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. The NBCP completed its pilot programme during this year and is now accessible to all areas.

We continue to provide the secretariat of the All Party Parliamentary Group on Baby Loss in Parliament. The general election in December 2019, meant that Antoinette Sandbach could no longer be Chair as she was not re-elected.

Victoria Prentis MP was Chair for a while before being appointed as a Minister and stepping down. We thank both of them for their dedicated work to highlight the issues around baby loss. We were pleased to appoint two Co-Chairs in early 2020, The Right Honourable Jeremy Hunt MP and Cherylory Mackrory MP.

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 highlight of the campaign.

The National Bereavement Care Pathway to improve the care of bereaved parents is now available in all areas

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.

74 families were allocated a Befriender to offer peer-to-peer support during the year. Befriending continues to be an important service for families. Our 2-year grant from the National Lottery Community Fund has enabled us to train more befrienders and we have recruited a diverse pool of volunteers; those who have experienced non-SIDS death, which is reflective of the increase in the number of families seeking support for different causes of death.

Our support services have continued during the COVID-19 crisis. The service is offered by telephone and online and is therefore safe during social distancing measures. Nonetheless, the COVID-19 pandemic has impacted certain aspects of our work and we have been unable to hold our annual Family Days from March 2020. We held 6 Family Days for bereaved families between June and December 2019 and look forward to resuming them when restrictions end.

In April 2020, and throughout lockdown, we extended our helpline hours to Tuesday and Thursday evenings and we provided this service for 5 months. We wanted to offer helpline support outside of office hours as we anticipated the difficulties for many families to call during the day with children at home, home schooling, and being able to find somewhere private to make a call. During the year, we had **767** people contact us for bereavement support, **328** of whom were contacting us for the first time.

During the year, we had

767

people contact us for bereavement support

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.



Beth's story

“ Jassy was baby number four. We had two boys and one girl so it felt perfect to be welcoming another little girl into the family.

Jassy had dark hair and looked just like her big brother, my eldest son, when he was born. She loved to be held and cuddled all day and all night. We certainly knew she was here and we used to joke and say she was going to be the boss as she got bigger. We said she was like a little frog with her big wide open eyes, taking in all her surroundings. She was starting to really watch and follow what all the big ones were up to before she died.

One night in April I took Jassy into bed with me, it was around midnight and only me in the bed with her. I woke at 5.20am and put my hand on Jassy's chest. She was warm but she wasn't breathing. I screamed to Terry that she was dead. He came running from our daughter Elsa's room and took Jassy from me. Together we ran downstairs into our living room.

The kids heard everything that went on that morning, me screaming and my eight year old son saw Jassy.

While I dialled 999, Terry placed Jassy onto the floor and the call handler talked Terry through CPR. Shortly afterwards, the first responders arrived and took over from Terry, followed by the paramedics and police. There was nothing that could be done. She was seven weeks and four days old.

We then had to make our way to hospital where we were asked lots of questions about Jassy and her health. Leaving Jassy there was devastating. There was an inquest, it was actually postponed twice. Jassy died April 20th and the inquest wasn't held until October.

The inquest result came back as unascertained. The result just left me with so many unanswered questions: how can a healthy baby just die? Was there anything wrong with her or any signs that we had missed? And obviously I was thinking that she shouldn't have been in bed with me.

We couldn't really think clearly at the time all this was going on, but desperately wanted to speak to someone who had experienced what we were going through.



A week after Jassy's death my sister contacted The Lullaby Trust on my behalf. The Lullaby Trust then got in touch with us and both Terry and I were paired up with our own Befrienders.

My Befriender would phone me and we would chat away regularly, probably once a week or more in the early days. It was so useful speaking to someone who had experienced a similar loss. Just knowing that my Befriender had been through such an awful time made me think that we would somehow be OK.

Terry and I were a good support to one another during this time. My mum, my sister and a couple of good friends were also really supportive.

I love talking about Jassy. Talking and remembering is all we can do. Life will never be the same after your baby dies but I'd like to say a big thank you to The Lullaby Trust and my lovely Befriender for helping me navigate through the early dark days of grief. It helped to know that someone understood and had survived, which then gave me a glimmer of hope.”

Looking forward: Our Future Plans

Reduce the number of SIDS deaths 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.

As part of a push to reduce deaths, we are focusing on the most at risk groups such as young parents. We received grant funding from the National Lottery, which allowed us to relaunch Little Lullaby our service for young parents in August 2020. We still have a Young Parent Panel to ensure all our advice and activities are relevant to young parents and they will be advising on the future direction of Little Lullaby.

Ensure support is available for all bereaved families by expanding our services to support more families who have lost a baby during the neonatal stage. This Autumn we launched a webchat function on the website. This allows people to talk to our helpline advisors through text if they would prefer this to talking on the phone.

We are continuing our partnership work with other baby charities and professional bodies to improve the quality of care that bereaved parents receive, through the development of The National Bereavement Care Pathway (NBCP). We will also continue to work in collaboration with other baby loss charities for Baby Loss Awareness Week. Baby Loss Awareness Week gives bereaved families the opportunity to commemorate their children and campaigns for better bereavement care for all parents wherever they live in the UK.

Keeping SIDS on the research and policy agenda by involving ourselves in projects that allow us to further our knowledge of SIDS, such as 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 SUDI registry to understand more about children who die suddenly and unexpectedly over the age of one.



We are looking to make policy and research a more integral part of our work. We plan to create targeted campaigns to increase awareness of SIDS amongst decision makers and

parliamentarians and to lobby for changes to prevent unnecessary risk to babies, such as regulation of the sale of unsafe sleeping products and clearer safety standards.

Your support saves lives

A huge thank you to our supporters whose generosity and dedication have allowed us to continue saving lives and supporting families despite the challenges posed by COVID-19. You are all amazing!

The 2020 Virgin London Marathon, Royal Parks Half Marathon, London Landmarks Half Marathon and Great North Run were all unfortunately postponed until 2021. A huge thank you to everyone who signed up, started training and raised some money. We hope to welcome you all back to complete your challenges next year.

One of the many highlights was the support we received from Simfest's simulated flights, including their epic 24/7 round the world flight. Their events were streamed online and raised over **£40,000** for The Lullaby Trust.

The Wheatsheaf Pub in Ewell also supported us in 2019 by organising lots of family-friendly fundraising events throughout the year and a 100km walk along the Thames Path, raising over **£13,000**.

Comedy writer, performer and best-selling author, Adam Kay generously continued his support of The Lullaby Trust throughout his sell-out theatre tour of *This is Going to Hurt Live*. Collections held at each performance up until March, raised over **£75,000**. Adam has also been instrumental in securing donations for the charity. We were delighted to receive **£25,000** in June from Chris Evans' charity auction.

We know it has been a challenging year for our supporters with the cancellation of events and restrictions so we truly appreciate your efforts to keep fundraising. You have made a huge difference to families in the UK.

**Simfest's
simulated flights
took them around
the world raising over
£40,000!**



Anna's story

Anna shares her experience of completing the Local Landmarks Challenge in memory of her son.

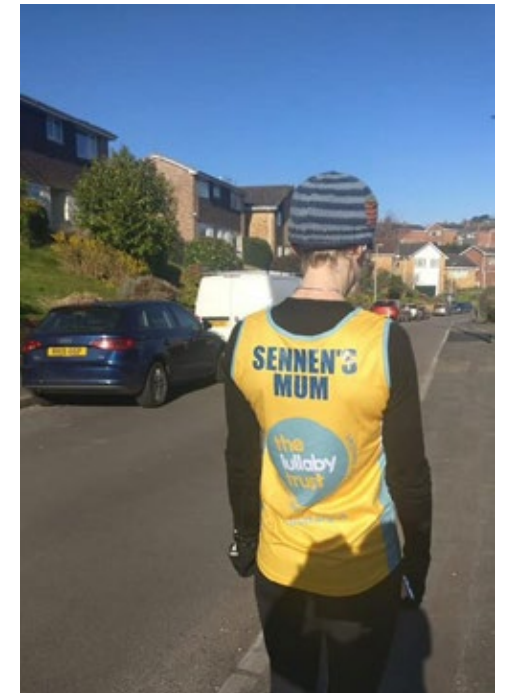
“ I took up running when I was seeking ways to try and live alongside my grief after our son Sennen died. I am not normally a sporty person, but I found running helped as it offered me some headspace, and I found it lifted my spirits. Observing details in our natural world helped bring me into the present and see that there is still beauty around me, despite living with immense sadness.

I chose to run the London Landmarks Half Marathon after reading about it in The Lullaby Trust newsletter. It coincided with the 3rd anniversary of Sennen's death and what would have been his 4th birthday. I wanted to do something special in his memory at a particularly difficult time of year and this event gave me something positive to focus on.

I was a bit worried when the LLHM was postponed due to coronavirus that I would not be able to run the half marathon distance alone (due to coronavirus restrictions) without being spurred on by the crowds and atmosphere. However, the day I chose was beautifully sunny and I was surprised how much I enjoyed doing it.

I chose to run alone in long loops from my home to a beautiful local meadow in Exeter. Knowing I was doing it in honour of Sennen's life really helped my motivation. Running past my driveway meant my husband and 2 other sons cheered me along and the jelly babies and smiling faces they offered helped!

The Lullaby Trust has been immensely helpful to us as a family, offering compassionate support, befriending and family days when I don't feel so alone in my grief. We have hugely benefited from their Care of the Next Infant scheme too, when we were very fortunate to have another baby after Sennen died. This offered extra reassurance when we needed it. I wanted to fundraise for The Lullaby Trust as their work is so important in saving babies' lives and supporting families affected. I definitely hope to participate in the LLHM once it can be rearranged and continue to raise funds for The Lullaby Trust in Sennen's memory.”



Thank You

To our corporate partners who have helped to fund our work this year

Halo, Snuza



Companies, Trusts and Foundations who have supported us in 2019 /2020 include:

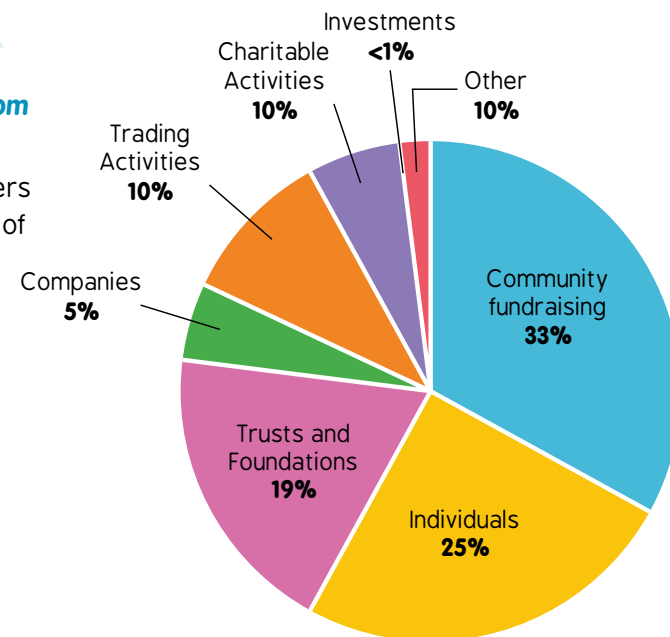
Audible
BBC Children In Need
Charities Aid Foundation
Dandia Charitable Trust
David Lloyd Leisure (Head Office)
Eve Sleep
Garfield Weston Foundation
Global Make Some Noise
Gwyneth Forrester Trust
H O B Trust
J E & J V Posnansky Charitable Trust
Katie Loxton
Mayborn Group Ltd
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Morrisons Foundation
Motcomb Street Traders Association
Postcode Community Trust
Reflections Marketing Group

Sandhu Charitable Foundation
Teddy's Wish
The Ashla Charitable Trust
The Barbour Foundation
The Childwick Trust
The City Bridge Trust
The Gro Company
The Jake Memorial Charitable Trust
The James Tudor Foundation
The National Lottery Community Fund (Reaching Communities)
The Reed Foundation
The Swire Charitable Trust
The National Federation of Demolition Contractors
Waitrose Belgravia
White & Case LLP

Income

Where our money came from

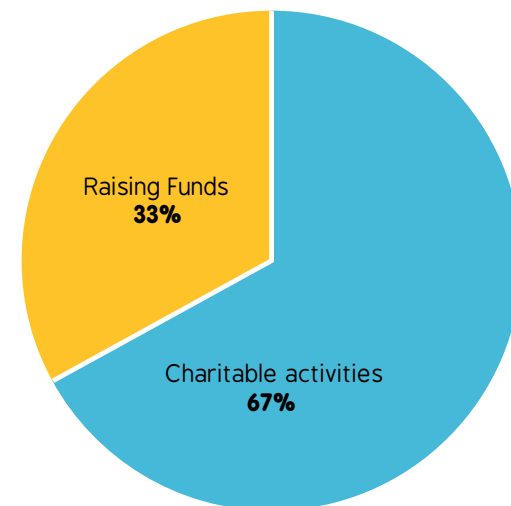
Thanks to the incredible generosity of our supporters we generated net income of **£1.51m** in 2019 /2020.



Expenditure

How we spent our money

This year we spent **£1.27m** (excluding the direct costs of our trading activities). For every pound we spent, **67 pence** was spent on our charitable work and **33 pence** 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 1 December 2020. These summary statements have not been separately audited.



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