

FAMILIES FIRST SPRING/SUMMER 2018

Poppy's story

"I can't think what it'd be like without Rainbow Trust's support."

Our Impact

See the difference we made to families last year

Meet Sophie

Our Policy and Campaigns Manager



**RAINBOW
TRUST**

SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD



Name name and name, their Family Support Worker

BABY TEDDY'S FOREVER FUND

Help families by creating a Forever Fund to share your story and raise money to fund our expert Family Support Workers.



Bella and Teddy with Fiona, their Family Support Worker

Dear Supporter,

Welcome to Rainbow Trust's magazine which tells you more about the families and children supported by our expert Family Support Workers.

As I write this, I am contemplating having been part of this remarkable organisation for a little over a year and how quickly time passes. In the past year we have made incredible progress and supported over 2,300 families. We have expanded our family support service in the South with a new Family Support Worker on the Isle of Wight so we can help more families than ever before.

This year also sees me mark a milestone birthday - 50 - and so I have challenged myself to complete 50 challenges across 50 different days to raise £10,000. I've kicked off the activities by taking my first saxophone lesson, knitting a rainbow scarf and getting a letter to editor published about how small acts of kindness really matter. To come, I will be abseiling, running 5K, walking 25k and much more.

I hope you enjoy this edition and thank you for your support as we plan for another successful year in this amazing charity.

Zillah Bingley, CEO

Teddy was born at 23 weeks and three days on 9 April 2017. As he was born so prematurely, he spent five months in hospital and the family was referred to Rainbow Trust. Family Support Workers Fiona and Lucky from our Central London team spent time with Bella, Teddy's older sister, at the family home so that Obobo, his mum, could give Teddy the one-to-one attention he needed.

"I just couldn't give either of my children the support and attention I wanted for them so having Fiona and Lucky was a huge help."
Obobo, Teddy's mum

By September, Teddy was well enough to go home. He was doing well but, having been so premature, was prone to infection. He developed pneumonia and his little body just didn't have the strength to fight the infection. Teddy died on 31 October 2017. He was six months old.

Why create a Forever Fund?

"I wanted to honour Teddy's life and the best way to do that was through a Forever Fund for Rainbow Trust.

This way he will always be remembered and, if it helps even one family, it will make a difference. Rainbow Trust supported my family and me, and gave me time with each of my children when they needed it most."

"Hopefully with this fund, more families will have the support when they need it most."
Obobo, Teddy's mum

STAY IN TOUCH

We take your personal data and privacy seriously - to find out more and read our Supporter Promise and Privacy Policy go to rainbowtrust.org.uk

Call us: 01372 220083

Email us: supportercare@rainbowtrust.org.uk **Visit us:** rainbowtrust.org.uk

Follow us: [facebook.com/RainbowTrust](https://www.facebook.com/RainbowTrust) twitter.com/rainbowtrustcc

Head Office address: 6 Cleeve Court, Cleeve Road, Leatherhead, Surrey KT22 7UD



To support Baby Teddy's Forever Fund or create your own, visit rainbowtrust.org.uk/forever-fund

LATEST NEWS



Harold Wood Friends Group celebrated raising an impressive £1 million in February. Our charity shop in Essex has been fundraising to support families for the last 25 years. Thank you to all the amazing and dedicated volunteers who helped reach this incredible milestone!



Heidi and Kate had a great day out at Sprouts Play Barn with Sarah, a Family Support Worker in the South West. The girls both have siblings who are seriously ill so are a great support for each other. While the girls had some fun, Heidi's mum spent time with her sister in hospital and looking after her newborn baby.



We have appointed a dedicated Isle of Wight Family Support Worker part funded by Layla's Trust. Working part time, Madelaine (far left of photo) has been providing practical and emotional support to 14 families, helping them at home, in the local community and hospital.



This year sees the launch of our first national Great Rainbow Bake on 7 May. Take on the challenge of rainbow baking with family, friends or colleagues. Find out how you can get involved, raise money and awareness at rainbowtrust.org.uk/great-rainbow-bake and follow #greatrainbowbake.



In the holidays Rayhanah and Harisah love meeting other siblings at the art group in the Evelina Hospital in London, with the help of Lucinda, a Rainbow Trust volunteer. Jamillah, their older sister is in hospital most of the time; their Mum needs to be with her because their Dad works.



TJ was two years old when he was diagnosed with leukaemia. Megan, his Family Support Worker supports the family weekly on the oncology ward at The Great North Children's Hospital. Megan also supports TJ's siblings and they enjoy being taken out to do fun things, such as ice skating, bowling and lots more.

Can you help us reach more families by making a donation today?
Visit rainbowtrust.org.uk/donate

POPPY'S STORY

When Poppy was diagnosed with leukaemia, family life was turned upside down. “Nicki, our Family Support Worker, helped make life so much easier.” Vicky, Poppy’s mum



Poppy (left) and sister Mia

Poppy was two when she was diagnosed with leukaemia on Valentine’s Day last year. Vicky and Simon, her mum and dad, had taken her to the doctor four times before a new doctor at the practice asked for her to have some blood tests.

“From around her birthday in November, she went from being a child I couldn’t keep in the pushchair, who wanted to explore and was very lively, to a child who just wanted to sit under a duvet and watch DVDs,” remembers Vicky. Blood tests revealed an abnormality in Poppy’s blood and she was rushed to hospital.

“That night was awful,” says Vicky. “Once in the hospital, nurses and doctors tried to put a cannula in her arm to start treatment, but she screamed and kicked out as she was terrified, and looked to Simon and me to make the hurting stop.” She was transferred to Great Ormond Street Hospital the next day, “We were shown into a room on

the oncology ward. Doctors came in and told me that they had found leukaemia in Poppy’s blood and they’d be starting chemotherapy that day,” says Vicky, “My head was screaming but I had to focus and listen to what doctors were telling me.”

Poppy was in hospital for weeks. She barely moved and when she was finally discharged, she couldn’t walk. “She’d spent so long in bed not using her muscles that they’d wasted away and she’d forgotten how to walk. We did physio with her in hospital and at home. I borrowed a baby walker from a friend and she used it like a Zimmer frame – she was so proud of herself when she could actually move around again,” said Vicky.

“We saw her determination that day and knew she was going to fight this every step of the way.”



Poppy during treatment

“I started looking around to see if I could access any emotional support for myself, Simon and Mia, Poppy’s sister, as I could see she was struggling too. I’d been away from her for seven weeks; Simon was dropping her off at someone’s house for breakfast and I was with Poppy. The novelty of being with different people soon wore off and she just wanted her family back together.

Our social worker put us in touch with Rainbow Trust and Nicki, a Family Support Worker, started visiting soon after.



Poppy and Mia with Nicki, their Family Support Worker

“Having Nicki to help made life so much easier - it didn't take long to feel comfortable with her, Poppy adores her - we all love having her here.”

We had been taking cabs for our weekly visits to Great Ormond Street Hospital - costing £130 for each round trip. Now Nicki often takes us to the hospital, which makes Poppy feel less stressed. I am calmer too, knowing that I can leave her with Nicki and I'm not just leaving her alone in her bed while I go off and try and eat something.”

Poppy's hospital appointments often start at 8am and she and Vicky can be there until six in the evening. Nicki takes them up to the hospital and spends the whole day with them. She picks Poppy and Vicky up at 6am and takes them to London for Poppy's lumbar puncture at 8am. It's a very long day so she stays with them all day. Nicki spends time with Poppy so that Vicky can speak to consultants without having to worry about keeping Poppy occupied.

“I can't even let myself think about what it'd be like without Nicki's support. She's made our lives so much easier, the girls adore her and I feel so much calmer knowing she is there to help us. She has helped all of us and I'd recommend Rainbow Trust to anyone who needed them,” said Vicky.



To make a regular donation to sponsor a Family Support Worker, visit [rainbow trust.org.uk/sponsor](https://rainbowtrust.org.uk/sponsor)

You can choose how often you donate and how much - it's totally up to you.

MEET SOPHIE: OUR POLICY AND CAMPAIGNS MANAGER

As a charity who supports families with a seriously ill child, it is vital we are involved in discussions with government which could impact the lives of the families we support.

My role is about influencing the policies and decisions made by government and public bodies to improve the health, care and support that children and their families receive. Whenever I can, I involve parents and Family Support Workers so that decision makers can hear first-hand what life is like with a seriously ill child, and what obstacles families face. These experiences and views can then be included in briefings that I send to MPs ahead of parliamentary debates.

The highlight of my job has been seeing a steady growth in Rainbow Trust's profile and influence. For instance, the experiences of families supported by



Sophie, left, with Claire, our Central London Family Support Manager, delivering an open letter to the Department of Health

Rainbow Trust have been quoted to improve proposals for the Parental Bereavement (Pay and Leave) Bill, currently in Parliament. If passed this will mean a right to paid statutory compassionate leave for employed bereaved parents, which, has never existed before.

Many people still don't know quite what Rainbow Trust does, so it's really important to explain how Family Support Workers can help families to cope better at an incredibly difficult time.

My role helps to remind people who hold the purse-strings - in government and in local authorities -

that Rainbow Trust receives less than three per cent of our funding from the state. This is despite our services saving the health and social care system at least £2 million each year!

It's our mission to change this so that Rainbow Trust can expand to reach more families, in more parts of the UK. I'm really proud to be part of this work.

If your family receives, or used to receive, support from Rainbow Trust, you can find out more about the Parent Participation Network by emailing sophie.dodgeon@rainbowtrust.org.uk



Read more at rainbowtrust.org.uk/about/our-influencing-work

YOUR SUPPORT CHANGES LIVES

Here are some of the fantastic things that you've been doing to raise money to fund our expert Family Support Workers. A huge thank you to you all!



Joe and Anna raised an amazing £1,035 from having a rainbow themed wedding and asking their friends and family to donate to Rainbow Trust instead of buying presents.



A massive thank you to the team at Chessington Garden Centre (and Poppy the Labrador) and their visitors for raising an incredible £8,922 from their Christmas Grotto and Wishing Well!



Manchester grandma, Joanne went sky high with friend Kath when she jumped 10,000ft from a plane, raising £1,355. Jo knows how vital this support is. Her grandson Frankie has chronic lung disease and Downs Syndrome. Frankie and his mum Steph are both supported by Rainbow Trust.



Knight Frank held their fourth Global Day of Giving - a biennial event where staff from across the global network undertook fundraising events to raise money for four charities. They raised a fantastic, £218,379 and Rainbow Trust has been lucky enough to receive 25% of this.

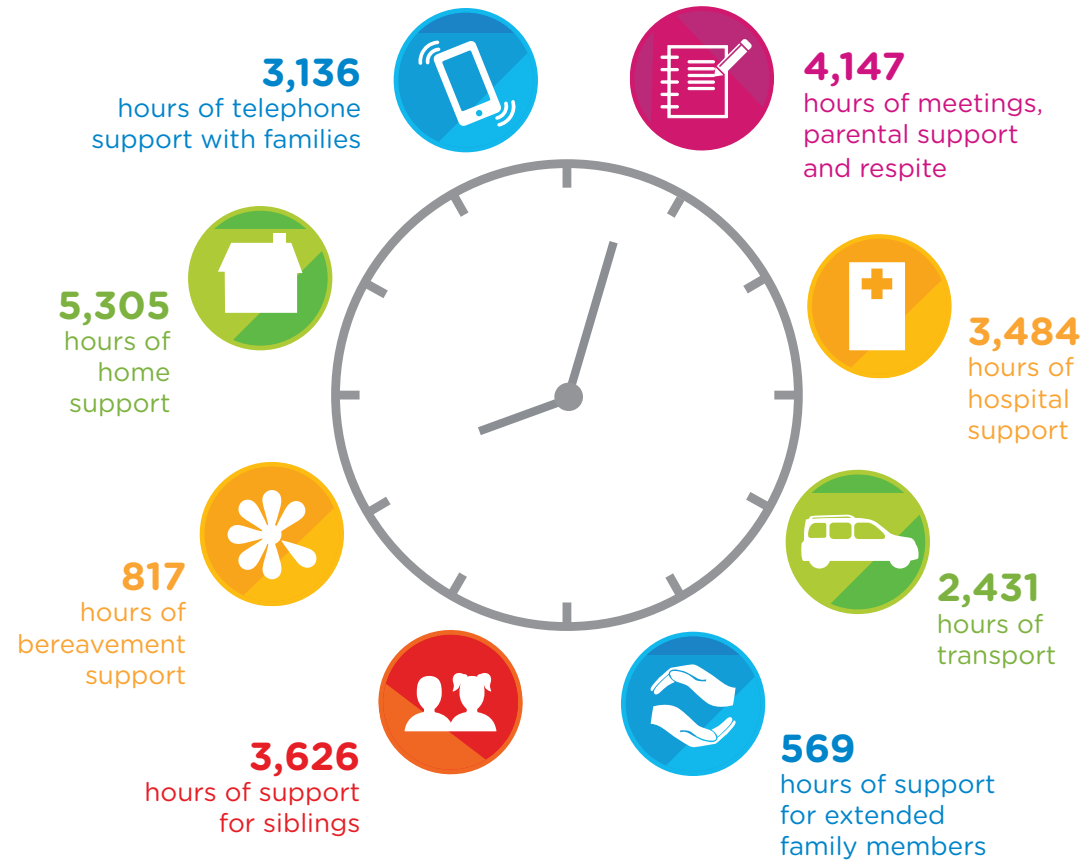
Want to get involved?

Visit our website rainbowtrust.org.uk to find out more about a fantastic range of fundraising activities and events all year round.

We'd love to hear from you!

OUR IMPACT

Last year we supported more families than ever before through our nine care teams.



“They seemed to be there from every angle; they supported me emotionally, they supported my children, they provided transport and respite care when it was needed. They did everything and whatever was needed.”

Fran, Michael's mum

Without you, our Family Support Workers would not be there for families when it matters most...

THANK YOU!

YOUR SUPPORT HELPS



Alexander

Alexander and Noel are identical twins, but their lives couldn't be more

different as Alexander suffered a brain injury during birth. He has a number of disabilities and is on oxygen 24 hours a day. Brodie, a Manchester based Family Support Worker, supports the family each week.

“It gives the kids a break and some attention as a lot of time is spent around Alexander because of his disabilities.” Brodie

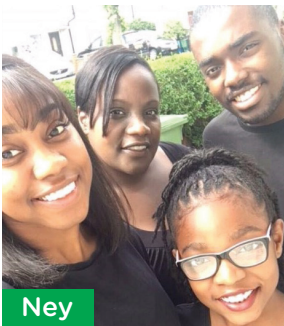


Samuel

Vicky's son, Samuel, was born with a severe heart condition

and needed monitoring 24 hours a day. The family are supported by Sarah, an Essex based Family Support Worker.

“Without Sarah, I'd have no kind of break. We take life one day at a time but having her support means we can have days out or I can do chores knowing Sarah is looking after Samuel as well as I would.” Vicky



Ney

Charmaine's two-year-old daughter, Ney, was diagnosed with leukaemia on New Year's Eve 2009. Lyn, a Surrey based Family Support Worker, attended appointments with them and provided support to make life much more bearable.

“I am so thankful we made it through that journey, and Lyn will always hold a special place in our hearts.” Charmaine

Rainbow Trust pairs families with an expert Family Support Worker who offers tailored support to the whole family.



How you can help

To help more families like these, please donate today at: rainbowtrust.org.uk/donate



Spread the word! When you have finished reading this magazine please share it with your family and friends.

