

# FAMILIES FIRST

Spring/Summer 2019

## Focus on sibling support

The importance of supporting brothers and sisters of seriously ill children

## A year in hospital

“Without Shelly’s support, life would have been very, very stressful”

## Saddle up

The Haire family calls on cyclists to ride for Team Henry

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

## Dear Supporter,

Rainbow Trust's service has never been more vital. Last year we saw a 12% increase in new families supported by us, and so far this year, on average two new families are referred to us each day. We can only respond to this increasing demand and help families cope thanks to the very generous support we receive from individuals and organisations like you.

Our recently published report, *See us, Hear us, Notice us*, is a great example of how we are using our voice to highlight the serious issues that affect the families we support. In this case, this is the lack of high-quality support for siblings of seriously ill children. Read more on pages 4 to 7.

To support more families in desperate need, we are launching our *About Time* appeal. Because we think it's About Time that every family coping with serious childhood illness has the support they need to face the challenges ahead.



Over spring and summer we will be establishing a special circle of founder supporters, committed to laying foundations for the next phase of Rainbow Trust's growth.

Thank you for your continued invaluable support.

A handwritten signature in black ink, appearing to read 'Zillah'.

Zillah Bingley, CEO

# YOUR SUPPORT MATTERS

Here's a snapshot of the children and families you have been helping us to support



Charlie with Family Support Worker, Billie, on a fun day out



Gracie meets her siblings for the first time



Lubena doing arts and crafts at home



Phoebe decorating Armistice Day biscuits in hospital



Jude at a hospital drop-in while she waits for treatment



Volunteer Martin 'gets stuck' at a hospital drop-in group



Hansraj enjoys a family fun day out



Marcus and Finley making Valentine's cards during treatment



Adam and Freya at a sibling fun day out

## STAY IN TOUCH

We take your personal data and privacy seriously - to find out more and read our Supporter Promise and Privacy Policy, visit [rainbowtrust.org.uk](https://rainbowtrust.org.uk)

Call us: 01372 363438

Email us: [supportercare@rainbowtrust.org.uk](mailto:supportercare@rainbowtrust.org.uk) Visit us: [rainbowtrust.org.uk](https://rainbowtrust.org.uk)

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

Head Office address: Cassini Court, Randalls Way, Leatherhead, Surrey KT22 7TW



# SEE US, HEAR US, NOTICE US

A child's life changes dramatically when their sibling is diagnosed with a serious illness. Our new report (pictured right) sets out why the support of brothers and sisters should be valued and funded by policy makers and government.

When a child becomes ill, a parent will have less time to focus on their brothers and sisters. Routines change, and the healthy child can struggle to understand what's happening. Even getting to and from school can be hard, and opening up about their feelings can be really difficult, as they try to protect their parents from more worry.



We supported 1,230 siblings last year



Sibling support can help children learn important coping mechanisms and find an outlet for their strong feelings. Practical support can help them get to school regularly and keep up with homework.

Funding sibling support can prevent future costs for public services. Our conservative estimate is that Rainbow Trust's sibling support saves around £418,000 each year for the education, health and social care system. Supporting a sibling while they are going through the trauma of having a sick brother or sister means they are better able to cope with life in the future.

Here are just some of the things siblings tell us:

*Take me out; I spend a lot of time in the house. Getting out gives me a break.*

*Don't forget about me!*

*Treat us equally, we know we are different, but don't make us stand out.*

*Try to talk to me about the future, even if you can't give me answers.*

We are calling for all children and young people with seriously ill brothers or sisters to have access to high quality sibling support when they need it before their education, mental health and wellbeing are more seriously affected.



Find out more and download the full report at [rainbowtrust.org.uk/seeushearus](http://rainbowtrust.org.uk/seeushearus)

# A DAY IN THE LIFE OF A SIBLING SUPPORT WORKER

**Natasha Anson has worked for Rainbow Trust as a Sibling Support Worker since 2017, and supports families throughout Greater Manchester.**

At **10:30am** I visit a family to discuss how Rainbow Trust can support their eldest child; he has worries and struggles surrounding his brother's leukaemia. These discussions are useful for families to share their needs and understand the support we can provide.

I leave at **11:30am**, and drive to the office to finish work on our Summer Sibling Play Scheme, which will give all children supported by Rainbow Trust's North West team a chance for some fun days out in the school holidays! I also write a few invitations and make calls to confirm venues and costs.

I leave at **12:30pm** for another family visit where one of our Family Support Workers and I arranged to meet a bereaved mother we both work with. Unfortunately, she has been called away at the last minute, but the children's grandma is there with two of the children. We spend time going through a progress journal, and look at the plant pots they've decorated. We plant forget-me-not flowers together, in memory of their sister.

At **1:30pm** I set off to my next appointment, grabbing lunch along the way. I collect Sarah, a sibling I

support, from school at **3:00pm** and head to a soft play centre for an hour of fun! I spend time with her once a week whilst her mum and sister are in hospital. She wants to have her tea at her friend's house so I drop her there at **5:30pm** and drive home.

Through the door and laptop open, I write up my notes, whilst they are still fresh in my mind. My very busy working day comes to an end at **7:00pm**.

As a Sibling Support Worker, no day is ever the same. Today was full of surprises and full-on! I thoroughly enjoy being on the go and knowing that I'm making a difference to the lives of the families we work with. The trust and confidence that these families have in Rainbow Trust is invaluable to us, and to be a part of it is such a privilege!



# ASK THE EXPERT

**Dr Finella Craig, Consultant in Paediatric Palliative Medicine at Great Ormond Street Hospital for Children (GOSH), talks to volunteer, Chris Evans, about the importance of supporting siblings of seriously ill children.**

**Can you tell me about the work you do at GOSH?**

We look after children with life-limiting and life-threatening illnesses, where there's uncertainty about their future. Some will be at end of life, and others might be with us for years, or even discharged from palliative care.

**How has Rainbow Trust helped the families in your care, particularly the siblings of ill children?**

Rainbow Trust is fantastic. What I love about them is they quietly get on with anything that needs doing for a family. They are particularly good at providing sibling support, so things like doing the school run, after school care, helping them with homework, or taking them out to do nice things.

Siblings get so little one-to-one time, so having a trusted person from Rainbow Trust who makes them feel special and listens to their worries, is incredible. It is a vastly understated service that is very valuable.



**What are some of the key issues that you see siblings face?**

Siblings can feel sad, anxious, neglected, guilty and angry. Having a sick sibling or being bereaved, can have a long term impact on friendships and relationships, and how siblings see their own value.

We also know siblings of sick children are less likely to achieve their educational potential, unless they receive support, which is another reason why the support from Rainbow Trust is so important.

You can read the full interview with Finella at [rainbowtrust.org.uk/ask-the-expert](https://rainbowtrust.org.uk/ask-the-expert)

→ **Help us to celebrate National Siblings day this 10 April**

Whatever their age, here's your chance to celebrate your fabulous brother or sister!

Tell us one word you would use to describe them on social media, using the hashtag

#SeeUsHearUs

Don't forget to tag us in!

Facebook @RainbowTrust

Twitter @RainbowTrustCC

Instagram @rainbowtrustcc



# A YEAR IN HOSPITAL



**While pregnant with her fourth child, Danneka and Andrew were told that their baby had a problem with his bowel, but that it could be rectified at birth. Unfortunately, that did not go to plan, and once born, their baby Ellis ended up staying in hospital for more than 11 months of his first year of life.**

“At my 20-week scan, doctors told Andrew and I that our baby had loops in his bowel which meant that food could not move properly through the digestive tract, so we were referred to the Royal Victoria Infirmary Hospital in Newcastle. Doctors said there was a simple procedure to rectify the issue, and that he’d be in hospital for two to three weeks when that happened. However, they ended up having to remove three quarters of his bowel, which left him in a much more vulnerable state than we had

anticipated,” says Danneka, Ellis’ mum.

With three other young boys at home, Danneka and Andrew faced a much tougher and uncertain road ahead.

Initially, Ellis spent two weeks in the Paediatric Intensive Care Unit, and had to be put on a ventilator to help him breathe. He had a tube inserted under the skin on his chest through which he was fed, and medication administered.

“The Sister on the surgical ward could see that I was really struggling to balance looking after my three boys at home, with spending time with Ellis in the hospital, so she referred me to Rainbow Trust,” remembers Danneka.

**“Family Support Worker Shelly came into our lives and immediately we felt a difference.**

I couldn’t be at the hospital with Ellis every single day. My other boys are only three, six and eight years old, and before Ellis was born, they’d never left my side! It’s been tough for them and they are struggling – they’ve become really clingy with me.

Shelly was able to visit and sit with Ellis in hospital on the days that I was at home looking after his three brothers. Knowing that she’s there for him, someone he knows and is so happy and comfortable with, means so much to us.



Shelly was also a huge support to me on the days I was at the hospital too. She would play with Ellis and keep him busy while I spoke to doctors and focused on listening to what they were saying.

Whichever way I turn, I feel guilty – if I’m with Ellis, I feel guilty not being with his brothers, when I’m with them, I feel guilty not being with Ellis.

Rainbow Trust and Shelly’s support has taken the pressure off us massively, and helps me deal with that feeling of guilt. Without her, life would have been very, very stressful, and far more upsetting all of us.

*Ellis, now 14 months, pictured here with his family and Shelly, has now been home for four months and is doing well*

*Photo credit for front cover and these pages: Sarah Deane Photographics*

➔ Help us to support more families like Ellis’s and make a regular donation at [rainbowtrust.org.uk/](https://rainbowtrust.org.uk/) sponsor

You can choose how often and how much – it is totally up to you.

There are so many more families that need our support.



# FUNDRAISING HEROES

Here are just some of our heroes who have helped to raise vital funds in the past few months



Family Support Worker, Fiona, attended The UK Air Cargo Club Gala Ball raising over £5,000



GoodGym Kingston packed bags for customers at their local Sainsbury's to raise funds



Actor Rob Delaney speaking at Trust in Fashion about how Rainbow Trust supports his family. The event raised £95,103



Team Sophia Rose completed the Yorkshire 10 Mile race and raised an incredible £1,721



Second year Westminster University students are crowdfunding for Rainbow Trust hoping to raise £1,780



Our Regional Fundraisers visited Chessington Garden Centre to thank them for their continued support raising over £35,000

# A DAD'S CALL FOR PEDAL POWER

**Nine-year-old Henry was born with a rare condition which has left him with severe kidney and bladder damage. Godfrey, Henry's dad, is preparing to donate his kidney to Henry when it's needed.**

"Nobody expects to be in our situation. Nicki, our Family Support Worker, provides brilliant emotional support when the stresses and strains of our situation get too much.

When Godfrey donates his kidney, he will be out of action, I'll be in the hospital with Henry, and Thomas, his brother, will be floating between people. That is when we'll rely heavily on Nicki," says Beccy, Henry's mum.

This spring, the family is encouraging supporters to saddle up for the annual Prudential RideLondon event around Central London and Surrey in support of Rainbow Trust.

“ Please sign up to Team Henry and sponsor us so that we can raise money for Rainbow Trust and say thank you to this fantastic charity so they can continue to help our family and many others like us. ”  
**Godfrey, Henry's Dad.**

Find out more or get involved at [rainbowtrust.org.uk/RideLondon](http://rainbowtrust.org.uk/RideLondon)  
 Sponsor Godfrey at [justgiving.com/fundraising/godfrey-haire](http://justgiving.com/fundraising/godfrey-haire)



Henry in hospital in March waiting to undergo his 50th treatment

Godfrey, Henry's dad

# COMING UP

There are many ways you can get involved in the coming months

Aprons on and spatulas at the ready... join the Great Rainbow Bake **6-12 May**

Challenge yourself to run: chose from Big Fun Run 5k's across the country; the Great North Run on 8 September or even enter our new virtual 5k run, **One Step at a Time**

Look out for more from **CarFest 2019**

- we're delighted to have been chosen this year as one of four new charity partners

- 26-28 July: Bolesworth, Cheshire
- 23-25 August: Laverstoke Park Farm, Hampshire



Visit [rainbowtrust.org.uk](http://rainbowtrust.org.uk) to find out more about how you can help.