



# FAMILIES FIRST AUTUMN/WINTER 2018

## **A mum's voice**

"I can talk to Nicki about anything, she helps normalise life for us"

## **Your impact**

See how your support helps families

## **Radio 4 charity appeal**

Gyles Brandreth fronts our national radio appeal

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD



## YOUR SUPPORT HELPS

Hadi was diagnosed with Spinal Muscular Atrophy Type One when he was just eight weeks old.

The disease affects all the muscles in his body because he is missing a protein called SMN.

He is tube fed, unable to swallow or to sit up unaided and can have difficulty breathing.

Family Support Worker, Vilja, from the West London team, has helped the whole family in coping and coming to terms with Hadi's illness. Hadi stood for the first time using a frame in June and saw life from a new perspective. It helped his family to feel optimistic about his future.

**"Whenever I come across a struggling family, I always mention Rainbow Trust because they do all they can to support families," said Hadi's mum.**



### Dear Supporter,

I hope you have had the chance to enjoy the summer - we have certainly been busy. The big excitement for us is that on 10 September we moved into our new head office.

For those keen on our Leatherhead heritage, don't panic! Our new office is about 350 yards behind our old one so Leatherhead remains our locale. Why move? Well, although Cleeve Court had become a little tired, the decision was in fact made for us by the landlord selling the building to a property developer. It was time for us to go and we now

have a new office at Cassini Court. It is a fantastic collaborative working space and we are all hugely excited to be here. It will allow us to work more flexibly which will help us as we continue to deliver a high quality service to families and a better supporter experience.

We always love to hear your views so do please email us [supportercare@rainbowtrust.org.uk](mailto:supportercare@rainbowtrust.org.uk).

Thank you for your incredible support.

Zillah Bingley, CEO

McKenzie was diagnosed with stage 4 neuroblastoma in October 2011, when he was just two years old.

He had six months of chemotherapy, then surgery, then radiotherapy which meant having a general anaesthetic every day for three weeks.

McKenzie's illness affected the whole family and they realised they needed support so they were introduced to Dawn, a Family Support Worker from the Southampton team (pictured right).

"Dawn supported us throughout, she helped us stay optimistic and she also helped us emotionally. If one of his older sisters was struggling, I'd ask Dawn to come and have a chat with her. She understood what we were going through and that is something that we really appreciated as most

people don't understand what it's like. We felt less isolated with Dawn and Rainbow Trust's support." McKenzie's mum

The family is delighted that McKenzie has recently celebrated being five years cancer free.



## 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](http://rainbowtrust.org.uk)

**Call us:** 01372 220083

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

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

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

# LATEST NEWS



Phoebe has Fanconi Anaemia, a rare genetic disorder. She recently had a bone marrow transplant and luckily her dad was a perfect match. Here she is on the hospital ward where one of our Family Support Workers from the North East team spends time with her, allowing her parents to have a break and spend some time with Harriet, Phoebe's sister.



Some of the children supported by our South West team had never seen the sea before...or been in it! This summer a group of siblings had a great day out at Weymouth beach and Sealife Centre, giving them a well-deserved break from the strains of having a seriously ill brother or sister.



Asher is just 12 months old and has Multiple Endocrine Neoplasia Type 2b. This very rare condition affects around 1 in 4 million people and causes multiple aggressive tumours throughout the endocrine system. His Family Support Worker from the Essex team helps the whole family with emotional and practical support.



Eight friends took on the incredible challenge of climbing Mount Snowdon in North Wales. The 'Mums up a Mountain' team was inspired to fundraise for Rainbow Trust as their friend, Karen, and her family is currently supported by us.



Four year old Ian-Drake has leukaemia. Here he is with Dexter, his four month old brother, making cards at the drop-in group on the oncology ward at the Great North Children's Hospital. It gave their mother a chance to have a break, and chat to other families in a similar situation.



There are many different ways of raising money to support families. The London International Kayak Fishing Festival raised £1,000 in June. Ian "Dizzyfish" Harris, said: "We are delighted that we have been able to raise funds for Rainbow Trust, which is a truly worthy cause, offering support to families who are in desperate need of it."

Can you help us provide support to more families by making a donation today?  
Visit [rainbowtrust.org.uk/donate](http://rainbowtrust.org.uk/donate)

## A MUM'S VOICE

We have three children, Connor (11), Esther (7), and Zachary (1). Esther and Zachary were diagnosed with Diamond Blackfan Anaemia (DBA) when they were born, a bone marrow disorder that means their bodies cannot produce red blood cells.

Esther had a blood transfusion every month for the first year of her life – it's like putting petrol in the car, it became normal. She's profoundly deaf in one ear, which naturally affects her education and daily life. For now, she is on steroids daily, which is working but we don't know how long that will last.

It was a huge shock to find out that Zachary also had it. Both my husband and I have been tested and neither of us are carriers, so we were told that Esther having DBA was a one-off. It was a real low point for us. Zachary wasn't the same as Esther.

He didn't sleep, he struggled to gain weight which we blamed on the blood. When he was five months old he was very poorly and was admitted into hospital which was when I contacted Rainbow Trust.

We needed a team; I knew we couldn't do this on our own. My mental health wasn't great - I hadn't had any sleep. We met Nicki from Rainbow Trust and she started coming to hospital appointments with us. That was amazing, but it's the emotional support, being able to chat to Nicki, which makes such a difference.

Having someone there for just us, somebody who's independent and professional, who understands. Thanks to her, we feel human again.

**“I wouldn't have been able to do the hospital visits alone, because my husband needs to work. Without Nicki, we'd have had to book taxis and I wouldn't be able to leave Esther's bedside or take any kind of break.”**

Continued overleaf





Nicki does arts and crafts with Esther in hospital – it’s amazing the level of support we get from her and knowing it doesn’t just end is such a relief. She knows we don’t know what the future holds and we are so very grateful for her support.

**“For us, having Nicki has been fantastic, just having someone there for us. I can talk to Nicki about anything, she helps normalise life for us.”**

Zachary is in remission now, but without Nicki, we’d still be really struggling. It’s been an incredibly dark time with Esther’s and Zachary’s treatment. I don’t like to think about it.

Thank you Nicki and Rainbow Trust for helping me feel human again and helping me see how we can get through this. If we had a crisis, I know I could call on Nicki. I wouldn’t want to be without her through any of this.



To make a regular donation and help us support more families, visit [rainbowtrust.org.uk/sponsor](https://rainbowtrust.org.uk/sponsor)

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

## **GYLES BRANDRETH: FRONTS OUR CHARITY APPEAL ON BBC RADIO 4**

**We are delighted to have been selected to benefit from BBC Radio 4’s Charity Appeal, which reaches just under two million listeners each week.**

The well-known writer, presenter and former MP, Gyles Brandreth, will be presenting the appeal for us. Gyles knows all too well the positive impact of Rainbow Trust as his family has benefitted from our support after

his grandson was diagnosed with an aggressive cancer when he was just 18 months old.

In the appeal, Gyles talks openly about his personal connection to Rainbow Trust. He also shares the story of another family we have helped, whose mother had to live in hospital for five months with Dominic, her 10-week-old son, while he underwent intensive cancer treatment.

Meanwhile Dominic’s dad was left trying to cope at home, looking after their five-year-old son, who didn’t understand what was happening.

The appeal first broadcasts on Sunday 30 September at 7.55am and 9.26pm and again on Thursday 4 October at 3.27pm. If you miss it, you can hear it again at [rainbowtrust.org.uk/radio4appeal](https://rainbowtrust.org.uk/radio4appeal).



Listen again at [rainbowtrust.org.uk/radio4appeal](https://rainbowtrust.org.uk/radio4appeal)

# #TEAMDANIEL

Five year old Daniel Rainbow and his family asked runners to take part in the iconic Great North Run in Newcastle-upon-Tyne which took place this September. By joining “Team Daniel”, runners raised money to support families, like theirs, for Rainbow Trust. The event has raised an incredible £14,000 so far!



Just after Daniel's second birthday, he stopped walking, started stumbling and wasn't eating. He seemed a grey colour and doctors thought he was anaemic. After tests, Daniel was diagnosed with neuroblastoma, a rare cancer that mostly affects babies and young children.

A few weeks after diagnosis, the family was introduced to Sabrina, a Rainbow Trust Family Support Worker from the North East team.

**Claire, Daniel's mum said: "With all the tests and treatment he had to have, Daniel withdrew into himself, but took to Sabrina straight away. At the time, he'd only speak to his dad and me, but he felt so comfortable with Sabrina that he bonded with her and would chat to her quite happily."**



Daniel with his family at the Great North Run

"We were very grateful for the support as Daniel's diagnosis came three days after I'd discovered I was pregnant. Sabrina helped us with hospital appointments and would sit with Daniel for a few hours to give us a break to speak to consultants, make phone calls or even to just grab a coffee and have a breather without having to worry about entertaining Daniel."

"Sabrina comes with me to clinic appointments and reassures me about stuff which is invaluable. She's there for Daniel – he adores her. She plays with him and he has so much fun

with her, which is so lovely to see," said Claire.

"As well as being there for Daniel, Sabrina is there for me too which has been fantastic."

"With Sabrina's help, I did make friends and now know a couple of mums - I'd be lost without them. They understand what we've been through, what our life looks like and what it feels like having a child with a serious illness. If it wasn't for Sabrina's encouragement to speak to other parents, I'd never have spoken to anyone," said Claire.



Want to get involved? Visit [rainbowtrust.org.uk](http://rainbowtrust.org.uk) to find out more about our wide range of fundraising activities and events all year round. We'd love to hear from you.

# IN HENRY'S NAME

In January, well-known American comedian Rob Delaney announced the very sad news that his gorgeous two-year-old son Henry had died, in an emotional social media post. Henry had been diagnosed with a brain tumour just after his first birthday in 2016.

The Delaney family had been receiving support from Fiona, a Family Support Worker from our Central London team, and continue to do so following his death.

Rob encouraged his supporters to make a donation in Henry's name to Rainbow Trust or Noah's Ark Children's Hospice and the response was overwhelming. So far we have received an incredible £45,000 – enough for us to fund a Family Support Worker for a year.

Thanks to everyone for their amazing generosity in memory of the family's very special boy.



*Rob with Henry*



*Fiona with Henry*



If your family is, or has been, supported by Rainbow Trust and you would like to help other families, then why not set up a Forever Fund to raise money in their memory?

Visit [rainbowtrust.org.uk/forever-fund](https://rainbowtrust.org.uk/forever-fund) to find out more.