

FAMILIES FIRST

SPRING/SUMMER 2021

Celebrating
end of cancer
treatment and
looking forward
to brighter
times

A week in the
life of a Family
Support Worker

Remembering
positive, **happy**
memories



**RAINBOW
TRUST**

SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

Dear Supporter,

A year on from the start of the COVID-19 pandemic, Rainbow Trust Family Support Workers are helping parents and carers of seriously ill children to navigate challenges anew.

In this edition of *Families First*, you will learn more about how having the trusted constant of a Rainbow Trust Family Support Worker, providing support either in person or remotely, makes a huge difference to families' lives.

So many challenges faced by families living with serious childhood illness are tough enough to deal with without a global health pandemic. At the end of 2020, our *Pandemic Pressures* report reinforced how COVID-19 had caused a vast number of new emotional and practical pressures on families already facing a high degree of stress and anxiety about the health of their child. Earlier this year, we asked families we support to tell us more about their situations compared to the first lockdown, and the results show that their outlook has not improved.

Many families are facing a steep uphill struggle as they try to balance worries about their child's medical care, their own mental health, their financial security and their continued isolation. We will continue to urge Government and decision makers to address the long-standing gap in funding for vital support to benefit families at a time of great anxiety, when they need it more than ever.

As the end of the third national lockdown nears, we look hopefully to the rest of 2021. Our new Care policies and procedures are a stable basis from which we will increase face-to-face support. Through weekly testing, personal protective equipment, social distancing, increased cleaning and sanitising of buildings and equipment as well as vaccinations, we can continue to adapt and be



Zillah, drawn by Kerindeep, Aged 11

there, safely, for families who know they can count on Rainbow Trust.

We are proud that, in November, when we asked families to rate our overall service, 97% of parents/carers who responded rated it as good or excellent. Thank you for your continued support of Rainbow Trust; you are helping us to reach families so much in need.

Zillah Bingley, CEO

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Since July last year we have started supporting 243 new families, which is an average of one new family each day. When serious illness affects a child, family life is turned upside down. Rainbow Trust pairs each family with a dedicated expert Family Support Worker to help them face and make the most of each new day.

Despite the restrictions brought about by the pandemic, Family Support Workers continue providing practical and emotional support to families caring for a seriously ill child in whatever way is possible. This includes virtual support sessions for children, emotional support for parents by telephone and video calls, and the delivery of essential medicines and groceries to families' doorsteps where necessary.

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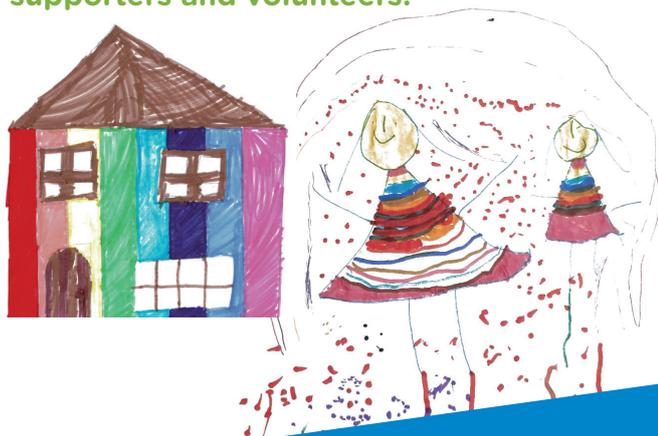
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OUR IMPACT 2019/2020

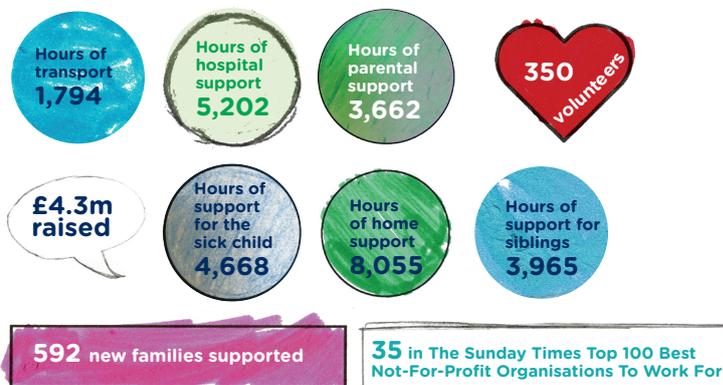
A year like no other

Our latest impact report shows how our service has improved multiple aspects of children's and families' lives across the country and celebrates the generous contributions of all our wonderful supporters and volunteers.



We asked children we support and children who have fundraised for us to help bring our impact report to life with their drawings, doodles and paintings.

Highlights in numbers



You can download a full copy here
rainbowtrust.org.uk/our-impact

WHAT PARENTS AND CARERS SAY

In February, we carried out a survey of families we support. The results gave clear indication of the vast pressures families with a seriously ill child are under, as they continue to face stress and anxiety over the health of their child during the pandemic.

71% of the families had a child who was still clinically extremely vulnerable

56% of respondents said that their family situation was worse or much worse compared to the first lockdown

Just over **half** said that their mental health was either worse or much worse compared to the first lockdown

Medical treatment has been affected for over **50%** of families including postponed tests and reviews, some therapies suspended and problems accessing medication

Additional financial strain is being felt by **40%** of families due to job losses, income reduction and being furloughed.

WHAT THE CHILDREN SAY

Separately, in our children's audit, when we asked some of the older children we support about the impact of social distancing and lockdown, 77% of those who answered said it made things harder for them.

We also asked some of the younger children what they would wish for if they had a magic wand.

“ If I had a magic wand I would...

... make Covid go away so I can see my Family Support Worker in person

... turn into Minnie Mouse

... make the whole world out of chocolate cake ”

27% of children who answered would make a wish to get rid of coronavirus and the lockdown

27% of children who answered would make a wish focused on getting better or their siblings getting better

You can read more about it at rainbowtrust.org.uk

Lauren shares her experience of bereavement and of the support Rainbow Trust offered at such a traumatic time

A DEVASTATING DIAGNOSIS

My partner, Richard, and I were told our baby had a heart problem at our 20-week scan. The sonographer told me that the left side of his heart looked smaller than the right and I feared the worst. I was very scared.

They referred us to a specialist at the Newcastle Royal Victoria Infirmary. We had a call the same day to book an immediate appointment and scans confirmed the sonographer's concerns. The consultant said that Cole's heart hadn't formed properly, showing me pictures of how a normal heart works and what was wrong with Cole's.

I was devastated, I felt numb. He explained that Cole had hypoplastic left heart syndrome, which is where the left ventricle of the heart does not develop properly.

He said that it is a life-threatening condition and that Cole would need surgery immediately after birth or he would die. He also explained that some parents choose to terminate the pregnancy or not to have surgery but I knew I couldn't do that. I knew I wanted to give Cole every chance.

Cole was born weighing 7lbs 7oz. When he was just three days old, they attempted a procedure that tries to create a new circulatory system.

It was the first of four operations in which surgeons tried to reconstruct the heart and insert a stent to help blood flow to the lungs. During the procedure, something didn't go according to plan and they had to put Cole on life support. They told us to prepare for the worst.

At the fourth attempt they managed to fit a stent in Cole's aorta, finally giving him a chance of survival.

Over the next few days he improved and, when he was 14 days old, doctors gradually weaned him off life support. He was still very unstable, and we were filled with worry. All of this was an emotional rollercoaster. I was in a bad place.

Invaluable help in the hospital

A hospital social worker referred us to Rainbow Trust and when Cole was 17 days old Family Support Worker Sian started supporting us. Sian would come to the ward, help with Cole's personal care needs and look after him.

We also have a daughter, Esme, who was three years old at the time, and we needed to be with her too. Neither Richard nor I drive, and the hospital is a 70 mile round trip from our home, so we couldn't be with Cole all the time. Sian being there helped ease the worry and constant concern about Cole and she would usually send photos and update us on how Cole was doing.



Cole remained in intensive care for three months but his health improved little by little. Sian would sing, read books, play with toys, play with musical instruments and sensory toys with Cole, to keep him entertained and help his development.

Then, Cole was moved on to a ward. He needed another operation to widen the stent in his heart and in time he would also need a heart transplant. At six months old, Cole went on the waiting list and, two months later, in early March last year, he had a heart transplant. This filled us with hope for him.

Just before the first national lockdown we were told Cole could have no visitors other than me and Richard for three months due to COVID-19, but we had to self-isolate for three days, waiting for COVID-19 test results, as Esme had a temperature.



Cole, smiling to the camera



Family Support Worker Sabrina

This was worrying because, due to COVID-19 restrictions, Sian couldn't visit the hospital. No one else could be there.

At the end of March, Cole very sadly went into renal failure and died. We were there with him. It was the most painful experience.

Family Support Workers help ease the pain

To begin with Sian helped support us in our grief by visiting us on our doorstep delivering memory boxes and activities for Esme. This support continued as she would check in and talk to me via text message.

Sian also helped source a £300 fund to help with funeral costs. She sent us a special card, as she couldn't attend the funeral due to lockdown. We were touched that each Family Support Worker in the team lit a candle in their own home.

It was lovely to see that Cole was being remembered in this way and that we were in their hearts at such a horribly sad time.

In May Family Support Worker Sabrina started to offer bereavement support. Sabrina did doorstep visits to deliver activities and referred us for a holiday to charity Ruddi's Retreat as well.

Sabrina regularly texted me for emotional support and we had long conversations because we couldn't have sessions face to face due to the ongoing restrictions. I really benefitted from being able to talk things through by text.

Family Support Workers Sian and Sabrina have been a light at the darkest of times. They've supported me and my family when we faced the worst.



Hypoplastic left heart syndrome is a rare form of congenital heart disease. As the baby grows during pregnancy the left side of the heart does not develop properly and is too small.

Around 250 babies are diagnosed with hypoplastic left heart syndrome in the UK every year.

Grief and bereavement are difficult to deal with. It is only thanks to your support and donations that we can give families expert, practical and emotional support for as long as they need it.

Richard, Esme, Lauren and Cole

rainbowtrust.org.uk/donate-magazine

CELEBRATING END OF CANCER TREATMENT AND LOOKING FORWARD TO BRIGHTER TIMES

Family Support Worker Wendy supports Phoebe and Rory's family while they face childhood cancer

Phoebe's mum, Katie, first discovered that Phoebe was not well in February 2020 when Phoebe was two and a half years old.

She had been sick in the night and was just not herself when Katie found a big lump on the right side of Phoebe's tummy. Katie and Matt, Phoebe's dad, took her to Bristol Children's Hospital where staff were unsure about the cause, so they did a scan.

After the scan she was rushed for an ultrasound and, at that point, Katie and Matt knew something wasn't right.

They were very worried and concerned that Phoebe's condition was clearly very serious.

They were both very emotional and had lots of unanswered questions. The surgeon arrived and told them that Phoebe had a tumour. They were left feeling scared, hurt and angry. One of the nurses helped to comfort them. Katie felt as though she had completely shut down and held Phoebe in her arms, not knowing what to do.

Phoebe has a seven-year-old brother, Rory, and Matt and Katie were worried about how he would cope, how they would explain that Phoebe was ill and that they had to be away from him for a whole week.

Katie and Matt were in hospital with Phoebe initially for seven days. She had MRI scans, CT scans, blood tests, a Hickman line fitted and her first dose of chemotherapy to shrink the tumour in that first week. They went back home for two days, and then back to hospital for the next dose of chemotherapy, which would continue weekly.

Phoebe had a stage two Wilms' tumour (cancer found in the kidney) and had an MRI scan to check if the tumour had shrunk. As it had reduced significantly, on 24 March, just after last year's first national lockdown started, Phoebe went back to hospital to have her kidney removed.

Due to lockdown only one parent could be there, and they juggled this between them. One week after the operation Phoebe was back on chemotherapy for 27 weeks, a double dose at hospital and a single dose at home, administered by a nurse.



Phoebe in hospital

A fun morning at Portishead - Phoebe and Rory had a great time running around at the beach with Wendy while their parents had time for themselves



Phoebe's end of cancer treatment party

The uncertainty that all of this brought to Katie and Matt was devastating. Katie was not coping well with her own mental health, confused about how to feel and process everything.

They were drained and exhausted.

A CLIC Sargent team at the hospital referred them to Rainbow Trust for sibling support and Family Support Worker Wendy started supporting Rory in April 2020. Katie and Matt were concerned that everything going on with Phoebe would affect him and that he wouldn't open up. But Katie told us *"Wendy's presence and personality has had a huge impact on both kids. Rory is very quiet, but Wendy brings him out of his shell. The energy Wendy has with them is effortless and some days we can hang back and enjoy watching them have fun with Wendy."*

Katie and Matt have a very supportive wider family, but they found Phoebe's illness had an effect on many relationships and friendships. Katie lost touch with a very close friend because they couldn't deal with Phoebe's illness. This has also had a detrimental effect on Katie's emotional wellbeing, so Wendy has been giving her emotional support. Katie says, *"Wendy always has time to listen and, although she supports the whole family, somehow she manages to support us all individually."*

Phoebe finished her treatment in October and rang the bell at Bristol Children's Hospital to celebrate, a joyful moment for Phoebe's family and hospital staff.

Wendy has continued supporting the family with some face-to-face visits in late October, art

activities for Halloween with both Rory and Phoebe, taking Rory to the cinema in half-term and also introducing him to another sibling she supports.

Throughout the changing Government guidance, Wendy has adapted the way she supports the whole family. They have enjoyed going out for walks, scavenger hunts, singing, doing quizzes, doorstep delivery of Christmas gifts, virtual calls including reading stories and anything else the family may need.

Katie says, *"We embraced Wendy's support; there is no need to be alone. You may have initial concerns that you may not connect but once you do you feel like the weight has been lifted. Life without Wendy would have been so much harder."*

About 70 children in the UK develop a Wilms' tumour each year affecting mainly children under the age of five.

One third of the families we support are caring for a child with cancer. Year on year cancer remains the most common reason for referral to our service and despite the improvements in treatment and prognosis, the impact on all family members is devastating.

Help families and sponsor a Family Support Worker like Wendy today.

Your sponsorship will enable families who have a child with a life-threatening illness to make the most of time together as the crisis continues.

rainbowtrust.org.uk/sponsor-us

YOUR SUPPORT REALLY MATTERS

Your support helps change lives

A snapshot of the children and families you have helped us support during the challenging past months.

➤ Marrveen, seven, after a virtual pancake session with Family Support Worker Sarah. His brother, Raynnav, two, has a serious condition that affects his development.



⬆ Family Support Worker Mandy is currently supporting baby Elodie-Arayah who was born at 33 weeks. Mum and Dad were struggling to get to the hospital so Mandy has been helping with transport.



⬆ Family Support Worker Sabrina received an amazing welcome from Jessica, who has Batten disease, when delivering activities to her house; Jessica drew this picture and asked her mum to send it to Sabrina.



⬆ Family Support Worker Wendy started supporting Joshua's family. Joshua, three, has acute lymphoblastic leukaemia. He loves playing with his dinosaurs virtually with Wendy and is really good at naming them all.



⬆ Family Support Workers Sean and Rachel received this lovely picture from Mia and Maisie which said 'stay positive' with a colourful rainbow.



⬆ Jonas came home from Great Ormond Street Hospital in November and this was the first time he had been out of hospital since birth. Family Support Worker Ema has supported his brother, Jacob, with play sessions since June.



⬆ Family Support Worker Charlotte went exploring with Gene when restrictions allowed. He is 11, has glomerulocystic disease, kidney disease, renal anaemia and hyperkalaemia.



⬆ Family Support Worker Jaimie took Lily, eight, out on a socially-distanced bike ride. Her outdoor exercise is restricted to her garden as her three-year-old brother, Charlie, suffers from a heart condition.



⬆ Family Support Worker Mandy spent some time with Penelope and her sister Tallulah, who has complex needs. Penelope was showing off her shoes and playing with her dolls.

This season we want to support more families living with childhood illness

Unable to socialise during the different restriction levels as the pandemic progresses we are helping families get through. Playing, arts and crafts, virtual reading, quizzes and conversations give the children a break and enable us to look after their mental health and wellbeing, helping their confidence, self-esteem and independence at a time when they need it most.

Thank you for all your support.

A WEEK IN THE LIFE OF A FAMILY SUPPORT WORKER

Abi is a Rainbow Trust Family Support Worker in Essex and shares a typical week with us

By Abi Smith

Every day I check my emails first thing in the morning. I send figures and information to Anne, our Director of Care, at the end of the day so we can monitor how the nature of our support and service is changing due to the pandemic.

MONDAY:

I picked up Annie and her three-year-old daughter, Daisy, and drove them to hospital for a 9am appointment; they have to stay overnight. Annie can get very anxious about these appointments; they can be quite traumatic for Daisy. Annie's anxiety has been heightened even more by the pandemic. She said that having Rainbow Trust's help to get to Daisy's appointments takes so much of the stress and anxiety away and it really helps her to have me to talk to.

Then I drove home to catch up over the phone with two families with daughters who have recently died to see how they are, how their other children are coping and about applying for a grant on their behalf to help with funeral costs. One mum expressed concern for her five-year-old, Matthew. I will pick him up from school on Thursday to talk to him about worries he may have.

TUESDAY:

Daisy's mum texted me last night to ask me to pick them up early this morning. The procedure didn't go well, and the medical team had to postpone it. On the journey home Annie was very tearful; we talked through her feelings and discussed coping strategies. She said that before Rainbow Trust came along she very rarely talked to anyone about how she feels but with my encouragement she now talks with some friends and family

and has even had the courage to ask for help and accesses counselling now.

After that I caught up with more families on the phone. I had a video call with two siblings which was chaotic and fun. We chatted, played games, read stories to each other and they enjoyed showing me some of their schoolwork.

WEDNESDAY:

On Wednesdays, we start the day with a team meeting by video. It's always so lovely to be able to see everyone, share successes and any worries or difficulties we may have had.

In the afternoon I had a weekly video call with nine-year-old Bella, who has a brain tumour. Bella hasn't been out of the house much since the first lockdown and she can get frustrated and bored. Mum finds it hard thinking of new things to do all the time to keep Bella stimulated and occupied and Bella can be quite demanding at times. The video calls allow Mum to have a bit of time to do chores, make calls, spend time with Bella's sister or just to have a quiet cup of coffee.

THURSDAY:

This morning I joined a Child Protection meeting regarding a family I support. Safeguarding is a big part of our job and we work closely with social workers, schools and other professionals that may be involved with the family.

I then had a phone call with Sarah, a single parent with four children at home. Her youngest, Tommy, is five and has cancer. Tommy relies on his tablet for his many lengthy hospital appointments but this and a smart phone were the only devices they had at home to do schoolwork on for all four

children. It is a very busy homelife for Sarah and she just doesn't have time to look at where she can get help to apply for a grant or fill in applications. With Sarah's permission I applied on their behalf and another local charity has now given them a laptop.

As agreed with Mum on Monday I picked up Matthew from school. We talked about school, his sister Jane's funeral tomorrow and questions he had.

FRIDAY:

Today it was eight-year-old Jane's funeral. Due to the current government guidelines Jane's family was restricted on the number of people attending the funeral and was unable to receive the comfort they need from family and friends. Rainbow Trust Family Support Workers are frontline workers and, because of this, I was specially allowed into the family home, following government guidelines and wearing PPE, to support the family. I took care of the youngest 15-month-old sibling whilst the family went to Jane's funeral. Mum is relieved that support won't stop now that Jane has died. I will continue to support the family until they feel they no longer need me.

Once at home, I updated my case notes and caught up with emails before running myself a big bubble bath!



You can help to make every precious moment count for families with a seriously or terminally ill child by sponsoring a Family Support Worker like Abi today.

[rainbowtrust.org.uk/
sponsor-us](https://rainbowtrust.org.uk/sponsor-us)

REMEMBERING POSITIVE, HAPPY MEMORIES

I feel immensely lucky to have a job that I love



By Rachel Bruen, Family Support Worker, North West Care team

For any child, a younger sister dying from cancer would be devastating. For Beatrice, coming to terms with the death of her four-year-old sister, Rosie, and then living in lockdown, the grief and bewilderment were unbearable.

Her parents, Ray and Annette, had already organised support from me to help her cope when Rosie was ill. I have helped the family with incredibly difficult conversations with Beatrice, explaining that Rosie was not going to get better.

Before lockdown I spent time with Beatrice, taking her out and giving her time and space for her own feelings and helping her with her constant worrying. I gave her a 'worry monster' teddy which has a zip mouth into which she can put her worry notes and the monster 'eats' them overnight.

When Rosie died, without the sanctuary of school or the welcome distraction of friends and after school activities, and becoming the only child in the house again, understandably, Beatrice struggled

with an overwhelming sense of loss and sadness.

The whole family was grieving intensely, and I was there to provide bereavement support to them. Despite being unable to visit in person during the first lockdown, and having to isolate during the second, I was still able to talk to Beatrice on Zoom calls to help her understand her feelings, deal with her worries, giving her an outlet and remembering happy, positive memories of Rosie.

It has been such a difficult time for Beatrice and her family, and I have seen the difference it has made to her to have consistent one-to-

one support to help her process her feelings and emotions, whilst reminding her she is a child and it is ok to still have fun.

I consider myself immensely lucky to work at Rainbow Trust as I have a job that I love. I feel it is a complete honour that families, like Beatrice's, allow me to help them through such an incredibly difficult time. If I am able to make things slightly easier and support them as they navigate childhood illness and grief, then it is my pleasure to do so.

Images are from BBC Children in Need: Life in Lockdown



“We couldn't get through it without Rachel and Rainbow Trust. We know Beatrice is going to be ok and that is thanks to Rachel.”

Annette, Beatrice's mum



“I made a coloured salt jar of memories with Rachel and a 'feelings volcano' where I put my thoughts inside. I feel lonely sometimes when Rachel is not here. Seeing Rachel makes me feel better.”
Beatrice

In November 2020, Rainbow Trust featured in *Life in Lockdown*, a powerful, uplifting and touching film which aired on BBC One featuring a number of BBC Children in Need funded projects. It showed how brilliantly resilient children and young people, like eight-year-old Beatrice (pictured), can be in the face of a global crisis.

FUNDRAISING HEROES *Thank you!*



↑ Anna, a paediatric nurse, raised over £1,000 with a sponsored skydive in November. Anna has seen the devastating effect COVID-19 has on people and wanted to do something positive to help others.



↑ Elizabeth, eight, signed up to ride 100 miles to raise money for Rainbow Trust, whilst her younger brother Edward, who at the time had just learned to ride without stabilisers, decided to ride 50 miles.



↑ Kennedys Law UK employees took part in four challenges during the pandemic - the Virtual Hairy Haggis Relay, 10K Steps for Justice, Make Up Your Grown-Up and the Virtual London Marathon, taking their total amount raised to £148,500.



↓ K2 Corporate Mobility virtually climbed the K2 mountain. They split themselves into teams to see who can raise the most money possible.



← Tomos and Menna completed our 'One Step at a Time' virtual 5K raising £101.



↑ Thank you to everyone who completed the Virtual London Marathon to raise money in October. And a very special thank you to Fred, who ran his 28th consecutive London Marathon for Rainbow Trust in his bear costume.

↑ Family Support Worker Angie swam the width of the Channel (22 miles) raising over £1,300. She was joined in the pool on her final day, socially distanced, by Caroline and Joanna - mums of two families she supports.



280,000 STEPS IN FEBRUARY

Over 1,000 people took part in our Facebook fundraising challenge.

Sign up to take part in our next Facebook fundraising challenge by visiting our Facebook page!



HOW YOU CAN HELP SERIOUSLY ILL CHILDREN

Feeling inspired? You can also help us fundraise

Cancelled and postponed live and mass participation fundraising events continue to have a severe impact on our income but there are so many ways you can still help.

30 miles. 30 days. Will you lace up your trainers this April for seriously ill children? Join our Run 30 Challenge to receive your free neck buff.

facebook.com/groups/run30inapril

Great North Run, Sunday 12 September 2021, Newcastle

Registration fee £20, sponsorship target £300

We will cheer you while you soak up the great atmosphere during the 13.1 mile course.

London Marathon, Sunday 3 October 2021, London

Registration fee £150, sponsorship target £2000

Join Team Rainbow Trust to run the streets of London in this iconic event. We ensure all our runners have a memorable marathon experience and you will be supported all the way to the finish line, and beyond!



And you can also...

Set up a PlayStation or Xbox gaming challenge

Ask for donations to Rainbow Trust instead of birthday presents

Climb the equivalent of Mount Everest in 12 weeks to earn an Everest-themed medal

Walk or run 10K steps every day for a month

Create your own fundraising event

Simply visit rainbowtrust.org.uk/events, chose your challenge and set up a fundraising page.

TIME TO DO SOMETHING AMAZING!

Join our Lottery for your chance to win £25,000 every week

Rainbow Trust
LOTTERY



We've teamed up with Unity Lottery and for just £1 a week you could win £25,000 while helping to raise vital funds to support seriously ill children and their families.

Just go to rainbowtrust.org.uk/get-involved/lottery or call 01372 220083 and we will send you a form.

WIN

£25,000

YES! I would like to help life-threatened children and their families today

Title _____ Name _____ Surname _____
Address _____ Postcode _____

I would like to receive emails:

£15 £25 Other:

I enclose my cheque made payable to Rainbow Trust Children's Charity or

Please charge my: Visa MasterCard Maestro Amex

Name on card:

Card No:

Security Code: Issue No: Start Date: /

Please call me on: _____

Please send your donation to:
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rainbowtrust.org.uk/donate-magazine



giftaid it

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Sign: _____ Date: ____ / ____ / ____

I want to Gift Aid this donation and any donations I make in the future or have made in the past four years to Rainbow Trust Children's Charity. I am a UK taxpayer and understand that if I pay less Income Tax and/or Capital Gains Tax than the amount of Gift Aid claimed on all of my donations in that tax year it is my responsibility to pay any difference.

Friends and supporters of Rainbow Trust like to receive information and appeals from us. **Your support is vital**, and we really want to stay in touch but please tick this box if you *don't* want to receive this information by post.