

FAMILIES FIRST

AUTUMN/
WINTER
2024

INSIDE:

- Rainbow Trust's support is unwavering: an update on Erhun
- A week in the life of Family Support Worker Joanne
- Your support matters, how you can get involved

**RAINBOW
TRUST**

SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD

Dear Supporter

In this edition, we are reminded about the ever-increasing complexity of situations that families with a seriously ill child face and how essential Rainbow Trust support remains.

You can read about Carly's struggle to balance her seriously ill child's needs, her lonely son and her own mental health, and how support continues through bereavement for as long as a family needs it.

I would like to congratulate former Director of Care Services, Anne Harris, on being made an MBE for services to seriously ill children and their families. Anne recently retired from her position at Rainbow Trust, one which she held for 17 years. The award is a testament to her dedication to help every family in the UK who has a child with a life-threatening illness receive the support they need.

In the last few months the London Marathon saw 60 runners for Rainbow Trust, we were once again one of CarFest's nominated charities, over 20 corporate teams attended our annual golf day, we announced our new Adventure Triple Challenge taking place in April 2025, and your support meant that the first Rainbow Week, a fun-filled week of activities, was bursting with colour.

There are thousands of families with a child with a life-limiting illness in the UK who are struggling to cope as they face the very real possibility that their child may die. Rainbow Trust Family Support Workers support the whole family, providing tailored practical and emotional support, helping siblings to learn coping mechanisms, parents to have some respite and the seriously ill child to have some much-needed fun.

In May, Rainbow Trust featured in the BBC Lifeline Appeal. A very special thank you to Gyles Brandreth for presenting it, the families who shared their stories of caring for a seriously ill child and supporters like you, who watched it and donated.

Shailza, mum to Riley and Stanley, was one such family who shared her story in the BBC Lifeline Appeal, talking about how Family Support Worker Jo supported her through Stanley's death and Riley's diagnosis with the same life-limiting genetic condition. I was reminded of how your donations and fundraising enable us to provide this incredibly important support which makes a huge difference to families coping alone.

Many more families need our support right now. As we continue to see referrals increasing, we are very grateful for your support and all you do to help families in crisis.

Thank you.



Zillah Bingley, Chief Executive



Cover photo: Riley, aged three, has lissencephaly, epilepsy and other complex health needs. Rainbow Trust Family Support Worker Carol supports the whole family practically and emotionally.

STAY IN TOUCH

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Head Office address: Cassini Court, Randalls Way, Leatherhead, Surrey, KT22 7TW
Registered Charity No. 1070532.

4,051

Hours of support for the seriously ill child

361

Hours of bereavement support

245

Hours of neonatal support



3,658

Hours of sibling support



1,274

Families received support

THE IMPACT of your support

This year your support has meant that 1,274 families don't have to cope alone as they adapt to their new reality of caring for a seriously ill child.

Thanks to your support, confused and scared siblings have an outlet for their feelings, a space to talk about their emotions and to ask questions about what is happening.

Overwhelmed and terrified parents have someone they know they can rely on and trust, who will support them in any way they can to ease the stress of caring for their seriously ill child. And seriously ill children who are surrounded by hospital equipment and medical staff all day can have some much-needed respite and a bit of fun.

Family Support Workers are only able to provide this essential lifeline because of your support.

Financial year July 2023 to June 2024

1,897

Hours of transport provided, including to vital medical appointments



Make a lasting impact for families caring for a seriously ill child by remembering Rainbow Trust in your Will

Writing a Will makes life easier for the people you love and gives you the confidence that they will be looked after as you protect your wishes for the future.

After remembering your loved ones, a gift in your Will to Rainbow Trust will make sure that Family Support Workers are there for families in crisis, giving them their expert support.

No matter how big or small, a gift in your Will is a wonderful act of kindness that will enable families with a seriously ill child to have the support they desperately need.



Free Will-writing service

Join other supporters and write your simple Will online. Help is available in case you have any questions throughout the process and legal experts check over each Will. Or you may prefer to book to write your Will over the phone or face-to-face by calling 020 4525 3605.

Simply go to rainbowtrust.org.uk/legacy or scan the QR code for more information or to request your free Gift in Wills guide.



We will respect your wishes and decisions at all times and treat all enquiries and pledges in strictest confidence.

“Balancing my seriously ill daughter’s care, my lonely son’s needs and my suffering mental health”

Alone in a hospital room Carly was told that her daughter may not make it to her fifth birthday. Shortly after, Rainbow Trust began supporting the family.

“After a normal pregnancy and birth I noticed that my six-month-old baby, Esme, was starting to miss typical baby milestones. Then, one day, out of the blue, Esme began to have odd movements, spasms.

We rushed to Southampton General Hospital where she was later diagnosed with a severe form of epilepsy.

When we first got her diagnosis, I convinced myself that she would be okay. But Esme just continued to get worse.

Her development plateaued and her seizures became more frequent and harder to control.



Esme in an ambulance on the way to hospital

Esme has stopped using her hands, has lost the ability to sit up, struggles to hold her head up and is non-verbal.

When Esme has fewer seizures, she laughs and smiles. I can see her lovely personality shining through.

But then the seizures ramp up again, and it wipes the slate clean. She has to learn everything again.

A lifeline of tailored support

On Esme’s first birthday her seizures got so bad we had to go to hospital. I was on my own, my family a hundred miles away and Arthur, Esme’s now six-year-old brother, was unable to be with me.

I had an adorable birthday outfit ready for Esme but, instead, she was lying in a hospital bed, having terrible seizures, with a tube down her throat.

On that day, I opened her birthday cards wishing her a wonderful day.

On that day, a neurologist told me that she may not make it to her fifth birthday.

I was at my complete lowest.

A psychotherapist at the hospital mentioned Rainbow Trust and asked if I would like to be referred. I can’t explain the relief I felt. Rainbow Trust Family Support Worker Georgia began supporting us in January 2022 and now Family Support Worker Michelle continues the support.

This support opened so many doors and has hugely helped both me and my son Arthur. Before we let the support in, we were just surviving, not living.

With Esme’s complex medical needs and frequent hospital trips I had to stop working and dedicate myself to her care full-time. This has been very isolating and I am constantly worried about finances.

Alongside this, Esme’s father and I separated. I can be at home on my own a lot without seeing another non-medical adult. Knowing that Michelle is there for us is so important. It alleviates the isolation and loneliness.

When Esme was diagnosed, my friendships became strained. It is difficult for friends to understand when you keep having to cancel because you don’t have anyone to look after your sick baby.

Esme needs special care to meet her needs and keep her safe, I can’t just get a babysitter like other people can.



Carly with Esme and Arthur



Family Support Worker Michelle and Arthur, six, on a day out at Paulton's Park

Michelle supports with whatever we need. It could be just a walk and talk to the local shop to pick up groceries or looking after Esme, allowing me to have time for myself and some much-needed respite.

I can offload everything I am feeling to Michelle. She is like having a friend whenever we need it.

Mum guilt

My biggest struggle has been the impact on my relationship with Arthur. The long, often back-to-back appointments or weeklong stays at the hospital with Esme mean I cannot spend as much time with him. He needs energy and attention that I cannot mentally or physically give.

I have massive 'mum guilt' and it has taken a huge toll on my mental health.

For a time I could not cope. I was borderline suicidal.

Georgia and Michelle's sibling support has been instrumental in ensuring Arthur gets the attention he needs to develop, without impacting Esme's care. He gets so excited for their visits.

Recently Arthur's room was a mess. He refused to tidy it up when I asked him. But he was happy to sort it out with Michelle so they

spent a couple of hours together, tidying up and chatting. Afterwards he was delighted with how well they did.

This is so important. Tidying up gave him the time to talk about how he is feeling with Michelle, while also helping him create an organised and uncluttered environment. The relief I feel about him being excited, happy and having fun is huge.

Because I can't work anymore, we haven't been able to go out like we used to. Michelle takes Arthur out and organises fun activities for him, giving him some time out of the house where the focus is just on him.

We have also attended some of the drop-in groups that the Rainbow Trust Southampton Care team hosts. I can bring Esme and Arthur and know they are safe and looked after while having fun. These drop-ins give me a non-judgmental space to chat and share with the Family Support Workers and other parents of seriously ill children.

Having Michelle around also gives me peace of mind that, if I ever have to rush to hospital with Esme, she will pick Arthur up from school, help him to understand the situation and make sure he is cared for so I can focus on Esme.

Trying to remain positive

Despite the difficulties, I try to focus on the positives and having Michelle's support has given me the relief and reassurance I need to do this.

Life before Rainbow Trust was incredibly difficult, it still is, but I now know that Michelle has my back, I can confide in her and she is a safety net for us.



No family should have to cope with the stress of caring for a seriously ill child alone.

Rainbow Trust Family Support Workers like Georgia and Michelle help alleviate some of this stress, giving families a constant to rely on. They offer tailored expert support, adapting to the particular needs of each family so they can focus on what matters the most.

Scan to donate or go to rainbowtrust.org.uk/donate-magazine



When the unthinkable happens Rainbow Trust's support is unwavering: an update on Erhun

From practical and emotional to bereavement support: how Family Support Worker Shelly continues to support a family in crisis.



In loving memory of Erhun

At Christmas in 2022 we shared two-year-old Erhun's story and his family's struggle with the rising cost of living. Erhun had a complex condition which meant he needed 24/7 oxygen therapy and constant care.

Family Support Worker Shelly began giving practical and emotional support to the family in January 2021. She regularly provided transport, driving Erhun, Rosemary, his mum, and Owen, his now five-year-old sister, from Middlesbrough to Newcastle for hospital appointments and for overnight stays at a hospice.

Travel was an impossible expense for Rosemary, a single parent who was unable to work due to Erhun's condition, his needs and his young age. Shelly's support eased costs and stress, ensuring Erhun did not miss essential treatments.

Shelly further alleviated this stress by dropping off and picking up Owen from school. Often Shelly and Owen would stop off at the park, giving Owen time to play and have one-to-one support.

Shelly also sat with the family in hospital to help look after Erhun and attended all the appointments to ensure Rosemary did not

miss any important information, supporting when there may be bad news.

This emotional and practical support was critical for Rosemary's family until January 2024, when the nature of support the family needed changed.

Sadly, Erhun died at just three-years-old of a cancerous tumour.

Erhun had been getting better, he was able to go to school and come off his oxygen therapy for a couple of hours a day. He loved this freedom, it made him smile and run around laughing.

However, at the end of last year Erhun was diagnosed with cancer. When it was discovered, the cancer was too advanced and far along that chemotherapy did not help. Rosemary had little time to prepare before Erhun died.

When a child dies all medical care and support stops and families are left completely alone. As there is no medical need any longer, the 'normal' for a family changes.

Family Support Workers like Shelly continue their support through bereavement, for as long as the family needs it. They are well placed to do this as they have



Shelly
Mar 7



Today I supported Rosemary and Owen at the cemetery, to celebrate what would have been Erhun's fourth birthday. It was the first birthday since he died.

We decorated his grave with glow sticks, windmills and birthday balloons, and Owen made her brother a very special unicorn garden and planted some seeds.

We celebrated by eating cake, singing songs, dancing and blowing bubbles.

I felt very honoured to be asked to be a part of it.

Happy birthday Erhun ❤️



Family Support Worker Shelly with Erhun and Owen



Family Support Worker Shelly with Erhun's sister Owen, taking Rosemary to college

supported the family through diagnosis, illness and death. Shelly has continued to provide weekly support for Rosemary and Owen as they grieve Erhun.

Shelly's support for Rosemary is tailored to her needs; whether it be getting Rosemary out of the house and into a different environment, or accompanying Rosemary when she visited Erhun's grave for the first time.

The death of a child is one of the hardest things a parent can experience.

Shelly's support gives Rosemary the chance to cry, share memories of Erhun, plan for the future and explore her grief with someone who understands and knows her situation.

For young children who have no experience of death, it can be very hard to process and understand the death of a brother or sister. Parents may struggle with helping their children to express their emotions when they are already feeling so much pain themselves.

Shelly helps Owen to learn coping mechanisms for her grief through play and by reading children's bereavement books. She gives Owen a space where she can talk about Erhun as much as she wants,

allowing Rosemary a chance to focus on her own emotions. Owen can ask any difficult questions she has about his death that Rosemary may struggle to answer.

Shelly's practical support has also been vital for Rosemary and Owen, especially around the time of Erhun's funeral. Shelly helped with funeral planning and arrangements and drove Rosemary and other family members to and from the funeral parlour to see Erhun, giving them the chance to focus on spending valuable time together and on their grief instead of worrying about practicalities.

During this incredibly hard time, Shelly's support has allowed Rosemary to focus on her bereavement while knowing that she is not alone. She has helped, and continues to help, Rosemary and Owen to adapt to their new circumstances as they learn how to build a life around their grief.

Rosemary now has a new job as a carer and has started a college course. Recently, Shelly drove her to and from the college to enrol in children's nursing and midwifery. During the journey, Shelly provided much-needed emotional and bereavement support. They spoke about Rosemary's plans for work and education, and her hopes for the future.

Shelly has also been providing more sibling support for Owen, taking her out, giving her the chance to play and discuss how she is feeling. These opportunities to chat about her feelings are crucial to ensuring that Owen's development does not fall behind.

Rainbow Trust's bereavement support is an essential aspect of support for the whole family. Family Support Workers are a stable presence, giving support for as long as it is needed.



Sponsor a Family Support Worker like Shelly today

The help of a Family Support Worker is tailored to each family's needs. They understand the family and know what they are going through. It is only thanks to your donations that we can give life-threatened children and their families this expert support. By sponsoring a Family Support Worker like Shelly today, you will be helping to ensure that no families have to cope alone.

rainbowtrust.org.uk/sponsor-us

Sponsor a Family Support Worker



BE INSPIRED

Last place finish, first place hero

After an incredible 32 years running the London Marathon for Rainbow Trust in memory of his daughter Claire, this year Fred crossed the finish line last in true champion style.

For 13 hours, Fred persevered, dedicated to raising awareness for a cause close to his heart. We are so grateful for Fred's continued support and dedication.

Wonderful supporters like Fred enable Rainbow Trust Family Support Workers to give families with a seriously ill child respite, ensuring that they do not have to cope alone.

If Fred has inspired you to join the Rainbow Trust community, visit rainbowtrust.org.uk/fundraise

Fred said:

“There was nothing like Rainbow Trust when my daughter Claire was ill. There are times where there's absolutely nowhere you can turn to and you need organisations like Rainbow Trust. I know I can pull out of a race at any time but seriously ill children and their families can't have a day off.”

1st
PLACE
HERO



JOIN THE RAINBOW TRUST COMMUNITY

There are many ways you can support and get involved: from marathons to skydives, a fundraiser in your local community or a sponsored challenge in your organisation. However you want to fundraise, we would love to welcome you.

Rainbow Trust Carol Concert

Thursday 5 December, Knightsbridge, London
Join us for a magical, candlelit evening hosted by Jane Garvey and celebrate the beginning of the festive season.

London Landmarks Half Marathon 2025

Sunday 6 April 2025, London
From cultural landmarks and heritage to the city's quirky and hidden secrets, runners get to explore the capital on a route like no other!

Manchester Marathon 2025

Sunday 27 April 2025, Manchester
Be part of one of the UK's premier running events, famous for its fast, flat and friendly route that is well-known for being welcoming to all abilities.

Great Rainbow Bake

Any time, any location
Hold a Great Rainbow Bake whenever and wherever. You can download lots of recipes, your fundraising pack and more by visiting our website: rainbowtrust.org.uk/bake

Sign up today at rainbowtrust.org.uk/events



Do something amazing today: fundraise at your special occasion

If you have a special occasion coming up, such as a wedding, anniversary, baby shower or birthday, make your celebration even more special by fundraising to give a family with a seriously ill child precious time together.



Scan the QR code or go to rainbowtrust.org.uk/special-occasion to make a difference on your special day.

Thank you!

to all our amazing supporters and fundraisers



Amelia, Luna and Livvie raised £1,000 by cycling 13 miles between their home and their grandparents' house.



Victoria and her children, Nansi and Elsi, took on the Guildford Inflatable 5km challenge in their colourful rainbow hair, raising £250.



Leweston School in Dorset have raised £6,400 over the academic year. They ended the year of fundraising with a 24-hour sportathlon and a colour run.



A team of six from **PhenoX Textiles** in West Yorkshire ran for Rainbow Trust in the London Marathon, raising over £19,000.



Through rain or shine, over the past few months 15 **Cubitt & West** branches have taken part in a sponsored cycle, raising over £6,000. A great team effort!



Polly took on the Jurassic Coast Ultra Challenge, walking 100km non-stop for 30 hours, raising £2,700.



After self-proclaiming that he didn't have the fitness to do a marathon or the baking skills for a cake sale, **Liam** from Manchester opted to shave off his locks, raising over £1,000.



Godfrey (right) and his friend Paul took on the Bath to Bournemouth off road challenge, approximately 90 miles of cycling.

Godfrey's family was supported by Rainbow Trust and he has been fundraising in many ways over the years.

Godfrey says: "Rainbow Trust is an amazing charity and has been a massive part of our lives. Having a seriously ill child is not what any parent dreams of and Nikki, our Rainbow Trust Family Support Worker, has always been there to support us when we need it; from school pick-ups to hospital visits or just keeping us all smiling".



On the longest day of the year, a team from **Samsic UK** took on the Yorkshire Three Peaks Challenge, raising £3,000.



Matt welcomed his daughter the day before he ran the London Marathon for Rainbow Trust. Despite limited sleep, Matt powered through the marathon, raising a fantastic £6,037.

A WEEK IN THE LIFE OF FAMILY SUPPORT WORKER JOANNE

When my 16-year-old son was diagnosed with cancer my world was rocked. I will never forget hearing the diagnosis, the shock, fear, numbness and terror.

It is at times like this that you need people who understand what you are going through and really care.

After my son recovered, I began to work at Rainbow Trust in the North East Care team. It is the most humbling job and I absolutely love it.



MONDAY

SIBLING SUPPORT AND CREATING FRIENDSHIPS

In the morning I collected 11-year-old Sienna, who has a serious blood condition, and Julie, her mum, from their home and dropped them at the Great North Children's Hospital for an appointment. Sienna had a bone marrow transplant in April and has to go to hospital regularly for check ups.

I then took Sienna's twin sister, Sophia, and their 13-year-old sister, Summer, with me to pick up eight-year-old Brooke, whose sister Summer Louise died from leukaemia last year, and six-year-old Nancy, who is affected by her brother Paddy's rare genetic condition.

We went to Mister Twister's, a local soft play and trampoline park close to Newcastle. The children had never met before but they all had a fabulous time playing and making new friends. Days out like this help siblings of seriously ill children to create support networks and to meet children in similar situations. On the way back, the car was filled with laughter, singing and promises to keep in touch. Result!

TUESDAY

A JAM-PACKED DAY OF SUPPORT

I had an early start as 12-month-old Iris had a neurology appointment at hospital. I took her two-year-old sister, Ellie, to the local park for a fun play session, allowing Iris' parents to focus on the appointment.

After that, I visited Maya. Maya's only son, Henry, had neuroblastoma and died just before his third birthday. Maya and I talked about Henry and the impact of his life and death. Sharing memories brings her comfort. We then spent some time sorting out Henry's grave, finishing off the inscription for the headstone and applying for funds to help pay for it.

Afterwards, we went to the cemetery to spend time at his grave where Maya feels closer to him.

I headed back to the Great North Children's Hospital in Newcastle for the parent support group I host every Thursday. It is open to all parents and carers of children on the ward, not just families that we support. The group is a space for parents to listen, chat, laugh, cry and support each other.

I then visited nine-year-old Goodluck, who has the same life-limiting genetic disorder as Favour, his older brother. Today I took Goodluck out for some time to himself to play his favourite game, Sonic the Hedgehog. We parked in a multi storey car park and went in a glass lift, both of which Goodluck had never been in before. He thought it was amazing! I have provided the family with a variety of support, such as helping with their application for an Education, Health and Care Plan which will give Goodluck access to an education that meets his needs.

WEDNESDAY

TEAM MEETING AND EMERGENCY DELIVERIES

We have our team meetings on Wednesdays. We catch up, ask for advice, discuss upcoming training, have wellbeing sessions, and pair newly referred families with Family Support Workers. We also share news and family updates, supporting each other when needed.

After the meeting I went to a local community food bank to pick up some food, personal hygiene and household cleaning parcels for families.



Goodluck enjoying some time at the beach with Family Support Worker Joanne



Siblings of seriously ill children creating new friendships



Daniel on the way to nursery

The cost-of-living crisis is having a huge impact on many of the families we support. They face additional costs for food, travel, and bills and many struggle financially.

In the afternoon, I had planned to do some admin but I received an emergency call from a parent who was running very low on medication and wasn't able to get it. I collected it from the hospital and took it to the family's house. The flexible support we offer means that families know they have help whenever they need it.

THURSDAY A FUN-FILLED OUTING

Today we had a team outing to Newcastle Foundation, a sports and community centre in Newcastle who kindly let us use their facilities for free.

After picking up four children I support, we met up at the centre with the other Family Support Workers and some of the families they support.

We have these meet-ups regularly and they are great for forming friendships; the children are always happy to see each other. A great time was had by all and many meaningful memories made!

After dropping off the children, I did some admin before logging off to enjoy dinner with my family.

FRIDAY NOISY NURSERY SUPPORT

On Friday I visited 21-month-old Daniel who was born with a serious heart condition, hyperplastic left heart syndrome, and spent the first year of his life in Freeman Hospital where he underwent various heart surgeries. He and Dan, his dad, had to relocate to Newcastle to be closer to the hospital, leaving their support network of family and friends behind.

Previously I had helped Dan to find a great local nursery nearby so today I took Daniel to the nursery and supported him during his 'settling in' session. We focused on mobility and speech - it was quite noisy but Daniel is making good progress. He has a great sense of humour so we laughed a lot. This time that we are at nursery gives Dan much-needed rest and a couple of hours to himself.

To end the working week, I had a non-managerial supervision session with a trained, independent counsellor. We meet every month and she helps me to process what has been happening and understand my feelings.

WEEKEND FAMILY TIME

My two granddaughters came to stay - I cherish every minute that I spend with them. My family means the world to me and I never take a thing for granted.

→ Sponsor a Family Support Worker like Joanne today

For families caring for a child with a life-limiting illness, life is turned upside down due to the many hours spent in hospital, constant care required and long drives to appointments. Family Support Workers help to ease stress and worry by providing tailored practical and emotional support, allowing families to spend meaningful time together and create long-lasting memories.

rainbowtrust.org.uk/sponsor-us

Sponsor a Family Support Worker



How YOUR support helps change lives



↑ Family Support Manager Natalie went with Jesse, five, and his family to a local fire station in Hampshire. Jesse, who has a heart condition, had fun playing in the water and being the boss.



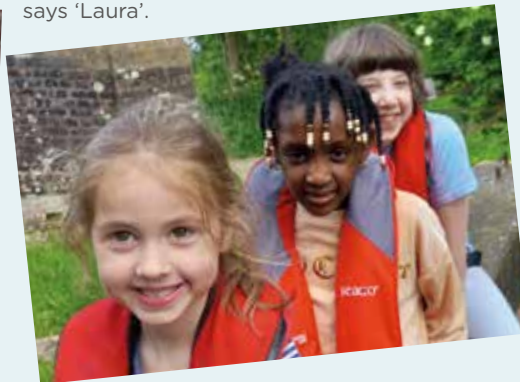
↑ Family Support Worker Laura has been learning to sign-along so she can help two-year-old Finley to practice his communication. Finley has lymphangioma. He now vocalises and says 'Laura'.



↑ Thank you to Voices of Virtue Gospel Choir, who held a fundraising concert and invited families supported by Rainbow Trust. Attending were Rosemary and Owen, whose story you can read about on pages 6 and 7.



↑ Tommy, three, has a neuroblastoma tumour and struggles with anxiety at nursery after spending so much time off due to treatments. Family Support Worker Emma spends time with him and helps with his confidence.



↑ Thanks to Alpkit and Bruce Boats, families supported by the Thames Valley Care team had a very special day out on a fully accessible canal boat.



↑ Family Support Worker Adam played games and read with two-year-old twins Oliver and Theo, allowing their parents to be in hospital with Olivia, their five-year-old sister who has acute lymphoblastic leukaemia.



← Gabi, aged four, and Family Support Worker Cindy spent a sunny morning at the park, giving Gabi a chance to have some time just for her. Gabi's brother Ezra, three, has achondroplasia, a genetic bone growth condition.

→ After collecting Gabbi, seven, from school, Family Support Worker Anna took her to a cafe, giving her some time where the focus was just on her. Adriel, Gabbi's two-year-old sister, has complex health needs.



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up to
£25,000

RAINBOW TRUST
SUPPORTING FAMILIES WITH A SERIOUSLY ILL CHILD

18+

while supporting families with a seriously ill child

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