

OUR IMPACT 2022/23

**RAINBOW
TRUST**

SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD



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WITH A SERIOUSLY ILL CHILD



Zillah Bingley, Chief Executive, and
Mark Cunningham, Chairman

Dear supporters and friends,

We are delighted to share with you the profound difference Rainbow Trust Children's Charity has made to the lives of children and families facing the unimaginable situation of a life-threatening condition. The challenges that lie ahead are significant, but we will meet them with the same unwavering resolve that has defined our organisation for nearly 38 years.

Our mission remains steadfast: to provide practical and emotional support when it is needed most and for as long as it is needed.

In the last year, we opened two new care teams in Reading and Liverpool and we will continue to expand staffing across the teams to meet the needs of families in these areas. We have also joined forces to create the Kentown Children's Palliative Care Programme, based in the North West of England.

We want to extend our deepest gratitude to each and every one of you who has played a part in our progress. Whether you are a supporter, volunteer or staff member, your contribution is essential. It is because of your compassion, dedication, and commitment that we can continue to make a meaningful difference in the lives of life-threatened children and their families.

Thank you for being an integral part of the Rainbow Trust network. Together, we are changing lives and creating a brighter, more hopeful future for those families who need it most.

Zillah & Mark

The difference we made

OUR WORK IN NUMBERS

1,185

Families
received
support

582

Newly
referred
families

1,173

Hours of online
family support

3,876

Hours of
sibling support

3,622

Hours of support
for the sick child

1,467

Hours of
telephone
support

5,350

Hours of
text message
support

2,464

Hours of
hospital
support

1,608

Hours of
neonatal
support

569

Hours of
bereavement
support



Our work is far-reaching, beyond just numbers on a page and it has only been possible thanks to the generous support of so many. Thank you.

What we do and why it's important

When a child has a life-threatening or terminal illness, family life is turned upside down and families face unprecedented challenges.

Rainbow Trust Family Support Workers are paired with a family, supporting them with practical and emotional help, whenever and wherever it's needed and for as long they need it, becoming a constant

in their ever-changing daily life. This tailored, expert and constant support enables families to make the most of their time together.

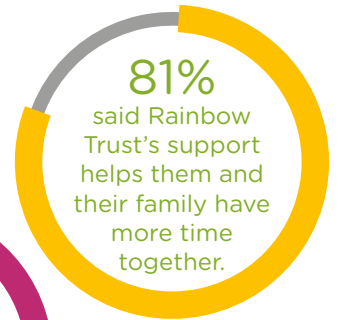
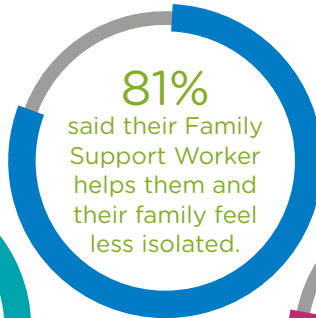
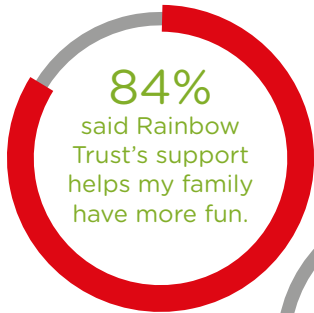
To us family means everything and we are determined that with your support no family will have to face these challenges alone.

“ If we ever need any help it's so comforting to know we can always ask our support worker. She has been amazing since the day we met her ”



We asked families we support what impact having a Rainbow Trust Family Support Worker has made to them.

“ My son has been left so vulnerable after his brain surgery following a cancer diagnosis, it helps that me and my family can have a bit of a break while he’s out with his Family Support Worker who I trust to look after him. ”



Percentages based on the responses of 100 parents/carers from our 2023 survey.

Supporting parents and their mental wellbeing

Caring for a seriously ill child is one of the most stressful experiences a parent can go through and it may last months or even years. You are faced with the challenge of caring for a seriously ill child, trying to keep your family together and maintaining your financial and mental wellbeing.

A Rainbow Trust Family Support Worker is a trusted person who helps families practically, for example with transport to hospital or supporting a sick child so parents can take a break. They also provide emotional support to help parents, siblings and family members as it can be hard to talk to friends and family about what is happening.

As the cost of living crisis continues families with a seriously ill child struggle disproportionately. They have higher energy bills as they run life-saving equipment at home and the cost of transport to hospitals continues to be a burden alongside rising mortgage, rent and food prices. Families are pushed to their limit. This year our Family Support Workers saw an increasing need from families who needed financial support. They helped by signposting families to grant making organisations and providing practical help to complete grant and government benefit applications.

Many families have told us that they have had to give up work to support their child and, alongside the obvious pressures this has, it is causing them to feel isolated and lonely. They can't afford to visit friends and families or have days out, to take a break from their normal everyday routines. The mental strain increases.



We supported
1,185
families, 5% more
than last year

Emily's story



Emily is 13 and has a neurological disorder that involves progressive weakness and reduced senses in the arms and legs. Emily also has severe scoliosis, an abnormal curvature of the spine. It causes Emily's internal organs to be squashed and she is in constant, excruciating pain. Emily's parents, Ben and Laura, have been told her scoliosis cannot be operated on and she could just stop breathing, there may not be a good outcome for her.

Emily has two siblings, Oliver, seven, and Caitlin, two. The family is supported by Family Support Worker Michelle from our Southampton team who provides the family with different things like sibling support, emotional support and help getting Emily to medical appointments.

“ *The support my family has received from Rainbow Trust is outstanding.*

My youngest daughter, Caitlin, sometimes finds it hard to leave me. Our Family Support Worker Michelle manages to distract her and keep her busy while I'm gone, she also picks my son up from school when I need to attend an appointment.

All my children love their time with Michelle; without her support things would be even more difficult than they already are.

Michelle is always very easy to talk to, and I now feel when things become difficult and I'm feeling alone I can always let my emotions out and talk about my feelings with her. She will sit and listen and will always have suggestions on how I can manage things.

As a parent with a child with a life limiting condition, in the past, I have felt very alone. Since having Michelle's support I no longer feel that way.

”

Helping siblings cope with having a seriously ill brother or sister

Having a brother or sister who is seriously ill can leave a sibling feeling alone and scared. Rainbow Trust's support for siblings enables children and young people to learn important coping mechanisms, find an outlet for their strong feelings and worries, keep up with their school work, and build a support network for themselves outside the home, before their needs escalate.

The consequences of a child not receiving support could be long-lasting, with an enduring emotional impact and possible negative consequences for their education and overall life chances. It is one of the most valued pieces of support that we provide to families, and it is available for as long as a family needs.

We provided

3,876

hours of support for siblings an increase of 27%, on the previous year

This year Rainbow Trust provided

70 sibling activity led days out and attended

142 different sibling support groups



Edith's story

Sarah and Jeff are parents to Edith, eight and three-year-old Bea.

Edith was diagnosed with Alexander disease at 18 months old, a degenerative disease that slowly reduces all your physical skills over time. They have had to adjust to a new way of living ever since.

Sarah got in touch with Rainbow Trust primarily for sibling support for Edith's sister, Bea, who was having a hard time dealing with her emotions. Family Support Worker Sammii, from our Reading team has supported the family since October 2022, providing sibling support for Bea but also helping Sarah take the girls out and have fun as a family.

“When Sammii is here it makes things a lot easier, to get out of the house. We still want to do so many things with the girls, and we want to make sure they have a rich and varied life, and lots of amazing experiences.”

Sarah's advice for families with a seriously ill child who are thinking about reaching out for support would be:

“Get in touch and be brave, it's really hard because by making that phone call you're admitting that you're at a point where you're really struggling. And admitting that there's something not quite working for you as a family and that you need help. Rainbow Trust has such a wealth of experience helping families in lots of different ways and everyone can benefit.”



Edith with her mum and dad and sister, Bea



Last year we supported 49 families through the death of their child

The death of a child is unimaginable, and life also changes forever. Life continues, but it will never be the same, not only for the parents, but also for siblings and other family members too.

Rainbow Trust is committed to supporting the whole family with personalised care for as long as it is needed. As the support we provide starts before a child dies, we are in a unique position of being able to support immediately and have already established relationships and made memories with the family.

Our support is both practical and emotional, helping to navigate arrangements that must be made. Our support to siblings is also vital, younger members of the family will experience grief in different ways and at different times. Having a Family Support Worker to talk to can help them to process and discuss their feelings which they may otherwise avoid through the worry of then upsetting their parents.

We provided

569 hours of
bereavement support
last year

Families we
support
rated our
bereavement
support as

9/10



Maddison's story

In April 2022 the McVety family's 16-year-old daughter Maddison died of a rare form of bone cancer, Osteosarcoma. The family has been supported by Rainbow Trust since Maddison's diagnosis in 2019 and continues to receive support from the charity.

Rainbow Trust Family Support Worker, Merissa from the Greater Manchester Care team started supporting the McVety family soon after Maddison's diagnosis when she was 13 years old. Merissa provided support to the whole family including practical and emotional support for Maddison's parents and in particular her younger siblings taking them on trips out and entertaining them at home with crafts and games.



Maddison (R) with her sisters, Izzy and Amelia

“ We are so grateful for the support we have received from our Rainbow Trust Family Support Worker Merissa, both during Maddison's treatment and now that we are coping with her loss. After Maddison died we lost contact with so many people. They didn't know what to do or what to say to us. People we knew would avoid us at the shops. Merissa understands and provides us with an outlet to talk.

Rainbow Trust, and Merissa, provided the support we needed at a time when we felt alone and abandoned, and they continue to do so. The whole family felt the warmth of Rainbow Trust's care - I cannot emphasise enough how amazing it is to have someone come to the house and ask how they can practically help you. We are so grateful the support will continue for as long as we need it. **”**

Maddison's dad Kevin McVety

Neonatal support

There are over 90,000 children born in the UK every year who require neonatal support.¹ When your child is born prematurely or needs additional support at birth the shock is enormous, both physically and emotionally.

Rainbow Trust is there to support parents during and after this time, we help with transport to and from hospital, we support parents on the neonatal wards by spending time with their baby when they can't be there, we help with siblings who are left at home. We are also there for the transition to home life, to support for as long a family needs us so they have the space to adjust to the shock of what they have been through.

We provided
1,608
hours last year of
neonatal support

54 families
were referred for
neonatal support
last year



Advocating for families

In 2023 Rainbow Trust successfully lobbied, alongside other organisations and with cross-party ministerial support, for the Neonatal Care (Leave and Pay) Bill to achieve royal assent.



This breakthrough piece of legislation will provide 12 weeks of financial support for these families, it means that they don't have to start their maternity or paternity leave immediately and are able to spend more precious time with their families.

¹ Bliss, *The National Charity for the Newborn*, 2024

James' story



James was born prematurely at 12 weeks. He weighed just 1lb 4oz, and spent the first four months of his life in John Radcliffe Hospital.

At three days old James had a bleed on his brain which resulted in fluid on the brain and various other complex conditions. He needs to be looked after 24 hours a day.

“ *Our world stopped when James was born. My husband Chris and I heard about Rainbow Trust through our Community Nurse and our Family Support Worker met James when he was eight months old.*

Rainbow Trust's support has been incredible and made our life easier. Our Family Support Worker provides play sessions for James and his sister, Bella, helping them to have fun. For Bella, monthly sessions have given her focused one-to-one time which is crucial because she has autism and finds it hard to build relationships with people. She has made Bella feel special and has been amazing at boosting her confidence and social skills.

Rainbow Trust makes you realise that you're not alone and that there are many other families who are in the same situation. The Family Support Workers can guide you to a more positive outcome in your life. ”



James with Danielle, his mum

Transforming children's palliative care

The Kentown Children's Palliative Care Programme launched in November 2022. It is a three-year pilot collaboration between Rainbow Trust Children's Charity, Together for Short Lives and the Kentown Wizard Foundation.

Bringing together nursing care, social care and information and awareness, it is designed to ease the impact on families caring for a seriously ill child by signposting them to services in their communities and supporting them to access these.

It is already evident that the partnership is having a significant impact and a two-year evaluation project, led by Edge Hill University, is currently underway to determine the extent of this impact on the families currently supported who are caring for a life-threatened or terminally ill child.



*Together for seriously ill children
and their families*

19 families
received support

“ *This collaborative approach enables us to reach and refer more families in need earlier. Accessing different strands of support quickly and easily helps to alleviate stress for families and has a positive impact on their mental health. We all work as one team.* ”

Angela, Family Support Worker for the Kentown Support team

Volunteering is the voice of the nation in action

This year volunteers supported Rainbow Trust by fundraising, supporting in our offices and directly with families.

- The number of hours our volunteers gave increased by **44%**
- In our 2023 survey volunteers gave us **4.5** out of 5 stars for a great volunteering experience
- **95%** would recommend volunteering with us to others.

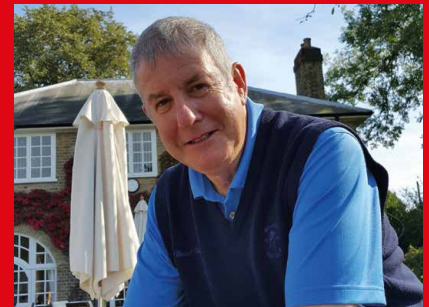
2,546

hours of volunteering support to help sick children and their families

We piloted some great volunteering opportunities for our corporate supporters and the return of drop-in groups meant that we successfully recruited new volunteers and welcomed many back. Support at our Surrey office continued to recover, and the return of many large-scale events saw event volunteering increase.

We improved the mechanism for volunteers to share their ideas and give feedback. We were also able to provide more opportunities for volunteers to meet each other including online training and, during Volunteers' Week, we ran an online celebration event for the first time.

"I feel I am valued, which is good and contributes to my satisfaction with the role."

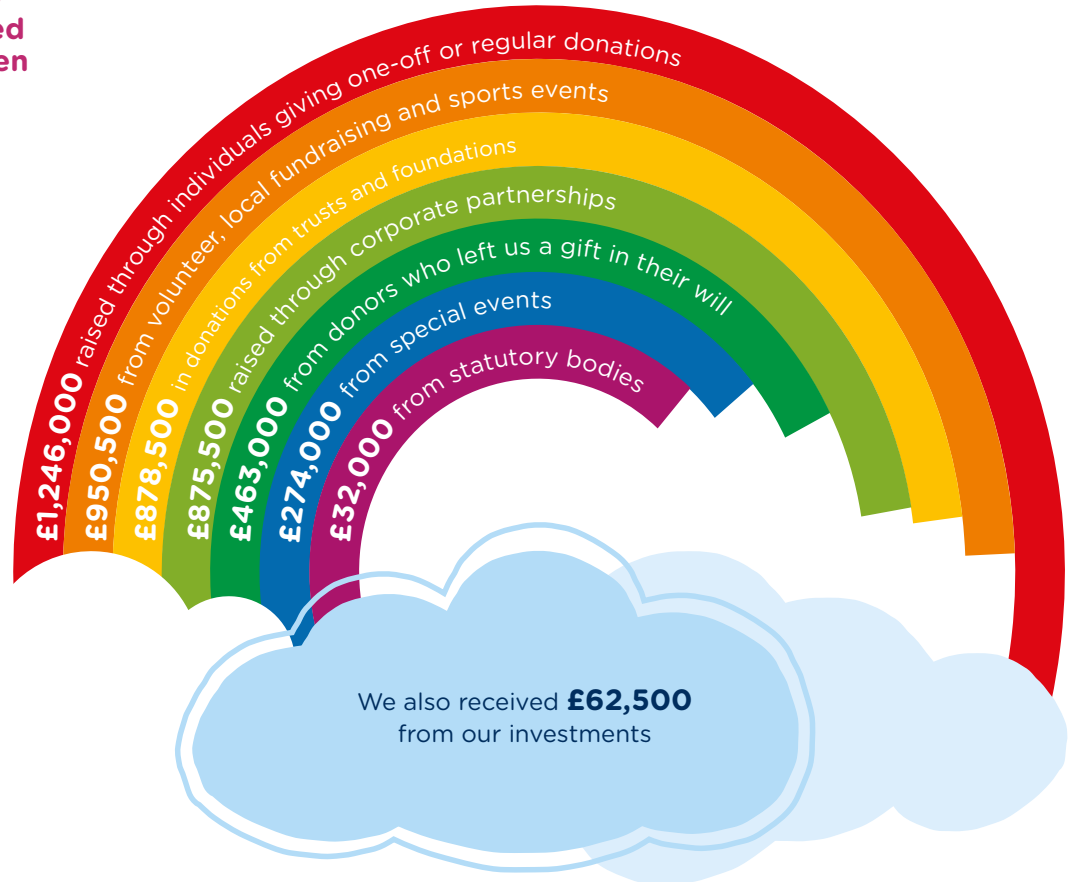


How you gave us your support

Last year, with thanks to your generosity we raised **£4.8m** to support children and families.

“ Our Family Support Worker has been my absolute rock. I would feel so lost without her. She has made such a big difference to our lives. ”

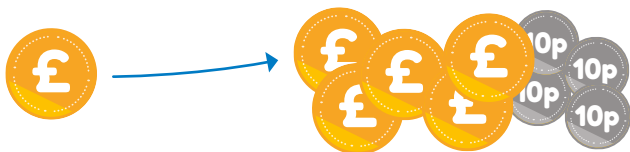
A mum supported by Rainbow Trust



How we spent the money you raised

We spend the money you give us with great care. We know how much thought, time and effort goes into the money that is so generously donated to us. We receive very little statutory funding, therefore fundraising and spending our money well is of the utmost importance.

Last year every pound we spent on fundraising, turned into £5.40



How much we spent on raising money

Donations and Legacies	£571,294
Fundraising events and commercial operations	£297,312
Acquiring new donors	£21,970

How we spent your money supporting children and families

Supporting the sick child (33%)	£ 1,105,091
Helping brothers and sisters (31%)	£ 1,029,117
Supporting parents (32%)	£ 1,055,467

Total **£3,189,675**

In the last financial year a combination of successful fundraising and lower than budgeted costs resulted in a surplus of £539,000. Total funds are now £5,045k of which £1,688k are general reserves, this level of general reserve represents four months of operating cost, the remaining funds are held for planned sustainability and growth. Overall, this is another very good financial result. We are mindful of the current economic climate and the vast uncertainty it brings which could have an impact on fundraising and operational costs over the next couple of years.

This is an overview of our income and expenditure in 2022/2023. This is summarised from our financial statements, which can be viewed on the Charity Commission's website.

Thank you to all our amazing supporters

There are so many to thank and so many stories to share, here are just a few of them.....



Rob Delaney published 'A Heart that Works', a moving memoir about the death of his son Henry aged two from a brain tumour. Thank you for helping to shine a light on the most traumatic experience that a parent can go through and the work we do.



Team Taylor Hughes (Paul, Guy, Ed, Dan and Tom) ran in memory of Charlotte, raising an amazing £19,664. Charlotte died of brain cancer at five months old, the family is supported by Rainbow Trust.



Thank you to everyone who didn't join us for our **No Ball Ball**, where staying in was the new going out!



Tristone Capital cycled from London to Paris, covering 309 miles over four days. The team of nine absolutely smashed their challenge, raising an incredible £19,491.



Thank you to **RBC Capital Markets** for inviting us to their 'Charity Day for the Kids'. It was amazing to share the impact of your support and how it reaches the families we support.



Thank you to **Carfest** for their continued support.



Taz and her friends took part in a Treetop Challenge in Essex. Their younger children also joined in by doing the lower-level Treetop Adventures too. Collectively the group raised an amazing £3,130.



Family Support Manager **Charlotte** and Family Support Worker **Ellen** received a wonderful £4,000 donation from **Kington Langley Scarecrow Festival**, who chose us as their charity of the year.



To celebrate the memory of our late Patron, **George Michael** on what would have been his 60th birthday, we released unseen archive images and footage of his support.



The team from **Investigo** completed the London to Paris bike ride, 340kms in three days. They raised over £15,000 - an amazing achievement.

Thank you

**Thank you
to everyone who
has supported us,
we couldn't do it
without you.**

So many people have made the work of Rainbow Trust possible. You have run marathons, skydived, disco danced, made donations online, sent cheques and donated at our events. You have volunteered in our offices, with our Care teams and at our events. Thank you.

Thank you also to the unwaveringly supportive of our trustees, celebrity ambassadors, event committee members and the Hampshire Friends. Your commitment to the families we support is immeasurable.

Trusts and foundations

Always Look On The Bright Side Of Life Charitable Trust
Barclay Foundation
BBC Children in Need
Community Foundation for Surrey
Community Foundation Tyne & Wear and Northumberland
County Durham Community Foundation
EBM Charitable Trust
Hospice UK
John James Bristol Foundation
Martin Charitable Trust
Masonic Charitable Foundation
Merlins Magic Wand Children's Charity
Oak Foundation
Surrey County Council
The Childwick Trust
The Eric Wright Charitable Trust
The February Foundation
The Ingram Trust
The James Tudor Foundation
The Kentown Wizard Foundation
The P F Charitable Trust
The Sir John Fisher Foundation
The Sterry Family Foundation
The Worshipful Company of Grocers
The Zochonis Charitable Trust

Organisations

Advent for Change
Almacantar
Bridewell
CarFest
Chessington Garden Centre
deVere Europe
Durham University
Charity Fashion Show
Filton Golf Club
FWD Consulting
Greenhalghs Craft Bakery
Hanover Search
Harbottle & Lewis LLP
Industrial Chemicals
K2 Corporate Mobility
Kennedys Law LLP
Ling Design Limited
Macfarlanes LLP
Maplestones Solicitors
Michael Josephson MBE
Charity Ball
Natta
RBC Capital Markets
Samsic UK
Simplyhealth
Specsavers Leatherhead
Sportfit Support Services
Sporting Bears Motor Club
St James Group
Taylor Wimpey
The I Love Claims
Community
TNV Construction Ltd
Topgolf
Tracks Publishing Ltd
Tyrrells Wood Golf Club

Looking forward, our plans for the coming year.

- 1 Ensure families have support when and where they need it
- 2 Develop and deepen our partnerships to coordinate care and expertise
- 3 To drive change for families through influencing policy
- 4 Inspire more people to support seriously ill children and their families
- 5 Use technology to grow and better understand our supporter base
- 6 Grow and manage our talent
- 7 Develop a culture of volunteering across the organisation.



“ We have an ambitious set of targets for the coming year, the achievement of which will allow us to not only meet the current needs of families we are supporting but expand our reach to help more families in these communities. ”

Zillah Bingley, Chief Executive Rainbow Trust

Thank you all the wonderful children and families who inspire us every day.

Thank you for sharing your stories with us so we can show our supporters what a difference they are helping to make and how much fun you have too.



Musa is five years old and has a brain tumour. Family Support Worker Monica took Musa and his siblings, Eisa and Nooriya, for some fun at soft play.



Niran and Family Support Worker Sammii had fun pumpkin picking while his parents were with his sister, Norah, who was receiving treatment at the hospital. Norah is five and has Metastatic Neuroblastoma.



Masud from Manchester who was diagnosed with a brain tumour when he was just 5 years old was thrilled to be BBC Children in Need with his Family Support Worker Merissa.



Ollie, five-years-old, has an immune deficiency condition. Family Support Worker Jen, visited him to play games while mum took a break.



Amelia, two-years-old, was born with a complex cardiac condition and was in hospital for several months from birth. Time with Family Support Worker Monica gives Amelia's parents some respite.



Alice, six-years-old has Neuroblastoma and was receiving her immunisation therapy. Family Support Worker Michelle played with Alice to give mum some time to grab lunch and feed Alice's brother, Oscar.



Gabi had lots of fun at the local park with Family Support Worker Cindy while mum and dad spent some special time with Gabi's younger brother Ezra in hospital.



Ten-year-old twins, **Dakota** and **Ocean**, had a fun day going ice skating with Family Support Worker Georgia. Their nephew Freddie, who they live with, was born with Chronic Lung Disease.



Charlie, five-years-old has a heart murmur and often has long stays in hospital. Family Support Worker Jaimie, takes Charlie out for fun activities for him to enjoy and to give his parents some respite.



Sophia was supported by Family Support Worker Jen in hospital while she was waiting for a bone marrow transplant and having chemotherapy.

Gene, 13 years old, created a beautiful masterpiece with Family Support Manager Charlotte. Gene has Kidney Failure and wanted to paint the heart to show how Rainbow Trust have healed his family.



“ *Having someone to talk to and rely on has made such a difference. I was unsure about having another person involved, but now I’m so glad I went ahead with the support. It’s like having that professional friend that you can always call on. Nothing is too big or too small.* ”

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**RAINBOW
TRUST**

**SUPPORTING FAMILIES
WITH A SERIOUSLY ILL CHILD**



Registered with
**FUNDRAISING
REGULATOR**

Registered Charity No. 1070532