



## IT'S ABOUT TIME

Helping families cope in their own way and in their own time

## OUR IMPACT 2018/19

**RAINBOW  
TRUST**

SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD



Zillah Bingley, CEO, and Mark Cunningham, Chairman

Rainbow Trust provides expert Family Support Workers to families who have a child with a life-threatening or terminal illness. When serious illness affects a child, family life is turned upside down, and time becomes more precious than ever.

Rainbow Trust pairs each family with a dedicated Family Support Worker who becomes a trusted and constant person in family life, providing practical and emotional support. This support helps families to face, and make the most of, each new day.

# WELCOME

to our impact report which showcases highlights from across 2018/19. It shows the impact our service has on thousands of families' lives and celebrates the generous and tireless contributions of our supporters and volunteers.

**We were proud to support 727 new families.** The number of new families who turn to Rainbow Trust is increasing, demonstrating the growing need for and awareness of our high-quality trusted service. Through continued effective management of family caseloads and the increased number of hours volunteers spent supporting families alongside our Family Support Workers, we were able to prioritise those in greatest need.

**Our campaigning and policy work was extensive.** We launched a comprehensive report *See us, Hear us, Notice us* about the importance of supporting siblings of seriously ill children.

**With the help of our generous supporters,** we have given more families at breaking point more time to cope, raising £4.6m across the year.

**We retained our position** in The Sunday Times Top 100 Best Not-For-Profit Organisations to Work For in the UK, reflecting the continued importance of our people to our strategy and their pride in, and passion for, the services we deliver.

**Thanks to our 375 volunteers** and their vast contribution to our care, fundraising, engagement, and support services, we saw a 15% increase in volunteer hours directly supporting families

# 2018/19 HIGHLIGHTS

**727** new families supported

**520** cases closed once families felt better able to cope

over  
**2,500**  
families  
supported  
in total

99% of families rated the service as **good** or **excellent**  
**99%**

**15%** increase in  
volunteer hours directly  
supporting families

Policy report  
published

See us,  
Hear us,  
Notice us



The families we support are facing their worst fear, the possibility that their child might die before them. The dreams and plans they had for their child's future are put on hold or lost altogether depending on the diagnosis.

From that first diagnosis, the parents we support start grieving – grieving for the future their child might not have and for the life that they had planned.

With Rainbow Trust's support, parents and children adapt to the new normal that their lives become. The new normal of hospital appointments, treatment, overnight stays away from home and often, for many families, being apart as their child goes through life-saving treatment.

We've helped parents have time with their healthy children while a Family Support Worker sits with the sick child in hospital. We've helped families share fun days out together, safe in the knowledge that they have the support they need around them. We've helped siblings find some fun again, laugh and smile having people around who truly understand them. We've also helped prepare families for the worst day of their life, the death of their child.

From a parent:

“With childhood cancer you get a lot of support, everybody wants to throw toys and presents at you, which is amazing, but Rainbow Trust has honestly been the charity that has made the most difference to our lives.”

Laura, Anna's mum.

From a Social Care Professional:

“It is so important that families have independent support from Rainbow Trust, someone that is not a health professional, a social worker or educational professional. Parents have given us direct feedback that the support has been incredibly important to the whole family. It is personal and bespoke support to that family. Rainbow Trust never say never, and this is incredibly important to these families at times of financial cutbacks and restraints.”

A Social Care Professional.

# Putting families at the centre of their care

It's so important for families to have control over the services we provide and that we empower them to make positive and sustainable changes to try and allow their lives to feel less chaotic and uncontrollable.

Every family we support is different, their needs constantly change and we strive to support them through all these changes.

To improve our ability to meet each individual family's needs, we have devised a new way to measure the impact of our services on a family's life.

Our **North East team** is trialling a new 'family-centred' approach focusing on the needs of each family member. Outcomes are developed by families themselves, with the help of Rainbow Trust Family Support Workers. We involve the whole family – including children – in planning their support. This gives families more control over the support we provide and makes it more personal.

If successful, we will roll out the new family-centred plans nationally in 2020.



North East based Family Support Worker, Shelly, reads to eight-year-old Thomas who had leukaemia

# Don't forget siblings - See us, hear us, notice us

**Siblings of seriously ill children can feel lost and abandoned when their parents are in the hospital with their sick brother or sister. They often need to be looked after by other family members and friends.**

With Rainbow Trust's support, siblings get the support they need when they need it. This support can enable 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 and prevent their concerns from escalating.

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.

In December 2018 we published findings on the negative impact that having a seriously ill sibling can have on a child in *See Us, Hear Us, Notice Us*. The report sets out why brothers and sisters need support alongside their sick siblings and how Rainbow Trust can help. It received coverage on the BBC news and brought their, often overlooked, needs to the attention of government ministers and MPs. Read our report at [rainbowtrust.org.uk/seeushearus](https://rainbowtrust.org.uk/seeushearus)

This year the **North West team** ran 18 sibling group days and five youth groups for children across the Greater Manchester and Lancaster areas. By bringing children in similar situations together, these groups help reduce feelings of isolation and children tell us that being with others who just 'get it' makes them feel more normal. Many strong friendships have been forged in these groups.



[rainbowtrust.org.uk/seeushearus](https://rainbowtrust.org.uk/seeushearus)



Janet, Family Support Worker, with Ava and Daisy

# Understanding makes a huge difference

Having a seriously ill child can be very isolating for parents who often tell us that their friends and family don't understand what they are dealing with. Several have lost friends as a result of their child's illness. For many parents, leaving the house with a sick child can be extremely difficult with all the medical equipment they might need in order to survive.

To tackle these feelings of loneliness and isolation, we run support groups where parents can talk to other parents who understand what they are going through. These groups have allowed parents to get out of the house regularly, make friends, develop their own support networks and improve their emotional wellbeing.

In November 2018, the **Essex team** launched the Button Tea group which is open to all parents and their pre-school children. The group provides an intimate space to share their fears, feelings and concerns. One mum opened up immediately, feeling so comfortable in the group, to share how she felt that she wasn't coping.



*The Button Tea group is making memories and sharing their lives with people who truly understand what they are going through*

# Helping young people's mental health

Living with a serious illness can have a powerful and detrimental effect on a child or young person's mental health. The sick child can often feel isolated from their peers as they spend so much time in hospital and frequently miss months of school. Young people often tell us their friends don't know what to say so eventually they don't say anything at all. Friendship circles diminish, and children are left feeling lost and 'different' to their peers.

The changes that children go through during treatment can also make many feel self-conscious and not want their friends to see them, which exacerbates that feeling of isolation.

One of the ways we support these young people is with days out to the park or cinema to help take their minds off the bad things. Having an adult they can talk to, who understands what they are going through, and who doesn't judge them, makes a real difference to these seriously ill young people.

Twelve-year-old Evie relapsed with Hodgkin Lymphoma and now has to use a wheelchair to get around. Ema, her Family Support Worker from our [West London team](#), visits and takes her out of the house which gives her a break from being at home all the time. It's also a distraction from coping with her illness. These outings provide Evie with the space to talk about how she's feeling mentally and physically. "We sometimes go into a coffee shop for a drink and to just generally chat and I always have a good time," says Evie. Without Ema, Evie would be stuck at home, and not able to get out and do what 12-year-old girls want to do.

Our support can help children like Evie, improve their quality of life by keeping them connected with the outside world.



*Evie in hospital during treatment*

# There for as long as needed

No parent should ever outlive their child, but the sad reality is that some do and Rainbow Trust is there to support the family for as long as needed through illness and bereavement.

Our Family Support Workers receive specialist bereavement support training so they can help the family prepare for the death of their child, support them with funeral arrangements and be there for the family afterwards as they cope with their grief.

Fiona, one of our Advanced Practitioners in our **Central London team**, recently supported a family whose child, Henry, was at end of life. Henry's parents spent

time asking Fiona all the questions they had about what was to come. This helped prepare them for the unknown and helped them support their other children to prepare for the death of their baby brother. Fiona spent time with the siblings too, helping them create memories that would always be special to them. With Fiona's support, the family was able to spend time together as they faced the worst time of their life.



*Billie supports Kira and Mika, siblings of Kareena who has cancer*

# More quality time for families

Families tell us that they are stuck at home for long periods of time. During treatment, some children may be unable to leave the house except for hospital visits because they have low immunity and are more likely to develop infections that can be life-threatening. This often means that siblings have to stay at home too as there is no one to take them out. Some families say they just find it too difficult to go out with the medical equipment that they need to care for their child.

Rainbow Trust teams run activities during the school holidays, providing transport where needed to ensure that children and parents can get out, meet others and spend quality time.

Last year the **Surrey team** took families out on eight 'fun days' to give them the chance to do something fun together. Parents have so much to do caring for their sick child that planning fun days out for the family is often not a priority.

In February 2019, the team hosted a very popular day out at Bocketts Farm in Surrey for 22 families.

They all enjoyed meeting other families who understood the challenges they were facing and parents could chat while their children were either racing about and having fun or being cared for by our Family Support Workers.

Quality time is precious when that time may be limited so Family Support Workers ensure that families can focus on what's really important.



*Sophie, who is in remission from leukemia with big sister Chloe and Sabrina, their Family Support Worker*

# 30% increase in support for premature babies

In the UK today, one in eight babies born requires neonatal support. With medical advances, many more neonatal babies are surviving beyond the first week of birth, although often have long-term illnesses, which means that families are requiring longer term support.

Parents are often unprepared and shocked by having a seriously ill baby. Mothers may still need medical care and families need help caring for siblings who may not be allowed on the ward. Having Rainbow Trust's support means that they can focus on being with their baby at such a crucial time.

Our **Southampton team** supported 29 families with a premature baby who needed extra care. In response to this demand, we established a new Neonatal Support Worker post in the team. Support provided can be different to our more general work as families need urgent, intensive support over a shorter period before being discharged.

*The right side of Hope's heart is severely deformed and she spent five weeks in hospital when she was born*



# More volunteers, more families helped

90 Rainbow Trust volunteers provided direct support to families last year, 33% more than the previous year. Volunteers support families in different ways depending on their skills, experience and interests. This includes practical support such as helping with housework or gardening and they also provide emotional support to families who are struggling to cope. With more volunteers, we can provide more hours of support to more families in need.

Through our volunteer project in the **South West**, we have increased the number of families in Bristol who are supported by a volunteer and a Family Support Worker. This means we can offer more support at peak times when Family Support Workers may be unable to meet high demand, for example after school. These volunteers can also allow us to support families who would otherwise miss out. Fourteen new volunteers have been trained and are now providing direct support to families both in Bristol Children's Hospital and in their homes.

Sarah is a Family Support Volunteer and has been supporting a family with a boy with complex needs who required 24/7 care. Sadly, the boy died, and Sarah has continued to support the family. *"Sarah and Rainbow Trust have been a huge support when there has been very little anywhere else. Nothing ever seems to faze her - her help, kindness and support have been invaluable and we can't thank her enough,"* said a bereaved foster mum.



Jade enjoys ice cream on a fun day out with Rainbow Trust away from her hospital bed

# Looking forward



In 2019 we launched our new strategy, through the *It's About Time* campaign. The strategic aim is to meet increasing demand from families in crisis and raise at least **£25 million over the next five years to do this.**

In the last decade family referrals to Rainbow Trust have doubled. Rainbow Trust is there for parents who are trying to come to terms with a devastating diagnosis. We enable time for a parent to have a desperately needed respite break while we help care for their seriously ill child. We make time for the brothers and sisters to help them feel less frightened and isolated.

We give time to parents to do the things they used to love, before family life was turned upside down. In short, every hour of our support helps families to cope.

In 2020 we will be focussing on

- Reaching more families and developing our service
- Increasing awareness, influence and reputation
- Developing funding opportunities
- Developing technology and improving data and systems to drive fundraising growth
- Developing our people.

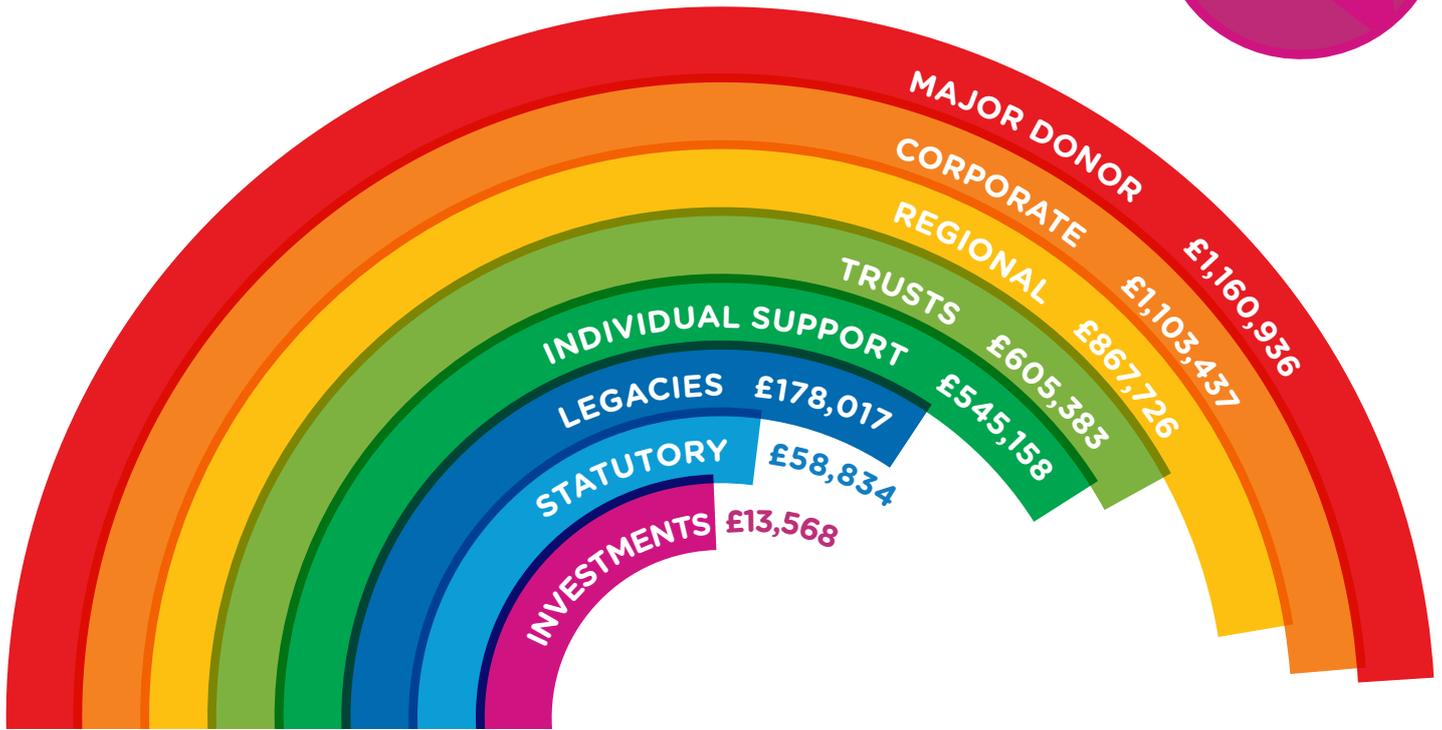
For families with a seriously ill child, *It's About Time*: time together, time apart, time to themselves. And *It's About Time* that we were able to support every family who needs us.

With the help of our generous supporters, we will help give more families at breaking point more time to cope.

Find out more and get involved in the campaign [rainbowtrust.org.uk/itsabouttime](https://rainbowtrust.org.uk/itsabouttime)

# How we raised our money in 2018/19

TOTAL  
INCOME  
**£4.6**  
million



# INCOME AND EXPENDITURE

## Summarised accounts

For the year ended 30 June 2019

<b>Income</b>	<b>2018/2019</b>	<b>2017/2018</b>
Donations and legacies	£3,007,208	£2,944,947
Fundraising events and commercial activities	£1,548,026	£1,550,773
Statutory income	£58,834	£112,101
Investment income	£13,502	£13,022
<b>TOTAL INCOME</b>	<b>£4,627,570</b>	<b>£4,620,843</b>
<b>Expenditure</b>	<b>2018/2019</b>	<b>2017/2018</b>
Carer and family support services	£3,237,118	£3,106,334
Fundraising costs:		
Grants and donations	£ 810,656	£ 835,460
Fundraising events	£474,088	£463,882
Commercial activities	£53,995	£60,495
Donor acquisition	£30,777	£32,798
<b>TOTAL EXPENDITURE</b>	<b>£4,606,634</b>	<b>£4,498,969</b>
<b>Net expenditure</b>	<b>£20,936</b>	<b>£121,874</b>

This is an overview of our income and expenditure in 2018/19 summarised from our financial statements, which can be viewed on the Charity Commission website : [gov.uk/government/organisations/charity-commission](http://gov.uk/government/organisations/charity-commission)

Registered Charity number 1070532.

# Hours of support

Support provided by 66 Family Support Workers across the regions

**5,930**

hours of parental support or respite



**1,945**

hours of transport



**5,210**

hours of hospital support



**8,990**

hours of home support



**5,157**

hours of support for siblings



Support provided by eight care teams across the regions





The Essex team ran **six** groups through the year for parents to meet each other and have some time for themselves



**94%** of children said they were happy at the end of their activity session



**98%** of children asked, always like Rainbow Trust visiting

“Our Family Support worker, Vilja, brought our family together. Without her, I don't think we would have fully overcome the situation.  
Ebony, 19-year-old sibling”

Volunteer Annabel helps Lucy at the Southampton team's sibling day out



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

“We can talk about what it's like for us, I'd feel more alone without the groups.”  
Jenny, Alex's thirteen-year-old sister

Kloe and Scarlett with Sarah, Family Support Worker. Their older brother has a brain tumour



“Without Shelly it would've been horrendous. She's given me time to spend with my other two boys who are so young. She's been a godsend!”  
Sue, Thomas' mum

Reed's School Colour Run, one of many of their fundraising efforts





After a Rainbow Trust visit, **85%** of children said they felt Rainbow Trust listened all of the time

“ Amanda visits me in hospital and makes it fun, she’s good company and isn’t my mum ”

Hope, a teenager supported by Rainbow Trust

Kieron was one of many runners supporting Rainbow Trust in challenge runs this year



We supported **50** families through bereavement last year, supporting them for as long as is needed

“ Helping families make memories with their child means they have a shared experience that they can all remember and one that the child will always be a part of. ”

Fiona, Rainbow Trust Advanced Practitioner

(L to R) Coby and little brother Asher, who has leukemia, and Kingston at a fun day out



Last year our teams ran **88** family and sibling days for the families we support

“ It’s so good for the children to have some fun when we are all so busy taking care of Henry. ”

Beccy, Henry and Thomas’ mum

Family Support Worker Billie plays with Charlie, whose brother died earlier this year





# 30%

increase in number of neonates we supported

“ Rainbow Trust’s support is like coming out of deep water and being able to breathe again. I couldn’t do it without Rainbow Trust. ”

**Ella Mae, mum of twins who were born prematurely**

*Ella-Mae with twins, Bella and Ruby*



# 375

 volunteers provided 21,378 volunteer hours of support which is worth £175,513.38

(Based on the living wage)

“ Volunteers enable us to get through more work and concentrate on areas that otherwise would be harder to prioritise. ”

**A Rainbow Trust member of staff**

*Family Support Worker Charlotte with Anna, who had bone cancer*



Our care teams spent 8,990 hours with families in their home, helping both practically and emotionally

“ We don’t drive so getting to the Royal Marsden Hospital was very difficult. Billie drives us and stays with us. We tried taxis but that was £120 a week which we just can’t maintain. ”

**Luvvie, mum to Kareena, Kira and Mika**

*Eight-year-old Freya, who has a rare metabolic disorder, shares a cuddle with her mum Kelly*



# Thank you everyone!

**Last year you helped raise an amazing £4.6m to fund expert Family Support Workers who supported over 2,500 families (including 727 new families) across the country.**

Thank you for every hour of support and every pound you donated. Here are some of your highlights:

**CORPORATES** Andrew Reid and Partners, Jacobs Media, Kennedys Law LLP and Lynch Haulage all chose us as their charity partner. We were invited to be the beneficiary charity for a number of fantastic events, including the prestigious TP ICAP Charity Day and the Optix Conference 2019. I Love Claims supported us for the seventh consecutive year, bringing their fundraising total to over £700,000. Cubitt and West Estate Agents continued to be a huge support, with Jason Willetts of Arun Estates raising £6,000 through a London to Amsterdam Bike Ride. Knight Frank has continued their invaluable support, making two unexpected donations, on top of their fundraising efforts.

**VOLUNTEERS** Our amazing volunteers donated 21,378 hours of their time so that families we support could make the most of theirs. More than 375 volunteers gave their time in our shops, offices, out in the community, at our events and alongside our Family Support Workers.

**EVENTS** Our amazing supporters climbed, ran, jumped, cycled, walked and swam to raise an incredible £518,000. Our 44-strong London Marathon team raised over £148,000 and 49 brave individuals walked across hot coals at Fire Walk London raising over £16,000! Our loyal committees, friends and ambassadors joined us at our festive Carol Concert at

St Paul's in Knightsbridge. This, along with Trust in Fashion, Strictly Cricket and our Race Night event, meant the special events programme raised over £428,000.

**TRUSTS** We are grateful to all the trusts and foundations that generously supported our work including: ABF The Soldiers' Charity, The Ingram Trust, James Tudor Foundation, The 29th May 1961 Charitable Trust, The Linbury Trust, Oak Foundation, The Rank Foundation, The Sobell Foundation, The Taylor Family Foundation and The Zochonis Charitable Trust. BBC Children in Need and Layla's Trust continued to support a Family Support Worker in our North West team and a part time Family Support Worker on the Isle of Wight, respectively. Thanks to Anton Jurgens Charitable Trust, John Horniman's Children's Trust, June Margaret Pavyer Will Trust, The February Foundation, Ernest Kleinwort Charitable Trust, The Lawson Foundation, E C Graham Belford Charitable Settlement, The D'Oyly Carte Charitable Trust, The Hospital Saturday Fund, Gerald Palmer Eling Trust, The Provide Foundation which is managed by Essex Community Foundation, The 7Stars Foundation and Lord Barnby's Foundation.

**REGIONAL** We received a £25,000 donation from the Mayor of Havering and £20,000 from Moor Park Lions Club. Hanover Dairies and Chessington Garden Centre continued their support as did a number of schools and universities. The Harold Wood shop raised an amazing £68,500 for us.

**INDIVIDUALS** Thank you to all the Patrons and Trustees who supported us as well as regular givers and Friends' groups and committees who have helped us raise vital funds throughout the year.



SUPPORTING FAMILIES  
WITH A SERIOUSLY ILL CHILD

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[rainbowtrust.org.uk](https://rainbowtrust.org.uk)



**Special thanks to the children and families featured, who are, or have been, supported by Rainbow Trust.**

**Photography:** Drew Cox, Claudia Frost, Sarah Deane, Carole Pearson and Catherine Prior.

**Cover image:** Three-year-old Kareena who has Wilms Tumour and is supported by Rainbow Trust.

Registered Charity No. 1070532