

FAMILIES FIRST

AUTUMN/WINTER 2021

Inside:

Family Support Worker Mandy **helps Belle's family** face cancer

A week in the life of a Family Support Worker

Thank you to our **amazing volunteers**



RAINBOW TRUST

SUPPORTING FAMILIES WITH A SERIOUSLY ILL CHILD

Dear Supporter

Thanks to the generosity of organisations, volunteers and individuals like you, in the 12 months from July 2020, we were able to support 1,075 families with a life-threatening child.

The recent easing of restrictions has meant that some hospitals have opened up to social care professionals so Rainbow Trust Family Support Workers have been able to start helping families in hospitals again as well as at home. Our hybrid support model continues to evolve to suit individual family needs and we continue to deliver vital practical and emotional support face to face and virtually.

The easing of restrictions has also given more opportunities for supporters to come together to raise money at live events. Over the summer, we hosted a very successful race night at Windsor, a Surrey golf day and in September runners challenged themselves at the Great North Run in Newcastle. As we go to press we look forward to a successful London Marathon in October and our Carol Concert in December. I hope you can join us at one of these events.



Cover photo

Harry is 12 and has a life-limiting Mitochondrial disease called Leigh's Syndrome. Harry and his family have regular support from Family Support Worker Abi, in the Essex Team. Harry and his sisters Iris, nine, and Florence, eight, have recently fronted our #FindOurRainbow campaign.



In August, we surveyed the families we currently support and some told us that overall, because of the pandemic, they feel more worried, isolated and tired as services they would normally access are still in short supply. This highlights just how much Rainbow Trust's help is needed. The positive impact that family Support Workers have on families with a life-threatening child is immense and more important in these difficult times.

Thank you for your support. Together we can help families living with childhood illness in desperate need of support.

Best wishes

Zillah Bingley, CEO

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It's always a pleasure to see you.
It's so easy for me to talk with you.
I feel like you understand me very well.
♥ I have to thank you for being here for me. I appreciate everything you're doing for us. Can't wait to see you...

Maddie, Anthony's mum, supported by Rainbow Trust.

To many of us, family means everything. So when serious illness affects a child, and 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.

STAY IN TOUCH

Call us: 01372 363438

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Visit us: rainbowtrust.org.uk

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THANK YOU TO OUR AMAZING VOLUNTEERS

We are committed to integrating and enabling volunteer support across all areas of the organisation. Our wonderful volunteers help us reach more families with a seriously ill child and also to fundraise and raise awareness about our work.

However, the past months have been difficult for everybody. At the beginning of the pandemic we had to pause our volunteering programme and then we had to adapt how our dedicated volunteers work with us so, when possible, they could continue to help our care and fundraising teams.

The hours volunteers gave fell dramatically, and we know that many of their contributions in the past months have been limited. But whatever they have managed to do - from assisting the fundraising team working remotely, to driving families to and from hospital in full protective clothing - we are very grateful to the entire volunteer team, for all of their time, effort, and dedication.

We are also very proud of Rainbow Trust volunteers for their support, patience, and generosity. Our amazing volunteer team brings a wealth of knowledge and skills and their exceptional commitment to supporting families with a seriously ill child is invaluable to us and the families we support.

This is why we wanted to say a heartfelt **thank you** to the entire volunteer team.

"I was very honoured and privileged to be asked by one of the families I volunteer with to read a poem at their daughter's funeral - I think this is testimony of how we are valued, trusted and part of the family in difficult times."
Annabel, Family Support Volunteer



Volunteer Project in the South West Care Team

The Family Care Volunteer Project began in 2016 and has continued to build on its impact year on year. To supplement the work of Family Support Workers, the Volunteer Project Manager, Alex Green, based in the South West team, leads on the recruitment, training, placement and support of volunteers.



Family Support Volunteers may help provide emotional support, be by a seriously ill child's bedside to give their parents some respite, take siblings of life-threatened children to school, or help with transport to and from medical appointments.

This support has a positive impact on the whole family, including siblings, the ill child and their parents or carers. And in a recent evaluation, families rated their overall experience of volunteer support 8.7 out of 10.

Figures from July 2020 to June 2021

 **275** 
volunteers

 **87**
care volunteers

 **1,593**
hours given

To find out more about volunteering opportunities please go to rainbowtrust.org.uk/volunteer

AMY'S EXPERIENCE OF RAINBOW TRUST'S SUPPORT

Family Support Worker Brodie helps Amy and her family whilst Henry is on the neonatal ward and at home



Henry and Family Support Worker Brodie

Amy was referred to Rainbow Trust in January 2020 by the neonatal team at Burnley Hospital, while her son Henry, then four months old, was an inpatient, awaiting open-heart surgery.

During the pregnancy Henry was diagnosed with Down's syndrome, as well as a heart condition called atrioventricular septal defect and cardiac failure. All this was very worrying for Amy and she wasn't sure how she would cope with it.

When Amy started receiving support from Family Support Worker Brodie, she was staying at Parent's Accommodation near the hospital with her other son, George, who was two years old.

Being at Henry's side and caring for George was very difficult and immensely demanding. Amy felt very alone, isolated and she was struggling to cope.

Brodie supported the family at the hospital. She would sit with Amy at Henry's bedside offering emotional support, someone to talk to. She would take George out to play so Amy could spend time with Henry without worrying about entertaining and looking after George. Brodie would also sit with Henry so Amy could go and spend quality time with George.

This support meant Amy did not feel guilty about spending time with one of the boys and not the other; she knew each week that she would have that time, as well as someone to talk to. Amy really welcomed this help because it made her feel less isolated and

gave her respite from looking after and worrying about both boys.

When the pandemic hit in March 2020, visitors were no longer allowed in the hospital due to COVID-19 restrictions.

Unfortunately, this coincided with Henry's open-heart surgery.

Whilst Brodie was unable to go into the hospital, she continued giving Amy support. They would regularly speak on the phone, giving Amy that constant emotional support, someone to talk to, to discuss her concerns. Brodie was able to give her advice and reassure her when she needed it the most.

After a couple more months in hospital Henry was improving and the consultants discharged him. This was wonderful news for Amy: she was finally able to leave the Parent's Accommodation near the hospital and go home with her boys.

In November 2020 Amy felt that she no longer needed Brodie's support and they agreed to stop. Amy continued to get in touch with Brodie every so often when she needed advice. She said, "I've always felt that Rainbow Trust's help was the only support I could turn to. Family Support Worker Brodie was always happy to help."

Things changed in May this year, when Henry was admitted to Blackburn Hospital with serious breathing and chest problems. He now requires oxygen 24 hours a day. Knowing where to get the support she needed, Amy immediately contacted Rainbow Trust and Brodie started helping them again as they were struggling with many of the same issues as before.



Henry, very ill in hospital

"Having Brodie by my side has been transforming and such a relief. I don't know how I would've coped all alone."
Amy



Henry giving Amy a lovely kiss



Henry enjoying time with Family Support Worker Brodie

Due to ongoing restrictions, visitors were not allowed on the ward, except for medical or social care professionals, and Amy was again feeling isolated. This time she wasn't even able to see her eldest son, George.

Thankfully, as a professional, Brodie was able to give respite care on the ward and sit with Henry while Amy had a break and spent time with George. Brodie has also stayed with Henry to enable Amy to go home and get the house ready for their return.

Now that the family are back at home Henry still needs oxygen 24 hours a day. Brodie continues to support Amy's family, giving her respite and emotional support until Henry recovers.

Atrioventricular septal defect refers to a hole between the heart's chambers that creates problems with blood flow control. Extra blood flows to the lungs, forcing the heart to work too hard. The cause is not known and can be associated with children with Down's syndrome.



Henry with older brother George

We were extremely fortunate to receive an emergency grant from BBC Children in Need's Next Steps programme to ensure we could continue to provide urgent support to children in the North West during the pandemic. Rainbow Trust was so grateful to receive this important funding at a time when we were unable to run our normal fundraising events and activities, so that children got the support they needed at a very difficult time.

So far, the funding has enabled Family Support Workers Brodie and Merrissa to provide support to 81 children and their families across the North West, adapting this support to changing guidance and doing whatever each family needed to ensure that they did not lose this consistent support at a critical time.

In the last 12 months we received 95 new neonatal referrals and each month we had an average of 42 open cases. 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.

rainbowtrust.org.uk/donate-magazine

FAMILY SUPPORT WORKER MANDY HELPS BELLE'S FAMILY FACE CANCER

Belle's mum, Jemma, tells us about her difficult experience dealing with Belle's diagnosis

Belle was our rainbow baby^{}. She is our only girl and the youngest of five children. At the age of seven months Belle became incredibly irritable. She began to regress in her development and was continuously in and out of the doctors and hospital.*

At around 10 months old she began vomiting randomly and sleeping more. This continued over the next few months, gradually getting worse. Her head began to grow so much that she could only wear clothes that had buttons so the opening was wide enough for her head to get through. By 14 months Belle slept for 23 hours a day, only waking for pain relief and a bottle. Her development had ceased and her head tilted and drooped.

My husband, Lee, and I took Belle to our local hospital many times but we got no answers, despite the severity in her decline.

In a last attempt, desperate, we took Belle to Southampton General Hospital. She was so unwell on this admission that an MRI was ordered that night.

Lee and I were devastated to be told that our 14-month-old girl had a brain tumour that was now so large it occupied two thirds of her brain.

Belle immediately underwent seven hours of surgery, which saved her life. They were able to fully remove the tumour, but Lee and I were told she would never walk or talk as to get at the tumour they also had to remove a quarter of her brain. This was so painful to hear and we were devastated.

We didn't know that the hardest part was to come, though. Due to the high grading of Belle's tumour she required 14 months of intensive chemotherapy.

This was worse than all that we had endured already, which probably says a lot. During this time Belle was seriously unwell and it was heart-breaking to witness.

At this point we were referred to Rainbow Trust for support. Our Family Support Worker Mandy has been wonderful. It was a huge relief for me to have Mandy's support, to know that we all have someone to openly talk to.

Mandy was also able to come to hospital and give me and Lee emotional support while Belle was admitted. This was incredibly helpful. Mandy quickly became a huge part of our lives and is always compassionate to our needs. There have been so many ups and downs during our cancer journey and Mandy has been there throughout.

The pandemic has been incredibly hard for us. As Belle has been having chemotherapy, her immune system is very weak so we had to shield. Having five children at home, unable to go out was a nightmare. The boys would constantly argue and we were all on



Belle, three months after her brain surgery



Belle's illness and recovery journey

top of each other. Additionally, I tried to juggle home schooling the boys with caring for Belle. At times it felt completely overwhelming.

Mandy was amazing. She has worked with our other children to give them time out from an incredibly traumatic experience and has given emotional support at school for them.

And she has been there for me too: I was always able to talk to Mandy when things were getting too much or when we had updates from the hospital that I wanted to talk through.

I don't know how we would have managed without Rainbow Trust's support.

To our delight, Bella did start to walk and talk and hit milestones in line with her age. This is beyond anything we could have imagined, given she has a large proportion of her brain missing. And she has continued to surpass and surprise all who know her.

Belle finished treatment in August 2020 and has continued to flourish. She is walking and talking, which fills us with joy. She is the essence of a real-life superhero. At the moment, Belle is disease free and living her best life.

Mandy has provided emotional support to our whole family throughout Belle's illness. She now visits us at home to support and help us find our feet in our 'new normal'.

Things would've been very different without Mandy by our sides.



Family Support Worker Mandy

Cancer continues to be one of the most common causes for referral to our service. The impact on all family members is devastating. We work with the whole family, helping in whatever way they want us to, giving them space to share their worries in the hope that we can make life a little easier and giving them time to focus on what matters the most.



Help families and **sponsor a Family Support Worker like Mandy today.** Your sponsorship will enable families who have a child with a life-threatening illness to make the most of time together because family means everything.
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.



↑ Kahmari, four, has Acute lymphoblastic leukaemia, a type of blood cancer. He enjoys doing arts and crafts with his Family Support Worker Wendy.



↑ Triplets Oliver, Owen and Oscar, six, enjoyed a trip to the circus. Oliver was diagnosed with stage four high risk neuroblastoma in February of this year.



↑ Kayla, five, was diagnosed with a medulloblastoma brain tumour in May 2020. After receiving chemotherapy and having surgery she rang the bell to celebrate being cancer free in June 2021.



↑ Family Support Worker Mandy supports Yasmin, two. Yasmin has been diagnosed with Ewing's sarcoma for the second time, 18 months after her successful treatment.



↑ William was diagnosed with mitochondrial disease in May. Family Support Worker Ellen has been supporting them since December with home schooling and transport.



↑ Mohammed, five, who has neuroblastoma, and his sister Aisha, six, enjoyed a trip to the park with their Family Support Worker Monica.



↑ Alex celebrated his fourth birthday in hospital due to complications from his tongue surgery. His family spent over two weeks in Bristol Children's Hospital.



↑ Rainbow Trust's North East Care team were welcomed back into hospitals in June this year. This is eight-month-old Noah, who is supported by Family Support Worker Sabrina.



↑ Kingston went to the beach with Family Support Worker Shelly and then painted rocks, one in memory of his younger sister, Ki Ki, and one for his little sister when she is born.



↙ Erin, seven, and her Family Support Worker Sarah had a special celebration: Sarah has supported Erin's family for six years.

It is only thanks to your support that we can help families living with childhood illness

We help families to get through the challenging circumstances they face while caring for their life-threatening child.

Family Support Workers give the children a break and give their parents some respite by playing, providing outdoor activities and fun, organising arts and crafts, reading and, sometimes, simply talking. These activities also help with their wellbeing, 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

Shelly is a Rainbow Trust Family Support Worker in the North East team and shares a typical week with us

By Shelly Duck

Names have been changed.



MONDAY:

Today was an office day. I had a team meeting with colleagues, did some much needed admin, contacted families to organise visits or to have updates and planned the diary for the week.

I also met with two new Family Support Workers from the North West team, who are in the process of learning how we all work and getting training so we welcomed them in our team meeting.

TUESDAY:

I visited Sara at James Cook Hospital in Middlesbrough. Sara is six months old and has been in hospital since birth because she was born with heart problems and chronic lung disease. Unfortunately, Sara does not have regular contact with her family because her parents struggle to spend the time they would like with her due to work and looking after her siblings. Sara needs her play, physical, sensory and developmental needs stimulated so I played and read stories to her. I also completed her personal care.

After that I went to the Great North Children's Hospital in Newcastle to support Simon. He is eight months old and has been in hospital since birth with bowel complications.

Simon's parents are not able to visit daily due to distance and having to look after his other siblings. I played, sang and did some games to stimulate and entertain him and held him while he slept.

During this visit I also completed a volunteer's supervision. Some of our volunteers help us in hospitals by carrying out activities with ill children or their siblings while they wait for treatment, giving parents respite and also freeing time so I can be with other families in the wards.

Once home I checked my emails and texts, responded to families and updated the database.

WEDNESDAY:

Today I completed four-year-old Terry's family plan review and then took him to soft play. Terry has acute lymphoblastic leukaemia and taking him out enables his parents to spend one-to-one time with his brother Theo. After that I saw Josh's family and completed their plan review. Then I took Josh, who is five years old and also has leukaemia, to soft play.

Family plan reviews are usually done every six months and are an important conversation with parents to check if changes are needed and to ensure that the support they are getting is helping them.

Once home I entered the support plans and updated a risk assessment on the database.

THURSDAY:

I attended a wellbeing conference call with other colleagues. The internal wellbeing programme focuses on the four themes of Body, Team, Work and Mind and it is designed to assist all employees with our wellbeing.

Then I drove to Great North Children's Hospital to visit two-year-old Clare, who has leukaemia, to give her parents a break. I spent time playing with her to assist with her development. I also completed Clare's support plan review and updated her risk assessment.

I called some families to catch up and organise some visits and then I picked up Kane from school and took him to the park and for some ice cream. Kane's sister suffers from non-Hodgkin lymphoma and Kane has been feeling isolated

and lonely because his parents spend long periods at the hospital with his sister. I provide emotional support to Kane to help with his loneliness and he really enjoyed his one-to-one time today.

FRIDAY:

I completed some e-learning. We all have mandatory training to do - like health and safety and manual handling. Afterwards I ran a drop-in group for ill children and siblings during clinic. I use arts and crafts to distract the children from treatment, stop them getting bored, emotional support and give their parents some respite.

I also supported Hazel at the same hospital, in a bubble room, which has controlled air flow to reduce the risk of infection or contamination. Hazel is three and had a bone marrow transplant due to an immunodeficiency condition. Because she is in isolation and can only see mum she needs social interaction and stimulus. I also supported Hazel's mum, who's caring for Hazel in the unit, giving her respite and supporting her to cope with the day to day living on the unit.

Then I drove home, while thinking about the many different needs of all the families I'm helping and how varied my week can be.

NB This week happened outside lockdown.



It's only thanks to your donations that we can give life-threatened children and their families expert, practical and emotional support for as long as they need it.

You can help a seriously or terminally ill child by sponsoring a Family Support Worker like Shelly today.

rainbowtrust.org.uk/sponsor-us

Your legacy brings light into someone's darkest days

Many of the parents we work with describe their lives as a very dark place when they meet their Family Support Worker for the first time. Some never imagined themselves as needing support before, some had a career, were happily raising a family and had a good life and then they find themselves desperate for some help.

What Family Support Workers do really can have a transformative impact on people, on families.

And every day supporters like you do something amazing too: fundraise, donate, volunteer and, in many cases, write Rainbow Trust into their Wills to ensure that our Family Support Workers can be there for families, when they need us the most.

The Rainbow Trust Children's Charity free Will-writing service

We have partnered with Guardian Angel and we are delighted to be able to offer some of you the opportunity to write your simple Will for free.*

How it works

You can write your own simple Will online at rainbowtrust.org.uk/legacy

by following these simple steps. Online help is available in case you have any questions throughout the process.

Visit www.rainbowtrust.org.uk/legacy and click on the link to the free Will-writing service



Answer a few basic questions about your current circumstances



Choose the type of Will you would like and start to enter your wishes online



If you are able, including a gift to Rainbow Trust will transform the lives of families with seriously ill children for decades to come



Make sure you enter the code RAINBOWTRUST-FREE to claim your Will for free

Alternatively, if you would prefer to have your Will written over the telephone, please call Guardian Angel's Freephone number to set up an appointment on 0800 773 4014.



Why I have left a Gift in my Will to Rainbow Trust

“When we put Rainbow Trust into our Wills we knew exactly the impact a legacy would have on families because we had been that family.

20 years ago our son was diagnosed with Hodgkin's disease - a rare form of cancer when he was only six years old.

I suffered with depression and I had to give up work to be with him 24/7. The tumour had grown around his aorta and he suffered a collapsed lung during surgery.

At the time, I could function but having a Rainbow Trust Family Support Worker around was a lifeline.

When he went into remission, my husband and I pledged to say thank you to Rainbow Trust so we have left a gift in our Wills. It just seemed like something small that we could do that would have a big impact.

”

Rosie, mum of two, legacy pledger.

If you wish to receive a free Gifts in Wills guide that shows the difference your legacy can make simply complete the form at rainbowtrust.org.uk/legacy or call us on 01372 220033.

FUNDRAISING HEROES



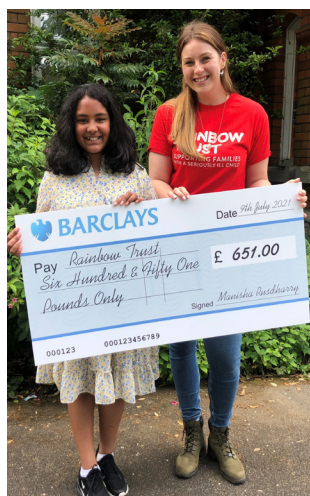
Alexandra and her team at Clarke Willmott raised over £2,400 for us by completing Tough Mudder London West.



This year K2 took on a steps challenge in January, virtually climbing the K2 mountain, and then walked the 'Race to the Kings' in June. They've raised an impressive £18,000.



Plum Play sponsored our craft tent at CarFest this year. We enjoyed seeing so many children having fun with craft activities at the event.



Manisha raised over £1,300 for Rainbow Trust and Dandelion Time by following her big sister's footsteps and cutting off her long hair.



Two members of the Caravan and Motorhome Club Singers, Margaret and Pauline, did a sponsored walk for Rainbow Trust. So far their Charity of the Year total stands at over £1,000.



Lisa held a 'Springathon' event to raise money for Rainbow Trust and for her brother-in-law, Tim, who was recently diagnosed with rectal cancer. So far they have raised over £9,900.



Thank you!



← Brothers, Dan, nine, and Connor, eight, are raising money for Rainbow Trust throughout 2021 by doing various fundraising activities, including mud crawl and baked bean bath. Their total currently sits at £1,400.

Family Support Worker Zak celebrates supporting Ruby's family for 10 years

A VERY SPECIAL TENTH ANNIVERSARY WORKING FOR RAINBOW TRUST



Very shortly after Zak joined Rainbow Trust in 2011, he started supporting Ruby's family when Ruby was four years old. Ruby's mum, Lauren, had learnt during her pregnancy that she suffered from the heart disease cardiomyopathy. This life-threatening, inherited condition affects the heart's ability to pump blood around the body, and unfortunately Ruby also inherited it.

Lauren was referred to Rainbow Trust because she had no support and she was struggling to cope with anxiety, managing Ruby's condition and needs and dealing with her own condition.

For the last 10 years Zak has helped, and continues to do so, in many practical ways.

Ruby is now 14 and has a younger brother, Austin, who is six years old. As the condition Lauren and Ruby have is genetic Austin has the same appointments and checks until doctors can be sure he doesn't have cardiomyopathy.

Over the years Zak would drop off

and pick up Ruby and Austin from school, take the children to the park for activities and games, and support the family at home by playing, cooking and assisting with anything that the family might need.

Zak often helps them with their shopping too because, due to the cardiomyopathy, Lauren and Ruby can't do prolonged physical activity so even going to the supermarket is testing and large crowds also trigger anxiety in Lauren.

The family has benefited from the emotional support given by Zak. Austin can open up to Zak, telling him about his problems, and sees him as a positive male role model. Over the past 10 years Ruby has shared her ups and downs with Zak and counts on Zak for additional emotional support when she needs it. Zak has been fundamental in helping Lauren cope with her anxiety.

Over time, Zak has managed to build a strong and stable relationship with Lauren, Ruby and Austin. The level of confidence and acceptance is very strong and is evident in many ways,

not least when both Ruby and Austin have appointments for scans and procedures in hospital at the same time: Zak drives the family there, so Lauren doesn't have to worry about traffic and parking, and then Lauren takes one child to their appointment and Zak takes the other one. A real testament to the vital work Family Support Workers like Zak do every day.

Congratulations, Zak, on your 10 year work anniversary and thank you for all your hard work.



Sponsor a Family Support Worker like Zak today.

Your sponsorship will enable families like Lauren's, who have a child with a life-threatening illness, to make the most of time together.

rainbowtrust.org.uk/sponsor-us

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

Title _____ Name _____ Surname _____
Address _____ Postcode _____

I would like to receive emails:

Please call me on:

☐ £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: / /

Expiry Date: / /

Please send your donation to:
Rainbow Trust Children's Charity, Cassini Court,
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T: 01372 220083 E: supportercare@rainbowtrust.org.uk
rainbowtrust.org.uk/donate-magazine



giftaid it

☐ Please tick, sign and date here to boost your donation by 25p of Gift Aid for every £1 you donate, at no cost to you.

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.