

Newsletter

Spring/Summer Issue

2024



Celebrate 30
years of Rainbows

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Learn about how your
support helps Freddie

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Become one of our
amazing volunteers

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Set up a regular donation today!

Complete the form below and return it to FREEPOST Rainbows Hospice to set up your regular donation.

Contact Details

Name:

Address:

Postcode:

Email:

Telephone Number:

- Please tick if you are happy to be thanked for your kind donation by email or phone call
- Please tick if you'd like to hear more about how you can leave a gift in your Will for Rainbows.
- Please tick here to confirm you want to Gift Aid your donation to Rainbows Hospice for Children and Young People. By ticking this box you confirm you are a UK tax payer and understand that if you pay less Income Tax and/or Capital Gains Tax in the current year than the amount of Gift Aid claimed on all your donations, it is your responsibility to pay any difference.

Regular Donation Amount

I/We would like to help the families supported by Rainbows with a regular monthly donation of:

£2 £5 £10 £20 Other:

Instruction to your Bank or Building Society to pay by Direct Debit



Name of Account Holder:

Account Number: Sort Code:

Name/full address of your Bank/Building Society

To: The Manager of

Bank/Building Society

Address:

Postcode: Service User Number: 291358

Reference:

Instruction to your Bank or Building Society

Please pay Rainbows Hospice for Children and Young People Direct Debits from the account detailed in this Instruction subject to the safeguards assured by the Direct Debit Guarantee. I understand that this Instruction may remain with Rainbows Hospice for Children and Young People and, if so, details will be passed electronically to my Bank/Building Society.

Signature:

Print Name:

Date:

Banks and Building Societies may not accept Direct Debit Instructions for some types of account.

Hello

On Thursday 22 September 1994 we opened our doors for the very first time. Thirty years on, not only has the Hospice grown, but our services have grown too, as we continue to build on our ambition to provide “the Rainbows experience wherever you are”.

We're proud to now have Rainbows Nurses in hospitals across the region. This year we're also planning to introduce our Community Hubs, meaning we'll be able to provide our services to our families wherever they are.

Looking back over 30 years of Rainbows provides the perfect opportunity to recognise how much you, our amazing supporters, have helped make possible.

It's hard to imagine a time when babies, children and young people with serious and terminal conditions didn't have access to hospices like Rainbows. It's like we've always been here – however this couldn't be further from the truth. And the challenge that now faces us is how we can continue to be here, for the next 30 years.

Next year, we need to raise £12.1m to keep our doors open and help over 3,000 people. We get less than 20% statutory funding, which is enough to keep our doors open for 10 weeks. The rest comes from you, our wonderful supporters. We simply can't help families without you.

As the new Director of Income Generation and Marketing, I want to take this opportunity to personally thank you for your incredible support. I'm looking forward to meeting many of you over the years to come. It's because of you, we can be here for children like Freddie, who you can read about on page seven.

Thank you for your fantastic support and here's to the next 30 years.

Nish

Nishil Saujani
Director of
Income Generation
and Marketing



Laya's Story

Laya is a little girl with a rare genetic condition who relies on the specialised care offered at Rainbows.

“Rainbows means I have a family and a home in the UK.” These are the words of Fareda, whose six-year-old daughter is cared for by us.

Laya has a severe neurodisability due to a rare genetic condition called UFSP2 gene. She also has epilepsy and developmental delay, which means she has constant seizures.

“There are a lot of unanswered questions about Laya's condition as it is extremely rare, with only 14 cases worldwide,” said Fareda. “It has been identified as a fairly new condition and still needs a lot of research.

“Another problem is that the Cerebellum in Laya's brain is not developing as normal. It is actually getting smaller and there is nothing they can do to stop it.”

When Laya was born everything seemed to be fine but at four-months-old she started having seizures which were diagnosed as epilepsy. An MRI scan and a range of tests at six-months-old indicated that Laya had underlying Mitochondrial Disease, a very rare life limiting condition.

Fareda was also told that her daughter would never eat or drink orally and that eventually she would lose all capacity to talk, walk or would never have a normal development. “I was told to expect a very short life expectancy for Laya. This was extremely difficult for me to accept and caused me huge anxiety and worries.”

Against all odds, Laya improved after four months and she started eating and drinking.



Her communication skills also improved and there was an increase in her development.

Fareda is a single parent and relies on the support of our charity.

Fareda added: “I have no family in England and have been on my own for six years, Rainbows has been like a second home to me. Rainbows is like my family. I have no one I can rely on as it is specialised care. But with Rainbows, I feel like everyone knows what to do. I cannot leave Laya anywhere else and go for a break for a few hours, other than at Rainbows as I know she is in really good hands. And she is safe.

“We have been coming to Rainbows since Laya was six-months-old. It is just amazing. It is a great place for relaxation and has great facilities. I get a much needed break. I wish I could pay back or do something to say thank you.

“Laya continues to teach me about life and together we face new challenges. She reminds me to find the beauty in everything and to be strong and brave, just as she is. She reminds me to smile because life has been tough, she reminds me to always see the light, as she's such a bright shining star. I am so blessed to be her mother.

“She is my greatest blessing. Without her, I wouldn't be as strong as I am today. Laya has taught me to respect and appreciate all the little things in life and not to worry. Struggles lead to great victory.”

Your £5 donation today could fund arts and crafts materials used for memory making with children like Laya
Donate at: rainbows.co.uk/donate



Our amazing supporters

Sporting Bears Motor Club drives support to £44,000

An organisation which offers “Dream Rides” for motor enthusiasts has raised £44,000 for us.

Sporting Bears Motor Club has been supporting our charity since 2008 and has just handed over its most recent donation of £9,300.

Set up in 1989, Sporting Bears Motor Club, and its members, visit motor shows with their classic cars. People can then choose a car they would like to be taken for a spin in and make a donation for their Dream Rides.

Alan Moss, Chairman of the Sporting Bears Motor Club, said: “As we are a motor club and not a business, we don’t charge for our Dream Rides but we ask people to make a donation. The British public are very generous and we find they are always happy to support charities,

especially ones like Rainbows, and 100 percent of all of our donations go to the charities.

“Our group is also very proud to be involved with Rainbows. Some of us have visited the Hospice and it is very close to our hearts. And our drivers, who provide the Dream Rides, do so out of their own pockets. They don’t charge for fuel or the upkeep of the cars. We are delighted to have raised so much over the years.”



Superstar dad rides to Paris for Rainbows in memory of his son

A father cycled 428 miles from Loughborough to Paris and raised £8,060 in memory of his son.

After a long battle with illness, Alex was 16 when he died at our Hospice in August 2022. He had Ollier’s disease, a rare bone condition, and Pulmonary Hypertension, which causes high blood pressure and affects the heart and lungs.

His father, Richard, is forever grateful to our staff for the care given to Alex, and the support provided for his family.

“Rainbows made a horrendous experience so much more bearable,” said Richard.
“The hospice and the staff were fantastic.”

“Alex had his first operation when he was 10-weeks-old. He was very small and even at 16, he was only one metre tall. At the age of 10, he was diagnosed with Pulmonary Hypertension after his lung collapsed, and we had a lengthy stay in hospital.

“Alex was ill throughout his life, and when his lung collapsed it was a major shock. He was in and out of hospital regularly, but took everything in his stride. He was so positive towards everything. At one stage there was the option of a transplant but as time progressed, his options diminished and ultimately there were none. That was extremely hard to deal with.”

Richard describes his son as a wonderful chatterbox who flourished at school and loved life. Despite being so poorly, Alex was determined to sit all of his GCSEs, and was able to do so. Unfortunately Alex never knew that he passed all of his exams, or got to complete his dream of going to Loughborough College.

Richard said: “I am so proud of what he achieved in his life. He was developing into a beautiful young man and to be told he was dying was devastating.

“Alex loved Rainbows. It was a really positive place for him. There is sadness there but all of the experiences are wonderful. He loved to go swimming, he loved to bake. He would chat to anyone. We made the most of our time and it was as good of a situation as it could have been.”



Celebrating 30 Years of Rainbows

1994
We opened for the first time

2000
We started to offer Therapeutic Play Services

2010
We completed our Building for the Future project, enabling us to accommodate young people over 18. The facilities included our Hydrotherapy Pool and Soft Play Room

2016
We opened our flagship store in Loughborough

2017
We launched our first Trainee Nurse Associate Scheme

2021
We launched a range of services helping to support families in the East Midlands. Services include Nurses in Hospitals and Long Term Ventilation

Your generous support has made all of this possible and we wouldn’t be here today without you, thank you!

1995
His Royal Highness, Prince Charles, officially opened the Hospice

2007
We introduced our Symptom Control Manual

2012
We opened the first of our shops in Melton Mowbray

2012
We first appeared on Children in Need

2014
Our Doctor (at the time), Dr Satbir Jassal was awarded an MBE for services to palliative care for children and young people

2016
Our services were rated Outstanding by the Care Quality Commission

2020
We provided bereavement support for families affected by Covid-19

2022
Our Cinema Room opened

2024
Our latest shop in Wigston opened



Your regular donation means we can be there for babies, children and young people with serious and terminal conditions when they need us the most.

£103,897

was raised last year by our amazing **856** regular donors!



£1 - £125

is the range of the donations given each month



Our longest running regular donation was set up in

2005!

Our regular donors really are amazing – we couldn't be here without them!

How your regular donation could help us to support local babies, children and young people:

£10 could pay towards the care of a baby, child or young person by our Care Team



£20 could pay towards the care of a family member who has been recently bereaved



£70 could fund an hour session of Music Therapy



£100 could fund one day's worth of healthy nutritious food at the Hospice



Support families like Freddie's and become a regular donor **scan the QR code** or **complete the form on page 2** today!



Freddie's Story

Rainbows is the beacon of light at the end of the tunnel for Freddie's family.

Four-year-old Freddie began having constant seizures when he was just two-weeks-old and he was rushed into hospital. His parents Catherine and Andrew said it was a very frightening experience.

Scans showed baby Freddie had Polymicrogyria, where the brain doesn't develop properly during pregnancy and Calcification, a condition characterised by abnormal deposits of calcium in blood vessels within the brain. He also has parts of his brain missing.

"The three issues together are a ridiculous amount of medical issues and it is only getting worse," said Catherine. "Having the three conditions together is very rare. We have been told there are only a handful of cases worldwide."

Freddie needs round the clock care as his epilepsy is difficult to control. The support the family has received from our charity since 2020, has been a "game changer" and Catherine and Andrew value our Hospice that helps not only Freddie, but his seven-year-old sister, Lizzie.

Freddie has Global Development Delay and is visually impaired, only seeing shapes and colours. He is also non-verbal and non-mobile – a dislocated hip and issues with his wrists and thumbs add more strain.

"Rainbows gives us something to look forward to," said Catherine. "It is a beacon of light at the end of the tunnel. Freddie loves Rainbows. He has become much more relaxed and is the best version of himself right now."

"He loves Music Therapy and massages from the Rainbows Complementary Therapists. He can't swim in public pools but he can swim in the Hydrotherapy Pool at Rainbows, and he can swim with his sister.

"Rainbows has also been great for Lizzie. She was struggling but she has benefit from the Rainbows Sibling Services, which has included counselling, and that has made such a difference. She idolises Freddie but sometimes it is good for him to be at Rainbows and for us to have time with her as she misses out on such a lot.

"We know Freddie isn't going to have a long life," said Catherine. "We could have weeks, we could have years. He is susceptible to chest infections, which are very dangerous for him.

"We take each day as it comes and handle it with difficulty, we didn't actually realise how serious his condition was until earlier this year. We now have to think quality over quantity and make the days as happy as we can. It takes too much energy to be sad."



"Rainbows has also been great for Lizzie and has made such a difference. She idolises Freddie but sometimes it is good for him to be at Rainbows and for us to have time with her"

Freddie's Mum

Meet Nikki

Nikki is our Retail Operations Manager and has been with our charity for over two years.

What do you enjoy about working at Rainbows?

Everything about Rainbows makes the hard work worthwhile. Even if you are having a bad day, or it's really busy, you know you are working hard for such a fabulous cause. And you always know you are making a difference to so many families, in so many ways.

What led you to work for Rainbows?

I have worked in different areas of retail for most of my life and I have also enjoyed doing lots of charity work and fundraising. So, Rainbows ticks all the boxes for me. I can put my love for retail and my love for charity work together and get to do what I have always wanted. It is perfect.

What is your vision for Rainbows Retail?

We have lots of shop openings coming up and I want them all to be a huge success. We receive such positive feedback from our customers and our shops are so well supported by the community. It really is a pleasure to see our shoppers happy and I want that to continue.

What do you do to relax?

When I am not working, I enjoy going on holiday, even if it is just for a weekend away. I love spending time with my family and friends, and I am also a big cricket fan.



Did you know?

Our shops help to **raise 8p of every pound we raise**. This enables us to provide a range of therapies at the Hospice including:

- Complementary Therapy
- Music Therapy
- Physiotherapy
- Hydrotherapy

The benefits of these therapies to our families include helping them to relax, relieving discomfort and muscle pain, providing symptom management and allowing them to express themselves.

Rainbows has arrived in Wigston

Rainbows has a brand new store in Bell Street, Wigston, Leicester, which was officially opened by TV and film star, Lydia Bewley.

Lydia, who is best known for her role in The Inbetweeners films and has been one of our Patrons for 12 years, said: "It is an honour to open the Wigston shop and I wish this store so much luck, love, happiness and fun. It has a lovely community feel about it and it is a beautiful store. As a mum, I appreciate how important the work of Rainbows is, and the services and support it provides to children and their families."

Mark Ashton, our Head of Retail, added: "It is wonderful for us to be opening our Rainbows store in Wigston. Wigston has a fantastic community spirit and we are very excited to be here. We would like to thank all of the businesses who have helped us set up the store and everyone who has supported us."

To volunteer in one of our shops today visit: rainbows.co.uk/volunteer

Our new shops

Over the next year, we plan to open more new shops! These will hopefully be located in:

- Long Eaton
- Lutterworth
- Arnold
- Hinckley

And we hope to venture into Northamptonshire and Lincolnshire soon!



Our amazing supporters

Young supporter runs 100 mile challenge for Rainbows

Five-year-old Stanley completed an epic challenge of running 100 miles.

In just four months Stanley carried out his mammoth task running after school and at weekends and raised £900 for our charity.

Stanley ran with his parents, Laura and Adam. Laura said: "Stanley decided he wanted to start running after being inspired when I completed my first marathon. He also wanted to help poorly children after seeing a TV programme.

"I suggested he combine the two and run for a charity so he had a look round.

He loved the Rainbows website.

"We don't go into the sad side of it but he understands that Rainbows makes it easier and nicer for poorly children who are going through difficult times, and as we are a very close family, he understands the importance of that.

"He enjoyed the challenge, he can now run 5k in one run, which is fabulous. He had moments where it was tough, but he really did push his little legs and kept going.

"We are very proud that he wanted to do this and it is nice for children to learn how to do things for others."



Baking to success!

Royal cake maker Fiona Cairns has been a Rainbows Patron for 13 years and regularly hosts cake decorating workshops at our Hospice.

Her team of dedicated staff are also super supporters of our charity and they have been raising funds through cake sales as well as taking part in a run/jog/walk at Braunstone Park.



Interested in fundraising for Rainbows?
Visit rainbows.co.uk/fundraise



Super Volunteers!

Volunteers continue to support everything we do at Rainbows, and without their dedication and support our charity simply wouldn't be here.

Volunteering with us isn't just about lending a helping hand; it's about creating lasting memories, meeting new friends, and making a meaningful difference to the babies, children, young people and families that we support. Whether it's being a welcoming face on our reception, organising fundraising events and raising essential money to support our work, or raising the profile of our charity on the high street in our growing number of retail stores - every act of kindness and donation of time helps us to brighten short lives.

In recent months our teams have been working on welcoming back volunteers with our Hospice Care Team. We have also been working to find even more ways in which volunteers can support our work, including some exciting new opportunities to volunteer with our Family Support Team working in local communities across the East Midlands.

But the magic of volunteering isn't just what you give - it's also in what you receive in return. Our volunteers often speak about the sense of purpose and fulfilment they find in volunteering with Rainbows. For others it can be a chance to give back to a special cause that holds a unique connection to them and their family; while others embrace the opportunity to forge new friendships, gain new experiences or use existing skills.

We understand that volunteering with us means something different to everyone who so generously gives their time; but we hope they will all be proud to have made such a positive impact in helping us support more babies, children and young people than ever before.



Become a Rainbows Volunteer today: rainbows.co.uk/volunteer

Help support Rainbows shops!

To help keep stock replenished, we are always looking for clothing, toys, games and books to sell in our shops.

Items selling for £20 could pay towards the care of a family member who has been recently bereaved. Every £40 we raise at our shops could fund an hour of care from our Family Support Team for our families.

To learn more visit: rainbows.co.uk/shops



Events 2024

From firewalks and skydives to iconic half-marathons, an afternoon tea and our annual Derby Cathedral abseil, there's lots of fantastic fundraising events for you to take part in during 2024! Which events will you choose?

Rock Choir for Rainbows - Saturday 29 June

Rock Choir Leicestershire are returning to De Montfort Hall with a spectacular evening of music to raise money for Rainbows.

A Slice of Inspiration: Rainbows Afternoon Tea - Sunday 30 June

An opportunity to hear from two extraordinary speakers, and our own inspirational Rainbows parent, while enjoying some local craft stalls and indulging in a delicious afternoon tea.

Skydive for Rainbows - Saturday 13 July

Take a leap of faith and feed the thrill-seeker hiding within, by taking part in our tandem skydive from 10,000ft.

Great North Run - Sunday 8 September

Spread the smiles as you complete the miles on this iconic route from the centre of Newcastle across the Tyne Bridge.

Robin Hood Half & Mini Marathons - Sunday 29 September

Lace up your trainers for this traffic-free course, perfect for new and seasoned runners alike. Young supporters can also grab their grown-ups and join us for the 'mini' 1.5mile route along the River Trent.

Derby Cathedral Abseil - Saturday 5 October

Calling all daredevils... our adrenaline-fuelled Derby Cathedral Abseil is back! Will you take on this popular 212ft challenge?

Rainbows can't do the work we do without the generosity and hard work of people like you so our team of experts will be there to support you every step of the way.

When you sign up to one of our events you will receive:

- Personalised support from your own Community Fundraiser
- Access to fundraising materials and electronic resources on our website
- A Fundraising Pack full of amazing ideas
- Help setting up your online fundraising page
- Training tips and advice if you're doing a physical challenge for us
- The opportunity to share ideas, promote your fundraising, and meet other fundraisers in our Brighten Short Lives Facebook group

Loughborough Firewalk Friday 21 June

Welcome the fiery energy of the Summer Solstice with a heart racing walk across hot coals. This is a fantastic opportunity to test your mind over matter, while putting your best foot forward for Rainbows.

To support Rainbows and sign up for one of our amazing events visit rainbows.co.uk/events

