



We care for babies, children
and young people in the
East Midlands – wherever they are.

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Newsletter

Autumn/Winter Issue

2024



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support with Gift Aid**

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We support over **750** babies, children and young people and their families.



This year, we need to raise **£12 million** and **only 13%** of this is government funded.



Hospice@Home has supported **14 families** to stay at home in it's first six months.



Hello

Over the last few years, we have been focussing our services to provide “the Rainbows experience wherever you are” so we can reach so many more families who need our support.

As part of this, we have been developing our Outreach Service and we are excited to tell you about our new Community Hubs.

The aim is simple, we want our babies, children and young people to be able to access the services that we provide at our Hospice in Loughborough, but without having to travel for too long.

Every month, we take our staff, such as our Music Therapist, our Complementary Therapist and our Advanced Clinical Practitioners, closer to where our families live. Each month is a different area across the East Midlands and the first few have been a fantastic success.

As we are reaching more people who need us, we need to grow our team and we are thrilled to announce that your support has helped us to fund a new Sibling Support Worker, a new Youth Worker and more Family Support staff.

Feedback we often receive from our families is that it is great to talk to others in the same situation. So, to encourage this peer-to-peer support, we are embarking on new groups for our families. This year will see the launch of a Dads' Group, a Bereaved Grandparents' Group, Activity Days for older siblings and young people, and Bereavement Walks.

This year, we need to raise £12 million and only 13% of this is government funded; the rest comes from you, our wonderful supporters. We simply can't help families without you.

Thank you for your incredible support.

Sam

Sam Herrett
Family Support Lead



Joshua's Story

Meet Joshua, a little boy supported by Rainbows, who forgets to breathe when he is asleep.

“No parent should ever have to think about resuscitation plans for their child.”

For Emma and Phil, this is a harsh reality. Their son, 10-year-old Joshua, relies on a ventilator to ensure he breathes during the night.

Joshua was born unexpectedly at 26 weeks and spent the first four months of his life in hospital. “There were lots of issues with his inability to remember to breathe,” said Emma. “Doctors thought it was because he was premature.

“Three days after coming home, he went into respiratory arrest. We had to resuscitate him at home and it was terrifying. He went back to hospital and it was really hard. We also have a 14-year-old daughter, Erin, and we desperately wanted our family to be together. Our first Christmas together, Joshua was in neonatal intensive care unit with little stockings hung on the end of incubators.

“It was presumed he had a respiratory virus but when we went home, he stopped breathing again. And that was our picture for the next eight months. No one really knew what was causing it.”

A sleep study revealed that when Joshua is asleep, he forgets to breathe. He now has non-invasive ventilation, which means he has a ventilator at night. He is a lot smaller in size than other 10-year-old children and he gets very tired. He also has learning disabilities and has numerous medical problems.

“We have been told Joshua has a neuromuscular gene change, which doesn't come from either parent. We know it is going to cause an issue but because it is so rare, we don't know what will happen.

“It is so worrying and it is always hanging over us. We don't know if he will have a short life span or a normal life. I am a planner and I have to accept that there is nothing I can do. It really is incredibly isolating.”



Joshua was referred to Rainbows in 2021 by the ventilation team at the hospital. “It is a very special place,” said Emma. “There are two places I can relax properly, one is Rainbows and the other is the ICU. We know he is always looked after and he is never left on his own.

“Rainbows is so important to us and it is so nice to see Joshua grow at Rainbows. When we first went to the Hospice, he wouldn't leave our sides but now he likes to go off on his own. He is more independent and this is what we want for him.

“Rainbows has also given support to Erin and given her a safe space. She always wants to go to Rainbows. I think it gives her a place where she can be herself.

“If you ask how I am coping day to day, the honest answer is I don't. A couple of years ago, I really broke down because I didn't process it. It took me six months, with counselling, to get me back to a place where I could manage.

“We are swimming in a situation we have no choice over. We are not going to pretend it is easy, we are not going to pretend we haven't cried a lot. Rainbows gives us a place to show all of our emotions and grieve for a life we should have had and a life Joshua should have had. We can still live, we don't let it stop us from doing things.”



Become a regular donor and help to support babies, children and young people like Joshua:
rainbows.co.uk/donate

Thank you to our amazing supporters

Group take on epic walk in united fundraising effort for Rainbows

Four friends from the Manchester United Supporters Club Leicestershire went to great lengths to avoid match-day traffic and support us.

The group, made up of chairman Ben Bryans, secretary Kishan Patel, head of travel Andy Noble and committee member Martin Skinner walked 88 miles from Jubilee Square, in Leicester, to Old Trafford to attend a United home game in May.

'Trek to the Trinity' was the equivalent of a marathon a day for three days, plus a further 10 miles on match day and raised over £8,800.

Ben said: "I grew up in Loughborough so I have always been aware of Rainbows and the work

it does. We had a tour of the Hospice and talk about emotional; these kids are true warriors and deserve everything. Rainbows give these children the best lives possible, and they need our help.

"We are delighted to have done this challenge and raised money for Rainbows."



Supporter takes on epic birthday fundraising challenge

To celebrate turning 60, Eddie Stanley cycled over 1,000 miles from Land's End to John O'Groats (LEJOG) to raise funds for us.

In May, Eddie started his ride at Cornwall's most southerly point and cycled around 85 miles a day for 13 days, totalling 1,087 miles.

Eddie was assisted by his wife, Sally, as his support vehicle driver meeting up each evening along the route.

Sally is a recently retired teacher, with 35 years experience working within early years. Some years ago, she taught a boy called Tom, who is supported by our charity. Tom (now 16), needs a heart and lung transplant and has endured many surgeries since he was two-days-old. Sally has remained in contact with Tom and his parents and has closely followed his progress.

Eddie had a serious bike accident three years ago that resulted in a stay in Intensive Care, several broken bones, surgery and a long road to recovery. Eddie said: "Passing 60 and being able to take on this challenge is only possible due to the help and support of family, friends and the medical staff at Royal Derby Hospital.

"Hearing how Tom and his family talk about Rainbows and the wonderful help and support they provide them, made me want to help Rainbows to continue to help Tom, his family and other poorly babies, children, young people and their families. LEJOG was a challenge, but we really enjoyed it."

It is not the first time Eddie, who turned 60 in March, has raised funds for us as 20 years ago, he took on the Three Peaks Challenge with friends.



Give 25% extra at no extra cost

There is no lower limit to the amount that an individual tax payer can give to charity under the Gift Aid scheme and every penny supports Rainbows.

At current tax rates, for example, on a £100 donation we can reclaim 25% making the donation then worth £125 – it really does make a difference!

Note: Gift Aid is not applicable to the purchase of raffle tickets or to membership of our Lottery. It only relates to a donor giving of their personal money.

To set a gift aid declaration up, or make any changes to an existing one, email us at supportercare@rainbows.co.uk please call us on **01509 638 049**

Claiming Gift Aid is like adding an extra topping to your ice cream cone **at no extra cost to you!**



Gift Aid statement for Rainbows

I would like Rainbows to treat this donation, any donations I make in the future and any I have made in the past 4 years as Gift Aid donations. 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 my donations in that tax year it is my responsibility to pay any difference. I understand that Rainbows will reclaim 25p of tax on every £1 that I give.

You must let us know if you:

1. Want to cancel your declaration
2. Change your name or home address
3. No longer pay sufficient tax on your income and/or capital gains.

Last year, we were able to claim over **£100,000** in Gift Aid to support our work!



Did you know?

We can also claim Gift Aid on items you donate to our shops meaning that we can raise more money to help babies, children and young people from across the East Midlands.



Breathtaking India or £3,000 - the choice is yours!

Our Autumn Superdraw is back and bigger than ever. We are giving players the opportunity to win a magical guided tour of India for two people or £3,000 in cash!

Have you always dreamed of experiencing India - the land of adventure, vibrant culture and magnificent architecture. Well now that dream could become a reality by playing our Superdraw for **just £1 per ticket!**

Why play the Rainbows Superdraw?

Throughout this newsletter, you'll have read about just a few of the **750 babies, children and young people** we support at Rainbows. By buying tickets for the Rainbows Superdraw, you're helping us to support our families and provide them with the Rainbows experience wherever they are including at home through our **Hospice@Home Service**.

This service enables families to have choice and flexibility in their care. Our Hospice@Home Team also works with the local community teams to enable the parents of our babies, children and young people to choose where they want to be at the end of their lives.

What could you win by playing the Rainbows Superdraw?

This year, we are letting the lucky winner choose their prize, either a cash prize of £3,000 or a 10-day guided tour of India* for two people! There's also the chance to win other cash prizes, ranging from £50 to £250.

The guided tour for two people (departing 9 October 2025) includes:

- Return flights from Heathrow Airport with checked luggage and transfers
- India's Golden Triangle, visiting the beautiful Taj Mahal - a must see for any visit to India.
- The sights, sounds and flavours of cultural hotspots such as Old and New Delhi and the 400-year-old deserted Mughal city of Fatehpur Sikri.
- You may even get to spot a tiger or two on a driving safari through Ranthambore National Park!

For your chance to win the £3,000 jackpot, or holiday of a lifetime, simply complete the entry form and ticket book with your details and return in the Freepost Envelope enclosed. The closing date is **Friday 15 November 2024** and the lucky winner will be announced on **Friday 22 November 2024**.

Other cash prizes include 2nd prize of £250, 3rd prize of £100 and 5 runner up prizes of £50.

The Superdraw makes a huge difference to the care we can provide. Our Spring Superdraw raised an incredible £24,000, so thank you for your support in reaching that amazing amount. The last lucky winner opted for the cash prize, which one would you choose?

Thank you and Good Luck!

*Winners will have to source their own travel insurance and visa in order to be able to travel to India.

Cope Children's Trust is licensed and regulated by the Gambling Commission under account number: 8465

To view Terms and Conditions including odds of winning and who is responsible for promoting the Rainbows Superdraw please visit rainbows.co.uk/superdraw

18 No tickets to be sold to or by anyone under the age of 18

GambleAware

Kindly Supported by
RIVIERA TRAVEL



**Win £3,000
or a holiday
to India!**

Buy your Superdraw tickets:
rainbows.co.uk/superdraw

Meet Hassan

Hassan, a perfect little boy who wasn't expected to survive pregnancy, or birth, due to a rare brain condition but is now supported by Rainbows.

Hassan has Encephalitis Synopsis, an inflammation of the brain so rare, his parents, Iqbal and Haram, have been told there are only three other children in the world with it.

In their journey, the family have been supported by our charity.

Haram said they first became aware Hassan may have difficulties at the 20-week scan. "He was moving such a lot, the sonographer was unable to scan his brain," she said. "Then at 24 weeks, they couldn't measure his head and we were told it was bigger than normal.

"A consultant told us that Hassan's skull was an abnormal shape. It was open at the back and parts of his brain were growing outside of his skull. He also had hydrocephalus – a build-up of fluid on the brain.

"We were devastated to be told that Hassan wasn't expected to survive pregnancy, and if he did, he would only live for a few hours. But he continued to surprise everyone.

"We planned to come to Rainbows for him to have comfort care but when Hassan was born, he was breathing well and didn't need any oxygen. He also took well to a bottle. Everyone was so surprised.

"After five days, he was perfect and getting stronger. We knew that we had to fight for his life. He was fighting and he wanted to live."

In July, Hassan went to Liverpool for the first of two operations to reconstruct his skull. He also spent six months at Nottingham's Queen's Medical Centre to relieve pressure from his brain.

"It has been a huge rollercoaster for us all. And incredibly difficult, but in this journey, Rainbows has been perfect, just amazing," said Haram. "After my surgery when I had Hassan, I struggled with an infection and health issues. Rainbows were such a great support to us.

"A Rainbows Nurse visited us in hospital and explained everything to us so well. She did activities with us, and we made memories.

"We realised that Rainbows would be the best place for Hassan. When we arrived at the Hospice, we saw other children with many conditions and spoke to other parents. We were given so much reassurance and confidence.

"I thought babies like Hassan wouldn't be able to do normal things that children do and enjoy life, but when he first came to Rainbows, he went swimming and had a massage, It was wonderful. The staff are amazing and have helped us so much. Hassan needs round the clock care and at Rainbows, I am able to rest and become a mummy again.

"We anticipate he will be having surgeries for the next six months to a year. Hassan is very lively and very chatty and the doctors have said he is doing so well. But we know we just take each day as it comes."



Leave a lasting legacy at Rainbows

Leaving us a Gift in your Will is a very special and thoughtful way of making sure we can continue to be here for our babies, children and young people.

As we endeavour to be here for families whenever and wherever they need us, we rely on legacies more than ever. Your gift could make a huge difference. It could mean giving a family the choice of where they receive our care as we strive to provide support in the Hospice, in hospital and at home.

Every legacy left to Rainbows will help to change the lives of the families we support, and we are grateful for every penny. You are always welcome to come and see how your gift will help by having a tour of our facilities and learning more about our charity.

To ensure your gift comes to us, quote our charity number 1014051 in your will.

If you choose to leave us a Gift in your Will, or want to know more please email emma.gulliver@rainbows.co.uk or call **01509 283 912** to speak to a member of our Individual Giving Team. We will always answer your questions quickly and honestly.

How can I leave a gift in my will?

There are several ways you can support us in your Will. Each one is equally as special to us:

A cash or 'pecuniary' gift

A single, precise cash gift from your estate.

A share of your estate or 'residuary' gift

After you have provided for your loved ones and taxes have been paid, you could choose to leave a share, or the full remainder (the residue) of your estate to Rainbows.

A specific gift

This type of gift is usually something like property or an individual item such as a piece of jewellery or an antique.



Did you know?

Gifts in wills fund the care of **1 in 5** of our families ensuring they can make magical memories together.



Kindly sponsored by:

The Loughborough Building Society

Loughborough Santa Run 2024

Sunday 1 December 2024 - 11am
Loughborough Market Place, LE11 3EJ

Join the Loughborough Santa Run 2024 and get festive as you take on a 2.5K or 5K route as you help to brighten short lives in the East Midlands.

Tickets (includes Santa T-shirt): Adult - £15 | Children - £8

Doggy Bandana and Santa Hat: £2.50 each



Use code **SANTA20** to get 20% off tickets during October



Sign up to help spread Christmas cheer:
rainbows.co.uk/loughboroughsanta

Christmas Concerts

Enjoy the magic of the season at one of our Christmas Concerts!

Derby Cathedral - Wednesday 27 November

Emmanuel Church (Loughborough) - Wednesday 4 December

Church of The Good Shepherd (Nottingham) - Tuesday 10 December

Northampton Cathedral - Wednesday 18 December

Book your tickets: rainbows.co.uk/christmasconcerts

Volunteer Spotlight

Meet Rebecca, one of our incredible Hospice Support Volunteers helping our Care Team.

Why did you become a volunteer?

I took a gap year before going to university to study medicine and was really keen to make good use of my free time. I want to become a doctor, and it's so important for me to get an insight into the way a healthcare teams run. I've admired the amazing work that Rainbows does with so many babies, children, young people and their families, and the opportunity to get involved, meet so many different people and contribute to supporting a phenomenal team, is a privilege.

What do you enjoy most about your volunteering?

I really enjoy the chats and interactions that I have with a whole range of people, whether that's the children and young people, their siblings and parents, or the lovely staff at Rainbows. I enjoy seeing new and familiar faces each time I'm in, and there's always lots of smiles!

How would you describe what you do as a volunteer?

My main role is supporting the Care Team in whatever way I can, which generally includes being there to greet people when they arrive, and helping to get all their bits and bobs in order. Once everyone is settled in, I enjoy spending time with the babies, children, young people and families.

What advice would you give to a new volunteer?

To ask where you'll be most useful and be willing to get stuck in and help out with whatever Rainbows needs.

What would you say to someone thinking about applying to become a Rainbows Volunteer?

The environment at Rainbows is uplifting and positive, and I've really enjoyed meeting lots of lovely people. Volunteering at Rainbows has given me new experiences and insights and is easy to fit in alongside other commitments.

To find out more about how you can make a difference as a Rainbows Volunteer, visit: rainbows.co.uk/volunteer



Over the last year, volunteers have helped us make a real impact:

Over **7,200**

The number of visitors and families our reception volunteers have met with a friendly and caring smile.

Over **18,700** miles

How far our volunteer van drivers have driven to collect and deliver donations to our Retail Team.

Over **26,750** hours

The amount of time all our volunteers so generously gave over the last year!

Willow's Story

Willow, the little girl who is working hard to reach her milestones in the safe environment provided by Rainbows.

Willow has Dilated Cardiomyopathy and severe heart failure. Her heart works at just 20 percent capacity. Her parents, Chloe and Cole have been told they 'must wrap their daughter up in cotton wool.'

Willow, who is described as incredible and strong, celebrated her first birthday on April 13. "We are so happy we get to celebrate her first birthday as we can never be sure in the future," said Chloe. "The hardest thing is we just don't know, so we need to live life to the full."

For the family, it has been a tough year and Chloe recalls the moment Willow suffered a cardiac arrest when she was just a tiny three-week-old. "Willow had been projectile vomiting, so our GP sent her to Leicester Royal Infirmary," said Chloe. "Within 20 minutes of us being there, she went into cardiac arrest. I dread to think what would've happened if we weren't in the hospital. We were totally in the right place at the right time and if not, she wouldn't be here today."

Medics performed CPR for 50 minutes in total. After 30 minutes Willow regained consciousness for 10 minutes, but then crashed again and had to have CPR for a further 20 minutes. "It felt like 50 years," said Chloe. "At one point, they said they would try for five more minutes and she came back after three. I am so grateful they gave that extra five minutes.

"No one knew what was going on, we just knew she was very poorly. She had scans and was taken to the Children's Intensive Care Unit (CICU). We weren't allowed in, and I didn't even know if my baby was alive. That wait was the worst time of my life."

Willow stayed in CICU for eight days. Chloe said: "She then had an MRI to 'see how much brain damage she had'. Doctors were amazed there was none, after being starved of oxygen for almost an hour. I will never forget that conversation."

At five-weeks-old, Willow was discharged but Chloe remembers the fear she felt when her baby started projectile vomiting again two days later. Willow ended up back in Cardiac Paediatric Intensive Care and had an operation known as the Hickman procedure – which is where a central line catheter is placed on the right side of the chest wall to enable

long-term access to veins. A surgery her parents were told their baby desperately needed, but also told it wasn't advisable and incredibly risky for heart patients. An impossible decision that Chloe describes as another worst moment.

But being such a little fighter, Willow's surgery was a success. It was then, while recovering at hospital, that Chloe and Cole met Katie Brant, a Rainbows Nurse.

"Katie told me about Rainbows and explained how the charity could help us. Rainbows was a place that had never crossed my mind," said Chloe. "We were offered a week of step-down care after leaving hospital and before going home, and that really helped us as I was worried about being on my own with Willow."

"At Rainbows we were able to be a family again. All three of us slept in the same room and that was amazing, it was so nice to be together. It was so nice to not have to be doing everything as well. Our dinners were cooked for us and we could eat together in the Dining Room.

"Since that first stay, we love going to Rainbows. We have to be careful everywhere we go because of germs as Willow is so vulnerable. But at Rainbows, we always know she is safe."

"Willow also loves Rainbows, she is non-stop smiles when she is there. We can't take her to swim anywhere because temperatures are too cold and will shock her, but the Hydrotherapy Pool at Rainbows is so warm and Willow loves to go swimming."

"We also go to Baby Group, Coffee Mornings and Parent and Carer Group. These all really help me not to feel isolated and it is so nice to have adult conversation with others who understand."

Willow has eight lots of medication 14 times a day and sleeps a lot. But she is working hard to reach her milestones, despite her heart's limited capacity. Doctors are amazed at how she is doing and Chloe and Cole continue to be grateful for every day.



By donating £50,
you could help Nurses in our
Care Team to provide an hour
of care to families like Willow's:
rainbows.co.uk/donate

Thank you to our amazing supporters

Young supporter bakes to fundraising success

Lilah was so moved by an assembly about Rainbows that she decided to organise a bake sale – and used her birthday money to buy all the ingredients for her cakes.

Nine-year-old Lilah was among pupils at Scargill Church of England Primary School, in West Hallam, who were given a presentation about our Hospice from one of our Community Fundraisers, Nicola. Lilah, who is in year four, then decided to bake her own cupcakes for us. She was helped by her brother Jonah, who was in charge of the sprinkles.

Their mum Leanne said: “Lilah is quite a character. She came home from school after the assembly on Rainbows and she was non-stop talking about it. She wrote down ideas and decided to make cupcakes.

“She worked really hard and designed a poster. Myself and Jay, her dad, are really proud of her. We are proud of her every day, and she is always so kind and thinking about how she can help others. Because Rainbows is about children, she wanted to help more so.”

In total, Lilah and the school, which belongs to Derby Diocesan Academy Trust, raised £238.50 for our Hospice.



Fundraising milestone reached in memory of amazing Casey

Casey Forrest died in 2015 at the age of 24. She had Lissencephaly - a rare birth defect involving an abnormally smooth brain. Casey was supported by our Hospice.

Over the last nine years, her family has been raising money in her honour. Their latest donation of £600 from a charity boxing event, has taken their total to £13,176.

Casey's father, Trevor, said: “Casey was supported by Rainbows for two years. Rainbows was a big help to us and Casey loved going there. We used to go and stay as a family. We could just be a normal

family at Rainbows. We could just be mum and dad rather than being the carers.

“Rainbows was always there for us and is still always there for us if we need it. Fundraising is our way of saying thank you and it keeps her memory going. And being involved with Rainbows, helps us.”

In 2023, Trevor and a group of friends, climbed Mount Snowdon. Other funds over the years have been raised from events such as fancy-dress parties, a Wolf Run and bucket collections in Rugby, where Trevor always dresses up as Mr T from the A-Team.

“We are proud to raise money in her memory and we are well supported by friends and family,” said Trevor. “Every penny is for Rainbows and we just want to give thanks back. If we can help anyone else, other families, then that is what we want to do.”

How shopping at Rainbows supports local families:



£5 could pay for our Play Team to provide arts and crafts fun and learning



£10 could pay towards the upkeep of our lovely gardens surrounding the Hospice



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



£40 could pay towards amazing youth work or sibling support from our expert team

Rainbows Retail

High Value Items

Did you know you can donate high value items such as jewellery, watches, vintage clothing and pop culture items like Pop Figures?

These items can be sold on our eBay page and help us to support families from across the East Midlands through services such as our new Community Hubs.

These hubs take the Rainbows experiences to our families wherever they are and provide services like Complementary Therapy, Music Therapy and consultations with our Advanced Clinical Practitioners without our families needing to travel.

Find your nearest shop today at: rainbows.co.uk/shop

Rainbows opens new shops

We are delighted to announce since our last newsletter, we now have two new shops in Arnold and Long Eaton.

Since opening, both have been extremely busy and we would like to thank everyone who has supported us in opening the shops, providing stock and buying our goods. We are always blown away by the kindness and generosity of our communities.

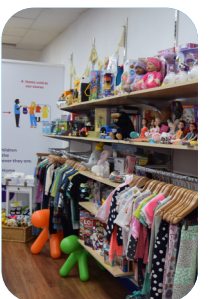
The new shop details are:

Arnold

Front Street
Arnold
Nottingham
NG5 7EJ

Long Eaton

34 High Street
Long Eaton
Nottingham
NG10 1HY





We care for babies, children and young people in the East Midlands – wherever they are.

Hospice | Hospital | Home

Volunteers Needed!

Our Volunteers play an important role in supporting families across the East Midlands.

Can you spare an hour or two to help brighten short lives?

Find out more:

rainbows.co.uk/volunteer
or call us on **01509 283 956**

Opportunities include:

- Bucket Collections
- Community Stalls
- Event Support (Stewarding/Registration/Refreshments)
- Shops (Customer Service/Donation Sorting and Steaming)
- Van Drivers
- Gardening
- Family Support
- Reception

And so much more...



rainbows.co.uk/volunteer

Rainbows is registered as Cope Children's Trust in England and Wales. Registered Charity No. 1014051.
Registered Office: Lark Rise, Loughborough, Leicestershire LE11 2HS.