

Issue One



Brightening short lives

## Newsletter 2023

### In this issue:

**Meet Katherine,  
one of our amazing  
Rainbows Nurses**

Page 4

**Check out our  
brand new line up  
of exciting events!**

Pages 5 & 6

**Meet Nevaiah,  
taking on every  
challenge with  
a smile**

Page 10



# Welcome to Rainbows

We are always in awe of the amazing ways in which people across the East Midlands support us here at Rainbows, and of course we are so grateful for every single mile run, hour volunteered and pound raised. In this issue you can see just some of what supporters across the East Midlands have been up to for Rainbows, and hopefully get inspired as to how you may be able to support us too.

We are now in year three of our five-year mission to provide 'The Rainbows Experience, Wherever You Are' for families across the East Midlands. This means families can access our vital services here at our Hospice building in Loughborough, in hospital, at home and out in the in the community.

The next two years will see big advancements, with Rainbows Nurses being placed in Northamptonshire, Derbyshire and Lincolnshire hospitals who will also work in the community. We are also formalising our plans to grow our Hospice at Home service, meaning specialist children's palliative care can be delivered within the family home. We also have plans to expand our community programmes, making our support more accessible for families.

It's an exciting time for Rainbows, and none of this would be possible without you, our incredible supporters who help us through fundraising and volunteering. Without the money you raise, we wouldn't be able to develop our support for families just like Eleni's featured on the next page - so thank you for being a supporter of Rainbows and helping us on this journey.

*Jane* - Jane Burns (Director of Supporter Relations)



## Screen star opens new Cinema Room

It was lights, camera, action at our Hospice as film and TV star, Rakhee Thakrar, opened a brand new Cinema Room.

For many of our families, going to the cinema is something they'll never get to do together. However, this new fully accessible, state-of-the-art Cinema Room makes it possible and can be adjusted according to the requirements of the baby, child or young person.

The room was created by Together for Cinema, an AV Industry 'good cause' enterprise, soon to be a registered charity, whose key focus is on designing and installing home cinema rooms in children's hospices. The items in the room were donated from various companies including Decorum who also completed the fit out.





# Meet Eleni

**“I honestly don’t know how we would have continued without the support of Rainbows,” said Eloise, mummy to three-year-old Eleni, who she describes as cheeky, sassy and with a beautiful soul.**

Eleni has a disorder that causes serious neurological problems and has up to 20 seizures a day.

Eloise said: “Life for Eleni started out the same as any newborn but concerns were quickly raised over the amount of time she was sleeping and not responding to feeds.

“We went for hospital tests. She was feeding when a doctor stopped in his tracks. I quickly passed Eleni to him and he put her on the bed and began resuscitating her. Eleni’s temperature was so low at 34.5 degrees and I watched in horror. A tiny Eleni was transferred to Intensive Care but she wasn’t waking up. She wasn’t moving and her breathing was being done by a ventilator. Myself and her dad, Neil, were terrified. We didn’t have a clue what was going on.

“At nine days old she was diagnosed with nonketotic hyperglycinemia; the prognosis was very poor. We were told that if she was to survive, she would live a life of seizures, be severely disabled and have not much quality of life. Because she wasn’t breathing on her own, we had no other option but to say goodbye.

**“At 11 days old, we gathered to say goodbye, including her then 14-year-old sister, Keira and her then four-year-old brother, Jenson.**

“Eleni’s ventilator was removed. I held Eleni waiting for her to let go. But she didn’t.

She didn’t go blue or struggle like we were told to expect. Her oxygen levels went up and she got stronger. We were waiting for the inevitable but in the back of my mind, I kind of knew. I knew deep down she wasn’t going to die. It didn’t feel like the end of her life.

**“She then went to Rainbows for end of life care. Eleni turned a corner at Rainbows. We didn’t have to do anything. I asked if I could try her on a bottle and she took it straight away. Her feeding tube was taken out and she did everything a newborn should. Eventually, we were allowed to take her home.**

“For 18 months, Eleni seemed to thrive. But for me, this was a cruel twist of false hope. I knew from talking to other parents of children with the same condition, that she would deteriorate.

“We decided to get support from Rainbows. I had avoided the hospice but I realised there was more they could offer, and it was different the next time. Jenson benefited from sibling support and we all got respite care.

“Rainbows generally makes life easier and helps us to get our heads around end of life care, which we know we will need one day.

**“Eleni loves it. She is very chilled and relaxed at Rainbows. Coming from a house of two boys – we now also have Billy, who is almost two – that are crazy, she loves the gentle atmosphere.**

“For now, we enjoy what we can. The future? I do think about it but then I kind of think, we will deal with that when it happens.”



# Before



## Supporter Rupert makes the 'hair'cut

**At the age of five, and during the first Covid lockdown, Rupert Pask decided to grow his short hair.**

Rupert's plan was to eventually be sponsored to cut his locks, donating the proceeds to our charity and his hair to Little Princess Trust – which makes wigs for sick children.

**So Rupert went to Alexander and Gregg Hair Co, in Loughborough, and his tresses were cut. He raised an amazing £1,056 for us.**

His parents, Andy and Faizia, were incredibly proud of their son. "Rupert has been very determined all the way throughout. He was awarded a kindness certificate from school," said Andy.

"Rupert chose Rainbows because we know the charity well and we really appreciate the work that Rainbows does. Also, one of our friends, Lauren was cared for at the Hospice, Sadly she died from cancer, aged 13, so Rupert wanted to do it for Lauren."



# After

**Want to fundraise  
for Rainbows?**

Contact our Supporter  
Relations Team by emailing  
**[supportercare@rainbows.co.uk](mailto:supportercare@rainbows.co.uk)**  
or by calling **01509 638 049**



# Meet one of our amazing Rainbows Nurses

**Katherine is one of our Band 6 Nurses and cares for the babies, children, young people and families who visit our Hospice.**

## **Tell us about your role**

I am part of the team who care for the families who come to Rainbows, helping each child or young person to try activities and therapies they want to do. I am often the shift co-ordinator on our Care Team, which means I ensure the shift runs smoothly as well as liaising with the other professionals who support our children and young people.

## **What difference do you hope to make to our families?**

I hope to make a difference to families whose children come to Rainbows for a break. I love helping families make memories and enjoy the relaxed atmosphere that Rainbows can offer.

I enjoy telling stories, singing and playing games with the children and young people while they are here. And for those who are here as they are coming to the end of their lives, I hope to be a caring, kind nurse who helps them feel comfortable and cared for.

## **Why did you apply for this role?**

I came to this role from a very happy job at a school for children with complex needs and after much thought, felt that I would like to be a Rainbows Nurse for the same reasons. It was a risk as I loved my old job, but it was definitely the right decision. The team are fantastic and I feel proud to be part of it.

## **You spend all day helping others, how do you relax?**

I love open water swimming in the summer, it helps me relax and makes me smile. I also enjoy painting and seeing friends.

## **Do you have a message for our supporters?**

My message to our supporters is THANK YOU! It is so important to be able to offer the experiences we do at Rainbows, and without you, we couldn't do it.

One of my favourite memories is when I was talking to a young person who had come to us after being in hospital for many weeks. I asked what they would like to do that day and they said "But what do the Doctors and Nurses need me to do today?" It was a joy to plan the day with them, not by what the medical team wanted but what THEY wanted to do. They decided to sit in our lovely garden and paint. We still carried out their care but let them decide how that worked. The young person relaxed and felt more in control of their situation. So to the volunteers who work so hard in our gardens and to the supporters who raised money for paints, thank you.

**Scan the QR code to watch Katherine's day in the life video!**





# 2023 Events

## Runners, bakers and superheroes unite!

From world famous runs to Peak District walks, bake-athons and more, there are lots of ways you can support our work during 2023. With more events being added throughout the year, make sure you keep an eye on our social media channels and website for all the latest events news.

### Open Day – Saturday 22 April

Our last Open Day was held in 2019, and as you may remember we unfortunately needed to cancel last year due to the passing of Her Majesty the Queen. We've taken the opportunity to review the date, and we're excited to let you know our next Open Day will be held on Saturday 22 April 2023! This means you'll get a chance to look around the Hospice, meet the team and find out how your support is making a huge difference.



### London Marathon – Sunday 23 April

Will you be on the start line running for Rainbows? This world-famous 26.2 mile route around the capital will see you run by some of London's most mesmerising landmarks, old and new.

**For those looking for a bigger challenge check out our trips with our partner organisation Adventurous Ewe on our website!**



Visit [rainbows.co.uk/events](https://rainbows.co.uk/events) to sign up for one of our super events today!

### Peak District Walk – Sunday 21 May

Experience the beautiful sights of the Peak District like never before, by joining us on one of our Peak District Walks. We've got two routes to pick from - a Treasure Trail or a Guided Walk - so choose your challenge!

### Leicestershire Golf Day – Wednesday 24 May

A little 'birdie' told us you're partial to a round of 18-holes... which is why we'd like to invite you to get your golfing gear out and enter a team into our 2023 Leicestershire Golf Day!

### Great North Run – Sunday 10 September

Spread the smiles as you complete the miles by running for Rainbows at the Great North Run. Every step you take during the most iconic half-marathon in the world will help to brighten short lives.

### Snowdon Trek – Saturday 23 September

View the sights of North Wales like never before! Along the way, you'll experience spectacular views and make new friends!

### Derby Golf Day – Friday 29 September

Join our annual Derby Golf Day at Kedleston Park Golf Club and enjoy this Am-Am Stableford competition on one of the finest courses in the Midlands.

### Derby Cathedral Abseil – Saturday 7 October

Calling all daredevils... we're excited to announce that our adrenaline-fuelled Derby Cathedral Abseil is back! Will you take on this 212ft challenge?





# Mansfield mum wins Hospice Lottery

A Mansfield mother who scooped £7,500 in the Rainbows Lottery is encouraging people to sign up and support those with serious and terminal illnesses in the East Midlands.

**Each week, the charity's Lottery has a jackpot of £1,000. There is also a second prize of £250, which is a rollover draw with the potential to reach up to £10,000. For every week the rollover isn't won, the prize increases by £250.**

Having a unique number in the Lottery draw costs **£1 a week**.

Winner Amy Davies said she was shocked to get the call and has put the money towards a planned house move. "When I got the call, because it wasn't a familiar number, it was really hard to believe," she said. "But I couldn't have been more delighted; I never win anything."

Amy signed up to the Rainbows Lottery in May at a Co-op in Mansfield.

She added: "It was something I had to do when the work of Rainbows was explained to me. I can't relate to what the parents of the children who use Rainbows are going through, but my two-year-old daughter was born 12 weeks early and spent a lot of time in hospital, so I have an understanding of how that feels.

"I would definitely encourage others to play if they can afford to. Not only might they be lucky like me, they will also be helping such an incredible charity.

**"When I went to the Hospice to collect the cheque, I was given a tour and it was such a beautiful and happy place. I will definitely be continuing to support Rainbows."**

Jennifer Varnam, Lottery and Supporter engagement Coordinator at Rainbows, said: "Every day our Lottery members are playing an important part in caring for children with life-limiting conditions. By joining our Lottery, you will be helping to make a real difference to local children and families who need our support the most."

Visit [rainbows.co.uk/lottery](https://rainbows.co.uk/lottery) to find out more about playing the Rainbows Lottery and how you **could win up to £10,000!**



# Children in Need at Rainbows

**We were TV stars in November as our charity featured on BBC East Midlands Today's Children in Need programme.**

The crew filmed its live 30 minute news programme from our Hospice and the show highlighted the work of our Play Specialist – which Children in Need funds.

There was also a showcase of all of our wonderful facilities along with interviews from children, young people and their parents.

Pudsey Bear also kept everyone at the Hospice entertained with his antics, including doing the Conga with the staff!



## Supporter Stories

**We now have electric car charging points at our Hospice thanks to a grant of £19,774 from East Midlands Airport (EMA).**

The money was from EMA's Community Fund as part of a pilot project to support community, charity and voluntary sector organisations to make the transition to more sustainable energy use.

The project included the installation of a three-phase fast charge unit, which will support two vehicles at any one time. This unit will be for parents and families who use our Hospice. A further two charging points, providing four outlets for our company vehicles and employee's own vehicles, were also installed helping us to reduce our carbon footprint and be more eco-friendly.

The electric wiring infrastructure was also put in place to enable more charging points to be added in the future to allow up to 18 spaces for parking and charging.



## Rainbows score with Notts County

Rainbows has scored an official charity partnership with Notts County FC.

The National League club has teamed up with our charity for the 2022/23 football season carrying out a range of activities to help raise funds and awareness of our Hospice and our work.



## Friends take on mammoth cycle for Rainbows

Eight friends completed a 150 mile Coast to Coast cycle challenge from Seascale to Whitby, in just one day, raising £6,724 for us.

Not only did they support our charity, Steve, John, James, Andy, Simon, Darren, Mark and Gareth completed the ride in memory of their friend Tony. Tony died of heart problems in July 2019, at the age of 49.

Team captain Steve said the guys trained hard with 50 plus mile training sessions at the weekends, combined with spin classes and circuit training. He added: "We did a similar challenge in 2021 and wanted to do another one in memory of Tony. He was our best mate; we all either went to school together or grew up together. It was devastating to lose someone before the age of 50.

"This also got us thinking about Rainbows and what those families have to go through and losses they face. We haven't been to Rainbows before but every time we met up to talk about potential fundraising, it was always Rainbows that came up. We are thrilled to have raised money for such a fantastic cause and we are very grateful to everyone who sponsored us for this challenge."







# Meet Nevaiah

**“Rainbows is amazing in every single way for us,” said Amandeep, mummy to six-year-old Nevaiah.**

“When her sister Aveena was born 14 weeks premature, life was tough. But we weren’t prepared for the journey when Nevaiah arrived three years later.

“Nevaiah was also born early by four weeks. She was starved of oxygen at birth due to complications, meaning she has a brain injury. We live with the fear that we could lose our little girl at any time.

“When she was born she was taken away to be resuscitated. We were told she was really poorly and were only shown photos of her, which was really hard. We spent three months in the Neonatal Unit and were told three times that she wasn’t going to make it. We sat in the car one night and planned our daughter’s funeral. I even went to buy her an outfit. But Nevaiah proved everyone wrong.

**“Looking after them both is hard. Aveena has Cerebral Palsy and brain damage from a bleed at birth. She has one kidney and will need a transplant. Even pushing a wheelchair and a pushchair to the park alone is tough. We knew we needed support and turned to Rainbows.**

“Initially we were concerned that no one could take care of Nevaiah like us. But after our first stay at the Hospice, we knew it was somewhere we could leave her and not stress about anything.

“The next few times we picked her up from Rainbows, she cried because she didn’t want to leave. During Covid, Rainbows stepped up for us as our existing care package collapsed. We know we always have Rainbows.

“Life is often scary for us. We’ve spent so many months in hospital, it has gotten to the stage where we don’t unpack our bags when we get home. One time Nevaiah was blue-lighted to hospital. We were told they held out no hope. Again she proved everyone wrong.

“Nevaiah was fitted with a tracheostomy but because the surgery was so urgent, we only found out after that we would never hear our baby cry again, which is so upsetting. After her operation, we could see tears rolling down her face but no noise.

**“At Rainbows the team are experienced with working with children with tracheostomies – which is so reassuring as we know Nevaiah gets the best care she possibly could.**

“Nevaiah is such a happy little girl, you go to her and she jumps and smiles. She will give anything a go to the best of her ability. She continues to amaze us.

“We don’t know what the future holds; it’s always in the back of our minds and there are good days and bad days. But the girls are both so happy. We give them everything a child should have and as parents, you just learn to cope.”

Visit [rainbows.co.uk/donate](https://rainbows.co.uk/donate) to support families like Nevaiah’s today!

# The difference your support is making...

## £6.6 Million

is how much it costs per year to run our services at and around the Hospice.

## 18%

We only get a little funding from government bodies, **roughly 18%**, which is enough to keep our doors open for about nine weeks. For the rest of our funding we rely on our supporters – **every gesture counts, every penny matters.**

**£10 could pay towards** the care of a child or young person being looked after by Rainbows staff

**£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

**£50 could pay for** a freshly cooked meal for all of our children and their families being looked after in the Hospice on any day

Visit [rainbows.co.uk/donate](https://rainbows.co.uk/donate) and become a regular donor to support Zoe (pictured) and other local babies, children and young people like her today!



We currently provide vital care and support for **300 babies, children and young people with terminal and serious conditions, and their whole family.**



[rainbows.co.uk](https://rainbows.co.uk)

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