

Issue Two



Brightening short lives

Newsletter 2023

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

I'm really happy to share with you some of the exciting developments that have happened at Rainbows, which means we are now able to reach more babies, children and young people who benefit from our support.

The first step of that has been putting Rainbows Nurses into hospitals. We've had Nurses in both University Hospitals of Leicester and Nottingham for two years now. They have transformed the support that we're able to offer to babies, children, young people and their families.

In the last 12 months our Nurses in hospitals have been in contact with over 2,400 families, often seeing families many times during their hospital admissions to give expert palliative care and advice, which is double what we had in the preceding year. We've also had 50 referrals to Rainbows; mainly for palliative care and advanced care planning support. Importantly, we're reaching far more babies than we used to, which is what we expected we would do. We're able to offer support to people when they really need it the most.

We have recently recruited a Rainbows Nurse, Karen Parsons, into Kettering and Northampton District Hospitals. She'll be working in the community as well; and you can read more about Karen's role on page 11 of this newsletter.

This is only the beginning of what we're trying to do.

Alongside our Nurses in hospitals, we have an exciting phase of work starting, which is our outreach project, and we're looking forward to sharing more information about this work in the near future.

None of this would be possible without the support of many people across the region, who are very generous with their time and money. On behalf of Rainbows, I would like to say a massive thank you for the part you're playing in enabling us to do all of this; it will make such a difference to babies, children and young people across the region.

Thank you for supporting Rainbows.

Anne-Marie

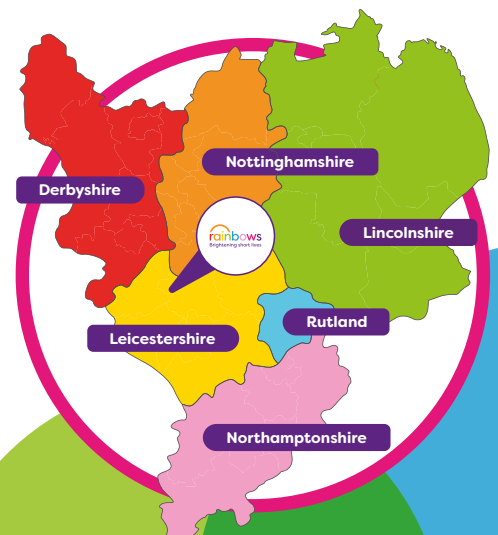
Anne-Marie Rosak

Head of Hospice & Community Services
Deputy Executive Nurse



Did you know?

In the last 12 months our Nurses in hospitals have been in contact with **over 2,400 families from across the East Midlands.**



Lucas' Story

Lucas was like any other nine-year-old boy. He was happy, active, noisy and loving. His family were looking forward to his imminent birthday but two weeks before the celebrations, mum, Kim, was given the devastating news that Lucas had a brain tumour.

She was told he had two years to live and there was nothing that could be done. The cancer was a very rare form with no cure. Surgery was never an option.

Sadly, Lucas died on 11 December 2022, seven months after his diagnosis. "I felt like we had been robbed," said Kim. "He never got to do a bucket list, we didn't have time to do anything with him. It was all so very cruel.

"Lucas was very chatty. He was a cheeky normal 10-year-old boy. He was hyper, very loving and an absolute pleasure to have around. There is definitely a big hole in the house.

"Lucas was never an ill child, I knew when he was ill because he wanted Mummy cuddles. When he began tilting his head to one side and being sick everyone thought he had an ear infection. But his symptoms persisted and worsened.

"Hearing the diagnosis was like they had pulled the rug from under our feet. He went downhill so quickly and by his birthday he was in a wheelchair. It was a very rapid tumour. He lost his mobility very quickly on one side and he was getting very painful headaches."

One day, Lucas caught a cold that affected him very badly, after that, he was unable to speak. He had lost his mobility and he communicated with his eyes. "The kid never shut up and then he couldn't talk, it was so hard," said Kim. "We knew the differences in him every single day. We knew when we woke up that he would have declined more."

Kim and Lucas came to our hospice in October 2022, Lucas never left. For an exhausted Kim, she was able to recharge her batteries and be mum rather than a constant carer as she leaned on our team.

"We came to Rainbows and we went swimming and he enjoyed a massage. Lucas loved coming to Rainbows. His older brother, Tyler, came to see him and they played in the pool together and I could hear the giggles. I hadn't heard giggles for a long time. A real belly giggle. I don't think he ever giggled again after that."

"At Rainbows I knew he was looked after. The support for Lucas and myself was amazing. His dad, Jamie, was also able to come at weekends. And Lucas' other brother, Rian, was also able to visit.

"One night, Lucas became unwell, I had been at home as I had a cold and didn't want to pass it on to him. The Rainbows Nurses called me to come in. I got there and climbed into bed with him and held him. Both Jamie and I were with him. When Lucas went to sleep I told him that I loved him so much and we will be okay if you have to go. Then I kissed him good night on the forehead then he went to sleep.

"The team at Rainbows are all amazing and they helped so much. It is like one big family."



Donate today and help Rainbows to provide bereavement support to families like Lucas':

rainbows.co.uk/donate



Run for Rainbows

Taking on a running challenge for our charity can be incredibly rewarding and we want you to be a part of it as you help to brighten short lives.

We have supporters who take on a vast range of running events from virtual challenges to running across deserts, from completing 10k races to experiencing full marathons. Whatever their challenge, our Community Team offers support every step of the way with training, fundraising or we are there for just a chat.

Neil Swift, our Supporter Care Fundraiser, personally looks after our London Marathon team, ensuring everyone has the best experience. He said: "This is an incredible event to be part of and we value the support of our runners immensely. Rainbows have a small number of charity places which are now filled, and we'd love to welcome TCS London Marathon 2024 ballot runners to our team.

"We will support you every step of your journey in the most positive way and I am always at the other end of the phone or email to help. In 2023, for the first time, we set up a London Marathon WhatsApp group, which was great for everyone and very popular as members can share their tips and experiences."

James took part in the 2023 event for Rainbows and said: "The sense of achievement is indescribable and the support you receive along the way from Rainbows is brilliant. I could not recommend this more."

Our current running opportunities include the Alton Towers 10k, the Barcelona and Paris Marathons, and the Hampton Court Palace 10k.

To run for Rainbows, visit rainbows.co.uk/events



Table Tennis Superstar

An 11-year-old whose passion for table tennis began on the dining room table during lockdown has raised £3,715.

Adam loves the sport so much he persuaded his dad, Laszlo to join him for a 12 hour table tennis marathon.

The event took place at Knighton Park Table Tennis Club, where Adam and Laszlo are members. To both their surprise, they almost doubled their target for our hospice.

Adam said: "It was the best day of my life. We can't believe how much we have raised, we thought we would struggle to get £2,000, so thank you to everyone who has donated.

Throughout the 12 hour day, the pair were supported by other players from Knighton Park Table Tennis Club, as well as friends.

Adam added: "I got to eat lots of sugar without being told off! Around the nine to 11 hour mark was the hardest and it felt like my arm was going to fall off, but then the last hour was great. I would definitely do it again but I am not sure Dad would."

Laszlo said: "I am amazed by everyone's generosity and kindness, we never thought we would raise so much money for Rainbows."





Famous faces visit Rainbows

We have been lucky to have welcomed some famous faces to our Hospice over the last few months.

Stars including Tom Grennan, Owen Warner, Jemma Donovan and Sam Bailey, have taken time out of their busy schedules to spend time with our babies, children and young people, staff and volunteers.

They also had tours of our Hospice learning more about our facilities and the work we do in the East Midlands.

Singer songwriter, Tom Grennan, visited just before his sold out show in Nottingham one Friday evening in March. He said: "It was amazing to be able to visit Rainbows and meet so many wonderful people and see the incredible work they do."

Owen and Jemma, who both star in TV soap Hollyoaks, visited in July and had a great time at Rainbows. For Jemma, who is the daughter of actor and pop star, Jason Donovan, and Owen, who also starred in I'm a Celebrity, our Music Room and Soft Play Room were particular hits.

Sam, who is one of our Patrons, loves spending time with us and was delighted to pop in again in June to see everyone and chat about fundraising.

It is wonderful to have the support of celebrities and we are very grateful for their visits which help to make a lot of smiles and create priceless memories.



Events

From festive fun with the family at one of our Santa Runs, to the daring challenges of our Firewalks, there's lots of fantastic fundraising events for you to take part in! Which events will you choose?

Santa Runs

Whether you want to hop, skip, dance or run "yule" be sure to have lots of festive fun at our 'mini looper' or 5km Santa Runs!

Loughborough Santa Run

Sunday 3 December 2023 - 11am
Loughborough Marketplace

Derby Santa Run

Sunday 10 December 2023 - 11am
Markeaton Park

Christmas Concerts

The best way to spread Christmas cheer, is to sing loud for all to hear... which is why this Christmas, we're inviting you to our Christmas Concerts. They'll be taking place at:

Derby Cathedral

Wednesday 29 November 2023

Emmanuel Church (Loughborough)

Wednesday 6 December 2023

Church of The Good Shephard (Nottingham)

Friday 8 December 2023

Northampton Cathedral

Friday 15 December 2023

Looking ahead to next year...

We have an exciting calendar of events planned for next year with our Open Day, Peak District Walks, Afternoon Tea, Loughborough Firewalk, Skydive Days and the Derby Cathedral Abseil, with much more still to come - so don't miss the opportunity to tick off that bucket list challenge or enjoy a special day with us in 2024!



Taking part in an event or fundraising activity for Rainbows? **Join our Facebook Group by scanning the QR Code.**



Firewalks

Can you handle the heat? If so join us for a night of fire and fun! No previous experience needed, as the pre-walk briefing session will make sure you have the skills and confidence to tackle the challenge of walking barefoot over coals.

Northampton Firewalk

Saturday 14 October 2023
Northampton Casuals Rugby

Derby Firewalk

Saturday 16 March 2024
Mickleover Golf Club



To sign up for one of our fantastic events visit **rainbows.co.uk/events** and help to brighten short lives from across the East Midlands.

Your regular gift will make a big difference at Rainbows

Your kind, regular gift would help us to pay towards the cost of providing emergency palliative and end of life care to babies, children and young people with serious and terminal conditions, like Lucas and Zoe whose stories feature in this newsletter.

With your support, we are able to provide care across five counties, covering the East Midlands. This means we can be there for families whether choosing to stay at home, in hospital or the Hospice itself.

What your monthly gift means for Rainbows...

£5 could pay towards arts and crafts materials for fun and memory making with our Play Team.

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

£20 could pay towards the care and support of a family who has been recently bereaved.

Regular donations are a vital source of income and help us plan for the future, ensuring we are here for all of our families.

If you would like to set up a regular donation please visit rainbows.co.uk/donate or call 01509 638 049

"At Rainbows the team are experienced with working with children with tracheostomies – which is so reassuring to us as we know our daughter is getting the best care she possibly could."

Rainbows Mum



Our amazing volunteers

Tarun has been a volunteer with us since 2010. He has done so many things including administrative support across various staff teams, dressing in costume at our events and assisting the retail team with deliveries and donations.

He said: "I love seeing the children and young people at Rainbows and seeing their happy faces. And knowing that I am giving something back is wonderful. Volunteering with Rainbows has given me the opportunity to see the inside of what a charity is like, and it is so welcoming."

Volunteers support everything we do at Rainbows, we have opportunities across our Hospice, the local community and retail where you can get involved in roles from gardening to administration.

Volunteers at the Hospice work as part of our wider team and help to bring smiles and laughter to our families, staff and visitors that access our services.

By volunteering with us, you'll become part of our amazing team. We have over 250 people who give their time, skills and experience to support us. **Without people like you, Rainbows simply wouldn't be here.**

There are so many ways to volunteer – so if you have a spare hour or a whole day to support us every week or once a year, we have an opportunity to suit you.

Visit rainbows.co.uk/volunteer to find out more today!



Our Magical Supporters

A couple who have been delighting audiences with magic shows for decades have raised more than £25,000 for our charity.

Clive Moore and Jean Ellis, of Derby, have been pulling it out of the hat and fundraising for more than 20 years.

“A lot of what we do is for charities, said Clive. “And in particular, Rainbows is a charity that we believe in and are very passionate about. The work that is done at Rainbows is incredible.

“We are delighted with how much we have raised for Rainbows and it has been a great pleasure and privilege to do it.”

Working with other magicians from organisations such as the Derby Magic Circle, Clive and Jean, who have been a couple for 30 years, have done a spell of shows including theatre and performances for children. They also give a History of Magic talk.

They have also made a lot of visitors very happy at the Rainbows Open Day, and other events, as they have performed as clowns.

Clive began his magical journey at the age of eight. He said: “When I was a child, I got a magic set as a Christmas present. My mother made me a cape and I was all set. My Uncle George, who was from Liverpool, was also a magician and I was in awe of him.”

Clive, who is a member of the Derby Magic Circle and the Northern Magic Circle, fondly recalled his favourite trick. “There had been so many different tricks over the years as magic is constantly evolving,” he said. “One of our favourites used to be an illusion where Jean was floating. Everyone loved that one.

“We do what we enjoy doing and it is wonderful as it also makes other people happy. Other members of the Derby Magic Circle are also keen to support Rainbows and we have worked a lot with Doug Gregg and Alan Humphries.

“Being involved with Rainbows is an honour and long may we keep on doing it.”

Alison Furlong, Head of Community and Events at Rainbows, said: “Clive and Jean are the most kind-hearted and caring people you are ever likely to meet. They’ve spread smiles and joy as they’ve entertained everyone aged from two to 102. We are so grateful to them both for all they do for Rainbows and I can’t wait to see them perform again!”

Did you know?

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 you, our amazing supporters.**

rainbows.co.uk/donate



Bereavement Support at Rainbows

Rebecca Sweetman joined us in January 2023 as our new Bereavement Support Lead.

“There’s so much to my role,” Rebecca said. “I recognise the importance of grief being seen and heard and provide emotional support on a one to one, or group basis, to bereaved families. I also run a monthly Bereavement Group for parents, which offers them a safe space to express their grief and connect with other bereaved parents. Currently, I am delighted to be setting up a counselling service.”

Our annual Remembrance Day is an established event at our Hospice. With the support of her colleagues, Rebecca organises this. “This is a very special time where bereaved families come together to remember, give thanks and celebrate the lives of their babies, children and young people,” said Rebecca. “They do so with words, music and candle lighting. We also offer a Christmas event, held round the Christmas tree in our Remembrance Garden, with lights, carols and hot drinks.

“Throughout the year we also invite families to create a glass leaf in remembrance of their baby, child or young person.

“These special, colourful leaves then get added to our wonderful tree sculpture in the Remembrance Garden.”

Alongside our families, Rebecca – who is a qualified Drama Therapist and has spent her career providing therapeutic and practical support to vulnerable people – is also a pillar for the emotional wellbeing of our staff.

“Another big part of my role is supporting our staff in their important and skilled work with bereaved families, again on a one to one or group basis or through training sessions,” said Rebecca.

“As all Rainbows staff have a role to play in the different areas of bereavement support, it’s important that there’s a Bereavement Support Lead to coordinate what, how and why we do what we do. I strive to ensure we are best meeting the bereavement needs of our families to support them in whatever way we can.”

Your chance to win with our Rainbows Superdraw!

Play our Superdraw for your chance to win £3,000 or our exciting new holiday prize to Italy.

Our annual Rainbows Superdraw has raised over £235,000 since 2015.

This year, we’re letting the lucky winner choose their prize. Either a cash prize of £3,000 or a seven night holiday to Italy for two people, thanks to our friends – and sponsors of the Rainbows Superdraw, Riviera Travel.

There’s also the chance to win other cash prizes, ranging from £50 to £250.

The Italian holiday will see you and one guest enjoy Lake Garda, Venice and Verona on an escorted tour, with breakfast and dinner included. You’ll also get to marvel at the breathtaking alpine scenery of the Dolomites and visit a local vineyard.

The trip includes return flights from East Midlands Airport to Milan Bergamo, with an item of checked/hold baggage each, and all tax included. Transfers between the airport and hotel in Italy; plus seven nights in a superior double/twin room, with a lake view at the four-star superior Europa Hotel. Departing from East Midlands Airport on Monday 29 July 2024 and returning on Monday 5 August 2024. Terms and conditions apply, including providing your own travel insurance.

Buy your Rainbows Superdraw Tickets today for your chance to win: **rainbows.co.uk/superdraw**





Zoe's Story

Abigail watched her unborn baby's heart take its final beat during a scan and thought she would never again feel such an unbearable pain.

But she had to keep strong as her baby, Zion, was a twin. Zoe was born a few days later at 26-weeks-old. For Abigail, her husband Jeremiah, and their young daughters, Samantha and Joan, their world continued to be thrown into turmoil as Zoe's health continued to deteriorate. But tiny Zoe was a fighter.

"We were told so many times that she wouldn't make it, but we kept going and refused to give up," said Abigail. "We were with her every day. I knew that she was always happy when we were around, even though she was in so much pain."

"We came home from hospital just before her first birthday and was referred to Rainbows. I was ready to accept any kind of help. I was put in touch with a Family Support Nurse who was so nice and helpful."

During her year in hospital, Zoe had a Tracheostomy and Gastrostomy and she is fed through a tube. She also has very weak muscles and endures a lot of physiotherapy.

"During my pregnancy with the twins, I felt completely exhausted and had high blood pressure," said Abigail. "At 23-weeks pregnant, doctors realised Zion was very sick. One night, I was struggling so much. I woke and could feel one twin wasn't moving. A few hours later, while having a scan, I watched my baby's heart take its final beat. I just didn't know what to do or how to react. I felt like I was in space unable to respond. I literally saw her heart stop beating."

Then Abigail became very ill and was advised to give birth to Zoe in order to save her own life. "Two weeks after her sister had given up and I was emotionally drained, I gave birth to Zoe via a C-section," she said. "It was a very strange time. I was scared and sad. I didn't know whether to cry or scream. I was just there."

For the family, life has been a struggle and they have all benefitted from the support of Rainbows. Zoe, who is now two-and-a-half, simply loves our Hospice and its staff.

"Rainbows has taken care of us so well," said Abigail. "When you see people who are so nice, you know they will look after your child with kindness and sincerity. I knew that I could relax and the first night we stayed at Rainbows, I couldn't wait to get to bed so I could actually sleep. That was the first time I had been away from Zoe but I had confidence that they would look after her. There was always someone there by her side making sure Zoe was okay."

"Rainbows has also been really beneficial for my other daughters as they take part in activities at the Hospice and they know there are people around them who care and understand."

"Sometimes this life is so unpredictable, I learned to try my best, even if you don't know the end result. Zoe makes me so happy, she is so resilient and always smiling."

Donate and help to brighten short lives at rainbows.co.uk/donate



Meet Karen, our new Clinical Nurse Specialist in Paediatric Palliative Care.

Karen is employed by Rainbows but works for the University Hospitals of Northamptonshire NHS group and Northamptonshire Healthcare Foundation Trust. She is part of our Nurses in Hospitals team as well as the larger Palliative Care Team at our hospice.

Working across Northampton General Hospital, Kettering General Hospital and Northamptonshire Healthcare Foundation Trust, Karen works with babies, children and young people with serious and terminal illnesses, who need the support of our expert team as well as supporting referrals to our Hospice.

With 26 years of experience in her field, Karen provides a different approach to care, a holistic one, which takes into account the child's family and offers support to them too. Karen is part of the 'face of Rainbows' in the hospitals but has a large expert multi-disciplinary team behind her at the Hospice and across the NHS Trust.

From diagnosis to end of life, Karen is alongside the family on their journey, parallel planning, liaising with other teams and ensuring Rainbows' services and therapies are offered not only at the Hospice, but also in hospital and at home.

Another aspect of her role is identifying new families, reaching out to those who may not know about our charity, and making sure they are referred to us to access the support they need. She can explain the wide range of services available from us and what can be offered at home or in hospital. She is also an advocate for families and bridges the gap between services to ensure they are being cared for in their preferred place.

Karen said: "It is about helping the families to find a way through the stress and emotions of caring for their child. I value the ethos of Rainbows and this role is all about very important choices for the families, ones they may not have known existed – whether that is at Hospice, hospital or home.

"I love the uniqueness of this role and recognise the gap for Northamptonshire in ensuring families know about Rainbows. I will provide holistic support for emotional, physical and spiritual needs of the whole family and I look forward to working within the community."

"It is about helping the families to find a way through the stress and emotions of caring for their child. I value the ethos of Rainbows and this role is all about very important choices for the families, ones they may not have known existed – whether that is at Hospice, hospital or home."

Karen Parsons

Clinical Nurse Specialist - Northamptonshire



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.

Do you book with Riviera Travel?



If you mention our name when you book, they will donate 10% of the cost back to Rainbows!

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14 day river cruises from **£2,469pp**



To find out more or to book:
Visit **rivieratravel.co.uk/rainbows**



Some elements are not commissionable – for full details see RivieraGroups.co.uk.
Riviera Travel retain the right to withdraw this offer at any time. Please remember to mention 'Rainbows' and your group name at the time of booking.

