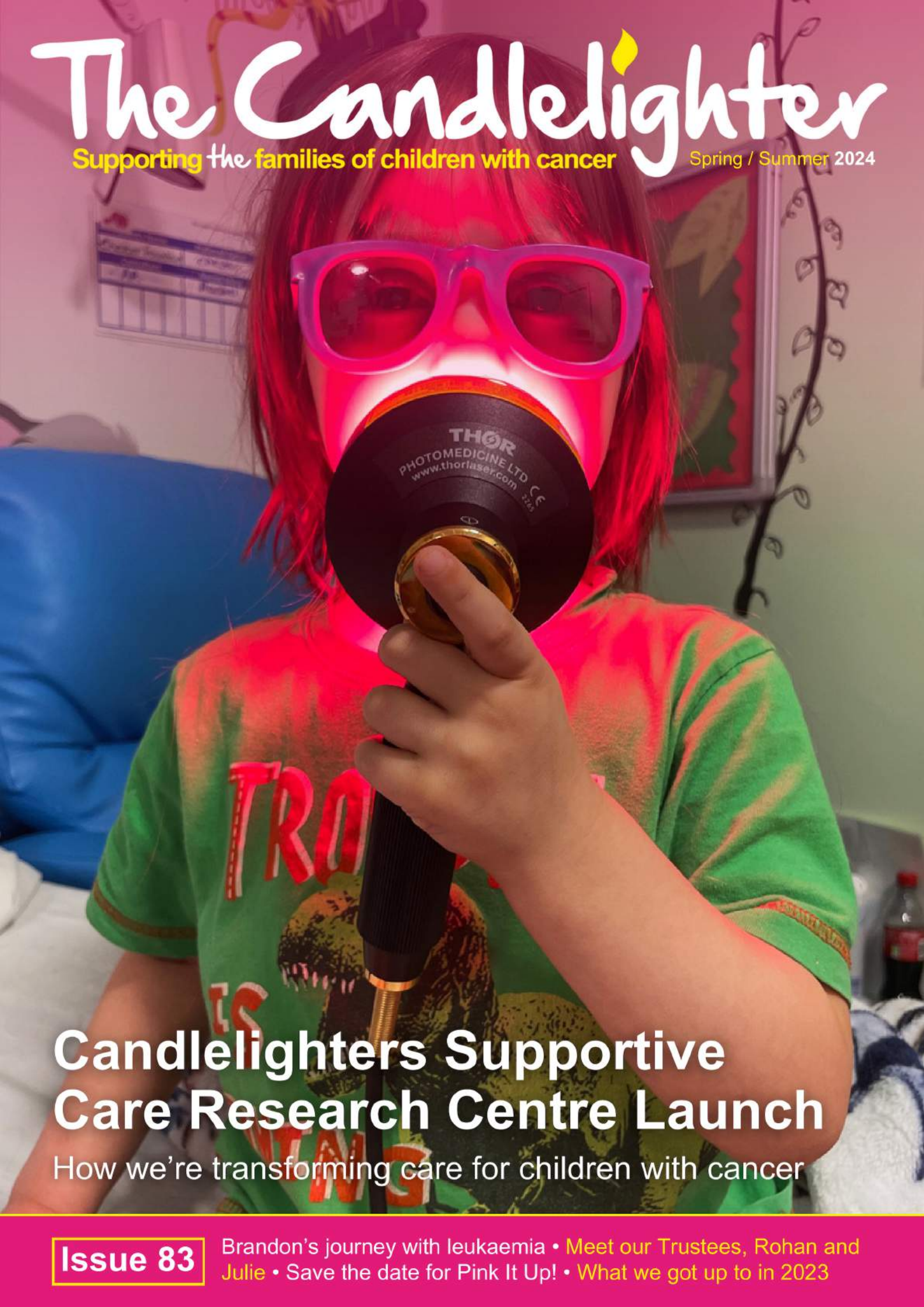


The Candlelighter

Supporting the families of children with cancer

Spring / Summer 2024



Candlelighters Supportive Care Research Centre Launch

How we're transforming care for children with cancer

Issue 83

Brandon's journey with leukaemia • Meet our Trustees, Rohan and Julie • Save the date for Pink It Up! • What we got up to in 2023

Hello

Welcome to our Spring/Summer 2024 Newsletter!

We're so excited to tell you about our most recent updates from Candlelighters, including our newest project launch: the **Candlelighters Supportive Care Research Centre**. This exciting partnership with the University of York saw us opening a new Centre to progress research that will save lives, reduce suffering, and bring hope to children with cancer. Supportive care includes treating side effects, managing pain, and reducing infection. Read about this wonderful work and the aims of the Centre on pages 4 & 5.

Our Trustees, Rohan and Julie, have told us about their roles and what they hope the future will bring for Candlelighters (page 6), and Samantha, mum to Brandon, from Cottingham, East Yorkshire, tells us about her family's journey with childhood cancer (pages 8 & 9).

As always, we're so thankful to you for your continuing support every year, from donating and taking on amazing fundraising challenges, to spreading awareness, volunteering, and all the other countless ways you have been part of the Candlelighters family. Your help means we can provide our services to families of children with cancer. You can read about what you have made possible throughout this issue!

Enjoy the read!

Emily

Candlelighters CEO

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Some wonderful ideas for a new Candlelighters Supportive Care Research Centre logo came from our first ever research group on Saturday 20th January... read more about the project on pages 4 & 5!



Thanks to you

Your generous support enables our team to be there to make the everyday of living with cancer a little more bearable. Here are some of the ways you've helped us do that recently...

Bell-ringing at The Square

In 2023, we began offering bell-ringing ceremonies for families to commemorate important milestones in their loved one's journey and mark the end of their treatment! Complete with refreshments and music, these occasions are a lovely space for families to celebrate and reflect.



Pottery Painting

Our 'Very Important Patients' (VIPs) had a wonderful morning pottery painting at our patient group! These groups are a safe place for children to chat with others who are in hospital and explore any worries they may be facing. We always make sure we have lots of fun and laughter in our groups which are held throughout the year.



Christmas grants

In December, 240 Christmas grants were processed. You helped to provide some relief to families who may be struggling while their child is on treatment. At Christmas, emotional, practical and financial support can be needed more than ever.



Wellbeing in the hospital

One patient had a gentle wellbeing appointment on the hospital ward with Kelley, one of our massage therapists, as he wasn't able to come to The Square. Kelley visited him and his mum at his bedside to provide a relaxing hand and foot massage which gave him a moment of calm during his treatment. The procedure even sent him to sleep!

Thank you!

Your support ensures families do not have to go through the devastation of a childhood cancer diagnosis alone. Donate to provide vital support for families by scanning the QR code!





Saving Lives, Reducing Suffering, Bringing Hope

In the last 25 years alone we have invested over £11m into childhood cancer research, to improve early diagnosis, survival rates, treatments, and develop experts for the future. Now, we've taken our commitment to the next level, establishing the Candlelighters Supportive Care Research Centre.

Amazing progress has been made in understanding and treating childhood cancers, and today, around 80% of children or young people diagnosed with cancer survive.

But despite advances in curative medicine, little has been done to improve the experience of living through and beyond cancer for children and young people. Children often receive cancer treatments designed for adults, and the impact on their smaller bodies can be severe. Many suffer horrible side effects, which can be traumatic, permanent, and, in some cases, deadly. Shockingly, of all children who sadly die with cancer, **1 in 3** die not from the cancer but because of the side effects of their treatment. Knowing how to manage side effects is a top priority for children, young people and families – but their questions often go unanswered.

Meet Ralph

Six-year-old Ralph has T-cell lymphoma.

The treatment he's receiving is incredibly effective; it began immediately, and he is responding well to it. But it's shocking to see what the side effects are doing to his little body.

The chemotherapy is aggressive and makes him sick. It decays his teeth and five have to be removed. His skin is sore and painful to touch. His immune system is severely suppressed, and he develops sepsis. If the side effects of Ralph's treatment aren't controlled properly, there's even a risk he could die.



Saving Lives, Reducing Suffering, Bringing Hope

The Centre

We urgently need ways to care for Ralph and children like him, that will limit their side effects, reduce their suffering, and improve their quality of life and chance of survival. The care they need doesn't exist yet – but it will.

We've established the first Candlelighters Supportive Care Research Centre (CSCRC) at the University of York.

The CSCRC will enable the world's leading supportive care experts to carry out high-quality research. It will invest in future supportive care specialists. And it will save lives, reduce suffering, and bring hope to young people with cancer – not just in Yorkshire, but around the world.

What is supportive care?

Supportive care is everything except the treatment of the cancer itself. Supportive care includes preventing side effects of treatment, managing pain, and reducing infection. It's the care that gives children as full a life as possible.

The centre will be led by Prof Bob Phillips and Dr Jess Morgan, and will look at how we can improve interventions and address side effects, for children and young people. **We believe our Research Centre can change the landscape of cancer care and transform what it means to undergo cancer treatment as a child.**

Supportive care isn't just a fluffy extra. It can save lives.

Professor Bob Phillips



Dr Claudia Heggie demonstrating a treatment for severe mouth ulcers on the Lord Mayor of York, Chris Cullwick

The launch

The centre was officially launched in November 2023 at the University of York. It received international news coverage as a landmark event in the progression of supportive care research. In attendance were researchers, care professionals, businesses, local officials, and families, all united by the desire to work towards a brighter future for children and young people with cancer.

Just the start

In the coming years, we will work to make the Candlelighters Supportive Care Research Centre a world-class centre of excellence, producing high-quality research and developing experts of the future. We are determined to develop effective, kinder care for young people with cancer.

Sign up to email updates about the Candlelighters Supportive Care Research Centre here:



Meet our Trustees!

Rohan and Julie tell us about themselves and why they joined the Candlelighters board!

Rohan Randhawa

Can you tell us a little bit about what you do? I currently work as National Manager for the charity arm of the English Cricket Board, that requires me to work with many different partners across the country.

What made you want to become a Candlelighters Trustee? Becoming a Trustee of Candlelighters is one of my proudest achievements to date as it allows me to give back to a charity that has helped me and my family. In June 2004 at the age of eight years old, I was diagnosed with stage three Hodgkin's lymphoma which was the start of a long, hard journey that took a significant toll on my, and my family's, wellbeing.

Candlelighters supported my family throughout the years I spent at St James's Hospital in Leeds by assisting with accommodation and providing ongoing family support. I'm extremely grateful for the charity as the care provided by Candlelighters made a significant, positive impact on our lives.

Now, at the age of 27, I can use my experience to inspire and motivate others going through similar challenges. Through being part of the Trustee team, I hope to bring comfort, hope, and positivity to young cancer patients and help them see that there is a light at the end of the tunnel.



Julie White

Can you tell us a little bit about what you do? I'm very privileged to be Candlelighters Lead Nurse for Children & Young People with Cancer at Leeds Principal Treatment Centre and for the Yorkshire & Humber Children, Teenage & Young Adult Clinical Network. A challenging title to fit on a name badge!

I have 23 years of experience working with children and young people with cancer. This helps me provide nursing leadership in delivering services at Leeds Principal Treatment Centre and across the Yorkshire & Humber Network. Most importantly, my job is to ensure that children's, young people's, and their families' voices are central in everything we do now and in the future.

What made you want to become a Candlelighters Trustee? I've strongly supported Candlelighters since my first introduction to the charity in 1993. I wanted to become a Trustee because children, young people and their families are at the heart of all they do. I hope my expertise, enthusiasm and commitment can contribute to Candlelighters' purpose of bringing light and hope to every family affected by childhood cancer across Yorkshire!



Donations in memory

from July 2023 - December 2023



Donations in memory are so precious. Whomever your donation remembers, we thank you for this very special way of showing your support.

| | |
|---------------------------|------------|
| Abbass | £30.00 |
| Abigail Rose Haley | £20.00 |
| Adam James Marshall | £40.00 |
| Adam Scarfe | £15.00 |
| Alayna Kamran | £37.50 |
| Albie Sugden | £5,022.56 |
| Alfie Musgrave | £350.00 |
| Alistair Hathway | £20.00 |
| Amanda | £50.00 |
| Amna Zaheer | £200.00 |
| Ann Rymer | £10.00 |
| Archie Vaughan | £300.00 |
| Barbara Stephenson | £284.25 |
| Beaty Lee | £125.00 |
| Belle & Neve Boitelle | £200.00 |
| Brett Woodfine | £120.00 |
| Bryan & Ann Elletson | £207.50 |
| Caroline Thompson | £165.00 |
| Catherine Hamilton-Sturdy | £187.56 |
| Charlotte Slater | £755.00 |
| Chris & Chloe Smith | £370.00 |
| Chrissy (C.C.) | £15.00 |
| Christian Buckley | £120.00 |
| Christian Milner | £2,030.00 |
| Christopher Chapman | £2,118.19 |
| Christopher Fewlass | £40.00 |
| Christopher Groves | £18.75 |
| Christopher Preston | £5,671.25 |
| Claudia Verdure | £6.25 |
| Colin Wilks | £232.00 |
| Daisy Morton | £2,197.05 |
| Daniel Bayes | £75.00 |
| Daniel Jackson | £75.00 |
| David Coopland | £18,150.00 |
| Dawn Harman | £398.50 |
| Dominic Roberts | £500.00 |
| Donald Wilson | £565.00 |
| Donna Flynn | £125.47 |
| Doris Arnold | £12.50 |
| Edith Wilson | £31.25 |
| Eileen Patton | £25.00 |
| Ella Crann | £472.50 |
| Ella Halliday | £50.00 |
| Elsa McGee | £647.00 |
| Eve Stainsby | £107.50 |
| Finlay Nuttall | £125.00 |
| Freda Jenkinson | £100.00 |
| Freya Lewis | £262.50 |
| George Harker | £37.50 |
| George Paton | £311.47 |
| Grace Wheeldon | £436.25 |
| Graham Elliott | £125.00 |

| | |
|------------------------|------------|
| Guy Metcalfe | £6,987.67 |
| Harrison Torr | £37.50 |
| Harry Buckley | £302.50 |
| Harvey Kendrew | £107.00 |
| Harvey Pettit | £130.00 |
| Hayley Rachael Blogg | £50.00 |
| Heather Hillard | £200.00 |
| Heather Rhodes | £694.27 |
| Helen Smith | £300.00 |
| Helen Louise Walker | £62.50 |
| Helen Wright | £332.00 |
| Henry | £18.75 |
| Henry Hamer | £37.50 |
| Holly Price | £112.50 |
| Hope Rooms | £37.50 |
| Hughie Wilson Eyles | £1,306.00 |
| Ian and Barbara Benton | £30.00 |
| Imogen Murray | £80.00 |
| Isabelle Ellis | £40.00 |
| Isla Greenwood | £5,584.11 |
| Jack Gales | £150.00 |
| Jack Ounsworth | £32.00 |
| Jack Waring | £125.00 |
| Jackie Gough | £25.00 |
| Jacob Ullah | £2,412.66 |
| Jaiden Worrall | £35.00 |
| James Brook | £2,748.70 |
| James Haige | £1,000.00 |
| James Wilson | £300.00 |
| Jane Eyre | £300.00 |
| Jayne Victoria Hewson | £50.00 |
| Jean Askham | £32.00 |
| Jenny Rose | £32.00 |
| Jimmy Wilson | £25.00 |
| Joan Haxton | £40.00 |
| Joan Jowett | £280.00 |
| Joanne Harker | £2,969.75 |
| John Dunnill | £680.00 |
| Joseph Mayman | £175.00 |
| Joshua Kinnear | £83.75 |
| Kate Burns | £25.00 |
| Kathleen Adcock | £150.00 |
| Katie Greene | £157.00 |
| Katie Raw | £6.25 |
| Kenneth Chapman | £31.25 |
| Laura Hart | £12,152.72 |
| Laura Loftus | £15.00 |
| Lauren Kisby | £1,592.50 |
| Lauren Young | £270.00 |
| Leslie Crabtree | £187.50 |
| Lewis Lightowler | £541.25 |
| Lewis Mangham | £229.37 |
| Lucy Moore | £1,462.50 |
| Lynda Merriman | £65.00 |
| Maci Craddock | £261.25 |
| Malcolm Clark | £25.00 |
| Margaret Garbutt | £295.00 |
| Margaret Walker | £37.50 |
| Marianne Shackleton | £198.00 |
| Marion Stanley | £381.25 |
| Marjorie Howley | £92.50 |

| | |
|---------------------------|-----------|
| Mark Butterfield | £793.05 |
| Mark Rennison | £777.00 |
| Mary Hartley | £165.00 |
| Matthew Marsden | £62.50 |
| Maureen Bradbury | £31.25 |
| Michael Norfolk | £700.00 |
| Muriel Coulam | £50.00 |
| Musadique Ahmed | £135.00 |
| Nick Gill | £5,000.00 |
| Noel Rigg | £713.13 |
| Nola Shipley | £62.50 |
| Nova Yates | £25.00 |
| Oliver Field | £70.00 |
| Olivia Arnold | £1,682.50 |
| Olivia Crook | £900.00 |
| Owen Paul Dubber | £250.00 |
| Paris Somma | £534.83 |
| Pat Smith | £187.50 |
| Paul Shardlow | £75.00 |
| Peter Bray | £50.00 |
| Peter Radcliffe | £543.83 |
| Peter Woodmansey | £1,020.00 |
| Poppy Scaife | £30.00 |
| Pru Walker | £75.00 |
| Raymond Deighton | £283.00 |
| Rebecca Jayne Varney | £18.72 |
| Richard Bainbridge | £542.80 |
| Rita Cuthbert | £32.00 |
| River | £18.75 |
| Robert & Kathleen Hartley | £62.50 |
| Robert Blundell | £188.00 |
| Rocky Redman | £116.25 |
| Rodney Victor Hudson | £100.00 |
| Roman Blu Callum | |
| Greenwood | £3,100.00 |
| Rory Welsh | £312.50 |
| Rosaria Pannocchia | £177.25 |
| Ross Burgess | £40.00 |
| Sadie and Lawrence Todd | £207.50 |
| Sandra | £15.00 |
| Sarah Louise Potter | £40.00 |
| Sebastian Smith | £648.00 |
| Shaun Markey | £62.50 |
| Shirley Hampson | £280.00 |
| Sienna Shield | £802.50 |
| Skye Sutcliffe | £403.00 |
| Sophie Watt | £314.00 |
| Stephen Smith | £18.75 |
| Steve Hutton | £350.00 |
| Summer Rose Thompson | £62.18 |
| Thomas Cammack | £62.50 |
| Thomas Herbert Codling | £531.00 |
| Thomas Hudson | £551.25 |
| Thomas Hutchinson | £137.50 |
| Trevor Wheller | £185.00 |
| Val Allan | £25.00 |
| Virginia Payne | £125.00 |
| William Telfer | £50.00 |
| Winifred Impey | £6.25 |
| Zack Barrett | £1,159.88 |
| Zoe Kilby | £871.51 |

Brandon's Story

told by mum, Samantha

Brandon, from Cottingham, East Yorkshire, was diagnosed with leukaemia in early 2022.

Brandon got a cold that he just couldn't shake. His symptoms clung on: his cough was not getting any better, he lost his appetite, he was sleepy, and kept getting bouts of diarrhoea. I took him to our GP twice: the first time they said it was a viral infection which would clear up on its own. A week later I took him back and he was prescribed antibiotics. This seemed to perk him up a little, but it didn't last. His brother Elliot's fourth birthday party came around, and Brandon spent most of the day in bed.

I got an appointment with the out-of-hours GP the next day, a Sunday, because on top of all the other symptoms he'd now developed a rash on his chest. He didn't know what was wrong, but he sent us to Hull Royal Infirmary for further investigation. They took bloods and a couple of hours later, a consultant came and told me that Brandon almost certainly had leukaemia. Brandon and I were taken to Leeds General Infirmary in an ambulance. The weeks after first getting to Leeds were a whirlwind of consultant visits, mind-boggling information, and constant treatment from nurses.

"Prior to Brandon's diagnosis, childhood cancer had never been a thought."

This was the stuff of nightmares. Elliot went to bed the night before his birthday with Brandon and I missing and woke up on his birthday with his daddy gone and his grandma home instead. Both Chris, my husband, and I were signed off work. I stayed in hospital the whole time with Brandon; Chris would drive every day from our home in Cottingham. More often than not, he would have to pay for parking on top of fuel. Chris went home every day to be there for Elliot, to try and keep things as normal as possible for him. I only saw Elliot on FaceTime calls. We were very grateful for the Candlelighters new patient grant we got, it all helped with travel costs for Chris.

Prior to Brandon's diagnosis, childhood cancer had never been a thought. It isn't talked about very much. Due to the nature of Brandon's diagnosis, everything happened very quickly. There was no time to process anything, we were just given

information and watched things unfold.

We were in hospital initially for five weeks, during which Brandon had his first round of chemotherapy. Being allowed home for five nights was the most amazing feeling. Then, it was back to start chemo round two.

Brandon got an infection after his immunity was wiped out. He was moved into an isolation room and we waited a whole day for there to be space in surgery for him. It was the longest day, waiting, watching him shivering in bed getting worse and worse by the minute. After surgery, he was taken straight into the Paediatric Intensive Care Unit (PICU) to treat his sepsis. When I first saw Brandon in there, my whole world crashed around me. There were so many machines: drips, syringe drivers, monitors... and I couldn't stay with him. I had to leave my baby there. Unbelievably, this wasn't the worst.



Brandon spent three weeks in PICU before he was well enough to go back onto the ward, and he had to learn to walk again. After spending the best part of three weeks sedated and immobile, Brandon's muscles had weakened and relaxed. He couldn't even sit unaided.

"The presence of Candlelighters made things feel a little less clinical."

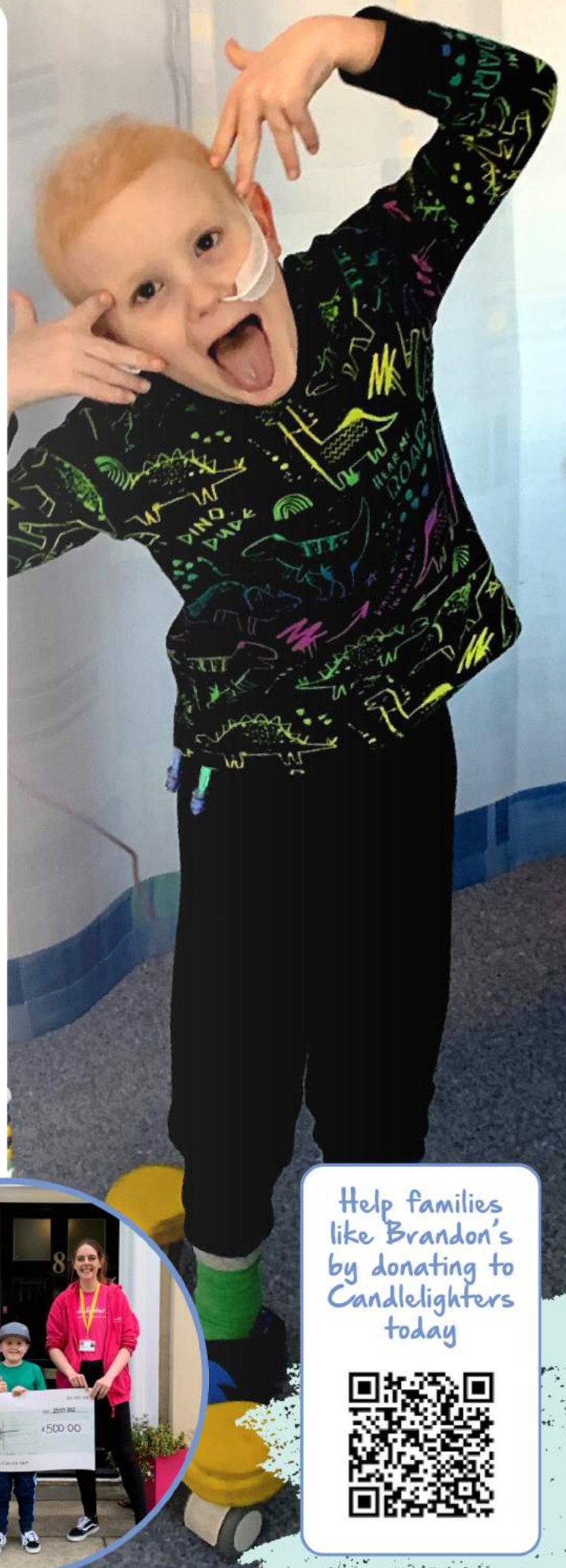
Candlelighters introduced themselves shortly after we first arrived in Leeds. Elaine [Candlelighters' Dinner Supervisor] popped her head in every morning and brought me some food - she could see I wasn't eating after we were first admitted. The Candlelighters' visits soon became a highlight for Brandon. He loved playing with Family Support Worker Ryan, which gave Chris and I a chance to have a break for an hour.

Candlelighters have been there for us since we first arrived in Leeds and are always a friendly face when we go back into the clinic for check-ups. We've been on a Candlelighters-funded holiday to Center Parcs when Brandon was well enough, which felt amazingly normal! I got talking therapy sessions and even had a massage - hospital beds can really wreck your back!

On the wards, the presence of Candlelighters made things feel a little less clinical. The kitchen area gives parents space to make drinks and food and to be able to step out of the room for a short while when needed. It was really nice to see someone who wasn't medical, who just wanted to see us, check in on us, and play with Brandon.

Brandon has been an outpatient since September 2022, and he was able to start back at school in January 2023. Since then, it's been onward and upward for Brandon and his recovery. Looking at him now, you wouldn't believe the year he had, and we are incredibly grateful to everyone who helped with this.

We fundraise for Candlelighters as a family because the charity is worth its weight in gold. Candlelighters played a big part in our journey and without them, it would have been unbearable.



Help families like Brandon's by donating to Candlelighters today



Pink It Up! 2024

Save the Date

JUNE
3-9



Join in with our annual Pink It Up fundraising week!

Raise money to support families and fund vital research by taking part in some pink fundraising! Head to our Pink It Up webpage for all the ideas and tools you'll need to get started...



Celebrating YOU



▲ **Rebecca Haestier raised money by swimming 20 lengths with two broken legs!** Rebecca, 14, had a cancer scare and met Candlelighters while she was in the hospital. She got the all clear, but decided she wanted to help raise funds after seeing what the Family Support Workers do on the wards. She raised £2,760 swimming with her two broken legs in cages.



▲ **In 2023, Bed Kingdom joined Club Candlelighters as Guardians** – pledging to raise £5,000 a year for three years.



▼ **The fabulous Team Hattie have raised £13,000 so far through a variety of activities,** including a walking marathon from York to Leeds, the Rob Burrow Marathon, Hattie's grandad and cousin shaving their heads, and bake sales.



▼ **Five-year-old Elsie, sister to Ted, wanted to do a challenge in support of her brother being so brave while he was in hospital with neuroblastoma.** She ran one mile non-stop and raised an incredible £1,123!



◀ **In recognition of the support Candlelighters provided for eight-year-old Isla and her family, and in dedication to Isla's love for dancing,** Wakefield Trinity Community Foundation and DanceXplosion hosted a 12-hour dancing event, with fun party games and workshops alongside the incredible feat. They managed to raise an amazing £3,927!



▲ **A group of friends, including Emma, mum to 18-year-old Rowan, who was diagnosed with angiosarcoma in March 2023, have raised an amazing £15,000 for Candlelighters!** They named themselves 'the Dingham Duck Cancer Crusade' and took part in many events, such as a 29km walk, the Harrogate 10k, Ilkley Marathon, running a pop-up bar at a local festival, a charity cricket game and a dazzling casino night!

▶ **Josh Martin did the Sydney Marathon and raised £871 in memory of his cousin Zoe Kilby.** Zoe was diagnosed with rhabdomyosarcoma in 2005, and passed away at the age of 17 in January 2007.

▼ **We are delighted that Allen Hart, one of Candlelighters' longest supporters, has joined Club Candlelighters as a Guardian,** pledging to donate £25,000 a year for the next three years.



Thank you so much to all of our wonderful fundraisers who have helped us to provide vital support for families. Want to do some of your own fundraising? View our Fundraising Pack by scanning the QR code, or email info@candlelighters.org.uk for any fundraising guidance!



Join #TEAMCANDLELIGHTERS in our 2024 fundraising!

May

12 Rob Burrow Leeds Marathon
12 Leeds Half Marathon

June

22 & 23 Total Warrior
23 Leeds 10k

3-9 June Pink It Up! Join us during the first week of June for some fabulously pink fundraising! Find out more on how to get involved on our website.

August

4 York 10k

September

8 Great North Run
14 Yorkshire Three Peaks

October

20 Yorkshire Marathon

Register for our events now to raise funds to support children with cancer. Scan the QR code to find out more and sign up, or contact info@candlelighters.org.uk



**Candle
lighters**
Supporting the families
of children with cancer

For family support, please call 0113 887 8333

To make a donation you can give online,
call 0113 322 9283, or send a cheque to the
address below.

8 Woodhouse Square
Leeds
LS3 1AD

candlelighters.org.uk

CandlelightersTrust
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Registered with

