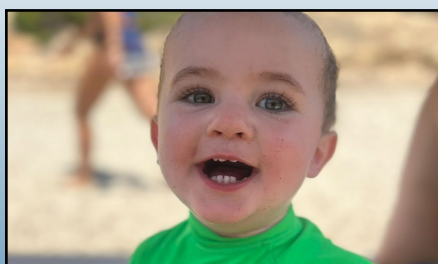




## CHECT Features on BBC Children in Need!



**"I don't think anything prepares you to hear that your baby has Rb."**

Read Kooper's story **Page 9**



**"We spotted a white glow after taking a photo."**

Read Shuhd's story **Page 7**



**Meet football and futsal star Adam Lione!**

Read Adam's story **Page 5**

# Welcome

**A special thank you to our incredible cover stars – including CHECT member Robyn who was photographed playing during filming with Nadine Coyle from Girls Aloud! We're so proud to feature these amazing individuals who help shine a light on the work we do.**

We were delighted to be part of BBC Children in Need's Night of TV, reaching over 3.7 million viewers last November. A heartfelt thank you to the families who took part in the exciting day of filming – your involvement was crucial to the success of the appeal. As ever, we are grateful to all our members who continue to raise vital awareness of retinoblastoma through TV, radio, magazines, newspapers, and online media. In this edition, you'll find just a few of those powerful stories, including Shuhd's on page 7 and Kooper's on page 9.

The CHECT team has been fortunate to spend some quality time with families at a number of meet-ups, including Christmas parties, a visit to the National Space Centre in Leicester, and a fun day out at Beale Park in Berkshire.

## Would you prefer to receive InFocus in a different format?

Please let us know on 020 7377 5578 or at [info@chect.org.uk](mailto:info@chect.org.uk) if you'd like to receive InFocus in large print (A3), braille, or electronically – PDF and HTML.

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Page 5-10: Real Life Stories  
Page 11-12: Fundraising and events  
Page 13-14: Children's Corner & TYA  
Page 15: Ways to help

We were honoured to acknowledge so many of our inspiring CHECT Champions with awards, and look forward to seeing many more of you at our Lambeth Palace gathering on 29 August – see the back page for details.

We are thrilled to be launching a new fundraising challenge for Childhood Cancer Awareness Month in September. To learn more about this exciting challenge please have a look on page 12.

A heartfelt thanks to everyone who took part in our recent members' survey. Your feedback is vital in helping us better understand your needs and improve the support that we offer. By sharing your thoughts and experiences, you are ensuring our work remains relevant, effective, and impactful for everyone affected by Rb. You can read the survey results on page 4.

We are also incredibly grateful to everyone who has taken on a fundraising challenge or hosted an event in support of CHECT. Your dedication and generosity enable us to continue our work across support, research, and raising awareness.

Finally, and as always, an enormous thank you to our amazing community – members, staff, volunteers, trustees, fundraisers, trusts, foundations, and supporters. Your ongoing commitment drives everything we do, and we are truly thankful for your support.



**Richard Ashton, Chief Executive**

## Have your say

Do you enjoy receiving your copy of InFocus? Is there anything in particular you'd like to read about? If so, we'd love to hear from you at [info@chect.org.uk](mailto:info@chect.org.uk).  
**Thanks for your support!**



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# News

## CHECT features on Children in Need



**On November 15, 2024, ahead of the BBC Children in Need Appeal Show, Girls Aloud members Nadine Coyle and Kimberley Walsh visited our Support Worker Lena, our Communications Manager Isabella, and two of our families at the Royal London Hospital.**

The singing sensations visited CHECT to learn about our work, which was filmed for a segment in the popular Children in Need show, after Children in Need generously awarded a grant towards our support services.

The 'A Night of TV' show, watched by over 3.7 million viewers, featured Nadine and Kimberley playing with Luka, Theo, and Robyn, while chatting with Lena and the parents about retinoblastoma and the work of CHECT.

Kimberley said, "I loved the project visit and joining in on playtime and a little bit of arts and crafts with the children. Robyn really did enjoy turning the paper bedpan into a hat with me – it's amazing what a little bit of creativity can do!"

"It's clear BBC Children in Need's funding is not just supporting children like Robyn, Luka, and

Theo, but also their families who have been through an incredibly difficult time. No one is prepared for their child to be diagnosed with cancer, and we learned today just how vital it is to have projects like the Childhood Eye Cancer Trust to support families when they need it most."

We want to extend a huge thank you to the parents, children, Royal London Hospital, Kimberley, Nadine, and Children in Need.



As well as visiting London, Children in Need visited Kriti, her sister Armanie and her mum Aazmeen at Birmingham Women & Children's Hospital to film an awareness piece for BBC News in the lead-up to the Big Night of TV. We are so grateful to the trio for their wonderful awareness-raising, as well as to Children in Need for helping us gain more attention.



## Further research announced



We are delighted to confirm that CHECT will be funding the next stage of "Developing an evidence-based psycho-educational intervention for teenagers and young adults who have had retinoblastoma." Having spent three years understanding the psychosocial experiences of teenagers and young adults who had Rb as children, Dr Nicola O'Donnell will continue to work closely with affected individuals and healthcare professionals, to develop a support intervention aimed at young people as they transition to adulthood. The research is expected to start in January 2026.

## A letter from Janet and Pelham Allen



**In 1984, Janet and Pelham Allen's then two-year-old son, David, was diagnosed with retinoblastoma. Despite ongoing treatment for four years, David sadly died in 1988. During this time Janet and Pelham set up the David Allen Retinoblastoma Appeal to fund research into Rb and raised an incredible £250,000. In 1994 the David Allen Retinoblastoma Appeal merged with The Retinoblastoma Society. Without this huge injection of funds and Janet and Pelham's commitment CHECT would almost certainly not exist in the format it does today. Their au pair even created the child-in-the-eye logo which the charity still uses! Here, Janet and Pelham Allen update us on life as it is today for them.**

As I sit here at my desk, our second grandchild is less than 48 hours old. I remember that I meant to write this after our first grandchild's birth, but - you know, life...

As with all new babies in the UK, there were tests to check on their health. Most parents hardly notice these and take their healthy newborns home, looking forward with great anticipation to the next few days, weeks, months, and years together.

That was us, my husband and I, 42 years ago, when our second baby was born and before many of these tests were developed. A couple of years later, our world was turned topsy-turvy with a diagnosis of Rb. Years of hospital visits, with him and our other two children, followed. The two girls were checked and found clear, but our little boy, blind and not yet 6, died from trilateral

Rb. Nowadays, with the use of chemotherapy, this rarely occurs. The wonders of modern science.

Our black-cloud story is, however, tinged with a silver lining. After diagnosis, we were encouraged to set up a research charity to work towards finding the gene first and then progressing to better treatment. This was at a time when the self-help group, the Rb Society, was in its infancy, and both charities were manned by volunteers, taking no funds away from doing good for patients and their families.

The David Allen Retinoblastoma Appeal, with the help of hundreds - if not thousands - of you (you know who you are!), raised close to a quarter of a million pounds, before merging with the now more secure Rb Society, which over the years became what we now know as CHECT. We had, early on, secured the services of a researcher who is passionate about Rb, Dr Zerrin Onadim, and under the supervision of the Institute of Child Health, she discovered the holy grail - the gene, so it was with optimism that we merged and we continued to work with the charity for a number of years, both on the general and the research committees. I believe Dr Onadim is still involved, doing great work.

Back to the present day, both our grandsons had the newborn checks, which now include a test for Rb. Both are clear. We are forever grateful that we and an awful lot of others put all our effort into the earlier years fundraising, enabling a test to eventually be included as standard in those checklists. Our daughter and son-in-law will not have to go through the terrible time we did, and they are two parents who definitely take notice of these checks and have come away reassured.

Thank you from the bottom of our hearts to all the researchers and fundraisers, not only for Rb, but for the other tests that are now performed, reassuring most parents, but at the very least enabling early diagnosis for those not so lucky. As we all know, early diagnosis is paramount to getting the best treatment available. **THANK YOU.**



## 2024 Members' Survey results

Thank you so much to everyone who took part in our 2024 Members' Survey. For the first time this year, we decided to look at responses in terms of three main age groups to give more specific feedback on the experiences and priorities of different age/stage groups. This excludes parents responding on behalf of adult children, and grandparents, which is recorded elsewhere.

**35%** of respondents were parents of children in active treatment (around 0-8 years)

**19%** of respondents were families whose children are post-treatment (around 9-23 years)

**21%** of respondents were adults who had retinoblastoma as children (24+)

### What CHECT support do you value the most?

**Active treatment:** diagnosis info, face-to-face support, emotional support, genetics info

**Post treatment:** diagnosis info, face-to-face support, treatment info

**Adults:** info for adults, genetics info, Beyond Rb Facebook group

### What is the most helpful thing CHECT has done for you?

**Active treatment:** emotional support, financial support, information and guidance

**Post treatment:** emotional support, general support (being there along the journey), family activities and experiences

**Adults:** emotional support, information and education, community building/Facebook

### Is contact with others affected by Rb important to your/your child's wellbeing?

**Active treatment:** 65% said very important/important



### If you have experienced feelings of loneliness and/or isolation, to what extent have these been reduced as a result of CHECT support?

**Active treatment:** 67% said a lot or a little

**Post treatment:** 46% said a lot or a little

**Adults:** 62% said a lot or a little

### If you have attended a CHECT meet-up, did you find it valuable?

**Active treatment:** 50% had attended, and of these 89% found them valuable

**Post treatment:** 79% of this group had attended, and of these 97% found them valuable.

**Adults:** although only 30% had attended, 92% of these found them valuable

The main reasons for not attending meet-ups were distance and convenience.

Top topics of interest across the board for an online session were late effects, research and psychology.

**We will be using these results to shape our information and support services going forward, to ensure we are giving you the best support we can at every stage. You can read more about the survey at [chect.org.uk/2024-chect-members-survey-feedback/](https://chect.org.uk/2024-chect-members-survey-feedback/)**

## Meet footballer Adam Lione

**After losing his left eye to retinoblastoma and having various treatments on his right eye, Adam Lione grew up to play football on the international stage.**

I had watched football from a young age, but I vividly remember watching the 2002 FA Cup final with my dad, where Arsenal beat Chelsea 2-0. I remember the feeling of excitement watching Ray Parlour and Freddie Ljungberg score amazing goals and being blown away by the thrill of watching someone you support win in a massive game. This then inspired me to embrace football, having been involved in grass-roots football for a few years by that point. I wouldn't say I've had to make major adaptations, having had the same level of sight from my infant years. However, I purposely played in positions that accommodated me best, playing on the left wing so that I could see the whole pitch easier.

My football journey started at a grassroots club called Essex Royals, based in Wickford. I started at a very young age, around 7. I played for a couple of teams in my school years, representing my school and trialling for Southend United, Colchester United and Leyton Orient. I then went on to play for Hullbridge Sports during Sixth Form and then played for the University of Worcester in both football and futsal (the variation of football we play for England). I represented the University's fourth and first football teams

and founded the futsal society to push myself to play regularly and develop my skills for England. I now play for Braintree Futsal in the mainstream National Futsal Series and Scorpions Futsal in the Partially Sighted League.

My pathway into Disability and Visually Impaired football started by playing in visually impaired tournaments for Arsenal when I was 10-13. These were fundamental years of my love of football. It was a small league consisting of Arsenal, Tottenham, Charlton, Crystal Palace and others, playing against each other a handful of times a year whilst training once a month. Having the love for football that I did, I also trained with Tottenham, despite being a devoted Arsenal fan!

However, my journey to playing for England started with an invitation to a Playground to Podium day – effectively a Paralympic Sport Taster Day. Then, at the age of 15, I was quite dismissive of disability sport. My previous experience was enjoyable, but I always felt as if I was “too good to play.” I attended merely as an excuse to get out of school, as I didn't overly enjoy school. On the day, I tried out different sports, but naturally, I was drawn to the football station. From that, I was invited to play with a pan-disability (all impairments playing against each other) football team called the Roch-



**“Football helped me to accept myself”**

ford Disability Football Academy. With them, I played in the Essex League, winning the league on a few occasions and also played in fixtures against Chelsea's pan-disability team at Cobham, amongst other experiences.

I was fortunate to be coached by Bob Pointer. He noticed my talent and arranged for me to attend a trial for the England Partially Sighted team...something I didn't even know existed at the time. At 16, I attended the trial and was invited to the first-ever Development Squad camp at Lilleshall National Sports Centre. And from there, my current 14-year England career began.

### **My key achievements are:**

- Playing in three World Cup finals
- scoring a hat trick in the most recent one v Ukraine.
- Featuring on the England Cap Wall at St George's Park for playing over 50 times.
- Featuring in the England Kit Launch in 2024 alongside Harry Kane, Bukayo Saka, Beth Mead and many others!
- Winning the FA Disability Cup three times.

Partially Sighted football is played under the rules of Futsal – five-a-side, indoors on a court similar to a handball court. Unlike blind



football, which is often seen in the Paralympics, we do not play with blindfolds or a ball with ball bearings, and the types of visual impairment are extremely varied.

I've played in the Men's Senior Partially Sighted Team for 12 years as of February 2025. My first tournament was in February 2013, a World Championships in Japan, in which we came third. I was initially only selected as a standby player but was called up to the squad due to some injuries to other players. I have gone on to play nearly 60 times for England, in eight different countries, playing in three World Cup Finals, scoring a hat-trick in our most recent final in Birmingham 2023.

Our key competitors are Spain and Ukraine. Spain is a very strong nation for Futsal and has a long heritage of the sport – whilst Ukraine is well funded and supported by their federation and have always been a strong nation in our sport.

We train twice a month, often at the home of all England teams – St. George's Park – and have major tournaments (Worlds or Euros) once a year and play a series of

international friendlies a couple of times a year.

Playing for England has given me more than I can describe in written form. It's allowed me to fulfil my dreams of playing football at international level in major tournaments and also a group of best mates that have all gone through adversity and trauma in different ways, but a space in which everyone is accepted for how they are and an understanding of everyone's different struggles. My early years in the squad truly played a large significance in accepting myself for what I went through, what I struggled with and what life can still give despite it.

My dreams within football have always been to win a major tournament with England, and to play for as long as my body allows! I am now doing my coaching badges, and I hope to begin my own foundation for children with a visual impairment to find their way in sport but also educate the parents and fellow coaches on how to support the child. Outside of football – I currently work as a TV Producer in live sports, and my ambition is to become a match director and producer across football and boxing. I have a desire to travel the world as much as possible so am looking at taking some time to travel around the US and South America.

No advice can make the experience any easier, for that, I'm sure. For the parents, I would say to first try to come to terms with what they have been through themselves. The experience of going through Rb can be

as hard on the parents as it is for the child, and I think those experiences can sit with you for life. It's very natural to believe that the best way to protect your child is to wrap them in cotton wool in fear of them becoming ill again, feeling different, bullied at school etc... all completely understandable worries. However, I believe the best thing my parents did for me was to treat me like a completely normal child, going to a mainstream school, mainstream sport and doing all the things a child who hasn't suffered from Rb would do. That may sound like a head-in-the-sand approach, but I believe it has allowed me to feel "as normal" as I can and feel settled in the world. I would, however, have difficult conversations with your child (at the right age) when possible, about their sight, how they feel about things, and what they believe their level of sight is like. I would keep conversations with others about retinoblastoma in front of them to a minimum, as you don't want the child to keep reliving the experience.

For those that have gone through it themselves, be kind to yourself and know that you are completely okay as you are. Insecurities are totally normal, and you are loved. To not let those that speak ignorantly get to you and embrace every opportunity that comes your way. Do what makes you happy, not others, but expect to make mistakes along the way. Do not be ashamed of who you are or what you've been through, seek help when you need it and appreciate the good and the bad days.

To read Adam's full story, visit:  
**[www.chect.org.uk/adamlione/](http://www.chect.org.uk/adamlione/)**



## **“A flash of light in a photo uncovered my daughter’s cancer”**

**Dad Faiz shared Shuhd's story as part of our Rare Disease Day campaign.**

Faiz said, “We first noticed symptoms of retinoblastoma in Shuhd when she was around five weeks old. Shuhd’s mother had taken a picture of her with the flash on. We then noticed a glare or white reflection in her eyes. I had not heard of retinoblastoma before my daughter was diagnosed. It was completely unfamiliar to me, and I did not know anyone who had been diagnosed with this condition. It was a daunting experience, but learning more about it and receiving support has been crucial.”

Faiz said, “We were panicking and extremely worried. We didn’t sleep and felt utterly helpless at that point. The urgency and uncertainty of the situation were overwhelming, and our primary focus was on ensuring she received the best possible care as quickly as possible.”

Faiz added, “Initially, we consulted our local GP, who mentioned that a referral to a specialist was necessary. However, they advised that this process might take some time. I then took her to A&E at St. Mary’s Hospital. There, we were referred to Great Ormond Street Hospital due to the urgency of the situation. We received a call from Great Ormond Street Hospital the following day, informing us that they had referred us to the Royal London Hospital for an examination under general anaesthetic.”

Faiz said, “It wasn’t until she was eleven weeks old and after thorough examinations at the Royal London Hospital that the diagnosis was fully confirmed as bilateral retinoblastoma – cancer in both of her eyes. This period was incredibly challenging and filled with uncertainty, but receiving a definitive diagnosis was a crucial step in moving forward with her treatment.”

After Shuhd’s diagnosis was confirmed, treatment was discussed.

Faiz said, “She had six cycles of chemotherapy, along with laser therapy and cryotherapy. During this treatment, she had an enucleation (removal) of the right eye while receiving chemotherapy. Each of these options carried its own set of challenges and



implications, but they were all necessary steps to address her condition effectively and to keep her alive.”

Faiz added, “Shuhd continues to be monitored after receiving treatment. After the initial treatments that she received, there was a relapse of her tumours a few months later.



However, after they were treated with laser therapy, we haven’t had any concerns during the last two or three visits. Despite this positive development, Shuhd will need to attend regular check-ups to monitor her condition in case of further relapse.”

Faiz said, “I cannot express my gratitude enough for CHECT and for my CHECT support worker. The support from this team has been incredibly helpful during the most challenging time of my life. Every time we visit, our support worker is there to check on us and provide the most incredible emotional

**“She has an incredible zest for life”**







support. We always receive messages and emails from them to check in on us and see how we are doing and if we need any support.

We are truly grateful for CHECT and the amazing work they are doing with families like mine."

Faiz said, "Shuhd is just like any other child. She loves to play, enjoys it when I read books to her, and adores walks in the park. She's a very happy little girl who loves being out and about. She has an incredible zest for life, always moving around with joy, and everybody who meets her is charmed by her delightful personality."

He added, "I found that it is far better to let those who love and care about you know what you're

going through. Their support can be invaluable during the most difficult times, providing comfort, strength, and encouragement when you need it most. It's essential to lean on your loved ones, as they can offer the kind of emotional and practical support that makes a significant difference in navigating such challenges."



**Thank you so much to Faiz and Shuhd for sharing their story to help us raise awareness during Rare Disease Day. Their story ran across the national press - helping us to reach more people.**

## Pathways to Diagnosis 2024

**Each year, we report back on families' experiences of being diagnosed with retinoblastoma (Rb) in the UK: the symptoms they noticed; the healthcare professionals they saw; and how long it took them to reach one of the specialist Rb centres (Birmingham Women's & Children's Hospital, BCH, or the Royal London Hospital, RLH).**

By recording and reporting this information, we can identify where problems are occurring, and what CHECT may be able to do to help.

### 2024 round-up

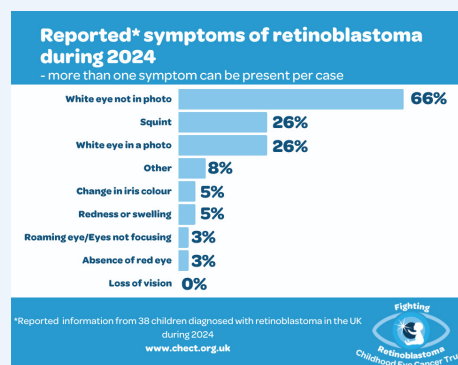
Overall, 44 children from the UK were diagnosed with Rb in 2024, and we have information from 38 of these families (screening families are not included in this survey). So

what were families' experiences in 2024, and also compared to the 10-year average from 2015-2024?

As usual, a white glow spotted in the eye was the most common symptom overall. In 2024 two thirds of parents (more than the 10-year average) noticed a white glow in their child's eye, 26% noticed it in a photograph, and 26% reported their child had developed a new squint (parents may report more than one symptom).

As is usual, GPs were the first port of call for most concerned families, followed by opticians and then health visitors. Compared with the ten-year average figures, more GPs and opticians made appropriate referrals when they saw children

with retinoblastoma in 2024. As a result, 61% of children were diagnosed at one of the specialist retinoblastoma centres within two weeks of first reporting symptoms to a healthcare professional, which is a significant improvement on the 10-year average of 53%. However, 8% waited more than six months, which is a concerning delay.



**Thank you so much to everyone who took part in the 2024 Pathways to Diagnosis survey – it really is so important for us to keep monitoring this information.**



## “We spotted a white glow in our son’s eye”

**Dad Shane shared Kooper’s story as part of our World Retinoblastoma Awareness Week campaign.**

Kooper’s dad, Shane, said, “My partner first noticed a white glow in Kooper’s eye in low-light conditions. I dismissed it at first and then noticed it myself a couple of days later – then kept seeing it. We Googled it and came across some advice that said to take a photo with the flash on (this does not always work), and the white glow in his eye was obvious then.”

Shane said, “It was a Friday when I noticed it and we said we would take him to the doctors first thing on Monday, which we did. The weekend was full of panic, Google searches, and worst-case scenarios – it was terrifying. The doctor referred us to the local hospital a couple of days later. It was another scary time, not knowing what was wrong. We’d read that there could be a few

other reasons for the obscured red reflex in his eye, so we tried to hold onto hope for a different diagnosis.”

Shane added, “We didn’t have a great experience at the hospital. Kooper was only a year old and didn’t want anyone poking at him – he wouldn’t put his face in the machine to have his eye examined. After an ultrasound, they told us he had a lump in his eye and that ‘it could be serious, or it could be not as serious’, which wasn’t overly helpful. They said he would be referred to Birmingham, but didn’t mention the retinoblastoma team. I think the heartbreak really hit when we left the hospital and got to the car park – and realised what we were dealing with.”

The family attended an appointment at Birmingham Women and Children’s Hospital in December 2024.

Shane said, “I don’t think anything prepares you to hear that your one-year-old has cancer, may lose his eye, or may never see out of it again – it was a very emotional time. We both phoned our parents and used WhatsApp groups to tell the rest of the family. They already had an idea after our first hospital visit that

it was likely retinoblastoma, so this was just confirmation. We used the information provided at the hospital to reassure them and explain the treatment plan. The doctor discussed different chemotherapy options – and also offered genetic testing, which we chose, as Kooper has an older brother and for Kooper’s own future and any children he might have.”

Shane explained, “Kooper has had four rounds of intra-arterial chemotherapy, laser therapy twice, and one round of chemotherapy injections. Results have been mixed – the first two intra-arterial rounds were somewhat effective, the third was very effective, but the fourth had little impact. They said at his last examination that the tumour looks smaller but the spores in his eye are growing, so hopefully the injection has had a positive effect on that.”

Shane added, “After treatment, when he is on steroids, Kooper becomes very distressed for four to five days which has been difficult. My partner and I both work, and we can’t send him to nursery when he’s like that, but he does like going on trips to the hospital.”

Shane said, “Kooper is our second child – he’s wild, and he has no fear. He’s recently started talking

**“Kooper is always the loudest child in the room!”**





properly and putting sentences together. He gives his big brother a hard time and is always the loudest child in the room! He loves Moana and Tangled. Things that have helped him while at the hospital include socialising with other children on the ward, having his iPad – especially when he needs to lie down for six hours after treatment – and the amazing staff.”

Shane said, “CHECT has been great, we had the initial grant which helped

with travel costs etc. Our support worker has been to see us every time we’ve been to the hospital, which probably has had the biggest impact, having an impartial point of contact to speak to and get information from, she always engaged with us and with Kooper. She also helped us with the DLA forms and also signposted us to different services. I took on the ABP Newport 10K for CHECT in April, and I’m running the Chepstow 10K in August to raise money for the charity.”



**Thank you so much to Shane, Lowri and Kooper for sharing their story to help us raise awareness during World Retinoblastoma Awareness Week.**

We can't raise awareness without the help of our CHECT families. If you'd like to share your story to help us to raise awareness of Rb, please contact [info@chect.org.uk](mailto:info@chect.org.uk).

## CHECT meet-ups

**Even the might of Storm Darragh, train cancellations and widespread flooding couldn't stop 13 families heading to London for the CHECT Christmas party. We had a lovely festive morning full of magic, dancing, crafting, Christmas songs and, of course, mince pies! And as you can see from the photos, everyone had their best Christmas outfits on.**

We also had a brilliant day at the National Space Centre in Leicester! Nine families joined

Lena, Sarah, and Lucy from the team for an afternoon filled with fun, rocket-making, star-gazing, and exploring the museum's fantastic exhibits.

Unlike the last few CHECT family days, there was no major weather event for our Beale Wildlife Park meet-up, just uninterrupted sunshine!

The park was beautiful, with peacocks wandering around and a little train to take everyone through the spacious grounds. We all met in the education centre

to have a sensory workshop about different kinds of forests. We even got to meet two very different animals – a hissing cockroach and a ferret (some of the parents backed off at this point!)

After the workshop we celebrated our seven CHECT Champions. It was then time for lunch and some serious crafting, before heading off to explore the park.

Keep checking [chect.org.uk/events](https://chect.org.uk/events) for meet-ups for all ages.





# London Marathon 2025!

**We're thrilled to share that 14 of our amazing supporters took on the challenge of the iconic 2025 London Marathon in support of CHECT – raising an outstanding £69,000, including Gift Aid!**

Each runner went the distance not just on the day, but through months of dedicated training and tireless fundraising. Their commitment and passion will make a lasting difference for children and families affected by retinoblastoma.

A huge thank you to every runner, donor, and cheerleader who made this incredible achievement possible – we're so proud of #TeamCHECT.

If you're feeling inspired and would like to join Team-CHECT for future sporting events, please email [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk)



## World Retinoblastoma Awareness Week!

**Thank you for making World Retinoblastoma Awareness Week (11–17 May) truly unforgettable!**

We were blown away by the incredible support—so many of you rocked your crazy glasses at work, school, and home to help raise awareness of retinoblastoma and vital funds for CHECT. Your photos made us smile all week!

We are also incredibly grateful to everybody who submitted images to help us create memorable awareness posts. We were astounded by the talent of Joseph, who created a series of signs and symptoms videos for us.



### **Missed out on running a Crazy Glasses event?**

You can still host your own Crazy Glasses Day and be part of the fun at any time of year. Visit our website to find out how to get involved:

[www.chect.org.uk/other-ways-to-help/crazyglasses](http://www.chect.org.uk/other-ways-to-help/crazyglasses)



### **Wonderful funding news!**

We are very grateful to Ulverscroft Foundation for their generous donation towards the costs of CHECT's events and social media - helping us to both offer support and raise awareness of retinoblastoma. Their grant will enable families and individuals to forge vital friendships for mutual understanding and peer-to-peer support, and also help us to reach more people. Thank you to Ulverscroft Foundation for your kind generosity!



# The Hospital-to-Hospital Challenge

## Introducing our brand-new fundraising event: the CHECT Hospital-to-Hospital Challenge!

We're challenging you to cover 122 miles (one-way) or go the extra mile with 244 miles (round trip) – the distance between The Royal London Hospital and Birmingham Women's and Children's Hospital, the only two hospitals treating retinoblastoma in the UK.

How you do it is up to you – walk, run, cycle, swim, or mix it up! You can go solo, participate as a family or within a team, and complete the distance in your own time and at your own pace.

Every mile you move and every pound you raise will support our work.

### Are you ready to take on the challenge?

Contact Priyanka at [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk) to sign up today!



## More challenge events

We're incredibly lucky that so many of our supporters enjoy challenge events in support of our work. That's why we've expanded our events calendar to include more international and iconic runs, such as the Tokyo Marathon, Berlin Marathon, Silverstone Half Marathon, and more. Have a look at our events page to find an event for you [www.chect.org.uk/challenge-events/](http://www.chect.org.uk/challenge-events/)

## Legacy

Leaving a gift in your will - no matter the size - for the Childhood Eye Cancer Trust, can make a lasting impact, ensuring future generations benefit from advancing research, support and widespread awareness of this cancer.

We've partnered with Free Wills to provide our supporters with the opportunity to make their own fully comprehensive Will for free. Your Will will be professionally checked, vetted and approved by a solicitor.

To learn more about legacy giving visit [www.chect.org.uk/legacy-giving/](http://www.chect.org.uk/legacy-giving/) or call Priyanka on 020 7377 5578.

## Thank you

We are very grateful to those supporters who have remembered our charity in their wills, and also to those who arrange donations in memory of a loved one. This is a wonderful tribute and we very much appreciate the thoughts of those who support CHECT even at such a difficult time. Our condolences and grateful thanks are extended to the families and friends of: Meryl Hobbs, Paul Stokell, Paul Castle, Tom Sherrington, Ted Branch, and Lauren Smolak.

## Children's corner & CHECT TYA!



### Martha's love for adventure

"Hi, my name is Martha, I am 9 years old. I had a poorly eye when I was 2 years old. This meant I had my left eye removed and chemotherapy. I'm fine now, and it's because of the amazing nurses, my family and friends, and of course, CHECT.

Do not worry if you're going through a tough time when you have a poorly eye. One day, you'll be the same as your friends, just even more special.

Having a special eye has not stopped me from achieving anything – life is a big adventure! I go dancing every week and I compete in the local dance festivals. I ride horses and I'm loving learning to canter. Going fast is really fun! Last year, I was in a production of Oliver with my stage school, it was brilliant. Now I'm busy rehearsing for a production of Frozen."

### Neng's book review: The Last Bear by Hannah Gold

"The writer presents April, the main character, as kind and fearless when she attempts to free the last remaining polar bear from a piece of plastic that has been entangled around its paw, demonstrating that she will do anything to help the injured and lonely bear. This is shown when she exclaims "Oh my! What have you done to yourself?". The dialogue illustrates April's horror when she spots the plastic. On one hand, April is kind and understanding but on the other she is curious and fearless as she repeatedly, over the course of the story, tries to find where Bear lives and also willingly rides Bear. The text itself is a heart-warming and emotional tale.



The last chapter showcases a very touching scene as it describes April having to leave Bear to return home in time for school to start. This is the part that made me cry because of how emotional it is. The book is a story of happiness, sadness and a call to the unrelenting wilderness of the north that is written through emotion.

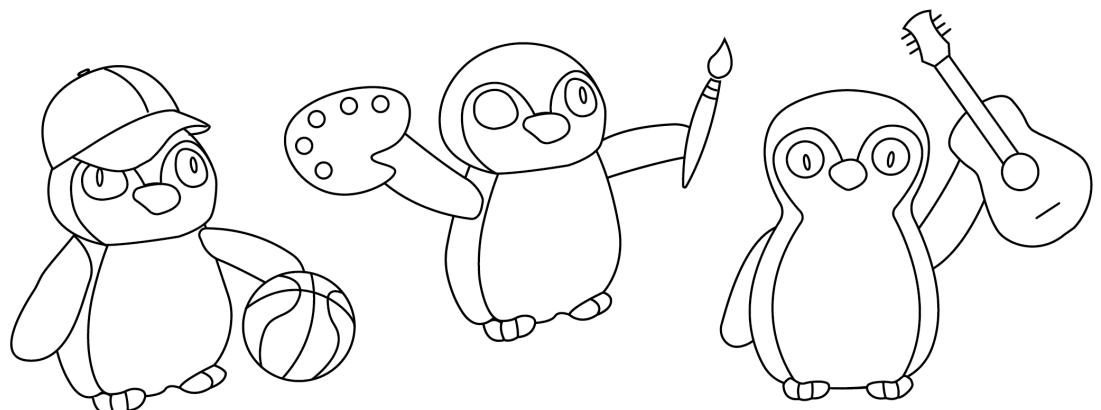
I like this book because, despite it being a work of fiction, it depicts the troubles that endangered animals living in the north, such as polar bears, face because of climate change. I would definitely recommend it to young readers. The book highlights the importance of taking care of our planet and the endangered animals that have been made that way because of us. The book is also the first in a two-book series about the main character and Bear and I would also recommend the sequel if you have finished the first as it is equally, if not more, heart-wrenching."

### Colour in Pip!

## PIP'S SUMMER HOLIDAYS

Colouring is great for mindfulness - so why not have some fun?

We'd love to see your finished work - email us at [info@chect.org.uk](mailto:info@chect.org.uk) or tag us on social media!





# Jack learns to drive!

**We spoke to Jack about his experiences with Rb, and his journey to learning to drive.**

My name is Jack, and I am 17 years old. I live with my parents and sister on the Isle of Lewis, in the Outer Hebrides of Scotland.

When I was eight weeks old, my left eye changed - it became swollen and would not open. I was seen at our local hospital, then transferred to Glasgow Children's Hospital for further investigations. It was there that the Ophthalmology team diagnosed a tumour in my left eye and the potential of a number of smaller tumours in my right eye. I was then transferred to the retinoblastoma team in Birmingham, where the diagnosis was confirmed as bilateral retinoblastoma. From then I had many trips to Birmingham for treatments including cryotherapy and laser therapy. I also had six cycles of chemotherapy, which I received at Glasgow Children's Hospital. When I was five months old, I had my left eye removed. Several more tumours then developed in my right eye. Due to the different treatments I received, the tumours in my right eye were successfully treated to preserve my vision.

I have attended the prosthetic eye department at Gartnavel Hospital in Glasgow since I was six months old. They have provided me with many prosthetic eyes over the years, all of which have been such a good match.

I went on to attend mainstream primary and secondary schools. In school, I had some difficulties such as ensuring I sat in a position that I was able to see the board clearly, that I had books with larger text and a tilt board to lay them on, and always remembering to consider my left side. I was well supported throughout school.

Socially, having Rb has not had a noticeable negative impact on my life. I have worked part-time as a waiter in a local hotel and currently work part-time at a local supermarket. I have not yet decided which career path to take after school.



My main goal was to learn to drive but due to where the tumours are in my right eye, this was never a certainty. In 2023, I applied to the DVLA for my provisional licence. After completing a lot of paperwork and attending my local optician for scans and vision tests, I received my provisional licence in November 2023. When I turned 17, I started driving lessons and successfully passed my driving test first time with zero faults. For a long time, driving seemed like the one thing that retinoblastoma would stop me from achieving, but this was not the case.

I do need to have DVLA scans and vision tests every three years to make sure that nothing has changed with my vision.

I attend a gym where I train for competitive powerlifting. The only vision-related issue that I have had to overcome at the gym is in relation to balance and coordination. It took some time, but I found ways to adapt and overcome it. I plan to compete in my first regional competition at the Scottish Northerns in February 2026.

My family always felt supported throughout my treatment and many hospital visits to the retinoblastoma team in Birmingham and CHECT. I was too young to understand or later remember the impact of my diagnosis at the time. From my perspective, this made growing up with the effects of retinoblastoma slightly easier.



**Want to write for CHECT TYA?  
Email us at [info@chect.org.uk](mailto:info@chect.org.uk)**

## Join us at Lambeth Palace

Join the Childhood Eye Cancer Trust for the first time ever at Lambeth Palace on 29th August 2025 at 12-4pm. To mark 10 years of opening Lambeth Palace's Gardens to the public, you will be able to join our charity day and explore the history of the home of the Archbishops of Canterbury.

For only £10 per adult (children under 12 and carers can visit for free), visitors of all ages can enjoy the day with us, exploring the palace's significant spaces including:

**The State Rooms** – The Archbishop's daily living room.

**The Guard Room** – Dating back to the 14th century, the name comes from when the Archbishop had his own private army.

**The Great Hall** – The original hall dates back to the 13th century and was used for banquets and feasts.

**The Crypt Chapel** – The oldest part of Lambeth Palace. Originally used for wine and beer storage, it was not used as a chapel until the Second World War.

To make this a memorable day during the summer holidays, the visit will also include fun activities for the family including sensory activities for the children. To purchase tickets and for more information, visit: <https://checht.org.uk/explore-lambeth-palace-with-us/>

**All proceeds will go towards supporting anyone affected by retinoblastoma in the UK.**



## Fantastic fundraisers

To everyone who has fundraised for CHECT – thank you. Your passion, creativity, and dedication help us to provide essential support to anyone affected by retinoblastoma, raise awareness of our work and the signs and symptoms of retinoblastoma, as well as fund life-changing research. Whether you've run, baked, cycled, climbed, or donated, we're so grateful for your support, thank you.



## Could your workplace support us?

We're looking to build new partnerships with businesses who share our passion for making a difference. If your company has a Charity of the Year programme and/or is interested in supporting children with retinoblastoma, please nominate us.

## Contact us

If you would like to contact us about any of our fundraising activities or would like to hold your own event, contact Priyanka, our Fundraising Manager, at [fundraising@checht.org.uk](mailto:fundraising@checht.org.uk) or on **020 7377 5578**.

