infocus

Summer 2026

Fighting Retinoblastoma Childhood Eye Cancer Trust

Art by Abbie

Celebrating talent special

“We spotted Rb on his third birthday.”

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“I was very sure I had seen a glow.”

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"Check out our bespoke eyes!"

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Welcome

As we bring you Issue 101 of InFocus, we are once again reminded of just how extraordinary our CHECT community is – with proof of that on every page.

None of this would be possible without the incredible people who make CHECT what it is. To our volunteers who give their time so generously, our trustees who provide guidance and leadership, our dedicated staff team, and our wonderful members who remain at the heart of everything we do – thank you. Each of you plays an essential part in helping CHECT thrive and be the community that it is.

From the families who have entrusted us with their personal experiences, to the fundraisers, campaigners and awareness champions who give their time and energy so selflessly, this magazine exists because of you.

A special thank you to everyone who has shared their retinoblastoma journey with us so far this year. The stories of Isaac, Brody and many others take courage to tell, and we know they make a real difference – helping other families recognise the signs of Rb earlier and feel less alone when they receive a diagnosis.

This issue is also a celebration of determination and achievement. We are delighted to feature young members including Liv, Gracie, Felix, Nancy, Abbie and Balfour. Whether they are breaking boards, scoring goals, performing on stage or playing piano by ear, their enthusiasm, resilience and talent continue to inspire us all.

Our thanks also go to everyone who has raised funds for CHECT this year. To our incredible London Marathon team, who ran through challenging conditions to raise an amazing £30,000 – you are truly outstanding. And to everyone who has taken on challenges from the Great North Run to skydiving, every pound raised and every conversation started helps bring us closer to a world where every child with retinoblastoma is quickly diagnosed and supported every step of the way.

The 2025 Pathways to Diagnosis data featured in this issue reminds us why awareness remains so important. The stories you share on social media, within your communities and with healthcare professionals continue to have a real and lasting impact.

As always, InFocus is your magazine. Whether you'd like to share your story, help raise awareness, take part in our Hospital to Hospital Challenge this August, or simply get in touch, we would love to hear from you.

Richard Ashton, Chief Executive

Would you prefer to receive InFocus in a different format?

Please let us know on 020 7377 5578 or at **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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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. **Thanks for your support!**

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OrCam lucky dip competition

CHECT has kindly been gifted by Essilor Ltd (Thornbury branch) four OrCam MyEye devices which we would like to offer free of charge to members via a lucky dip.

The OrCam MyEye is a small, wearable device that attaches magnetically to the side of most glasses. Using a camera and text-to-speech technology, it reads text aloud (newspapers, books, screens) and recognises faces or products. It is specifically designed for people who are blind, visually impaired, or have reading difficulties (such as dyslexia). They can be used by adults and children (typically aged 6+).

How to enter
To enter by 5pm on 1st September, please email **info@chect.org.uk** with OrCam Lucky Dip as the subject line, and your name, address and telephone number in the body of the email. Alternatively, you can call us to enter on **020 7377 5578**.

We will notify the lucky recipients by 5th September.

Eligibility
Entrants must be members of the Childhood Eye Cancer Trust (CHECT) who either have a retinoblastoma diagnosis themselves, or are the parent of a child with a retinoblastoma diagnosis.

Entrants must either have a CVI (Certificate of Visual Impairment) themselves, or be the parent of a child with a CVI.

If you are entering on behalf of a child, they must be aged 6+.

Please note
CHECT is not responsible for the condition of the OrCam device, or any malfunctions which may occur after receipt. The OrCam device is not for resale.

Up the O2!

We had a great turnout for our April Teen & Young Adult event to climb over London's O2 Arena – with ten young CHECT members aged 11–22 and various friends and family members.

In fact it was such a good turnout we had to spread everyone over two climb groups: one led by Lena and one by Petra. Sarah was relieved to keep her feet firmly on the ground! Everyone took the climb up in their stride, and we enjoyed fantastic views of the capital from the viewing platform at the top. The descent was steeper than anyone had imagined, but by taking it slowly we were all soon back on the ground.

Having now worked up quite an appetite we headed to Zizzi's inside the Arena for some of the largest pizzas we had ever seen! It was lovely to spend time chatting together with friends old and new. Once the group had refuelled and recharged, many of them then bravely took on the final challenge of the day – the O2's outlet shopping section!

Interested in future CHECT events?
Head over to our meet up page: **www.chect.org.uk/meet-ups/**

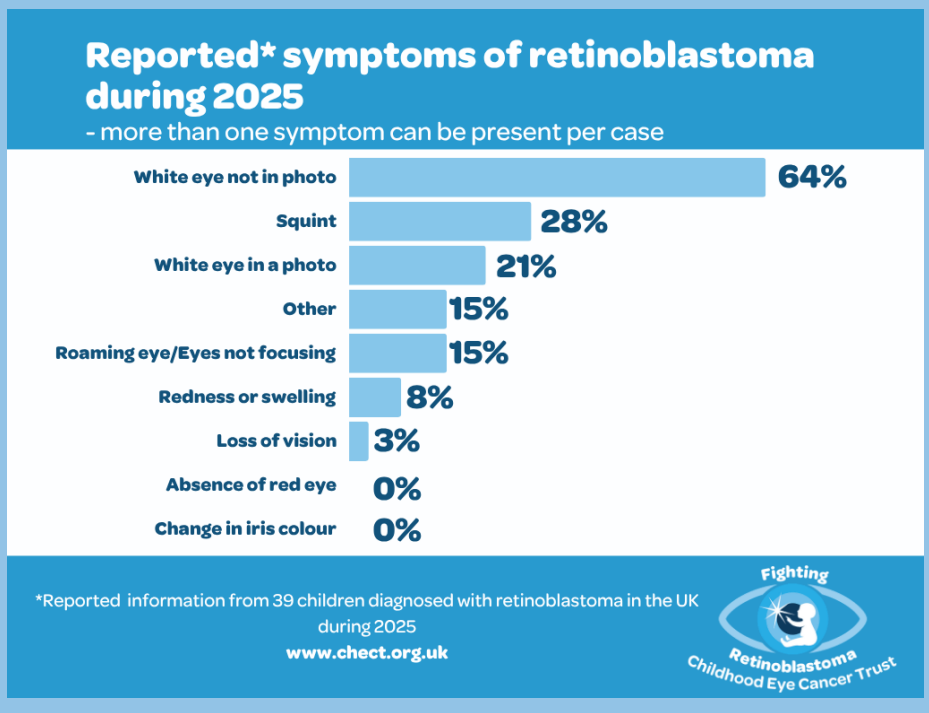
Pathways to Diagnosis Results 2025

Each year, the Childhood Eye Cancer Trust reports 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.

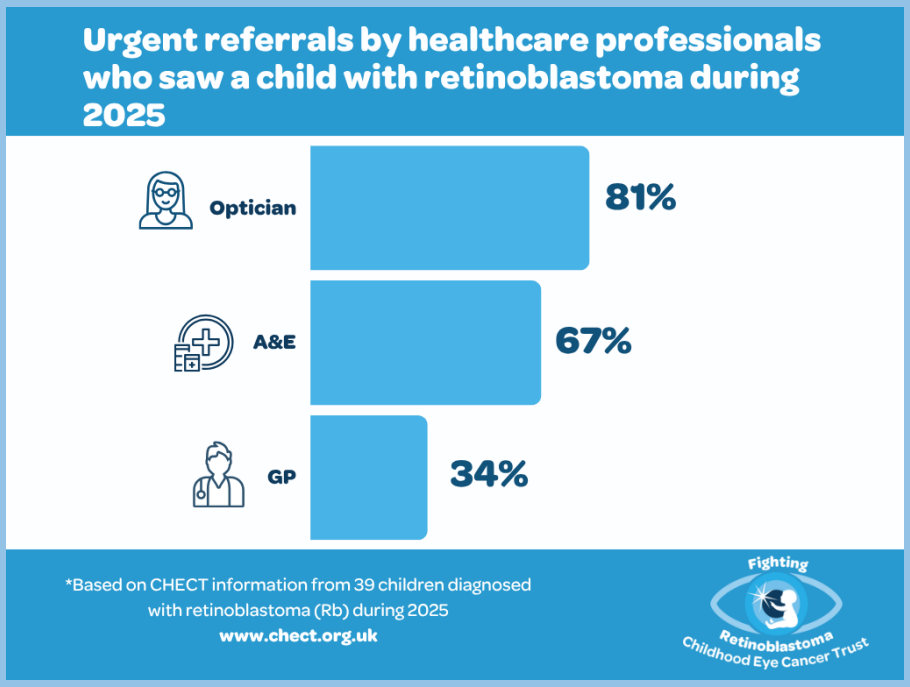
2025 round-up

Overall, 45 children from the UK were diagnosed with retinoblastoma in 2025, and we have information from 39 of these families. Two children were diagnosed through screening, one of which was through the groundbreaking Generation Study. So, what were families' experiences in 2025, and how do they compare to the 10-year average from 2015-2024?



1. Symptoms:

A white glow in the eye remains the most common symptom overall. This year more than the 10-year average noticed a white glow in the child's eye, and slightly fewer than average noticed it in a photograph. This is significant because the glow is likely to be noticeable earlier in a photo than with the naked eye. A new squint is still the second-most important symptom, but slightly fewer families than average reported this as a symptom in 2025.



2. Healthcare professionals (HCPs) – who did you see first?

As is usual, GPs were the first port of call for concerned families, followed by opticians and then health visitors and 111.

3. Healthcare professionals' referrals

Overall fewer healthcare professionals made urgent referrals when seeing a child with Rb compared to the 10-year average. The only profession to perform better this year was opticians, with a significant improvement on the 10-year average for urgent referrals made.

4. Number of healthcare professionals seen before referral to Local Ophthalmology Department

The number of children who were correctly referred on after their first appointment with a healthcare professional was equal to the 10-year average. However, the number of families who had to see four HCPs before getting the appropriate referral was disappointingly more than double the 10-year average.

Can you share leaflets in your community?
Please order at: www.chect.org.uk/shop/

5. Time from visit to first health professional to Rb centre:

Fewer families were referred during the recommended two-week urgent referral period than was average over the past 10 years, and it is the worst year since 2020, when just 35% of children were referred within the urgent two-week period.

6. Previous awareness of retinoblastoma

Perhaps unsurprisingly given the stats in point five, existing awareness of retinoblastoma was the lowest it has been over the past ten years, down on the average of 20%. Among those with prior awareness, knowledge had come predominantly through media coverage and social media – highlighting the critical role that public story sharing plays in early detection.

Overall, the figures from this year were concerning. That said, we have to bear in mind that we are talking about a very small sample group where a few bad experiences can quickly impact the picture. However, we will be looking carefully to see what happens next year, and whether this is the start of a worrying decrease in rapid referrals for children with retinoblastoma from primary to secondary (local ophthalmology department) and tertiary healthcare (specialist Rb centre).

REAL LIVES

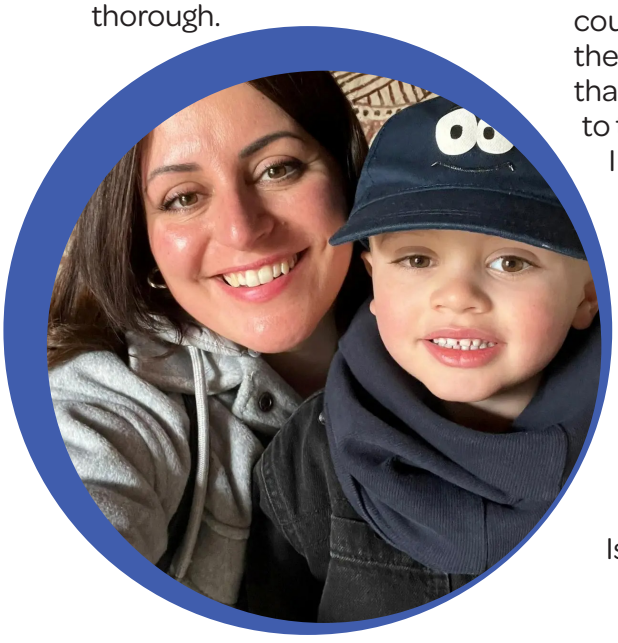
"We spotted our son's cancer on his birthday"

Mum Maria shared Isaac's story as part of our World Retinoblastoma Awareness Week campaign.

We noticed a glow in Isaac's right eye, but only in certain lighting and at a certain angle. We first properly noticed it on his third birthday once everyone had gone. I spotted the glow and mentioned it to Isaac's dad, who instantly knew which eye I was talking about. That's when I realised it wasn't just a trick of the lighting, but that something really was there.

I went straight onto the internet, and a quick Google made me realise it could be serious, so I booked an appointment at Specsavers for the next day, which was a Sunday, but I just didn't want to wait. I wanted them to reassure me that it was all fine.

Specsavers were great; they were so patient with Isaac, and the optometrist really was very thorough.



He eventually said that he could see something, but that Isaac needed to be referred to the local eye unit to have a proper examination with diluted pupils. I asked him if he thought it was cancer and he said that I should try not to worry as it was super rare.

I remember calling my GP every day that week to see whether he had already sent the referral. On Friday I received a phone call from my local hospital saying they had an appointment for that day. They did an eye test which Isaac passed without any problems. The consultant quickly checked his reflexes and said all seemed fine. I thought, okay, maybe everyone was right and I was too worried about it all. The consultant went quiet and asked his assistant for the ultrasound machine. He then said that he could definitely see a mass at the back of Isaac's right eye and that he would like to refer him to the Royal London Hospital. I knew then that he thought it was retinoblastoma and I started crying and so did Isaac's dad. Isaac was very confused and asked me why I was crying and I just didn't know what to answer so I just hugged him. That afternoon was horrible for us; we just didn't know what was going to happen. Would Isaac be okay, or would he die?

"I just hugged him"

It was just a horrible day.

In the evening came some relief. A Clinical Nurse Specialist from the Royal London Hospital called us as she wanted to speak to us before the weekend. She explained

a lot about retinoblastoma in general and answered so many of our questions. We got an appointment for the following Wednesday – that's when Isaac was diagnosed with unilateral retinoblastoma, cancer in one eye.

Telling our family and friends was hard, but the hardest part was explaining to Isaac's brother Simeon what was happening. Simeon is older and had questions and worries. We valued the support we got a lot, but it was still hard trying to keep everyone informed.

We were given some treatment options, and we decided on systemic chemotherapy which we felt was the best option for

Isaac at the time. One of the hardest things for me personally was the fitting of the central line and all the tests before treatment, maybe because everything was very unfamiliar to us.

Isaac then received six rounds of chemotherapy, which he took in his stride. I was absolutely amazed by him. He managed to form so many positive relationships in the hospitals we went to. Despite all the pain and scary things that he had to endure, he was always loving, caring, and made us all laugh sometimes.

During chemotherapy we were in hospital a lot, he kept getting high temperatures. Isaac's best medicine was definitely his brother, Simeon. We were so proud of both of them, Simeon was a star big brother who really cared for his brother a lot.

"Isaac is a very happy, confident boy"

After chemo, Isaac was given the all-clear but with regular check-ups. We celebrated a happy Christmas without any hospital visits or overnight stays. Unfortunately, at the first check-up after Christmas they discovered some seeds (retinoblastoma 'seeds' are small pieces of the tumour that have broken off and dispersed in the eye), which they treated with cryotherapy (a freezing treatment which can be used on small retinoblastoma tumours). Several rounds later, they discovered a small relapse of Isaac's tumour. We felt so deflated but decided to give it another try. So, we got booked in for plaque treatment. A plaque is a tiny piece of radioactive material which is attached to the outside lining of the eye to kill targeted cancerous cells inside. It was done at the Royal London Hospital, and we had to isolate for most of our stay. Isaac really struggled with the plaque treatment; he was in pain and very uncomfortable. He refused to open either of his eyes for two whole days, but we were hopeful the plaque would finish the tumour off for good. After the plaque, Isaac had to have some more cryotherapy. But luck was not on our side again, and only three months after the plaque, he relapsed again.

We decided that Isaac had endured enough and that we were not willing to take any more risks. We opted for an enucleation – removal of the eye. It was a hard pill to swallow after over a year of trying to save his eye, which had very good vision, but we just wanted him to have some peace.

For the enucleation, we all went to London, and Simeon was prepared in a really lovely way about what would be happening with Isaac and his eye. The staff at the Royal London were truly fantastic, as was our support worker from the Childhood Eye Cancer Trust (CHECT); they made it all that little bit easier to cope with.

Isaac is now nearly five and a very happy, confident boy. Isaac loves everything about dinosaurs and monster trucks; he is very caring and has made some good friends. Sometimes he is a bit wary in new locations and realises that he does not have a full field of vision. But all in all, he manages amazingly. He is aware and understands what happened to him. He still talks about the playworker at the

hospital who he calls his best friend. We are very open about it all and have been throughout the process. We found it the fairest to Isaac.

Our support worker from CHECT was a big support throughout it all. Not only was she a great listener and so caring, but she also managed to organise some financial support for us, which we valued so much. We also got the little extras that were great for Isaac. Pip the Penguin – a teddy whose eye you can remove – which he received after his eye removal is still a much-loved toy at home. He likes to show others how he can remove its eye.

Would you like to help us raise national awareness?
If you would like to share your story, please contact **info@chect.org.uk**

"A white glow in our toddler's eye revealed his cancer"

Mum Laura shared Brody's story as part of our Christmas awareness campaign.

I noticed a white glow in Brody's right eye when he came into the kitchen. It was November 2024, so the nights were dark and the lights in the house were on. When he came into the kitchen, for a split second, I saw a reflective glow in his eye. The first time I saw it, I thought perhaps I hadn't seen it properly, or that it may just have been the kitchen lights catching his eye a certain way.

I remember being extremely worried after the second time seeing it; I was very sure that I had seen a glow. Brody had a doctor's appointment a couple of days later that week for something unrelated, and I asked the doctor to have a look in Brody's right eye because I had seen this cloudy, reflective glow. The doctor looked in Brody's eye and told me all was fine. I came away from the appointment feeling reassured that everything was ok. However, a day or two later, I saw the glow again.

I remember Googling what causes a white glow in a child's eye. The only information that came up was retinoblastoma. I was worried, so I got an urgent appointment at Specsavers. The very kind optician said to me that he could see what I was saying about a cloudy glow in Brody's eye and said that he was going to do an urgent referral to the hospital. Within an hour of leaving the opticians, our local hospital called to arrange an appointment. This is when I really started to panic, and I just knew that this was serious. My family tried to keep a positive outlook, but I felt certain something was very wrong.

"Looking back, it's all a bit of a blur"

We were due to wait a week for the hospital appointment, and I couldn't rest. My husband and I decided to find a private paediatric ophthalmologist to see Brody sooner. We originally found a local specialist and booked an appointment, but the day before, the secretary contacted me and cancelled as the consultant was unwell.

We searched everywhere for an urgent private appointment, and on Wednesday 27 November 2024, we travelled to Manchester to see a paediatric ophthalmologist who, after doing an examination, said he was 99.9% sure Brody had retinoblastoma. We were absolutely devastated and gripped with fear as to what this meant for Brody and for us as a family.

We were referred from the private ophthalmologist in Manchester to Birmingham Women's and Children's Hospital and were seen within a week. Brody had an examination under anaesthetic, and the consultant confirmed to us that Brody had unilateral retinoblastoma in his right eye. He had one large Grade D tumour. They were hopeful they could save his eye, but said vision in that eye was unlikely due to the tumour's location. We were told they did not believe it had spread to the optic nerve, but Brody would need to have an MRI to confirm this.

Before Brody was diagnosed, I honestly don't think I had much awareness of retinoblastoma. I vaguely recall seeing something about a white glow in the eye on Facebook, but my knowledge was very limited.

The whole situation, looking back now, is a bit of a blur. The shock, fear and panic we felt, whilst trying to maintain normality and balance for Brody and my other children, was extremely difficult. I cried a lot initially; my worst fear as a mother had come true, and

the unknown around treatment was a lot to handle.

Thankfully, the Childhood Eye Cancer Trust and the doctors and staff at Birmingham Women's and Children's Hospital were so supportive and really helped to explain and describe what lay ahead. When I spoke with family and friends about our situation, everyone was so supportive. I initially only told family about it until I had managed to process it to some degree.

After the consultant spoke with us about Brody's diagnosis, we spoke with an oncologist who explained to us Brody's treatment options. Chemotherapy was required, but how it was delivered – either systemic chemotherapy (where the drugs circulate through the whole body via the bloodstream) or intra-arterial chemotherapy (IAC) – where the drugs are delivered directly to the eye through an artery – was something we could decide on. After discussion, we decided that IAC would be the best option for Brody and would minimise side effects.

Brody had IAC. We were advised that this would likely be three rounds, but we were extremely lucky that his tumour responded so well to it that we only needed to have two rounds of IAC chemotherapy. He is now having laser therapy, which has been ongoing since after the first round of chemotherapy.

Brody is now three and doing great; he is a full-of-beans wee boy. We still attend Birmingham Women's and Children's Hospital monthly for examinations under anaesthetic and laser treatment. As Brody has gotten older, he now knows what is happening when we go to Birmingham. He knows the drill, so to speak, and gets very distressed when he has to have eye drops to dilate his pupils and go down to theatre. However, once he is out of the hospital, he is back to his happy, bubbly self very quickly. Hopefully, as he gets older, he will better understand how important these visits are for him. I don't think he will ever like it but will hopefully understand how necessary they are.

"Brody is such an outgoing character"

Brody is such an outgoing character; he is switched on, plays football at toddler football sessions, and attends a lovely playschool where he has some wonderful wee friends. Brody is close to his key worker at playschool, and she and the other staff there have been excellent during all of this. They have brought stuff round to our house to keep him entertained during hospital visits and have been so supportive.

I think what has helped Brody the most is keeping things as normal as possible. As a family, we have maintained our normal life as much as we can, and I truly believe that sense of normality has helped massively. As hard as it is initially, I do think this is so important.

I reached out for support from the Childhood Eye Cancer Trust and my Support Worker contacted me. At this time, our fears and uncertainty of the unknown were at their greatest. She really helped to calm me and reassure me. I was crippled with fear at the very start of Brody's journey, but having a reassuring, kind and compassionate voice of reason was an absolute blessing.

I could contact CHECT with any questions. I was provided with information, nurtured through my pain and upset, and spoken to about potential benefits that could help financially. Brody was sent packages with books and a cuddly toy explaining chemotherapy after a referral made by our Support Worker. The care from CHECT has been invaluable and is still invaluable now, one year into this journey.

We really appreciate every story shared with us – and we can't raise awareness without you!

Children's corner & CHECT TYA!

Liv's on target for success

We spoke to 16-year-old Liv about her impressive sporting abilities and how she overcomes issues with depth perception.

I started Tae Kwon Do when I was 7 years old. I wanted to try martial arts and I liked it. Me and my mum do it together, she is a 3rd Dan black belt. My favourite thing about Tae Kwon Do is breaking boards. Gaining my Black Belt 1st Dan in 2021 has been my greatest achievement so far, and I am currently due to take my 3rd Dan in June.

I also started archery last September. I am 16, and started just over 6 months ago. I tried archery a few years ago at a sports event and really enjoyed it and always wanted to do it. My favourite thing about archery is when I score – I took part in my first archery competition a few weeks ago and was awarded a silver medal in my age category.

Sometimes having had Rb affects my hobbies. I had bilateral Rb and had an enucleation at six-months-old, because of this I have no depth perception and when sparring I am sometimes not able to judge how close someone is to me.

I have to break boards using my non-dominant hand and foot as I cannot see if I stand with my other side forward as that is where my blind side is. If people approach me from the right side, I do not see them, so I have to be more aware when I am sparring.

In archery I have had to learn to bow as a left-handed person although I am right-handed so that has been a challenge at the start. I'm looking forward to taking part in more competitions and gaining some higher Archery Award Levels as I progress.

Gracie's love of dance

We spoke to 16-year-old Gracie, who has been awarded for her success in dance.

My favourite thing about dancing is how it lets me tell a story without needing words. When I'm on stage I feel completely free and confident, and I love connecting with the music and the audience. It's also the best feeling when all the hard work in training finally comes together in a performance. I actually started dancing when I was about 18 months old. Even while I was going through treatment for Rb I still went to dance classes. It was always my favourite part of the week and something that made me really happy. My mum said I always loved music and moving, so dance just felt like the perfect place for me.

One of my biggest achievements has been competing and placing first in competitions against really strong dancers. Recently I won 1st place with a perfect score, and the judge specifically mentioned my storytelling, musicality and performance, which meant so much to me. For me it's not just about winning though; it's about proving to myself that I can keep improving and doing what I love. I lost vision in my left eye because of Rb when I was two, so I don't have sight on that side. Sometimes that means I have to work a bit harder with things like balance, spacing or spotting in turns. My teachers have been really supportive and I've learned to rely a lot on muscle memory and practice. It's just normal for me now; I've always focused on what I can do rather than what I can't. Right now I'm really excited about the national competition coming up at Butlins! It's a huge competition with dancers from all over the country, but it's also so much fun and the atmosphere is amazing. I'm really looking forward to performing there and just enjoying being on such a big stage.

Felix's musical future

We spoke to Felix about his love for music.

At three years old, I started to fiddle around on the piano as I liked to make the sounds. When I was about four years old, I used to sit at our piano and copy tunes that I had heard, teaching myself before I had lessons. At this age, I also had my right eye removed and more chemotherapy. My treatment on my left eye continued until I was seven years old and I spent long days and nights in hospital. I would always take a keyboard in with me to play on. I started having piano lessons with a teacher at about five years old and still have piano lessons now at seventeen years old.

My favourite thing about playing the piano is enjoying making music and listening to the sound that I produce. I love how each note has its individual pitch. I enjoy performing and playing so other people can enjoy my music.

There have been multiple achievements. My greatest achievement so far with my music has been getting a distinction at ABRSM Grade 7 piano. I also got a distinction in my ABRSM Grade 5 music theory a couple of years ago, and last summer I passed my music GCSE with a Grade 9.

Only having one eye – and I can't see very much out of that eye – means that I can't see the music on the stave to read it. This means that I have to learn the piano by ear and memory. I have to remember all the notes, which fingers to use, dynamics, articulation and pitch. I have perfect pitch, so this really helps me know what key I am playing in and is very useful for my aural tests when working out modulations and cadences. Due to my music theory, I understand how music is notated, as I have learnt this all on a large stave; however, I can't read the music to play from as my vision is not that good. I think that losing my vision has heightened my hearing and I can pick out the pitch of notes which is incredibly useful and a great advantage.

As a dedicated musician, I am looking forward to working towards my ABRSM Grade 8 piano exam. At the moment I am doing a two-year Music Performance Diploma at college and get to perform most weeks. At college I also enjoy composing jazz music for the piano. My future career will be music-related. I may become a performer, a composer or a pop artist.

Nancy's sporting success

We spoke to ten-year-old Nancy, who was diagnosed with retinoblastoma, about her sporting hobbies.

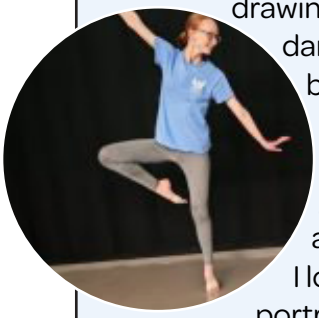
I currently play football twice a week with my school and a team on Saturdays. I also play for my local cricket team through the cricket season. I also love to horse ride!
I started horse riding when I was just four, I've been playing for my local cricket team for the last 2 years and I started football in the last year. With my local cricket club, I have played games around Essex County. My biggest achievement with horse riding was being able to get back to it only 3 weeks after having my eye removed!

Sometimes at the stables I wear a patch on my eye as the horses do kick up a lot of dirt which can result in my eye being sticky. For cricket and football, I wear my sports goggles to help protect my sight – cricket balls are very hard!! I'm looking forward to the cricket season starting again and the football fields not being so muddy!

Abbie's creative flair

Abbie, who had Rb as a toddler, is now aged 18 and a talented dancer and artist. We spoke to Abbie about her talents.

I love being creative whether this is using my body or drawing. I love dancing because it is expressive, fun and I get to move around a lot. I love drawing portraits of people, usually my favourite singers or actors. I started dancing when I was one years old in my mum's dancing class and took part in my first dancing show three months after being treated for Rb at 19 months old.



I have always drawn and painted and enjoyed making things. I used to come home from preschool with huge creations and pictures! Last year there was an exhibition of my artwork at Lantern Arts Centre. I was very proud to be able to let other people see what I had drawn.

I have just completed my grade 6 ballet exam. In my dancing I find it harder to turn to the left as I have a prosthetic left eye. It hasn't stopped me but means I just have to try harder or adapt the dances. I am currently studying A-level dance and a teaching certificate for freestyle dance. I look forward to helping children learn some dances.

A Q&A with baller Balfour

We spoke to twelve-year-old Balfour about his favourite things to do.

I was diagnosed with Rb when I was 3 and a half. My mum had noticed a white glow in my eye at certain angles when she was putting me to bed and at first she thought it was a reflection of the lights but thought it wise to get it checked out. I had an appointment at the optician who confirmed there was a growth in the back of my eye but that it wasn't necessarily anything to be concerned about, but she suggested we see a specialist as soon as possible. We saw a specialist within 2 days who confirmed it was retinoblastoma and, unfortunately, I would have to have my right eye removed. But the good news was that it hadn't spread. I don't really remember it all, but my parents say it was a terrifying whirlwind as they went from thinking everything was fine, to finding out I had cancer, to having my eye removed and it being confirmed I was cancer-free, all within a matter of weeks. I just remember getting lots of attention and puking on my dad when I came round from the anaesthetic! Having a prosthetic eye has never stopped me doing anything and apart from sometimes walking into lamp posts it doesn't really impact me, and I embrace it. I have started a collection of custom artificial eyes and have a black and red target one and am hoping to get a reptile-style one next.

What are your favourite hobbies or activities?

Football and music. My dad is big into football, and both my parents enjoy music. I enjoy football because of the feeling of scoring or slide tackling someone.

What's the coolest thing you've made, learned, or achieved through your hobby?

I have learnt bass guitar through my love of music. I'd like to try a six-stringed guitar.

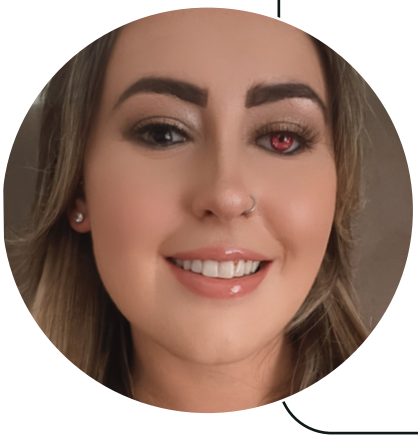
Who inspires you in your hobbies?

Football-Conor Bradley (Liverpool right back) as he is Northern Irish like me.
Music-Flea (bass guitarist of Red Hot Chili Peppers) as he is a very talented musician and overcame a lot to make it big.

Bespoke eyes!

Ever wondered what it's like to design your own eye? We sat down with CHECT members who have had a bespoke artificial eye created just for them.

Danni



This is my collection! I got my first bespoke golden-coloured eye from the National Artificial Eye Service (NAE) in 2022 after I came across an influencer from America on Instagram with a different coloured eye – I was completely unaware that this was a service the NAE could provide until then, but I jumped at the chance to get one as I received constant insulting comments from people about my natural artificial eye, and I hoped it would give me more confidence to accept my differences and be myself. Since then, I've got at least one bespoke eye every time I've needed a fitting, and hardly wear my natural eye. I tend to go for eyes that look like normal irises but in different colours, and most frequently with glitter for an extra bit of shine. I'm so grateful to the NAE for my collection, and hope to keep building it.

Jude

Jude has been so excited to have a range of custom eyes. He has a Minecraft Eye of Ender, a galaxy eye and a Demon Slayer eye. Jude loves showing off the designs and has really enjoyed the positive attention they bring. They are often a talking point that enable people to ask Jude questions about his eye and he's really confident doing this, which is great to see.

Josh

Josh chose this design as he loves dinosaurs. We're hoping it will give him some confidence as he sometimes reflects back on having an artificial eye and gets upset about having to have one. Josh lost his eye at 18 months old and occasionally asks us if he can have his real one back! When he wears his dino eye he feels like showing the world "This is me". He has since asked if he can own a whole collection of them.

Dela-Rose

Dela-Rose chose that eye as it's pink and glittery and she loves glitter, and the pupil heart is for her family and friends. She said it makes her feel special, loved, and happy.

Our fundraising superstars!

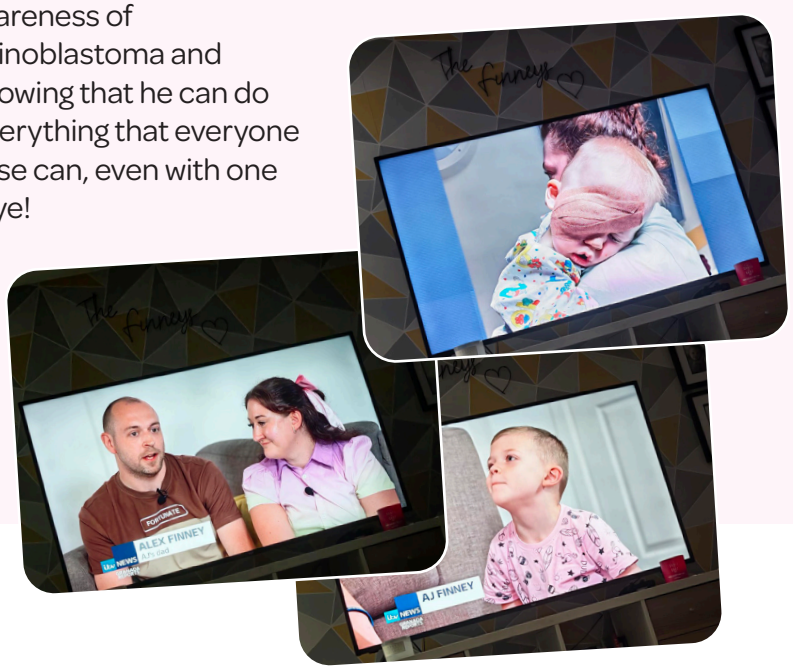
AJ raises awareness & funds for Rb Week

World Retinoblastoma Awareness Week was a busy one for the Finney Family. Mum Tasha reported on the week:

AJ, with help from his mummy and daddy, created awareness packs to give out to his friends - the packs included a CHECT balloon, wristband and sticker as well as a signs and symptoms leaflet, a pack of sweets and a poem as if written by AJ. The packs went down an absolute treat and parents were touched by AJ's story. On the Friday of World Retinoblastoma Awareness Week, all of AJ's reception friends wore blue and managed to raise a huge £160, which went towards the total raised at their charity event the following day.

On Saturday 16th May, parents Tasha and Alex hosted their 5th annual charity evening to raise funds for CHECT. Their night was held in Horwich and featured winners and finalists from Britain's Got Talent - Lost Voice Guy, Jon Courtenay, Steve Hewlett and Lillianna Clifton entertained their 250 guests and went down a treat. An extra special treat on the night was AJ and his mummy performing an Irish dance, AJ's new hobby and mummy's from a lonnnnnng time ago too - AJ had only had 8 lessons and he was amazing! There was also an auction, hosted by Bolton Wanderers legend John McGinlay, and a raffle with some incredible prizes on offer. The evening raised an incredible £9,100!

Just a couple of weeks later, AJ also featured on his local ITV news station (Granada), raising vital awareness of retinoblastoma and showing that he can do everything that everyone else can, even with one eye!



London Marathon

Congratulations to our London Marathon team for completing the 2026 London Marathon and raising £30,000 for CHECT! It was another hot year, but our team did incredibly well and we are so proud of them! If you are one of the lucky ones with a ballot place in the 2027 London Marathon, we would love to have you on the team!

Gaming for Good

You can now raise funds for CHECT through livestreams, gaming and with your friends online on Tiltify. Stream across platforms that integrate with Tiltify such as Twitch, YouTube and Facebook Live. For information head to **chect.org.uk/digital-fundraising/gaming-for-good/** or contact **fundraising@chect.org.uk**.

World Retinoblastoma Awareness Week

We are so thankful to everybody who raised awareness and who fundraised during this important week! The next World Retinoblastoma Awareness Week will be 9th–15th May 2027 - so save the dates!

Remembering your loved ones

We've partnered with Free Wills to provide you with the opportunity to make your own fully comprehensive Will for free. Your Will will be checked, vetted and approved by a solicitor. For more information head to our website **chect.org.uk** - click on 'Get Involved' and 'Legacy Giving' or contact **fundraising@chect.org.uk**.

We are eternally grateful to those supporters who have remembered our charity in their Wills, and to those who have collected 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 Edith Neill, Robin Williams, Mark Prouse, Graham Maudrell, Meryl Hobbs, Rita Margaret Blanche Galvez and Paul Castle.

#CCAM!

September is Childhood Cancer Awareness Month (CCAM)! We'd love you to help us to raise awareness and funds - learn how to get involved at **chect.org.uk/childhood-cancer-awareness-month-going-for-gold/**- or give us a call on **020 7377 5578**.

HOSPITAL TO HOSPITAL CHALLENGE

AUG OR SEPT 2026

Take part in our virtual CHECT challenge!

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

How you do it is up to you – walk, wheel, cycle, swim, skate, or mix it up during either August or September! You can take part on your own, participate as a family or as a team, and complete the distance in your own time and pace.

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

Sign up at: **www.fundraise.chect.org.uk/event/hospital-to-hospital/home**

What happens next

Once you have completed your registration, your bespoke fundraising page will be ready for you to use.

- We'll send you a pack containing a tracker and some CHECT merch!
- Update your fundraising page and share your challenge with friends, family and colleagues to earn badges and raise funds for CHECT.
- Keep track of your progress on Strava or by using your physical CHECT tracker and upload it to your fundraising page.
- Celebrate your achievements along the way and once you've completed the challenge you'll receive a personalised thank you certificate from us!

What your hard work and funds do for those affected by retinoblastoma:

£22 could fund a **Pip the penguin** toy, helping children and babies come to terms with having their eye enucleated (removed).

£57 could **fund a place** at a regional event for a family feeling isolated, giving them the opportunity to meet others who truly understand their circumstances.

£103 could go towards providing **a support grant** for a family facing financial hardship, ensuring they can access the support they need without worrying about the cost.