

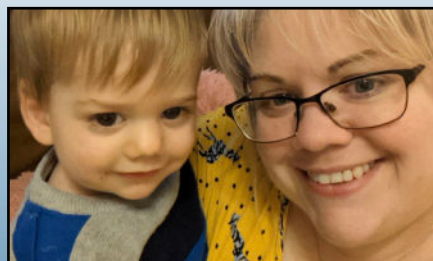


Our Rb Week fundraising stars!



"We spotted Rb as Arlo played in the sunlight"

Read Arlo's story **Page 6**



"I spotted our son's Rb as I cooked dinner"

Read Thomas' story **Page 7**



"You must stay strong and let the difficulties motivate you"

Read Michael's story **Page 9**

Welcome

Welcome to the summer edition of InFocus! We extend our heartfelt gratitude to all families who shared their fantastic Crazy Glasses photos for World Retinoblastoma Awareness Week (Rb Week), enhancing our front cover.

In recent months, we've hosted various exceptional in-person and online events, celebrating numerous members at our Family Members' Days. Presenting our CHECT Champion Awards to brave young members has filled us with immense pride. A special tribute goes to these extraordinary children whose contributions raised Rb awareness on national platforms like the BBC and ITV news and radio.

We deeply appreciate the families and individuals who entrusted us with their stories or assisted in spreading awareness through the press. We're privileged to feature some of these stories in this edition.

The active participation of countless

members has uplifted our charity, whether they joined us on our enlightening Beyond Rb day trip, participated in the engaging TYA (teens and young adults) podcasting event, or enjoyed the camaraderie of our family days. Witnessing new friendships blossom and radiant smiles has truly warmed our hearts.

Alongside our support gatherings, we've seen numerous successful fundraising events, and we're immensely thankful to all who generously dedicate their time and resources to support us. Your support is crucial as we receive no government funding, sustaining our efforts in support, research, and awareness.

I'd like to express my heartfelt appreciation to the remarkable team at CHECT - our dedicated staff, volunteers, and Trustees. Despite being a small charity, we've made significant strides in our mission to support everyone affected by Rb, thanks to their unwavering dedication.

In conclusion, sincere gratitude to all members, trusts, foundations, fundraisers, and supporters who empower us at CHECT to sustain our vital efforts in support, research, and awareness. Your generous support is deeply valued and genuinely appreciated.



Richard Ashton, Chief Executive

Want 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 you'd like to read about? Would you like to submit content for our blog? If so, we'd love to hear from you at info@chect.org.uk.

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The opinions expressed in this newsletter are those of the individual authors and are not necessarily those of CHECT or the editor.

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Good News and events

Amazing Maisy!



Mum Kay Lewis has released 'Amazing Maisy', a book about her daughter, Maisy, who had Rb, and their experiences. Maisy said, "I'm honestly so proud of my amazing mum who has written this book. It has been so lovely to read and learn about things I never knew. I have such an amazing family, and I hope this book can give

anyone some hope that needs it, or even just enjoy reading our story. This book is full of emotions, so definitely keep your tissues nearby!"

How lovely!



What a great photo of Play Specialist Gemma at Royal London with her treasure box, spreading her magic to two very special and brave girls, Daisy and Penelope after receiving their eye drops.

Rosie the pianist!



Rosie was one of two winners chosen to be the recipient of the Ffion Miles Music Bursary in 2023, in memory of the late Ffion Miles. Ffion was not only known for her love of music, but her passion for helping those who had Rb and/or who had a visual impairment. Rosie has used the funding to buy a piano.

Rosie said, "I was very pleased when I found out, and have really enjoyed playing on the new piano the money went towards."

Mum Emily added, "We were so happy for Rosie when we found out about the award. We put the money she received from the bursary towards a new piano and have found it's made a huge difference to her piano playing. She's really enthusiastic about playing and helped her to play and practice more."

Ivy's sparkly eye!



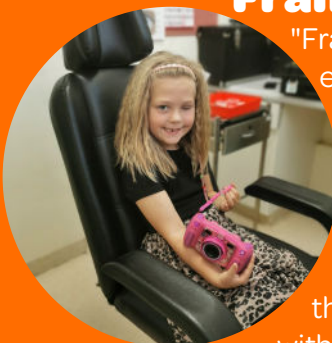
"My daughter got inspired by other kids showing off their special artificial eyes, so she asked her ocular prosthetist to make her a glittery blue eye. She just got it and embraced her individuality. She's very happy with it, and all thanks to you guys sharing stories of other kids with Rb. I'll be forever grateful."

Taylor's on target for success!



"Taylor is 11 now and has taken up 3D field archery. He recently entered his first competition in Cubs in the Isle of Wight and came home with a gold and silver medal. Although he's lost his right eye and should be shooting left-handed, he's right-handed so he's taught himself to canter the bow and is a pretty good shot."

Frankie's trip to the ocularist!



"Frankie's Ocularist had some new equipment that she hadn't used on any child at that time and thought that she would give it a try on Frankie. It was a camera that took close-up photos of the seeing eye to capture the true colours and details within the eye. The prosthetic was then made using the photos rather than guess-

ing with existing coloured prosthetics and trying to get a close match. When her new prosthetic came back, we were blown away! The quality and how realistic the eye looked was amazing. There was so much detail within the prosthetic it was a fantastic copy of her seeing eye. Our experience with the National Artificial Eye Service has been extremely positive and with advancing technology it can only get better."

A letter from CHECT's Trustees



Hello everyone, my name is Ian Ellington. As chair, I am writing on behalf of all of the CHECT Trustees to give you a short update on the work of the Trustee Board and to signpost a couple of things to look out for later in the year.

The Trustee Board is a group of volunteers, like me, who work alongside the staff team to help shape the strategy of the charity and to provide oversight and governance – basically, to ensure that the charity is being well run and that we are spending our time and resources on our core charitable aims. I have been involved for over 10 years now, and during this time I have seen the charity develop significantly. I'd like to take the opportunity to thank and congratulate the staff team on the great work they are doing every day to support our members, raise awareness of Rb and promote and fund research into the condition – as well, of course, to raise the money that makes all of this possible. For a small charity, I am constantly amazed at how much we manage to deliver.

We are lucky, also, to have a strong and diverse trustee board with a good balance of skills and experiences – including many of us who have had a personal experience of Rb. In my case, my son Tom was diagnosed with unilateral Rb when he was two and had his right eye enucleated. Even writing these words, 15 years later, makes me feel very emotional, and I remember vividly how traumatic it was, but also what incredible support we received from the specialist clinical team and CHECT. Working in partnership, they helped our family navigate

the most difficult period of our lives, and I am happy to say that Tom is now a thriving 17-year-old, who has played football at a very competitive level, has just passed his driving test (watch out for a grey VW Polo in the Maidenhead area!) and is looking forward to attending university next year.

This personal experience helps us understand some of the issues that our members are dealing with. However, we are aware that we could always benefit from more diverse perspectives. Being a trustee can sound daunting to people who have never done anything like this before (I hadn't). But there are no special qualifications needed – over and above a

willingness to devote some time and energy to the charity – and we are keen to attract people from as wide a range of backgrounds as possible. Please do get in

contact with Richard Ashton if it's something that you might be interested in. You can contact Richard at richard.ashton@chect.org.uk.



Things to look out for:

Members' Survey and Feedback Email

Whilst there is good communication from CHECT via social media, emails, and the InFocus Magazine, we are also keen to ensure that there are open channels of communication between members and the trustees.

In our upcoming member survey, due in the autumn, we are keen to gather your views on how the charity is doing and what you, as members, might like us to do more of. Please watch out for this and take the opportunity to give us your feedback.

We are also keen that there is the opportunity

for you to make suggestions, ask us questions, and give your feedback, and we are launching a specific email address for you to contact the Trustees directly. It is **trustees@chect.org.uk** and will be included in future member communications by way of a reminder.

Articles of Association

In the past twelve months, we have been reviewing our articles of association. These are legal documents that set out our charitable purposes and how CHECT is managed and run. Our articles were originally written in 1987, when the charity was first established, and having reviewed them, we have concluded that some updates are required.

We have taken legal advice, kindly provided free of charge by Eversheds Sunderland, and we are proposing to formally refresh our articles later in the year. We are not changing any of our main purposes or charitable aims, but we are looking to streamline and modernise the articles and remove any unnecessary administrative burdens. For example, one of the changes we are looking to make is to formally "allow" us to hold virtual, rather than face-to-face meetings to take key decisions.

Once the review is complete, we will call a society meeting to gain agreement via a formal vote by our members. It is anticipated that this will be held as part of an Annual General Meeting held remotely on Saturday 23rd November 2024. Further details will be sent via email in due course.

Finally, we are a largely member-supported charity, and many of you do amazing things to raise money for CHECT. Thank you for all of these efforts; we really couldn't do it without them... And if any of you are motivated to start a fundraising effort, but don't know where to start, I know that Richard and the team would be happy to give you some ideas and support, so just get in touch!

To contact CHECT's trustees, please email trustees@chect.org.uk.

CHECT events!



We've so enjoyed meeting everyone who has come to the last few CHECT events around the UK – thank you to you all for making the effort to come and see us.

Since the last In Focus, we have travelled to Glasgow, London and Cardiff to meet up with families, and hosted a get-together with some of our adult members in Sheffield. Our next in-person event will be an activity day for teens and young adults just outside Birmingham in September. And there'll be two more family meetups before Christmas, so keep checking the webpage at **www.chect.org.uk/events**!



Pathways to Diagnosis

Each year, we report back on families' experiences of being diagnosed with 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 and 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 we may be able to do to help.

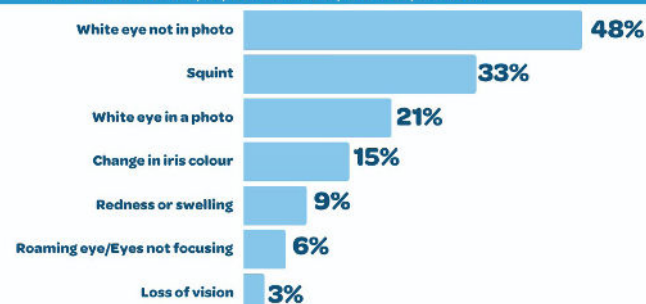
Overall, 51 children from the UK were diagnosed with Rb in 2023, and we have information from 33 of these families. Eight children were diagnosed through screening, either due to family history or other conditions, and we were unable to gather Pathways from the remaining ten. So, what were families' experiences in 2023?

A white glow in the eye remains the most common symptom overall. This year 21% of parents spotted white eye in a photo; but less than average saw the white glow in their child's eye (48% in 2023 vs ten-year average of 57%). After a white glow, a new squint was the next most common symptom, observed in a third of children later diagnosed.

This year fewer parents took their child to the GP in the first instance on noticing something unusual with their eyes than any year since this study started in 2012. And more than any other year they took their child to an optician in the first instance. This may be either because families are struggling to get an appointment with their GP, or because GP surgeries are 'triaging' eye queries towards opticians. Either way it is an interesting scenario, and potentially positive for those families concerned, as opticians have a much better track record at making

Reported* symptoms of retinoblastoma during 2023

- more than one symptom can be present per case



*Reported information from 33 children diagnosed with retinoblastoma in the UK during 2023

www.chect.org.uk



appropriate referrals for children with Rb than GPs (69% vs 45% from 2014 – 2023).

Encouragingly, this year saw more children than ever since 2012 following the appropriate referral route. 67% of children received urgent referrals after their first consultation with a healthcare professional to their local ophthalmology department (and then onto one of the specialist Rb centres). This is compared to the ten-year average of 44%.

Unsurprisingly, this was reflected in the overall speed of referrals. In the last ten years, 22% of children were diagnosed at one of the specialist Rb centres within a week of first going to a healthcare professional with signs of Rb. In 2023 this was 59%. Overall, 72% of children were diagnosed within the recommended two-week period, second only to 2022 when 73% of children were diagnosed within this time period.

We want to thank all families who take part in Pathways to Diagnosis for helping us collect this important data.

New research award

We are delighted to announce our research award to

Professor Yellapantula for his project "Prognostic stratification and early detection of relapsed retinoblastoma using aqueous humour-based cfDNA screening".



fluid from the eye called the aqueous humour. This team will be examining aqueous humour collected during treatment, to see if they can:

- 1) detect relapse earlier than current screening methods
- 2) use end-of-treatment cfDNA levels to inform the prognosis of retinoblastoma
- 3) discover the genomic and clinical features that differentiate low and high risk of relapse.

Learn more about our research on our website!

Cancers shed DNA fragments, called cell-free DNA (cfDNA), into bodily fluids, which helps us to detect genomic changes driving tumour growth. Retinoblastoma cfDNA can be found in the watery

REAL LIVES

"We spotted Arlo's Rb as he played"

Mum Megan spotted an unusual glow in her son Arlo's eye in August 2023.

I had noticed something and the next day my sister had him for the day and she called me and said that his eye was completely white while playing in his cousin's room directly in the sunlight. I was pregnant at the time and had my health visitor coming that week so I thought I would ask her advice and she said to take him straight to the hospital. Arlo had just turned five.

We took Arlo to our local hospital on the Isle of Wight. He had all the routine eye tests and then he was taken for more tests; at this point we knew there was something wrong. The doctor told us there was a very large mass at the back of Arlo's eye, he then called another doctor out of surgery to have a look at the photos. This doctor was from Moorfields Eye Hospital, he didn't confirm to us that it was cancer, but he made the referral to the Royal London Hospital.

Arlo was put under general anaesthetic, and they checked both his eyes. While Arlo was still in recovery and waking up, the surgeon came to talk to us and told us that unfortunately Arlo did have retinoblastoma and that he wasn't able to see out of his right eye and wouldn't have been able to for some time. The tumour was so large, they needed to perform an enucleation – a removal of the eye, as this was the safest option.

Being 36 weeks pregnant at the time I was extremely emotional; I rang my mum first and told her and then she said that she would tell the rest of the immediate family for us. My husband also made phone calls; he was my rock throughout it all.

On 23 August 2023 Arlo had his enucleation and as the tumour was so large, he did need to have four rounds of chemotherapy. He started the chemotherapy on the 21 September (four days after his baby sister was born).

After Arlo's operation he was so strong, he took it in his stride; he was using his hand a lot to feel things and to play with his brother, we made sure we got him lots of toys he could fiddle with, just while he was healing. The days after surgery, Arlo's working eye was very swollen.

Thank you so much to Megan, Richard and Arlo for helping us to raise brilliant national awareness during World Retinoblastoma Awareness Week.

Arlo really struggled the most with his central line, he wasn't a fan of letting anyone see it and the chemotherapy was really hard on him, he was very sick, but he took it in his stride. Arlo didn't lose any of his hair. Watching him go through the chemotherapy for me was very hard; I wasn't able to be at appointments with him as I had just had a baby, so my husband took on all the appointments with Arlo.

Arlo is doing so well; we are so incredibly proud of him. He's cleaning his eye himself; we've had his moulding done for his prosthetic eye and he stayed awake for his post-op appointment! He's back at school full-time and is loving it. His big brother is his best friend and such a good big brother always making sure Arlo is comfortable and okay at school.

Retinoblastoma has definitely made Arlo more clued up on his body, we tried to explain everything to him in such a way he could learn about his body. Arlo's sight had been gone for a while before his eye was taken so he had already gotten used to the sight loss.

The Childhood Eye Cancer Trust helped us with financial issues, support and connecting us with other parents of retinoblastoma patients. The Facebook group has been so helpful to ask other parents questions and our support worker is always just a message away for us. I can't thank her enough for her support.

Arlo is a very bouncy, loud, loving and funny little boy. He's always playing tricks, mostly on me, and his dad is the best climbing frame for Arlo. He loves music and having dance parties in the kitchen and is obsessed with Pokémon. In fact, Pokémon Go and his Nintendo Switch were his lifeline when he was at appointments. He used to sleep a lot at appointments as he used to tell us that "time goes quicker when you sleep."



"I spotted Rb as I cooked dinner"

Mum Sarah was cooking dinner when she spotted an unusual glow in her son Thomas' eye.

My daughter was holding Thomas in her arms as I was cooking, and I noticed his eye looked like a cat's eye. I couldn't see it again so then I wondered whether it was just the lighting. It was playing on my mind, so the next day I moved Thomas around in different rooms near lighting and eventually I saw it again.

After asking my health visitor if I was being paranoid, she said there was no harm in checking with a GP. I remembered years ago seeing something about a flash on the camera, but I had no idea what it was for or where I saw it, so I took some photos of his eye using the flash. When I Googled it, it came up with cancer.

It took five days of calling in November 2022 to get a GP to see Thomas after initially being told to wait two weeks. The GP looked and didn't seem worried but when I showed the photos, he said he would refer him to the hospital, but he reassured me that Thomas was fine. He called me later that day and said that Medway Hospital would see us

the next day, who then referred us to Maidstone Eye Hospital.

That day was such a worry, Thomas had eye drops put in, and when the Doctor called us back into his room to discuss the results, I was in the bathroom. When I came out, he was waiting for me...I knew then it wasn't good news, no Doctor waits for someone outside the WC do they?

Before he said anything I asked, "Is it cancer?". He said, "I'm sorry it's not good news...". My world just fell apart. I just sobbed - bless him - he just kept talking and holding my hand trying to comfort me... showed me this eye model, said some words. I knew he was saying things, but I just couldn't work out all of it...it

was like slow motion and like another language. He said whatever you do don't Google 'retinoblastoma', look on CHECT's website instead.

He showed me what it looked like on his computer and all I saw was eye cancer, he just kept saying I'm really sorry I couldn't give you good news and that it was amazing that I picked up on it so early. He also said he couldn't see it in the other eye, but he couldn't be sure and that the specialists would be able to see much better than he could.

The next day I called my children's schools to inform them that Thomas may have cancer and I wanted to put things in place for them before I told them. Wednesday came and Thomas went to the theatre to be put to

REAL LIVES

sleep for them to look into his eyes. The doctors came and were asking so many questions about family histories, about my pregnancy and his birth, he was also born with a cleft palate, so he had to have special bottles and I was expressing breast milk. It felt like he had been down for a lifetime. The specialists who did the check came back with other doctors and nurses and we all sat down and that's when he said unfortunately there was cancer in both eyes. He had two tumours in one eye and a massive tumour in the other which took most of his sight. Even now this makes me well up.

We told my two eldest children the night that we came back from the hospital after the diagnosis of retinoblastoma because they didn't want to go to bed without knowing what was going on. It was so heartbreaking to see them so upset. The cancer specialist nurse at the Royal London gave us a book to help us to explain it to our other child, as he just found it very hard to understand why his baby brother had cancer. Telling the rest of the family was still hard because how do you explain to your in-laws and your mum that their grandson who is only 15 weeks old has cancer and has already lost most of his vision in one eye through having a large tumour?

I found people avoid the conversation of cancer. Some asked, "Is he going to die?". "No, oh that's good news then." We had a lot of, "He'll never remember this" and, "He's still a baby. He'll get through it." That was really difficult

"I found people avoid the topic of cancer"



because yes, he won't remember it, which is a good thing, but it was just really difficult because he was so poorly through treatments.

Thomas received his first round of chemotherapy on 25 November 2022, and his second round on 22 December. He has had six rounds of chemotherapy altogether, as well as three blood transfusions, infusions of potassium and magnesium, two platelet transfusions, and two sepsis infections. Thomas suffered from allergic reactions to the dressings, and he also ended up on a feeding tube due to not drinking much milk.

When Thomas was diagnosed on the Wednesday at Royal London, that Friday we were also given a letter from my landlord to say that they wanted us out in two months, and they were giving us a Section 21. We emailed them saying what our situation was with Thomas, asking whether we could stay a little bit longer until we finished his treatment, but we didn't get a reply. So, while we were going to and from the London hospitals for a MRA and other tests I was also looking for a house and trying to pack up our home that we lived in for 14.5 years. It was very difficult and very stressful! We had no money. We had no house really and we were put through to CHECT on the day that we had the diagnosis, and their support worker was allocated to us - she's been a godsend. She helped us out with some grants. Medway Hospital was brilliant and gave us a grant as well and some Christmas presents for my four children. My mum gave us some food money because we literally had nothing, and it was just such a stressful time. Then we found a house which was a relief just as our old landlord

got back to us and said yes. You can stay for another year, but we'll put the rent up. We decided to move into the other property we had found on the 6 January, but on the 5 January, Thomas got really sick. I immediately rushed him to hospital. He was very grey, had a temperature and was making little grunting noises. I was just in floods of tears. They were treating him for potential sepsis until they had the blood cultures back to find out what was going on. The next day we were supposed to be moving. Our family were helping with the move and there was me in hospital with a very poorly son and I don't think I've ever felt so alone as I did at that time. Luckily, I had a friend called Kate to Facetime who offered me so much support. It wasn't until a couple of days later that the doctors finally told me that Thomas did have sepsis. He started to feel a lot better after a blood transfusion. I am so grateful to whoever donated the blood because they helped to save my son. Thomas perked after the blood transfusion. We were finally discharged after a week. We were allowed home on home visits, but we still had to go back overnight. Coming home to a house filled with boxes was not ideal but we made it work and then Thomas had a second round of chemotherapy and had his final round last April.

Thomas later rang the bell on the 10 May, but by 30 May he was back in hospital with his second round of sepsis. It was a really horrible bug again which took a long time to get rid of, so we ended up going to Great Ormond Street for an emergency Hickman line removal. We remained in and out of hospital until June while Thomas was poorly. And in-between all of the hospital trips, he also had



appointments for his cleft palate operation which was delayed for his cancer treatment and recovery.

Thomas hates hospitals. He's all happy beforehand and as soon as he sees the hospital, he goes quiet. As soon as he sees anyone in scrubs, he tells them "No" straight away even when they haven't even said or done anything. He's also very wary of people in general, although he has started going up to staff at a local playgroup which is lovely to see. He's very clumsy at home due to his vision and if we're in an unfamiliar place he is very wary of the new surroundings. The impact of Rb and the treatment has been a lot really and he's only 18 months old. In that time, he hasn't had that baby time because it's been spent in hospital.

Thomas is a very happy little boy. He loves playing with his older brother rough and tumble on the floor. He will tell his sister to read him books, and they'll sit on the floor, reading books and singing. He's such a cheeky little boy who loves food, Hey Duggee and going out.



A huge thank you to Sarah and Thomas for helping us to raise national awareness

during Rare Disease Day! 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@checht.org.uk.



My name is Ayokunle Michael Omotayo (Michael). I was diagnosed with Rb in my left eye in 1995 when I was 2 ½ years old.

Growing up with Rb was interesting. I was very aware that I only had one eye, which made me different from many of my peers. My parents did a great job of reassuring me and made me feel loved, valued and confident to excel in whatever I put my mind to. My mum was very overprotective of me, often keeping me close to her wherever she went, and she was always worried about the eye falling out unexpectedly. It also didn't help being the youngest of three children. My older siblings were also very overprotective of me and always had my back regardless. I remember having one or two instances where another child had made fun of me and I would go home and cry to my mum, but kids will be kids and these instances were rare and didn't last too long.

From a young age, I was very enthusiastic about education, and I excelled in school. My mum always made up my "special" bag containing a patch, sunglasses and later with an extra prosthesis as I had a collection of them. I also had a written explanation of my eye condition for the teachers and what to do if the eye accidentally fell out. I vividly remember the one occasion where this happened whilst I was in reception. I got carried away and started playing with

the eye, and the eye fell out! I was very brave as I held the eye in my hand, but this caused a great stir in class from the other children who were also frantically screaming that my eye fell out! I was immediately taken to the headteacher's office, who called my mum. I remained in the head's office until my mum's arrival. I was calm, confident clutching the eye in my hand awaiting my mum's arrival. She rushed in from work and was so proud of me as she quickly took the medical bag, cleaned the eye and fixed my eye back. As she took me through the corridor, other children were glancing in amazement, not really sure if this was real or if they were dreaming. As if this was not enough, I also attended after-school clubs as my parents had job commitments. One of the parents of the children in my class approached my mum a couple of days after the incident at school and said, her son came home the other day and told her that my eye had fallen out during story time. My mum: whether out of shame or overprotection, quickly responded, "You know children and their imaginative stories!".

Despite having an artificial eye, I was quite smart. I remember the teachers having to get books for me from the older years when I was in the reception. I also had a love for sports at an early age.

Through the years I achieved great results in my SATs, GCSEs and A Levels. I gained admission to Aston University and studied Mechanical Engineering and graduated with a 2.1.

I would say Rb had very little

to no effect on my ability to succeed in education. Within these years I also formed very good friendships and got invited to birthday parties (although I wasn't allowed to go to any sleepovers). I was a charming, likeable, and popular boy that people gravitated towards.

During secondary school, I largely developed my love for sports. I took part in every sport but mainly enjoyed rugby, football and basketball. Playing these sports with one eye was quite challenging, but I was determined and very resilient. It's something I always kept to myself and consistently aimed to overlook to not give myself any

excuses. I remember always

having sprains on my left ankle due to my proprioception (your body's ability to sense movement) not being the best on that side due to no peripheral vision.

However, a positive of this negative was

that it made my reactions a lot faster. Nonetheless, I was still able to perform well in these sports by staying determined and working hard.

When I was 19 years old, I started going to the gym which helped emphasise my passion for health and fitness. After university, I decided to play American Football. In late 2016 at 24 years old, I dislocated my left ankle which resulted in me having to undergo ankle ligament reconstruction surgery. I had a further three ankle surgeries over a 4-year span due to some pain and complications that persisted during the recovery process. I wouldn't say Rb was the main cause of this injury, but it did have

"Stay strong and allow the difficulties to motivate you"

From then to now

its part to play based on having no peripheral vision on that side whilst trying to execute complex athletic movements. To help combat this, I had to train extra hard to improve my balance and stability on my left side during the recovery process. Despite this, I was still determined to push myself through a difficult recovery period and ended up competing and performing well at the BSN Combine in Indianapolis and the XFL Showcase in Washington DC in 2019 while still recovering; an achievement I hold very dear to my heart.

I am currently a personal trainer and sports performance coach. My determination to overcome obstacles and passion for helping others enabled me to combine my love for sports, health and fitness.

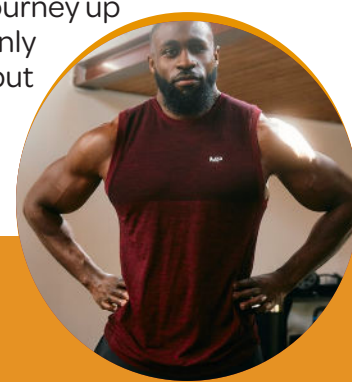
As a survivor of Rb, I know first-hand what it's like to have adversity staring back at you when all you want is to achieve your personal goals. Life throws up various challenges, be it physical or mental, and I take great pride in having been able to overcome these on my personal journey and now being able to help others with their own journey. I only realised the true importance of representation when I bumped into a young boy while leaving an eye check-up appointment towards the end of 2022. It was the first time I had seen someone else with my condition in the flesh and I saw myself in him. It was something I had never really thought about considering how rare retinoblastoma is, but it made me realise how much I had managed to achieve in my life so far despite what one would call a limitation. It made me think, "What if I had someone like me to look up to at his age?". It would have made

me a lot more comfortable and confident, especially during my teenage years when you're very impressionable and a lot of your character and thought processes are developing. Representation is very important as it allows those who come after you to have a relatable role model, someone they can look up to, take inspiration from and aspire to emulate will enable them to understand that they can also achieve great things too. Realising how important representation was made me further come out of my comfort zone and apply to join Zebedee Talent Agency. I've been doing some things I would have never imagined but really enjoying it and excited for what's ahead on this journey.

My advice to anyone who has had retinoblastoma will be to not let it hold you back. Unfortunately, losing vision in one eye is something you cannot control, and you will experience things that most people won't. Despite this, you must try to stay strong and allow the difficulties to motivate you. Overcoming obstacles in life in any situation is very rewarding but doing it with a limitation will give you that extra confidence and self-belief that's needed to navigate through life. My advice to parents whose children have retinoblastoma would be to still try to treat their child as though they had vision in both eyes. Of course, some compassion will need to be shown as the differences will be evident, but it's always good for a child to understand that they are "normal" from a young age. It can go a very long way! Take an interest in your child's

passions, and try to encourage them as much as you can. These passions can allow them to express and bring the best out of themselves, which can further increase their self-confidence. It can also allow them to form friendships with other children and allow them to feel fulfilled. I would also encourage parents to encourage their children to engage in physical activity. Besides promoting a healthier lifestyle, principles of discipline, persistence and accountability will be learned subconsciously which can set your child up well for life. Understandably, there may be some worries about you or your child's independent life as an adult, but I can assure you that this can also be navigated through. I have a full driver's licence and passed my test when I was 21 (DVLA wrote to me confirming I could drive before I started learning). Relationships and dating life have been great and cool too, having no vision in my left eye hasn't affected my ability to do so!

Finally, the opportunity to write this account and my drive to attain and overcome adversities of life have been quite a therapeutic process and I sincerely hope it's helpful for others. The journey up till now certainly wasn't easy, but if I can do it, YOU or your child can too! **Keep Going!**



Would you like to share your Rb story? Email info@chect.org.uk.

Fundraising



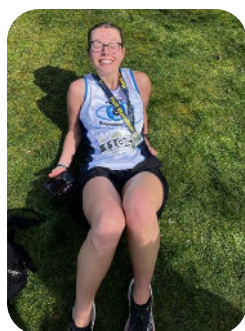
London Marathon!

We are thrilled to celebrate our 14 incredible runners, who took part in the iconic TCS London Marathon on 21 April 2024, raising a fantastic £45K including Gift Aid. We are so proud of them, for dedicating the time and effort to train and fundraise for CHECT, resulting in all 14 of them crossing the finish line on the day.

Thank you to the friends and families who were able to support and celebrate with us all. It was a brilliant day, and we look forward to supporting #TeamCHECT at our next London Marathon in 2025.

If you would like to join #TeamCHECT and take part in an event for us, why not have a look at our calendar of new challenge events for this year on

Well done, Katy!



I was diagnosed with bilateral Rb when I was 6 months old and subsequently had my left eye removed.

I decided to run for CHECT at the Leeds Running Festival. The day of the half marathon was definitely a high. I managed to complete my first ever

half-marathon in 2 hours and 22 minutes, which I was thrilled with.

Fundraising for CHECT has been a joy. They sent me a running vest and even a good luck card, which was hugely appreciated. I will never forget my first big running event and how incredible it felt to give back to such a worthwhile charity.

World Retinoblastoma Awareness Week

During World Retinoblastoma Awareness Week (14-20 May), we were thrilled by the incredible support from individuals hosting bake sales, auctions, football matches and crazy glasses days.

These amazing efforts not only raised awareness of Rb but also collected crucial funds for CHECT.

We loved seeing all your photos! Why not host your Crazy Glasses Day at home, work, or school? Visit our website to find out how you can get involved:

www.checht.org.uk/other-ways-to-help.

TeamCHECT London Marathon 2024!



our website www.checht.org.uk/other-ways-to-help/events or get in touch with Priyanka at fundraising@checht.org.uk.

CHECT's Lottery!

Play CHECT's lottery for a chance to win up to £25,000!

For just £1 a week, you can enter the CHECT lottery draw and win up to £25,000! Plus, for every £1 you spend, 50p will go directly to CHECT to help families and individuals affected by retinoblastoma. When you sign up, you'll be given a six-digit lottery number, which will remain yours for as long as you keep playing. You can pay for as many numbers as you like, and winners are selected at random every Friday. Find out more on our website: www.checht.org.uk/other-ways-to-help. You must be 16 or over to enter.



Thank you!



Grandparents Ian and Heather have demonstrated their heartfelt generosity by donating £5,000 to CHECT following their grandson's diagnosis and treatment of unilateral retinoblastoma at the Royal London Hospital.

The impact of Ian and Heather's kindness provides a vital lifeline for families like theirs who are experiencing the challenges of Rb.

Ian and Heather said, "We thank CHECT for the outstanding support you provided to our grandson and his family during the treatment of his retinoblastoma. Our grandson now has a special eye but continues to excel at sports and academically. We commend you for the superb work that you do."

We would like to express our profound gratitude to Ian and Heather for their unwavering support of CHECT. Their generous gift will play a pivotal role in ensuring we can continue to support every family in the UK who has been impacted by Rb.

Sweet farewell, Maddie!



We have some bittersweet news to share with you. Our dedicated Fundraising Officer, Maddie, left in June. Maddie has been an invaluable member of our team, supporting

numerous successful events and helping us reach our fundraising goals with her passion and dedication. While we will miss her greatly, we are excited for her as she embarks on a new chapter in her career. Please join us in thanking Maddie for her hard work over the last two years and wishing her all the best in her future endeavours. But please don't worry - our fundraising team is still here to support you! We would love to chat with you about taking part in an event, creating your own event, or becoming a corporate partner.

Please email fundraising@chect.org.uk or call 020 7377 5578.

Great grant news!



CHECT is delighted to be a new beneficiary of BBC Children in Need. This very generous grant is helping to fund our support work for the next three years. A huge thank you to Children in Need!



We are also enormously grateful to the National Lottery Community Fund's

Community Organisation's Cost of Living Fund for awarding CHECT an extremely generous grant towards the costs of our work supporting families with retinoblastoma. Thanks so much to the National Lottery and the Government for making this possible.

A wonderful tribute

We are very grateful to those supporters who have remembered our charity in their wills, and 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:

John Breeze
Helen Cassidy
Teresa Colligan
Tony Dollery
Jillian Lorraine Pike
Margaret Patricia Hancock
Diane Earp
Lilian Hirst

Donald Grazebrook
Gaynor Thomas
Nancy Mather
Anthony Ritchie
Karl Silburn
David Vernon
Andrew Fleming
Joyce Hogg

CHECTYA! Teens and Young Adults

Understanding how having Rb affects how you think & feel

We spoke to Nicola O'Donnell about her CHECT-funded research.



Experiencing Rb can leave some people feeling complex emotions, including worry, anger, or sadness. These feelings can occur when they are least expected, sometimes even many years after their diagnosis and treatment. There isn't much targeted support to help

teenagers and young adults with these feelings, and we want to do something about this. This support needs to be both backed up by scientific evidence and reflective of the wants and needs of real people affected by Rb, which is how my PhD was developed.

To achieve this aim, I have spent the last 2.5 years conducting three research studies. These will provide a proposal for the design and testing of the intervention which we will develop, which I will secure funding to do when my PhD ends in September 2024. The first of my PhD studies focused on understanding the experiences of teens and young adults who have had Rb. This study is important because it will help us to understand some of the challenges that young people face and inform what support they want and need.



To make sure that I spoke with a variety of different individuals, I worked with both of the Rb treatment centres in the UK; The Royal London Hospital shared with GOSH and Birmingham Children's Hospital, as well as CHECT. Eligible participants included teenagers aged 13-19 years and young adults aged 20-29 years who had been

diagnosed with any form of Rb at any stage of their childhood. Overall, 32 young people enrolled in the study: I conducted interviews with 17 young adults between mid and late 2022. In addition, I hosted online focus groups with 15 teenagers during 2022 and early 2023. Young people shared their experiences of dealing with medical trauma from their childhood, including feelings of survivor guilt, and strong memories from their treatment (even from when they were so young, other people believed they wouldn't remember). They shared difficulties faced during adolescence, including struggles with identity, and trying to adjust to the late effects of their cancer while still seeking a sense of normality. Lastly, as they grew older, self-acceptance involved seeking out support and information to cope with the long-term effects of cancer. These insights, combined with a review of existing research into cancer wellbeing interventions, form the evidence required to develop a tailored support tool for this group of young people.

Excitingly, I have received a lot of interest in this work, and the first academic paper that summarises the findings has now been published in the British Medical Journal, available on the CHECT website. I recently got a group of teens and adults who have had Rb together and hired a podcast studio in Birmingham. CHECT's support worker Sarah Turley and I met with James, Yoadey, Yuri, Tom, Katie, and Kieran (none of whom knew each other previously) to make my research as accessible as possible. They recorded the audio for a video summarising the research findings. They also sat down as a group to create a podcast about what it is like to be a young person who had Rb. It's important to say that none of the young people who created the video and podcast were participants in the research; it is incredibly important to keep participants' identities private, and it is such a privilege to be able to highlight their experiences to improve Rb support in the future.



To view the videos and podcasts produced from this day, visit CHECT's YouTube, TikTok or Instagram accounts. We want to extend a huge thank you to all the participants who took part in this project. Remember, our support team offers lifelong support.

Katie & Will shine in spectacular concert



Katie and Will met at a CHECT event. Katie went on to put on a successful concert to raise money and awareness for CHECT, where she also sang a vocal quartet with Will. We asked the pair whether retinoblastoma had any impact on their relationship with music:

Katie: For me, music is a really special space and a chance to express myself when emotions become more complicated. But it is also a space where having one eye truly doesn't matter and when you are in a group of musicians, all that matters is the ability to connect with the music and the technical ability of the instrument, and that has always been very refreshing for me. Of course, there have been some challenges in the past, as at some points I have found communication between other players during a performance more difficult to pick up on, however, I have always found ways around this, not to mention the fact that it is wonderful to have a supportive community of friends within any activity you love.

At the end of the day, words from a past conductor will always stick with me: "No matter what changes in your life, good or bad, music will always be there".

Will: Retinoblastoma has definitely impacted my relationship with music in positive and negative ways. Of course, there were the annoyances when I was younger of dealing with the importance of sight in choirs and orchestras, but fortunately, experience has led me to adapt to my greatly reduced peripheral vision. Playing and performing music has always been a large part of my life, as I've grown up around a family of musicians, but I feel that going through experiences such as retinoblastoma has deepened and strengthened my emotional connection to music and other aspects of my life. Performing music, especially singing, is all about truly expressing yourself and who you are. For me, this has meant coming to terms with and accepting every part of myself, including my prosthetic eye. While of course this is an ongoing struggle for me, performance has definitely built up my self-confidence, allowing me to put my true self out into the world. Without music in my life, I wouldn't be the person I am today, but if I didn't go through the experience of retinoblastoma, I certainly wouldn't be the musician and performer I am today either!

Read the full interview over at our dedicated TYA blog: www.chect-tya.org.uk.

Your questions answered!

During Teenage Cancer Awareness Month in April, we asked you what you'd like us to cover on our blog and Instagram channels. Here, we tackle one of those questions: "How to self-advocate while dealing with doctors who don't understand the lifelong impact of Rb".

What a brilliant question! Two of our leaflets in particular are perfect for this. Our leaflet 'Supporting adults who have had retinoblastoma' is designed to be shared with your GP, and 'My Rb summary' is an interactive document where you can record your Rb history to share with healthcare professionals at medical appointments. These can be

downloaded from the CHECT website at www.chect.org.uk/about-retinoblastoma/adults-after-rb/, or we can send hard copies to you if that is helpful. In terms of other information on the website, there is the Genetics page, as well as information on late effects, which might be helpful to share with the GP and other healthcare professionals.

The CCLG also has useful publications for teens and young adults, particularly 'Living Beyond Cancer'.



Remember, if you have any questions, our support team is on hand to help or point you in the right direction. You can contact us by emailing us at support@chect.org.uk or by phone at 020 7377 5578.

Colour in Pip the Penguin's fundraising bakesale!



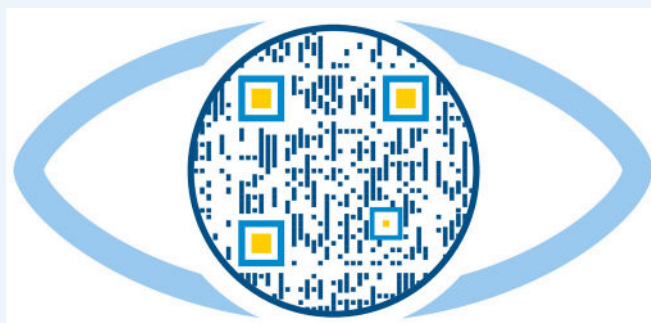
Ways to help

We know times are financially tough, and we really appreciate your support in raising awareness and funds during this difficult time for all. We receive no government funding and rely on the generosity of our supporters to pay for our work, offering support to every family in the UK with a diagnosis of retinoblastoma. Please help us to continue our vital services.

Our QR code

Simply scan the QR code on your smartphone and follow the instructions to donate what you can (you may need to enable QR codes in your camera settings).

Your gift will come straight to CHECT, without having to download an app. Please rest assured that we do not receive your bank details.



*BOPP is regulated by the FCA and licensed by PISP and AISP



Or you can make a donation in the regular way by:



visiting our website: **chect.org.uk/donate**



or by texting **CHECT** to **70470** to donate £3.

Please consider making a monthly donation to CHECT. Regular gifts are a fantastic way to contribute to the resilience of our charity and provide us with a reliable and dependable source of income. You can sign up at **chect.org.uk/donate/regulardonation/**. We always enjoy receiving your thoughts and feedback. If you have any questions about your fundraising, making a donation, or becoming a CHECT corporate partner, then please get in touch with us at: **fundraising@chect.org.uk** or **020 7377 5578**.

Thank you!