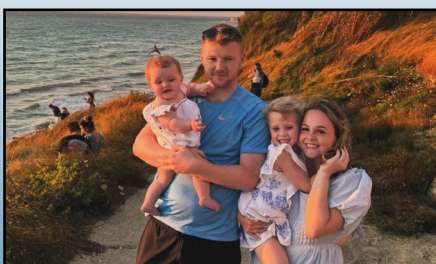




## Your news and stories!



**“We spotted Rb when our daughter’s iris changed colour”**

Read Esmae’s story **Page 5**



**“We knew our son had Rb after our friends raised awareness of Rb”**

Read Thomas’ story **Page 7**



**Adaline’s experience at the Paralympics!**

Read Adaline’s story **Page 13**

# Welcome

Welcome to the winter edition of InFocus! A big thank you to all the families who contributed their wonderful Christmas photos, making our front cover shine.

It has been a delight to celebrate many of you at our recent Family Support events, where we presented the CHECT Champion Awards to some incredibly brave young members. A special shout-out goes to these amazing children, whose efforts have helped raise awareness of Rb at a national level.

We are so thankful to the families and individuals who have shared their personal stories or helped raise awareness through the media. We're excited to feature some of these inspiring stories in this edition.

We've had great success with several fundraising initiatives, including our '50km Your Way' campaign in September. We extend our heartfelt thanks to everyone who has given their time and resources to help us

fundraise or donated to CHECT. Your support is absolutely essential, as we do not receive government funding, and it allows us to continue our work in support, research, and awareness-raising. We hope many of you can join us in raising awareness and funds for our important Christmas campaign this season.

We are also incredibly grateful to everyone who took the time to fill out our recent members' survey. Your feedback is invaluable in helping us better understand the needs of our members and improve the services we provide. By sharing your thoughts and experiences, you're helping us ensure that our support remains relevant, effective, and impactful for everyone affected by Rb.

I also want to take a moment to express my deep appreciation to the incredible team at CHECT – our dedicated staff, volunteers, and Trustees. Despite being a small charity, their hard work has helped us make tremendous progress in supporting those affected by Rb.

Finally, a sincere thank you to all the members, trusts, foundations, fundraisers, and supporters. Your continued generosity is what allows us to keep moving forward in our mission, and it is truly valued. Wishing you all a joyous festive season and a prosperous New Year!



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](mailto:info@chect.org.uk) if you'd like to receive InFocus in large print (A3), braille or electronically - PDF and HTML.

## Contents

- Page 1-5: News & Support
- Page 3-10: Real Life Stories
- Page 11-12: Fundraising and Events
- Page 13-14: Children's Corner
- Page 15: Ways to Help



## How many Pips can you spot?

Pip the Penguin has been hidden throughout this issue!

### Contact us

CHECT office hours are Monday to Friday, 9am-5pm.

CHECT, Royal London Hospital, Whitechapel Road, London, E11FR.

Facebook - /chectuk

X - @chectuk

Instagram - @chect\_uk

LinkedIn - childhood-eye-cancer-trust

YouTube - /chectuk

TikTok - chect\_uk

CHECT TYA Instagram - @chect\_tya

T: 020 7377 5578

E: [info@chect.org.uk](mailto:info@chect.org.uk)

W: [www.chect.org.uk](http://www.chect.org.uk)

### OUR TEAM

RICHARD ASHTON  
Chief Executive  
E: [richard.ashton@chect.org.uk](mailto:richard.ashton@chect.org.uk)

PETRA MAXWELL  
Head of Support Services  
E: [petra.maxwell@chect.org.uk](mailto:petra.maxwell@chect.org.uk)

SARAH TURLEY  
Support Worker  
Monday, Wednesday, Thursday & Friday  
T: 07526 594 762  
E: [sarah.turley@chect.org.uk](mailto:sarah.turley@chect.org.uk)

LENA COPLEY  
Support Worker  
Monday, Wednesday, Thursday & Friday  
T: 07706919996  
E: [lena.copley@chect.org.uk](mailto:lena.copley@chect.org.uk)

ISABELLA GREENWOOD  
Communications Manager  
E: [isabella.greenwood@chect.org.uk](mailto:isabella.greenwood@chect.org.uk)

FRANCESCA WILFORD-DAVIS  
Head of Finance  
E: [francesca.wilford-davis@chect.org.uk](mailto:francesca.wilford-davis@chect.org.uk)

BETH LARDNER  
Creative and Operations Manager  
E: [beth.lardner@chect.org.uk](mailto:beth.lardner@chect.org.uk)

LIZZIE SMALLDON  
Trusts & Foundations  
Fundraising Manager  
E: [lizzie.smalldon@chect.org.uk](mailto:lizzie.smalldon@chect.org.uk)

PRIYANKA KOTECHA  
Fundraising Manager  
E: [priyanka.kotecha@chect.org.uk](mailto:priyanka.kotecha@chect.org.uk)

LUCY PURVIS  
Fundraising Officer  
E: [lucy.purvis@chect.org.uk](mailto:lucy.purvis@chect.org.uk)

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

© Childhood Eye Cancer Trust (formerly The Retinoblastoma Society) 2004. Registered Charity No. 327493.

## News



### Could you be the next Bursary winner?



**The Ffion Miles Music Bursary was set up in 2022 in memory of the former CHECT member and her love of music and her commitment to helping those who had also suffered from retinoblastoma (Rb), and visual impairment.**

This year was the third year the Bursary has been awarded. As in previous years, it was incredibly difficult to choose between the applications we received. However, at their latest meeting, the CHECT trustees selected Leah Braik to receive this year's bursary.

Leah is ten years old and was diagnosed with bilateral Rb when she was five months old. She currently attends a specialist school for children with visual impairment. Despite her daily struggles (in addition to being severely sight

impaired, Leah also has autism), she is a talented pianist and also plays the violin. Her parents will use the Bursary to buy Leah a piano so that she can continue her love of music outside of school.

In honour of Ffion's love for music, we are pleased to announce the return of the Ffion Miles Music Bursary, open to all CHECT members, regardless of age, for 2025. The Bursary, awarded annually, can be used to support any musical pursuit. This may include musical training, music therapy, event attendance (including travel), the purchase or loan of instruments, music software, or anything else that nurtures a love for music.

If you or your child are a CHECT member and would like to apply for The Ffion Miles Music Bursary, please email [support@chect.org.uk](mailto:support@chect.org.uk) and explain how you would use £1,000 to foster your musical interests. The recipient will be selected by the CHECT board of trustees. Applications must be submitted by **30 April 2025**.

### GIVEAWAY: 'My New Normal' book by Livi Deane



**We were thrilled to join CHECT Ambassador and member Livi Deane at the launch of her powerful debut memoir, 'My New Normal', at the iconic Waterstones store in Piccadilly. Our Communications Manager Isabella and Head of Support Services Petra were proud to be there, supporting Livi on this special occasion.**

Livi's book is a deeply personal account of her journey after being diagnosed with Rb at the age of 12. Part of Katie Piper's 'The Unseen' series, 'My New Normal' sheds light on the challenges of living with this rare form of eye cancer. Katie Piper herself, renowned for her advocacy and personal journey, was also in attendance, adding to the excitement of the event.

During the launch, Livi sat down for an insightful

conversation with Katie Piper. Together, they discussed Livi's experiences of living with Rb, the impact of losing an eye, and her journey of embracing life with a prosthetic. These are just some of the moving topics covered in her book.

The evening was a celebration of resilience and hope. After the talk, Livi cut a cake and posed for photos with her loved ones, fellow authors, and supporters, marking the fulfilment of her childhood dream of becoming an author. 'My New Normal' offers readers an intimate glimpse into her life, from navigating her teenage years with cancer to finding self-acceptance, and ultimately becoming an author, a mother, and a model for esteemed brands like Vogue Portugal and Primark.

**We're excited to host a giveaway of 'My New Normal'. For a chance to win a copy of the book, please email [info@chect.org.uk](mailto:info@chect.org.uk) with your name and address by the 31 December. The lucky winner will be announced and contacted in January!**

## Ana's Story: From then to now

### Ana shares her experiences with Rb and how life is today.

One day, while I was playing on the carpet, my mother called my name. When I looked up, she noticed a white shadow in my left eye and immediately grew concerned.

Despite reassurances from family members who believed it was merely a reflection in my large, bright blue eyes, my mother decided to take me to the doctor. She had also started noticing that I would bump into things more often than usual and would close one eye to focus or make funny faces.

When I was 14 months old, my mother took me along to my brother's eye check-up. The doctor suggested checking my eyes as well since we were already there. Ironically, this same doctor would later diagnose my Rb when I was 22 months old, but at that time, he saw nothing unusual.

At the second appointment, the GP initially suspected cataracts, as they were unaware of what Rb looked like. They recommended booking an appointment with an ophthalmologist for further monitoring. Believing it wasn't urgent, we scheduled an appointment for 15 days later. During this visit, the ophthalmologist noticed signs of Rb and, after conducting several tests, confirmed the diagnosis. The tumour was quite advanced and had spread outside the eye, posing a high risk of reaching the optic nerve and brain.

Dr. Camacho swiftly arranged for us to travel to Madrid to see Dr. Abelairas at La Paz Hospital. Within 48 hours of our arrival, my left eye was removed, and I began a series of treatments to eliminate the tumour in my right eye. My treatments included cryotherapy and radiotherapy on my right eye. Contrary to many people, I only had two artificial eyes in my lifetime. I find it leaks and sometimes I get infections, mostly during winter.

From a young age, I always rebelled against my disability. I despised appearing weak or different in front of other kids. This fuelled the development of

a strong character and a deep empathy for other children with special needs. I would fiercely stand up for them and ensure they were included, often quite assertively.

Driven by a desire to excel, I poured my energy into school, ballet, and dance, striving to be popular. I believe this was my way of overcompensating and, in my mind, distracting from my disability.

As a child, I was very happy and witty, but as I grew into a teenager, I became miserable and frustrated. I struggled to accept my reality and constantly felt inadequate, regardless of my achievements. Since my diagnosis, I have suffered from various eye issues due to the aggressive treatments I underwent.

Navigating life as a child, teenager, and now an adult while in constant discomfort or pain has been exhausting. Performing everyday tasks often requires immense physical effort, despite my outward appearance of being okay. This experience has forced me to develop resilience and strength, shaping my character and approach to life.

Having had Rb has undoubtedly shaped who I am today. I often wonder who I would be and how I would look. Would I have achieved more, or would I have been content with much less? Would I still be the brave woman I am today? I am who I am thanks to my experiences and how I managed to approach them. Part of it is my personality, and part of it comes from my parents, who always encouraged me to dare and pursue my goals without limitations, other than my own.

While I have grown comfortable in discomfort and gained a clear perspective on what is important, I remain resilient. However, I also find myself in a constant loop of feeling unsuccessful, like a failure, and unable to simply be content with myself.

I started working at the age of 15 with the goal of learning as many languages as possible so I could leave my country and explore the world. I used my earnings to spend summers abroad studying English, aiming to move abroad one day. At 18, I decided to attend university and pursued

**"This experience has forced me to develop resilience"**



a law degree in three different countries - Spain, France, and Australia - all supported by scholarships. I worked various jobs, from cleaner to au pair to receptionist, to support myself while doing it. I remember being very conscious of interviews because of my disability and got rejected by many because of it. One lady at Camden Town Market after a whole day trial said to me, "We really like you, but are conscious of tourists feeling funny about interacting with you because of your glasses. If you could take them off, we would hire you."

My passion was to use my degree to combat discrimination and make the world a fairer place. In Australia, I studied Aboriginal Law. In Spain, I worked with the Red Cross, assisting African refugees. By then, I was fluent in Spanish, French, and English, and helped translate their stories and assist with their legal statuses upon arrival in Spain. During my third year at university, I raised funds to travel to a very poor and remote island in Madagascar, where I lived for a while, working with a local NGO on various community projects.

After completing my degree, I explored different career paths. My creative needs weren't being fulfilled in the legal field, so I transitioned to marketing, starting as an assistant. Today, I am a Marketing Manager for a financial services company in London, navigating the corporate world in the UK.

I am extremely passionate about health and well-being and constantly strive to become the best version of myself through continuous learning and self-improvement. I am working on YUV – Your Unique Vision, which is an online community and space focused on eyes, trends, products and the Your Unique Vision Podcast. I am also starting to do inclusive modelling and look forward to my first campaign.



## Imogen's update!

In 2021 we shared Imogen's Rb story. We spoke to her mum, Lorna, to see how she is now.

Imogen was diagnosed with bilateral Rb in November 2020, and over the following eighteen months, went through intensive treatment

including chemotherapy, IVC and radioactive plaque treatment. We knew Imogen lost the vision in her right eye very early on, but we were unsure

how she would cope with the reduced vision in her left eye as she grew older.

Fast forward to today and our four-year-old is constantly surprising us with her ability to adapt to new situations. She's navigated starting pre-school, and a whole new environment to explore, taken part in UCAN sessions (a creative arts charity for those with sight impairments) and likes to prove that she can climb to the top of every climbing frame in the park with absolutely no hesitation, her vision never holds her back! We have support in place to help Imogen if she needs it as she progresses through school and beyond, but as ever, we will follow her lead and let her show us just what she is capable of!



## Sam's mascot day!

**A huge thank you to the Free Kicks Foundation for providing a great mascot day out for our member, Sam, whom we were delighted to nominate for the experience!**

Mum Nicky says, "The official pictures from Sam's day as a mascot at PNE v Luton came! It was a fantastic day; one he'll always remember. Especially meeting the players and the walkout!

Once again, thank you to Free Kicks Foundation, CHECT, and of course everyone at PNE who made Sam's day".

Thank you to the club for such wonderful photos.



# REAL LIVES

## "We spotted Esmae's cancer when her iris changed colour"

**Mum Elise first spotted that three-year-old Esmae's eye did not appear right while on holiday in July 2023.**

We noticed that her iris had changed colour and also looked a bit bloodshot on holiday in July 2023. We just put it down to having chlorine in her eye. We came back from holiday, and a few days later I had my 20-week pregnancy scan, so my mother-in-law and sister-in-law looked after Esmae. They mentioned when I was back that her eye looked strange. As I went to look, I just saw white cloudiness in her pupil.

I rang the opticians immediately and they saw Esmae the next day. They did an eye test and straight away they noticed Esmae could not see anything out of her right eye, which was very concerning. They then explained that we needed to go to A&E at the Birmingham and Midland Eye Centre, as they couldn't see anything in the back of her eye. At this point, Esmae's dad and I were worried; we knew something was not right.

When we went to the hospital, they were looking in Esmae's right eye many times. Numerous doctors came in to have a look as well. One doctor asked us if there was any eye cancer in the family. I think I knew then that it was really bad.

The hospital managed to get Esmae an appointment at the Birmingham Women's and Children's Hospital. Esmae was still in the recovery room there when they broke the news to us that she had retinoblastoma. They discussed the only treatment they could offer was an enucleation (removal of the eye) as the tumour was so bad.

The tumour was grade E, and it had made her completely blind in her right eye.

We broke the news to both of our moms in the room where they told us. We wanted to do this as we were so upset, and telling our moms would be so hard. So, we did this

while Esmae was still in the recovery room. Our moms then told our family as Esmae's dad Callum and I found it hard to break the news.

Esmae had her eye removed on the 18 July 2023 to stop the cancer from spreading. Esmae received high-dose chemotherapy, a more intensive regimen because of the cancer found in her optic nerve.

On the 3 August, the oncology doctors explained they found cancer cells in her optic nerve. Due to this, she had to have six rounds of intensive chemotherapy. Callum and I were heartbroken.

They went through all the side effects of chemotherapy, and we were both so scared. Esmae was about to lose her hair and have an operation to insert her central line. They even mentioned she would have trouble having babies in the future, so they offered to have one of Esmae's ovaries removed and freeze her eggs for when she is older. We just couldn't believe our little girl would have to go through even more terrifying things. I had to explain everything to Esmae when we got home, as the next day Esmae had to get her central line inserted and begin chemotherapy on the 7 August 2023. Esmae then went on to have an ovary removed on the 31 August just after her 4th birthday due to her intensive treatment.

Esmae has completed her treatment now and is doing so, so well after having her eye removed, central line put in, her ovary removed, six rounds of intense chemotherapy, six lumbar punctures, six spinal chemotherapies, and many MRI scans. She has an MRI scan every three months for the first year to double-check everything. She is a happy, healthy, beautiful 5-year-old girl. She's gone back to school full-time now and is enjoying the things she couldn't do while having chemotherapy.

I honestly think all of this has made Esmae more confident. She still struggles a little bit with taking her special artificial eye out, but I know she will get there soon. She is still doing things a 5-year-old should be doing, and she enjoys life every day.

**"All of this has made Esmae more confident"**



CHECT has been amazing. Our CHECT support worker, especially, was always there playing with Esmae, making her feel comfortable at the hospital, and also always there for her dad and me. She would always ask how we were and if there was anything she could do to help us. She did a lot for us, and we couldn't thank her enough. She also helped me through a tough time with work as they terminated my contract for being off with Esmae.

Esmae has always been a funny, beautiful, happy, outgoing girl. She loves to go out with friends and family. She enjoys being spontaneous and going on trips with mommy and daddy and her little sister. Going through treatment was hard for Esmae. If

some of her family members were poorly, she wouldn't be allowed around them as her immune system was low due to having chemotherapy. We had to be very careful going out, with Esmae wearing a mask and sanitising her hands. Seeing her cousins and having a new little dog to look after and waiting for her sister to be born really helped get Esmae through this, as well as the love from myself and her dad during a really difficult time. Esmae also made it a lot easier to handle for me and her dad as she never complained and always did everything that was asked of her with her little cheesy smile on her face.



## "A school vision screening spotted Rachel's cancer"

**Mum Geraldine, from County Cavan, had never heard of Rb before.**

The school noticed that Rachel might need glasses because her sibling wore them, so she was referred for a further eye appointment. It wasn't until months later, on 12 October 2022, that our lives changed forever.

During the eye appointment, after Rachel's pupils were dilated, the tumour was discovered. Up until that point, there was nothing different about the appearance of Rachel's eye. Her appointment was in a hospital, and within minutes, a consultant was in the room. I was alone when I was informed that a tumour had been found behind Rachel's right eye. I was told to go home and pack, and the next day we were in Children's Health Ireland in Temple Street, where Rachel underwent an eye and brain MRI. We were in such shock; our family was changed forever in a split second. Thankfully, the cancer was contained.



I was told about intra-arterial chemotherapy and chemo injections in Temple Street, but I was informed that they couldn't be done in Ireland, and that it would be the

best treatment for Rachel. I travelled on my own with Rachel over a period of 22 months, as my husband stayed at home to mind our two other kids and the family farm. The news that Rachel would need to travel to the UK for treatment was an additional shock for the family. Six days later, we were at Birmingham Women's and Children's Hospital, where we met the specialist retinoblastoma team.

Rachel's eye was saved but she does have vision loss in that eye. Her vision loss has not affected her, as she has excellent vision in the other eye. Rachel is aged seven now in great form, finished all her treatment, and was discharged from the UK in August. She will have her check-ups in Dublin now. Rachel is a loving, caring girl, and she's full of fun. She liked the VIP treatment she received while flying over and back to England. We took 44 flights in total, and the Aer Lingus crew were amazing, fast-tracking Rachel through the airport. We will not miss all the travelling. We will be forever grateful to the amazing retinoblastoma team in Birmingham.

Our CHECT support worker, Sarah, was always there for a chat and to offer support in any way she could. She told me about Daisy Lodge in Co. Down, which offers family breaks for children with cancer, and we enjoyed a stay there this year.

**Thank you so much to Elise and Esmae, and Geraldine and Rachel, for helping us raise brilliant national awareness during Childhood Cancer Awareness Month.**



# “We spotted our son’s rare cancer because our friend’s child was diagnosed the same year”

**Thomas was diagnosed with Rb at two-years-old.**

Parents Sarah and Ross said, “Our goddaughter’s brother, who was born the same year as Thomas, was diagnosed with retinoblastoma in May 2023. His family had been sharing details of his journey and raising awareness. As a family, we felt quite helpless but tried to offer whatever support we could.”

The family never imagined they’d find themselves in the same position months later. “We were sitting down for Sunday lunch on Bonfire Night, and as Thomas gazed toward Sarah, Ross noticed a crescent-shaped reflection in Thomas’ left eye. Ross tried to photograph what he saw using his mobile phone camera without flash.”

Sarah and Ross said, “In light of the awareness that we already had regarding retinoblastoma, we decided to take more photographs with various cameras, both with and without flash and in different settings. We noticed, using a

DSLR camera with flash, that Thomas’ left eye presented a white glow at certain angles. When looking directly at the camera, both eyes had red-eye, but this looked slightly duller in his left eye. We feared that the signs pointed to retinoblastoma, but we kept thinking about how rare the condition was and that it was unlikely, particularly given our goddaughter’s brother’s recent diagnosis.”

After a sleepless night of worry, Sarah contacted an optician, but since the specialist was unavailable, an appointment was set for two days later. Still concerned, she visited another optician, who advised a GP visit. The GP reassured them after an eye exam, but Sarah remained uneasy.

Sarah and Ross said, “We just couldn’t shake the feeling that something just wasn’t quite right, and on Tuesday evening, when Sarah was settling Thomas to sleep, she took another photograph using her mobile phone with flash, which showed a white glow. Sarah decided to contact the optician who provisionally diagnosed our goddaughter’s brother. After reviewing the photographs, they arranged an urgent appointment for Thomas that afternoon. After spotting a large white mass in his left eye, the optician sent an urgent referral for Thomas to be

assessed by the retinoblastoma team at Birmingham Women’s and Children’s Hospital. We will be forever grateful for the care and urgency that the optician’s team provided in Thomas’ case.”

Thomas was diagnosed on 10 November 2023 with Grade D retinoblastoma in his left eye.

Sarah and Ross said, “The hospital team delivered the news in a sensitive and caring manner. However, hearing that our son had cancer was devastating. Although we had our suspicions, nothing really prepared us, and we felt numb and overwhelmed. To be totally honest we also felt scared and angry, particularly when we began to discuss Thomas’ treatment plan. The team shared that the aim of any treatment was to get rid of the cancer and to try to preserve the sight in Thomas’ eye, with the least possible side effects, both in the short and long term.”

Sarah and Ross added, “Telling our loved ones was very difficult; we tried to have those discussions in person, but Sarah’s family lives down south, so those conversations happened over the phone. We had so many questions and fears, and we knew that family and friends shared these too, as we’d been in the unique position of seeing the situation from both sides. Telling Thomas’ sister Evelyn was hard, she was five at the time. She understood that Thomas had a poorly eye and a lump had formed, which required special medicine to help

**“When things feel tough, we say to ourselves ‘Be more Tom’ ”**







make it go away. We told her the special medicine had to go into his body through the central line. She was so brave about it all, we just tried to answer her questions in an honest and age-appropriate way. We were blessed to have an amazing support network, family, friends, parents of children in our daughter's class, and work colleagues. Their acts of love and kindness meant so much to us."

Thomas underwent four rounds of systemic chemotherapy, and three rounds of chemotherapy injections directly into his eye, as well as cryotherapy and laser.

Sarah and Ross said, "Treatment started mid-November; Thomas had his central line inserted on Ross' birthday. Christmas was around the corner, but it felt like a burden rather than something to celebrate. Before Thomas' diagnosis, we arranged to spend the festive period with Sarah's family, staying in converted barns. The medical team encouraged us to go, if Thomas was well enough, and ensured we had a referral for the local oncology department in case of emergency. As difficult as it was for us as parents, it was important to us that Thomas and Evelyn had as near-to-normal a Christmas as possible. Having that to focus on was probably a blessing in disguise and thankfully, we were able to all enjoy special time with family."

The parents added, "Thomas was very poorly at times, particularly during the systemic chemotherapy which lowered his immunity, having to have many hospital visits and admissions. Thomas has understandably found the process difficult, and sometimes even basic observations have been too

much to bear. The distress and upset he has displayed at such a young age have been very hard to witness. Despite it all, Thomas has kept his playful, gorgeous, and mischievous little personality shining for all to see because he's just absolutely ace."

Thomas continues to visit Birmingham monthly for observations and laser treatment.

Sarah and Ross said, "Thomas hasn't had an easy time since his diagnosis, and his treatment isn't over yet, but he has overcome many challenges, and he continues to smile his perfect cheeky smile. Thomas is attending preschool and hitting all milestones. So far, it is understood that Thomas' vision has been impaired only slightly, and it's hoped that the patching therapy that he's currently undergoing will help to improve this."

The parents said, "Our CHECT Support Worker has been an amazing support. She wrote an employment support letter explaining how retinoblastoma is rare and a very complicated cancer, which is hard to predict; hence the regular monitoring and treatments of children under anaesthetic. Each child has their own treatment pathway, which is dictated from appointment to appointment. This can be very difficult for families and future planning - getting back to work can require some flexibility and understanding of this complexity. This really helped Sarah feel less guilty about the lengthy absence and lack of clarity she was able to provide to her employer. She also supported Sarah emotionally, with chats in person when Thomas had examinations under anaesthetic,

but also with telephone calls in between. The guides, resources, and real-life stories of families affected by retinoblastoma, which are available through CHECT continue to be an invaluable source of information for us."

Sarah and Ross said, "Thomas loves being outside, he likes to whizz around on his bike or in his police patrol car. Thomas likes to explore, he is happy to go on adventures with his family, taking in all the sights and sounds of nature. Thomas was well supported by amazing play therapists, with one giving him his treasured 'Chemo Duck', who has attended every hospital visit since! Stickers always helped, and strangely, he enjoyed role-playing doctors, even attending some appointments dressed as 'Dr Tom.' His sister, Evelyn, was very supportive and tried hard to make Thomas smile during difficult times. Evelyn loved to visit Thomas in the hospital and would often bring a new toy for him to play with or a special drawing for him to put on the wall. She gave Thomas her very best cuddles and kisses. Thomas has faced his journey with so much strength and bravery; he's an example to all around him. When things feel tough, we often say to ourselves, 'Be more Tom'. We are so proud of Thomas and the strength he has shown."

**A huge thank you to Sarah, Ross, and Thomas for helping us to raise awareness during Christmas!** We can't raise awareness without the help of our CHECT families. If you'd like to share your story to help us raise awareness of Rb, please contact [info@chect.org.uk](mailto:info@chect.org.uk).

# REAL LIVES

## Laura's real life story

**As part of Childhood Cancer Awareness Month, we spoke to Laura, who had retinoblastoma as a child. Here, she shares her experiences.**

### Growing up

I am a great believer that everything happens for a reason and here's why. I grew up in a little village in County Down. I have 5 brothers (2 older and 3 younger). So you could say I had plenty of protection growing up. At the age of 5, my mum noticed something white in my left eye. It would come and go every now and again. Then the headaches began. They became quite a regular thing, so on 27 April 1988, I was taken to my local GP who broke the news to my mum and dad that I had no vision in my left eye. He told my parents to take me straight to the Royal Victoria Hospital in Belfast. There I met my consultant Mr Page. There were several specialists waiting to examine me. Later that day they told my parents it may be Coat's disease (which is a rare disorder involving abnormal development of blood vessels in the retina). I was sent home and we were to return to the Royal on Monday for further tests. On Monday I was admitted to the children's ward where I stayed for a week. It was after numerous tests that I was diagnosed with retinoblastoma.

### My diagnosis

My parents took me home with the instructions that if my headaches got worse or if my eye went red, they were to take me straight back in. Weeks passed by and I made my first Holy Communion and celebrated my 6th birthday. As the time went on my headaches returned but much more severe. On the 1 August, my headaches got so bad that I was admitted back into the children's

ward, and this is when my parents were told the devastating news that I was going to lose my eye. Mr Page was so supportive of my parents, explaining everything, and the very next day I had my operation. Two days passed, and I could go home with the understanding that I was going to go to St Bartholomew's in London for further treatment. We went home and settled back into family life. A few days later my parents received the news that my cancer was all retained inside my eye, and I didn't require any further treatment. I returned to school and got on with my life.

### School days

School was hard, some kids were mean, but I tried to not let it get to me. I had my friends and they helped me through. They never treated me any differently. I finished primary school and started secondary school. Now this was going to be a totally different ball game. I didn't know these kids and would they treat me any differently? It was very hard at times, but I never let it define me. They asked questions, and some made fun, but I had a large group of friends who stood by me.

**"I felt like I was a lifeline to these families"**

### Adulthood

I completed my GCSEs and then commenced a course in childcare at my local college. I completed my certificate and diploma and then decided I wanted to go into nursing. While at college I met my future husband. We clicked straight away, and we were inseparable. He supported me in everything I did. He helped me through my bad days and was my shoulder to cry on. I commenced my nursing course in September 2003 and had some of the best years of my life. I graduated in 2006 with a BSc degree. Now I had the task of finding a job. So off I went and had interviews for the Southern Trust and the Belfast Trust. At the end of September, I was offered a post at the Belfast Trust which I accepted. I had no idea where I was going to be based as I had applied for all wards and departments. Then the letter arrived... "Theatres". Oh no, I'd never worked in theatres as a student but hey ho, I accepted, and that



# From patient to nurse!

was it. My first day was so surreal now thinking back. I arrived on Level 3 and entered A-Block Theatres. I met the theatre manager who said, "Laura we're placing you in Eyes and ENT theatres". My first thought was "Oh no I'm not going to like this, what if I faint, what if I see something I don't want to see? How was I going to feel watching people having their eyes worked on or even removed?". But I took a deep breath and headed off to level 6. I met the Sr of the department who took me down to Theatre 3. My heart was beating so fast. I met a few members of the nursing team, and I was introduced to the consultant working that day. To my total shock, it was Mr Page. He smiled that same smile that he'd done years ago that comforted me and said, "I've met you before, how do I know your face?". I was speechless, I mean what were the chances? It had been 20 years since I had my operation and he remembered me. He said, "You're Laura, my goodness I feel so old now!". He just smiled again and said, "You're gonna be fine".

In the 9 years I worked there I encountered so many families who were going through what I had been through. I felt that I was like a lifeline to these families. I got asked many questions about how I coped and how I got through, with the main question being, "Has it ever held you back?". No! It has never held me back from doing what I wanted.

In my final year of university, I got engaged. So now I was working in a job I adored and planning for my wedding.

Now this was scary, I mean, all eyes were going to be on me, plus I was going to have my photos taken. I never liked being in photos much, so this was going to be a challenge.

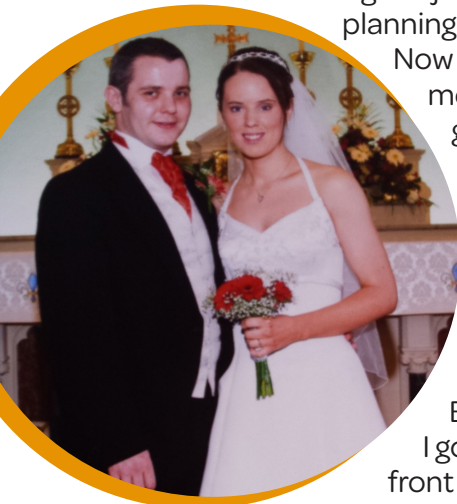
But on 7 November I got married in front of my family and friends. Seamus is my rock;

he is always there when I have a bad day and

picks me up. In August 2009, we welcomed our first child Orlaith into the world. She was perfect, but that worry was there. 'What if I give her the gene and she gets cancer?'. 'Would I be able to cope like my parents did?'. All these questions were going through my mind. She was placed under the care of Mr Page who carried out her routine checks. 21 months later, we welcomed our baby boy Tiernan into the world. Again, he was placed under Mr Page and had his routine check-ups. 'Would he be okay' or 'Did he have the gene?'. I never stopped worrying about them constantly checking photos and watching their eyes. But they were ok. After many years of service Mr Page, retired and the kids were placed under a new consultant Ms McLoone. In 2014 we welcomed another baby girl, Eimear, into the world and things were a little easier. She was automatically referred and was having her eyes checked every 6 months and every appointment was as terrifying as the last. Orlaith is now 14, Tiernan is now 13 and Eimear is 10 and all of them are in the clear. They attend the opticians yearly to keep an eye but so far so good. I will always be so grateful for the nursing and medical staff who looked after me and my parents and now the staff who look after my children.

If it wasn't for the support from my parents, my brothers, my husband, my children and my whole family, I don't think I'd be where I am today. They have all supported me in every decision I have made, and they continue to support me in all my challenges. The most recent being the 2021 squat challenge for CHECT. I am so grateful to them for all the help and support that they continue to offer families going through this process as this wasn't available or spoken of to my parents at the time, but it is such a valuable lifeline.

**Our support team provide lifelong support to everyone affected by retinoblastoma. If you would like to talk to a support worker, please contact [support@chect.org.uk](mailto:support@chect.org.uk) or call us on 020 7377 5578.**



Would you like to share your Rb story? Please email [info@chect.org.uk](mailto:info@chect.org.uk).



# Fundraising



## 50km Your Way!

This September during Childhood Cancer Awareness Month, 34 supporters took part in our 50km Your Way challenge to raise vital funds for CHECT.

This challenge encouraged participants to complete 50km in the month in their own way – whether it was walking, cycling, swimming, or any other activity of their choice. We were amazed to see how people came together, got active and inspired one another over the course of the month. Thanks to all of you who took part, we raised over £10,000 which is fantastic. Your efforts have made a real difference to the families we support, and we are so grateful. Keep an eye out for future events and get in touch with the fundraising team at [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk) to get involved.



## Send joy this season!



This year we have brand new designs on our Christmas cards!

These are lovingly drawn by children who are affected by Rb or know someone that is. We have packs of 10 mixed hand-drawn cards which

cost £6 (including P&P) and packs of 10 individual cards for £3.50. Visit <https://chect.org.uk/other-ways-to-help/christmas/> to order yours now.

## Our amazing team at the Great North Run



We are incredibly proud to celebrate five of our dedicated supporters who took on the Great North Run this year in support of CHECT.

Together, they raised over £4,100, which will go towards supporting our families and advancing research into retinoblastoma. We are incredibly grateful for their dedication and the support they have shown to CHECT. Thank you to each of our runners and everyone who supported them along the way! Your efforts mean the world to us, and we are so proud of what you have achieved.

**If you're inspired by their stories, stay tuned for future running events and join Team CHECT to help make a difference!**

## Introducing Lucy



We are delighted to introduce Lucy who recently joined the CHECT team as our new Fundraising Officer.

Lucy has already settled in wonderfully and is bringing great energy, passion, and dedication to her role. With a strong background in fundraising and a commitment to helping children and families affected by Rb, Lucy is excited to take on new challenges and help drive our fundraising efforts. Please join us in welcoming Lucy to CHECT!

# Thank you!

## Thor the dog to the rescue!

**Caroline and Philip, whose son was diagnosed with Rb, shared their dog-friendly approach to fundraising for CHECT!**

Our son, Danny, was affected by unilateral retinoblastoma at the age of two and a half. His diagnosis was not immediate, and we faced the heart-wrenching decision of removing the eye or leaving the tumour that could potentially spread. The journey continued with hospital visits, fitting prosthetic eyes, and facing other children and parents at school. However, Danny overcame his obstacles. Growing up on a farm, he started driving quad bikes and progressed to tractors and combine harvesters. He excelled in sports, representing the county in swimming and speed skating. Now 26-years-old, Danny is a qualified diagnostic mechanic with many skills and lives happily with his girlfriend in their own home.

Aston on Trent is a sleepy village in South Derbyshire where a very special dog, Thor, resides with us. Thor is a German breed, Leonberger, born on 24 February 2023, and despite his young age, he has already begun his career as a show dog with ambitions to compete at Crufts, following in the footsteps of his champion father. Thor will eventually be trained as a well-being dog, visiting care homes and possibly schools to meet more children. He enjoys fuss and kisses, and his laid-back attitude, even towards the littlest children, makes him an instant hit with all who meet him.



CHECT's support was invaluable to our family before diagnosis, during, and after surgery. We are forever grateful for the help that got us through such a traumatic time. This is why we chose Thor to be an icon for the children of Aston on Trent. During Aston on Trent's Well Dressing festival, we let all the children take photos with Thor at The Malt, a local pub that's great for families and dogs. Well dressing is a Derbyshire tradition where people make beautiful pictures from natural materials. This event, held in Aston on Trent since 1997, includes a fun-filled festival weekend in the village. Children of all ages met Thor, had pictures taken, and if a donation was made, received a Thor's Fan Club T-shirt, with all proceeds going to CHECT. Phil can be seen in the photo modelling the T-shirt at The Malt, beside Caroline and Thor at the start of the event. Laura, the landlady, let us use the restaurant at no cost, and the T-shirts were donated by us and a local businessman, Paul, who invested a lot of his time setting up the event and organising everything else. Every penny of the £247.58 donated went straight to CHECT. We would like to thank all the people who supported our cause and made the event possible.

## Remembering your loved ones

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:**

Alicia Boparai, Jeanne Muriel Hamblin, Iain Wilkinson and the Wareing family.

## Stephen Clegg: Paralympic glory

**We had the pleasure of speaking with Stephen Clegg after his incredible achievement at the Paris 2024 Paralympics.**



Winning two gold medals in Paris was the most emotional experience of my career. It was the culmination of a decade of work. I had come very close to winning gold in the last Paralympics, and it was difficult to process and regroup after that loss. Coming into Paris, I felt a lot of pressure to redeem myself. The only emotion I remember feeling after winning was relief; I had finally done it.

My drive comes from an overwhelming urge to keep improving myself. What I love about swimming isn't necessarily competing, it's the training, the discipline, and the consistency required to improve. Medals are just the reward for the work.


I owe all my success to my team! I can't put into words how fortunate I am to have such a caring and

supportive network that gives up so much in their own lives so I can pursue my dream.

For me, my understanding of how my visual impairment impacts me has changed over the years. For a long time, everyone told me it only impacted how I orientated my way around the pool. More recently, I have learned it is a skill acquisition deficit. Over the years, my coach and I have had to adapt our training to work around that. My advice for other athletes is to figure out how your disability impacts you, and don't accept the limitations others put on you.

I spent the last decade chasing one thing. No one tells you how it feels once you actually get the thing you've been chasing. I know I'm not done with this sport, but I need to consider what I want to achieve in the pool. Outside of the pool, I want to make sport at any level more accessible for people with disabilities. I want kids to understand that sport is a great option for mental and physical health and a way to build friendships. I hope with time and the right people working together, we can make necessary changes.

## Adaline attends the Paralympics!



**In the crowd cheering Stephen on was his niece, Adaline, who had been diagnosed with Rb. Here, mum Felicity reflects on the experience.**

We had such an incredible time watching my brother at the Paralympics; I'm so proud of him and I'm over the moon that he got his golds. It was amazing that Adaline got to see him compete. She was cheering him on as loud as she could with her 'Uncle Stephen' T-shirt and banner!

I felt so nervous. It's such a tough race and anything can happen on the day. I was overwhelmed with happiness for him when I saw that he had got the gold! He is so dedicated and hardworking. This is his third Games, so it's been many years of hard work that's got him where he wanted to be. He really deserves it. We all had such a wonderful time in Paris and came back home elated, we even managed to fit in a day at Disneyland which was so lovely getting to see Adaline's little face light up when she saw all of the characters.

Adaline was so excited all the time. She loved seeing

Stephen afterwards when he came up to meet us. It was a really special memory of her getting to see him with his medal and he gifted her his gold mascot which he got during his medal ceremony, so she gave him a massive cuddle.

This is our family's fifth Paralympics. It all began with my sister, Libby, who competed in the Beijing 2008 Games as a 100m and 200m sprinter. She went on to win two golds at the Rio 2016 Games. She ran blindfolded with a guide runner to help keep her in her lane. After Tokyo, she retired and is now a fantastic mum. Recently, she had her first chance at presenting during the Paris Games.

My brother James was also a swimmer, like Stephen. He competed in the London 2012 Games and won a bronze medal. He's no longer competing and now travels the world. James recently learned to snowboard with his girlfriend, and he loves playing guitar too! All three of my siblings have an eye condition called Stargardt's disease. Although it's different from Adaline's Rb, our family is certainly familiar with life with a visual impairment. I hope our family's journey can show other parents of visually impaired children that they can achieve anything they set their minds to.

# Children's Corner!



## Kitty's day at the CHECT office!

**Hi, I'm Kitty! CHECT does such amazing work, not just for kids with Rb, but for their families too.**

**They give support in so many ways - emotionally and practically - to make sure families know what to expect and**

**how to deal with everything.**

I was lucky enough to visit the CHECT office to help raise awareness during Childhood Cancer Awareness Month, and they were so welcoming! While I was there, I interviewed two amazing people: Priyanka, who is the Fundraising Manager at CHECT, and Lena, a Support Worker at the Royal London Hospital. It was super interesting to hear how both of them help families like mine. Priyanka's job is all about raising money, so CHECT can keep doing its work, and Lena helps families cope with the really tough times. Seeing how dedicated they are, has made me realise how important it is to have charities like CHECT, so no one feels alone in their journey with Rb. If you want to hear more about our chat, check out my YouTube channel, KittyVisionUK!

I also had some fun while visiting! We made TikToks to spread awareness about Rb. In the first one, I took out my prosthetic eye with the caption "Tell me you've got retinoblastoma without telling me you've got retinoblastoma." It was a funny way to bring attention to Rb. Then, I teamed up with Beth, the CHECT Creative & Operations Manager, and we did a dance to "Green, Green Grass." After each move, we popped up facts about Rb on the screen. It was a cool and fun way to raise awareness.

Another special memory was when I entered the CHECT Christmas card competition. I designed a card with Pip the Penguin standing by a door with a stained-glass window above and the words "Merry Christmas". It felt amazing to contribute to CHECT in my own way, and it's nice knowing my design might bring a smile to someone's face during the holidays.

We can all do something to help kids with Rb, whether it's making TikToks, designing cards, or just learning about how awesome CHECT is. Together, we can make a difference - one dance, one card, and one smile at a time!

## Jaxon shines in sports!

**My name is Jaxon. I am 8 years old, and I'm from Dublin, Ireland. I travel to Birmingham Women's and Children's Hospital for my appointments. I was diagnosed with bilateral retinoblastoma when I was 2 years old. I have undergone many different types of treatments.**

Ten days before my 3rd birthday, I had my right eye removed. After that, I continued receiving treatment for my left eye. My tumours were stable for a few years, but in April 2023, I had a recurrence and needed more treatment. My last treatment was in

December, and I now have regular check-ups.

Although I've had many hospital appointments for treatment, scans, and check-ups, I never let Rb

stop me from doing the things I love, especially playing sports. Having only one eye hasn't restricted me from playing. I play sports every single day, including soccer, Gaelic football, and hurling (these are Irish sports).

I always make sure to wear my sports goggles when playing these games and when I'm in the schoolyard to protect my remaining eye. I've always been aware of and understood the importance of protecting my eye, and my teammates think my sports goggles look pretty cool. They were curious about why I wear them, and once I explained, they were very accepting.

I feel really comfortable wearing my goggles because they have a prescription and a strap that goes around the back of my head, keeping them secure. They fit well and don't fall off my face while I'm playing. I feel confident when I wear them.





## Ways to help

**Inflatable 5k** - Our Inflatable 5k events are a fun, family-friendly way to raise money for CHECT! Suitable for ages 5 and up, the course is packed with giant inflatable obstacles, offering a unique challenge for everyone. With different dates and locations to choose from, visit <https://runforcharity.com/childhood-eye-cancer-trust/inflatable-events>

**Corporate partnerships** – We are looking for new corporate partners to help us raise our income. This could be through a Charity of the Year partnership, by donating a percentage of sales, through payroll giving or team-building events. For more information, please get in touch with Priyanka at [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk) and have a look at our corporate fundraising page:

<https://chect.org.uk/other-ways-to-help/corporate-partnerships/>



**Leave a gift in your Will** - Leaving a gift in your Will is a powerful way to create a lasting impact for children affected by retinoblastoma. Your support can help fund vital research, raise awareness, and provide life-changing support for families facing eye cancer. No matter the size, your gift will contribute to a brighter future for children. For more information on leaving a gift in your Will, please email [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk) – your legacy could be a lifeline for future generations.

**Introducing our Regional Fundraising Champions Programme** – Next year, we want to launch our Regional Fundraising Champions programme – a programme which sees a passionate group of loyal supporters across the UK who are committed to raising awareness and vital funds for CHECT. These individuals will be well known in their local communities to organise events, encourage others to get involved and raise awareness of Rb.

If you are passionate about our cause and want to make an impact in your local community, we would love to hear from you. As part of our programme, you will receive the necessary training and support from our team. For more information, reach out to our Fundraising Manager at [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk) or contact us on **020 7377 5578**.



**Regular Giving** - By choosing to give regularly to CHECT, you provide vital, ongoing support that helps us fund research, raise awareness, and offer essential resources for families affected by retinoblastoma. Your commitment makes a significant impact, ensuring that no child faces this journey alone. If you have any questions, or need any help planning your own fundraising activity, get in touch with Lucy or Priyanka at [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk) or **020 7377 5578**.

**Or you can make a one-off donation in the regular way by:**



visiting our website: [chect.org.uk/donate](https://chect.org.uk/donate)



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

**Thank you!**

