# infocus

Winter 2026

Fighting Retinoblastoma Childhood Eye Cancer Trust

## Childhood Eye Cancer Trust

1987 - 2027



# You're invited!

## CHECT's 40th Anniversary Members' Weekend at Warwick Castle 24th – 26th September 2027



**"I honestly thought he may just need glasses"**

Read Oliver's story **Page 3**



**"Our Support Workers help is truly inspiring"**

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**"Get ready to celebrate 40 years of CHECT"**

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# Welcome

**As we bring you Issue 102 of InFocus, we are reminded once again of just how special the CHECT community is – and how much there is to look forward to in 2027 as we approach our 40th anniversary.**

None of this would be possible without the wonderful people who make CHECT what it is. To our volunteers who give their time so generously, our trustees who guide and support us, our dedicated staff team, and our members who remain at the heart of everything we do, thank you. Every one of you plays an important part in helping CHECT thrive and in making our community the warm and supportive place it is.

A special thank you to everyone who has shared their retinoblastoma story with us in this issue. Oliver, Dayaan, Kyle and Nathan's stories take real courage to tell, and we know they can make a real difference – helping other families recognise the signs of retinoblastoma (Rb) earlier and feel less alone when they receive a diagnosis.

Our thanks also go to everyone who has fundraised for CHECT this year, whether you took on a challenge, organised an event or simply helped spread the word in your community. You'll find some of your achievements later in this issue, and we couldn't be prouder. Every pound raised and every conversation started helps take us closer to a world where every child with retinoblastoma is diagnosed quickly and everyone affected by Rb is supported every step of the way.

As the year draws to a close, we are already looking ahead to 2027, which will be a very special year for CHECT. It marks 40 years since we were registered, 30 years since we commissioned our first research project, and 20 years since the launch of World Retinoblastoma Awareness Week. We are holding a Members' Weekend at Warwick Castle in September to celebrate, and nothing would make us happier than seeing as many of you there as possible – old friends and new faces alike. You can read more about it on pages 9–10.

As always, InFocus is your magazine. Whether you'd like to share your story, help raise awareness, take on a challenge or simply get in touch, we would love to hear from you. From all of us at CHECT, thank you for being part of our community. We wish you a very happy and peaceful festive season and New Year.



**Richard Ashton, Chief Executive**



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

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## Have your say

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

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

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# The Ffion Miles Music Bursary Winners

**2026 marks the fifth year of the wonderful Ffion Miles Music Bursary. Set up by Ffion's parents, Helen and Dewi Miles, in memory of their daughter and the huge part music played in her life, the Bursary offers CHECT members the opportunity to develop their love of music.**




Each year since the Bursary was launched, we have been oversubscribed, making it an incredibly difficult task to narrow the field down to a few winners. We want to say thank you to everybody for your applications and well done to the winners of the Bursary.

**A few words from this year's recipients:**

**Eliza**
Eliza already plays the piano to a high standard and was keen to take up the saxophone. The Bursary contributed towards her buying a saxophone so she can start lessons.

'Hi, I'm Eliza. I am 12 years old and I am at Grade 6 on the piano. I've been playing since I was five years old, so I wanted to start playing the saxophone as a second instrument. Over the last few weeks, I have had my first couple of lessons and I'm really enjoying it. It has become one of my favourite pastimes. I have really liked learning new pieces and I'm really excited to learn more.'

**Stefan**
Stefan loves playing the piano and will use the Bursary to be able to have piano lessons.

'Thank you for giving Stefan the opportunity to learn the piano. Your support has helped him find joy through music after losing his vision, and he has developed a passion that brings him happiness. So, thank you for making such a meaningful difference to his life.'

**Matt and George**
Matt and George submitted a joint father/son application and have invested in a new electric drum kit after having to part with their old one.

'Thanks to the generosity of the Ffion Miles Music Bursary, my grown-up son George and I (both bilateral retinoblastoma survivors) have been able to rekindle our shared love of playing drums. The grant allowed us to buy an electronic drum kit on which we can practise wearing headphones, something Mrs Holt is also very grateful for! Thank you.'

**Thomas**
Having played the piano as a child, Thomas rediscovered his love of music in sixth form, returning to the piano and teaching himself guitar.

'I would like to say a heartfelt thank you to Ffion's parents for awarding me the Music Bursary. This generous gift has enabled me to expand my guitar equipment by purchasing a new amplifier and pedals to take to university with me. These will make a huge difference as I continue to develop as a guitarist.

I am incredibly grateful for this opportunity and for the continued support the charity provides to young people with retinoblastoma. Thank you for helping me pursue something I am passionate about and for making this possible.'

**The next round of the Ffion Miles Music Bursary opens early in 2027. We look forward to hearing about members' love of music and how they or their child would like to use the Bursary!**

REAL LIVES

# "I thought I was imagining things"

**Mum Olivia shared her four-month-old son Oliver's story for Childhood Cancer Awareness Month.**

When Oliver was around four and a half months old, I noticed his right eye wasn't focusing the same as his left. I only noticed this at certain times of the day: early in the morning not long after waking up or when he was starting to become tired.

At the start there wasn't any glow in his eye, no turning of the eye. I'd always feared taking a picture of Oliver with the flash on because I didn't want to hurt his eyes, so we never saw the glow from that (which I really kick myself over now). I would ask our family if they could notice anything, but nobody could. I would stare every day. To me, it felt like as the days were going on it was becoming more noticeable. In my head I honestly thought he may just need glasses.

**"I thought I was going crazy"**



I rang my health visitor on 19 June 2025 and explained what I had noticed. She made an appointment to come out and have a look on 23 June. Some days I wouldn't notice anything. I really did start to feel like I was going insane or imagining things. When our health visitor came, she agreed that his eye wasn't focusing like his left, but she wasn't overly concerned. She put in a non-urgent referral to our local children's hospital, Alder Hey.

The following morning, I was giving Oliver a bottle. He was lying propped up facing upwards towards me in bed. He looked to his right towards the window when I saw the glow in his eye. I honestly thought I was going crazy. I tried taking as many pictures and videos as I could, screenshotting them. It was so hard trying to capture it in photos of a baby who had just turned five months old. I rang Tom, who was at work, and sent him the pictures. I showed my mum and we all agreed to ring the hospital.

I rang Alder Hey and explained we were on the waiting list for an appointment but hadn't yet received one. I asked if I could send pictures of Oliver's eye as we were worried by what I had seen that morning. At 12.30pm the same day they rang me back and just said, 'The doctor has had a look at your pictures, and she has asked if you would be okay to bring him in today'. My heart was beating out of my chest.

We went in for a sight test. Oliver was doing so well. The ophthalmologist asked me to place my hand over Oliver's right eye, and he was still following all of the lights, flashing cards and black and white lines perfectly. She then asked me to place my hand over his left eye. Suddenly, he was so distressed, shaking his head trying to move my hand. We went in for a further few tests, and I remember feeling increasingly sick. I looked at Tom and said, 'I really think there is something wrong.'

The doctor came in and asked us to explain what we had been noticing with Oliver's eye. After we had finished explaining, the doctor said, 'I'm so sorry to be the one to tell you this, but your son has suspected retinoblastoma.' Tom and I probably just stared, confused. She followed with, 'He has a cancerous tumour in his eye.' The word cancer, how do you even wrap your head around it, especially for a baby? We were both crying hysterically. Straight away I honestly thought our son was going to die.

The doctor explained it was treatable with chemotherapy but wasn't too sure of all the treatment options. That's when she told us we would be going to Birmingham Women's and Children's Hospital as they specialise in retinoblastoma. She told us she had only seen this four times in twelve years.



We didn't sleep for four nights straight. We were Googling everything. This new word we had just learnt had literally taken over our happy little life. How did we go from our lovely baby bubble, newly engaged, to this? Our lives really did fall apart. Luckily, the hospital was on hand to answer our questions.

A week later, at Birmingham Women's and Children's Hospital, doctors confirmed Oliver had a large tumour in his right eye, with the possible start of a second tumour in his left eye, which was treated with laser at the same appointment.

The clinician felt that intra-arterial chemotherapy would be the best option, along with monthly laser treatments to his right eye. Things were moving so fast. It really was a lot to wrap our heads around.

**"Oliver really is thriving"**

Once Rb was confirmed, telling family and friends really was the hardest part for us. In some ways it felt more real saying it out loud, which made it even harder as we were still trying to understand it ourselves. I really did skirt around the word 'cancer'; we both did, and to be honest we very rarely say it now as it's still too upsetting. I was five months postpartum when we found out and I think navigating life with a newborn and getting used to parenthood are such huge changes anyway, but having this diagnosis as well really was difficult and definitely life-changing. We were lucky to have such a supportive network around us.

Oliver went on to have four rounds of intra-arterial chemotherapy alongside ongoing laser treatment. The first round went amazingly, which the doctors had predicted. He then went on to have three more rounds after this, with much slower progress, which again we were told would happen. After his third round of chemotherapy, Oliver's retina started to detach, which was then another worry, hoping each month it would slowly settle back down, which it did thankfully.

After each round, Oliver really was just back to his happy little self after a few hours. You really wouldn't think he was going through treatment. He was meeting his milestones earlier than normal; nothing was stopping him.

Oliver really is thriving. I think if we could have seen how he would be a whole year on, we may have been more positive at the start. At his last appointment, the clinician explained there wasn't much room left for any more laser, which was really positive. Because of the position of Oliver's tumour, doctors feel he is more or less blind in his right eye but can't be too sure until he's slightly older. Honestly, even that doesn't stop Oliver. He climbs on everything, he's started running recently, he is obsessed with birds, which he can spot from miles away.

We can honestly say a year on from his diagnosis, life is as perfect as we'd planned from the second we found out we were pregnant. Oliver really is the funniest baby, he's obsessed with flowers at the minute and smelling them, with the funniest little scrunch face when doing so. He loves shouting for his dad from the second he opens his eyes until he goes to sleep. He loves hide and seek pointing for us to go and hide repeatedly. Most of all, he is besotted with football, he even shouts "goallll" whilst punching his fist in the air when it is on the TV. Oliver really is just a happy little 18-month-old, living his life exactly how he should be. Nothing holds him back.

I don't know how we would have got through any of this without Childhood Eye Cancer Trust (CHECT). What an amazing charity it is, especially our lovely support worker. Any questions we would feel maybe too silly to ask the doctors, she would be waiting for us to come back from seeing them and would sit down and speak to us for as long as we needed. She put us in touch with other services that benefited us as parents. Honestly, nothing is too much, a truly perfect team. We had the opportunity to visit Chester Zoo recently with the CHECT team. We met other amazing families; it's refreshing to be able to talk to people who know exactly what you have been through. Without CHECT, we would never have had the chance to do that. We will be forever grateful.



# "Family photos revealed my son's cancer"

**When Dayaan was three years old, he was diagnosed with retinoblastoma. Now aged seven, mum Shamila reflects on the treatment Dayaan has received over the years for our upcoming awareness campaign.**

As a baby, Dayaan had eye infections. Nothing else felt a concern at the time, until we went away as a family. In all our photographs, Dayaan's eyes had a white glow when using a flash.

Still not thinking much of it at the time, we made him an optician's appointment just to get his eyes checked. They obviously knew what they were looking at and said they would refer us to an eye specialist, not explaining fully why. We received a call the next day from the Royal London Hospital, who mentioned the 'Big C' word. I felt my legs go to jelly, and my stomach was in knots! I couldn't speak and couldn't understand how and what was happening. This is wrong surely!

**"I had to be positive and hold it together"**

At the Royal London Hospital, it was confirmed that my three-year-old beautiful baby boy — so full of life with the biggest laugh and hugest personality — had retinoblastoma in his left eye. My whole world had been turned upside down. I could not think. I stopped hearing what was being explained to me at the appointment, and I just remember wanting to come home to my other son and just ignore all this outside noise. We were told we would get a call and have someone talk us through everything properly within the next few days.

Telling my family was the worst thing I've ever experienced in my life; repeating this horrific new reality of ours, while still not even being able to pronounce 'retinoblastoma' or even begin to say 'cancer'. I still had to be positive and hold it all together in front of Dayaan. I wanted to completely break down and scream, but I didn't want to scare him. Instead, I went into complete autopilot, took charge, and asked questions. I did a little research and spoke to some families that had gone through this.

Dayaan had six rounds of systemic chemotherapy at John Radcliffe Hospital in Oxford. We went back and forth for check-ups in between. Dayaan's immune system was so low. My poor little baby lost so much of his hair, his eyebrows and eyelashes. I then found out I was pregnant.

Dayaan continued with treatment. Along the way, he got infections, and, on a few occasions, we had to stay in hospital. He was on IV antibiotics and was stuck in hospital rooms, isolated because of the risk of infections. It didn't end there, as Dayaan then had his first relapse.

He had five cycles of intra-arterial chemotherapy (which goes into the eye via your artery) at Great Ormond Street, followed by intravitreal chemotherapy (which goes directly into the eye). By this point, Dayaan was six and I had a newborn baby girl. Dayaan had been battling this horrendous



"We saw a shift in Dayaan with his confidence"

cancer for three years, but things did start looking a little positive for almost 11 months.

Just when we thought the cancer was gone for good, Dayaan relapsed again with more active tumour seeds. I couldn't imagine how we could go through anymore. Dayaan was then offered radioactive plaque treatment. We felt we had come too far in trying to save his eye to give up.

The radioactive plaque treatment was successful. We had brilliant results. Finally, we had got to a point when the breaks between appointments and anaesthetic were longer. At 11 months clear, we had talks of even moving up to clinic rather than day ward. Dayaan has been so strong, so amazing and so positive throughout everything. He has held us together as a family, smiled, laughed and charmed his way through every knock and every appointment. He has been singing and dancing through hospital corridors. He never let anything affect him or dim his light. However, in July this year we found the cancer was back. We couldn't do any more treatment and have been advised we should now do a removal (enucleation) of his left eye.



Losing an eye was the one thing we had been trying to avoid for him. He really didn't want this, and suddenly, we saw a huge shift in Dayaan with his confidence and personality.

"We are beyond proud of him"

It's been a couple of months now since Dayaan had his enucleation. Slowly, as time has gone on, he most definitely is getting his spark, smile and confidence back. We treat it one day at a time - he is an absolute soldier; we are so beyond proud of him and everything he has gone through. We just know he has the brightest future ahead.

The CHECT team are a phenomenal group of people. But as a family, we have had the support of one of the most incredible women I've met in my life. Not only has our CHECT Support Worker supported us over the last four years, but she has always gone above and beyond to make sure we have all been ok and looked after. CHECT has helped mentally, emotionally and financially in the hardest of times. They have helped us in ways that I can't begin to explain. Our Support Worker's help, knowledge, and passion are truly inspiring. We couldn't have got through most days without her care and support.



# We can't raise awareness without you!

We want to say a huge thank you to everybody who helps us to spread awareness of retinoblastoma. Would you like to share your awareness story with us? Do you have photos that show signs and symptoms you'd be happy for us to share? Please email **isabella.greenwood@chect.org.uk**

# From parents around a kitchen table to a national charity

**CHECT wasn't created in a boardroom, designed by consultants or launched with a glossy five-year plan. It started much more simply – with families affected by Rb coming together because they wanted to help one another.**

Back in the mid-1980s, parents and the professionals caring for their children could see that families needed more than medical treatment. They needed clear information. They needed to meet others who understood what they were going through. And they needed somewhere to turn when things felt frightening, confusing or overwhelming.

In 1986, parents attending Moorfields Eye Hospital were invited to meetings to talk about setting up a support organisation. The response was immediate. Families volunteered to help other families, keep people in touch and raise the money needed to get things started. And from those early meetings, the Retinoblastoma Society was born. In July 1987, it officially became a registered charity. Over time, we would become the Childhood Eye Cancer Trust – CHECT.

Those early days looked very different from life today. There were no websites, Facebook groups, WhatsApp chats, emails or Zoom calls. Support meant letters, newsletters, telephone calls and, whenever possible, getting people together in the same room. Parents around the country began supporting other parents facing a new diagnosis. Families met at events and weekends away. People swapped stories, shared advice and reassured one another that, however difficult things felt, they were not facing Rb on their own.

Awareness mattered too. The charity began helping more people recognise the signs of retinoblastoma, including the familiar 'white glow' that can sometimes appear in a child's eye. But at the heart of everything was one very simple idea: no family affected by retinoblastoma should have to go through it alone. That idea has stayed with us ever since.

As the years passed, the charity grew. More families got involved. More support became available. Better information was produced and our links with the UK's specialist retinoblastoma teams became stronger. We also began funding research, helping to improve understanding of Rb and its treatment. CHECT became more organised, of course. It had to. But what mattered most was holding on to the warmth and personal connection that had been there from the very beginning.

By the 2010s, CHECT was supporting families right across the UK. Our support workers were there during diagnosis and treatment, but also afterwards – helping families navigate follow-up, school, emotional wellbeing and all the practical things that can come with living through Rb. And as we listened to our members, something else became increasingly clear. Retinoblastoma doesn't necessarily stop affecting someone when treatment ends. For some people, its impact can be lifelong.

So today, we are there not only for parents of newly diagnosed children, but for teenagers, young adults and people who had Rb many years ago. We offer emotional and practical support, financial help, trusted information and opportunities to meet others who understand. We campaign for earlier diagnosis, fund research and make sure the experiences of people affected by Rb help shape the work we do.

A lot has changed in nearly 40 years. Our founders probably couldn't have imagined WhatsApp support groups, video calls, online events or social media campaigns. They might also have been slightly puzzled by some of the language charities use these days. But they would absolutely recognise what really matters. They would recognise the parent who wants to speak to someone who understands. They would recognise the relief of meeting another family who has been through something similar. They would recognise the value of sitting down with someone and simply being able to say, "Yes, we've been there too." And they would recognise the determination to make

things a little easier for the next person who comes along.

That feeling runs right through CHECT's history. Our members have always been at the heart of the charity. Early diagnosis has always mattered. And the experiences of people affected by retinoblastoma have always helped shape what we do next. That is why our history is about much more than a charity growing over 40 years. It is the story of people taking difficult experiences and turning them into something positive for others.

2027 gives us plenty to celebrate. It marks 40 years since the charity was registered, 30 years since we commissioned our first research project and 20 years since the first World Retinoblastoma Awareness Week. That gives us a wonderful chance to look back and celebrate everything our members, volunteers, staff, supporters and healthcare partners have achieved together. There is a lot to be proud of.

But anniversaries are not only about looking back. They are also a chance to think about what comes next. We want CHECT to be here for the generations to come, just as it has been there for thousands of people over the past four decades. That means continuing to raise awareness so that children with Rb are diagnosed as quickly as possible. It means funding research that can improve treatment and outcomes. And it means making sure people can find support whenever they need it – at diagnosis, during childhood, through the teenage years and into adult life.

We want to reach more people, listen to more members and make it easier for anyone affected by Rb to feel part of the CHECT community. We are still a small charity, funded entirely through the generosity of people who believe in what we do. But being small has never stopped CHECT from thinking big. After all, everything we have today started with a small group of families who simply thought things could be better – and decided to do something about it.

Forty years later, that same spirit is still at the heart of CHECT. We may have changed a great deal since those first meetings, but one thing hasn't changed at all: nobody affected by retinoblastoma should have to face it alone. And as we celebrate our first forty years, we are already looking forward to everything we can achieve together in the years ahead.



# 40 years of CHECT. One unforgettable weekend at Warwick Castle!



**For more info & to buy tickets, visit chect.org.uk/40th**

**Celebrate 40 years of CHECT at Warwick Castle by making a weekend of it.**

In 2027, the Childhood Eye Cancer Trust celebrates 40 years of supporting people affected by retinoblastoma.

From Friday 24 to Sunday 26 September 2027, we are delighted to invite all our members to join us for a very special 40th Anniversary Members' Weekend in the beautiful surroundings of Warwick Castle, staying at the on-site hotel and lodges.

Set at one of the UK's most iconic historic attractions, this promises to be one of the biggest CHECT events we have ever held – bringing our community together for a weekend full of fun, friendship and celebration.





**A weekend for everyone**

Whether you are coming with young children, joining us as a teenager, or attending as an adult affected by Rb, there will be something for everyone.

Your ticket includes breakfast on Saturday and Sunday, together with entry to Warwick Castle on Saturday, giving you access to attractions including Zog Playland, the Trebuchet Show, Birds of Prey displays, the Horrible Histories Maze, the Kingmaker exhibition and much more.

Alongside everything the castle has to offer, CHECT will also be running activities throughout the weekend.

Children can enjoy a party, castle-themed crafts and our special CHECT Champion Awards.

Teenagers can take part in dungeon tours, workshops, games and dedicated chill time.

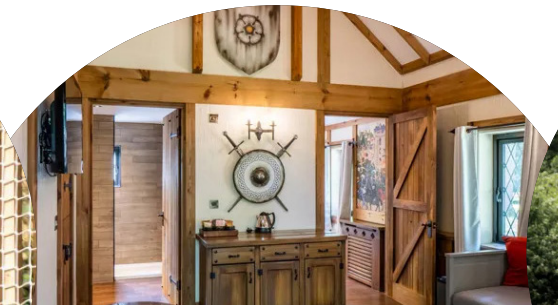
Adults can attend research talks, hear about developments in the Rb world and enjoy time catching up with old friends and meeting new ones.

There will also be opportunities to try something different, including archery, touch tours, quizzes, games and evening entertainment.

Whether you want to take part in everything or









simply experience the castle grounds and spend time with other members of the CHECT community, the weekend is yours to enjoy your way.

**Just for CHECT**

One of the things that will make this weekend particularly special is that CHECT has exclusive use of Warwick Castle's hotel and lodges.

For the whole weekend, the entire accommodation will be reserved for CHECT, creating a relaxed, welcoming and supportive atmosphere for our community.

**Celebrating our CHECT Champions**

Another highlight will be the CHECT Champion Awards, celebrating the bravery, resilience and achievements of those affected by Rb.

The awards are always one of the most inspiring moments of a CHECT event and a wonderful reason to come together and celebrate our incredible members.

**Come and be part of something special**

Whether you have attended CHECT events before or this will be your first, we would love you to join us for this landmark celebration.

We will come together, have fun and create lasting memories in a truly spectacular setting.



**Book early and get 20% off**

Our Early Booking Offer saves you 20% on the standard ticket prices if you book by 28 February 2027. Places are limited, so book early to secure the best possible price and make sure you don't miss out.

## Special anniversary offer!

To help as many people as possible attend, CHECT is subsidising half the accommodation cost. If you're able, please consider making a donation when prompted during the booking process. Your generosity will help us to continue to provide lifelong support, fund research and raise awareness.

**Book now: chect.org.uk/40th**



# Kyle: I started to embrace the thing I spent years trying to hide

**I was just three months old when Rb changed my life, although at the time I was far too young to understand what was happening.**

During my first baby checks, a nurse noticed something different about my eyes, but my parents were told everything was fine. I was also a very distressed baby and cried constantly, apart from when I was in the car. My mum took me to the doctor's multiple times, but they thought I was a baby who cried a lot. It wasn't until my parents took a photograph of me and noticed the white glow in my eye that things finally changed. They took me back to the doctors, where I had further checks and was diagnosed with retinoblastoma.

Thankfully, the cancer was caught in time, and the doctors were able to remove it, but it meant losing my eye at just three months old. Because I was so young, I don't actually remember the diagnosis, the treatment or losing my eye. Everything I know about those first few months comes from the stories my mum and dad have told me over the years. They are the people who remember what happened and what they went through, and their memories have become part of my story too.

I have never known life with two eyes. For me, having one eye has always just been part of who I am. But growing up, I didn't always feel that way. At my first primary school, I had grown up with many of the same children from a young age, so nobody really thought much about the fact that I had one eye. That changed when my parents moved me to another primary school. I started Year 4 as the new kid, and I immediately stood out. I was different from everyone else; unfortunately that made me a target.

The bullying wasn't just name-calling. It could become physical too. Even on my first day at my second primary school, I experienced bullying. I was pushed around and physically picked on, as well as being called horrible names such as "freak", "pirate", "alien" and even Mike Wazowski from Monsters, Inc., along with many others. At that age, I didn't always understand why people were treating me that way or why having one eye made me such a target.

It really affected me. I felt unwanted and isolated, and school became somewhere I didn't want to be. Thankfully, I also made some really good friends who helped me. Secondary school brought another challenge. There were even more people, and I constantly felt like I had to explain myself. I never knew how someone was going to react when they noticed my eye. I became very self-conscious. I struggled with confidence and found it difficult to maintain eye contact with people. I would constantly wonder, "Are they looking at my artificial eye?". As I got older, those worries didn't disappear. They even came into my relationships and dating life. When you're trying to meet someone romantically, you naturally worry about whether they are going to accept you and whether your eye is going to be something they notice or judge you for. For a long time, I carried those worries around with me.

When I was younger, I often asked myself, "Why me?". I spent a lot of time focusing on what I couldn't do rather than what I could. But as I got older, something changed. I started to realise that I couldn't change what had happened to me. But I could choose what I did with my life.

I started thinking: "What if this is just who I am? If this is the person I'm meant to be, why shouldn't I try to become the best version of myself that I can be?". That was a huge turning point for me. I started learning to embrace the thing I had spent years trying to hide.

After leaving school, I went to college and discovered a passion for sport. I started coaching football and realised how much I enjoyed helping other people. Then I was given an opportunity to help coach martial arts. At the same time, I started training myself.

Martial arts became much more than just exercise for me. It helped me build confidence. It taught me discipline. It taught me that I could push myself and do things that I had once believed weren't possible. Four years later, I've had four kickboxing fights, with my fifth coming soon. I'm now a head kickboxing coach at my gym. I teach children's classes, self-defence, cardio and kickboxing, and I also work with my local college on different projects.

Looking back, it's strange to think that the child who struggled so much with confidence and being different would one day stand in front of a room full of people and teach them. But that's exactly what happened.

I don't think accepting myself happened overnight. But eventually, I realised that constantly worrying about what other people might think was holding me back more than my eye ever did. My eye is part of my story. It doesn't have to be something I hide or stop me from being a coach. It doesn't stop me from competing. It doesn't stop me from helping people. And it doesn't stop me from being myself.

I've learned that I don't need to be defined by the things that happened to me. I can acknowledge them, learn from them and still decide what kind of person I want to become.

Now, another chapter of my life is beginning because I'm expecting a child. Becoming a dad is something I'm incredibly excited about, but it also brings a different kind of worry. Because of my own experience with retinoblastoma, there is a part of me that worries about my future son going through what I went through.

Because I was diagnosed so young, I know that a child doesn't understand what's happening to them in the way an adult does. I also know what it can be like growing up afterwards and having to deal with the emotional side of being different. There are moments when I think about what it would be like if my son ever had to go through something similar. That thought is frightening, and I don't think I'll ever be able to completely switch that worry off.

But I've also learned something throughout my life: you can't spend your life being controlled by fear of something that might happen. If that day ever comes, I will deal with it the best way I possibly can. I will be there for him. I will understand more than most what he might be feeling, and I will make sure he knows that having Rb or losing an eye will never stop him from being who he wants to be.

If there is one message I want people to take from my story, it is this: Don't let anyone tell you what you can and can't do. I was made to feel that certain sports weren't possible for me. Now I'm coaching, competing, teaching and helping other people. I've learned that being different doesn't mean you have to live a smaller life. If you're a child who has retinoblastoma, has lost an eye, wears an artificial eye or is struggling with how different you feel, I hope my story shows you that your diagnosis is only one part of who you are. And if you're a parent whose child is going through retinoblastoma, I hope my story can give you some hope about the person they can become.

I was once the baby who lost an eye at three months old. I was the kid who hated school, struggled with confidence and wondered why this had happened to me. Now I'm a kickboxing coach, a competitor, a person who helps others, and soon I'll be a dad.

I can't change the beginning of my story. But I can choose what I do with the rest of it. And that's what I intend to do.

**Read Kyle's full story on our blog!**



# Why Nathan wants to break records for CHECT



**My story with Rb started when I was a young child. Looking through family photographs, a member of my family noticed an unusual white glow in one of my eyes. We didn't know it at the time, but this is one of the classic signs of retinoblastoma.**

I was referred to specialists over many months, until I eventually came under the care of the late consultant ophthalmol-ogist John Hungerford – the man who ultimately saved my life. I was diagnosed with bilateral Rb, meaning the cancer was present in both eyes. For a time, my mum and I lived in and around St Bartholomew's Hospital in London while I underwent treatment, including cryotherapy and radiotherapy. Eventually, I was able to return home.

But the cancer kept coming back. To protect the remaining vision in my right eye, my left eye had to be removed. It was replaced with a prosthetic eye, often called a glass eye. Every now and then, I even get a shiny new one. Today, I am completely blind in my left eye and visually impaired in my right. My vision isn't great. But I consider myself incredibly lucky. There was always a very real possibility that I could have lost sight in my right eye too.



Growing up with a visual impairment hasn't always been easy. There have been challenges and obstacles along the way, but, like everyone, I have good days and bad days! I never quite made it as a professional footballer or a top-10 padel player, but I've always tried to approach life with a simple attitude: Just send it and do what makes you happy - what's the worst that could happen? I owe that to my mum and dad, who always encouraged me to give things a go, and to my incredible family and friends who have support-ed me throughout my life.

Then it became personal all over again. In December 2019, my wife and I welcomed our beautiful daughter, Izzy. Because Rb can be hereditary, CHECT strongly encouraged us to have Izzy checked as soon as possible. We were told there was a 50/50 chance she could have Rb too. In January 2020, our greatest fear became reality. Izzy had Rb. She needed chemotherapy to treat the cancer and prevent it from spreading.

And then, just as we were trying to navigate our daughter's cancer diagnosis, the world entered a global pandemic. We had to completely isolate ourselves while travelling back and forth for Izzy's treatment at Royal London Hospital and Great Ormond Street Hospital. It was an incredibly frightening and uncertain time.

But throughout it all, CHECT was there. They helped coordinate appointments and travel. They found us places to stay overnight. They supported me, my wife and Izzy when we needed it most. They weren't simply a charity we knew about. They became part of our family.

Thankfully, because Izzy was diagnosed early and treated quickly, her outlook is more positive than mine. We hope she will retain healthy vision in one eye, although she is expected to lose most, if not all, vision in the other. But Izzy doesn't let any of that define her. She's a tough kid. Despite everything she's been through, she throws herself into life and takes every opportunity to have a go. She'd have every right to complain, but she never does.

And then came Sophie. In August 2023, our youngest daughter, Sophie, was born. Thanks to advances in research, we were able to establish through a blood test before she was born if she had inherited the condition. I'll never forget the feeling of finding out that Izzy had Rb. And I'll never forget the relief of finding out that Sophie didn't.



That's why I'm doing this. CHECT has been there for my family at some of the most difficult moments of our lives. I honestly don't know what our journey would have looked like without them. So now, it's my turn to give something back.

This November, I'll be taking on 50+ hours of continuous padel with my three amazing friends Charlotte, Marcus and Toni, attempting to reclaim our own Guinness World Record and raise money for CHECT. It will be exhausting. It will be uncomfortable. And there will undoubtedly be moments when I wonder why on earth I agreed to it. But I know exactly why I'm doing it.

For the children and families who are just beginning their own Rb journey. For the parents who are waiting for answers. For the children who deserve the best possible chance of keeping their sight. And for the families who, like mine, need to know that someone is there — today, tomorrow and for life.

If we can turn 50 hours on a padel court into support for even one family, it will be worth every minute.

## Ross' Goals for Good

**We spoke to Ross after he completed his incredible 'Goals for Good' challenge, in which he ran 1 km for every goal scored during the World Cup and encouraged people to donate to charity. Ross chose to support CHECT, a cause close to his heart, and has been sharing his journey with us every step of the way. Over to Ross to tell us more about his challenge...**



After five months of training for Milton Keynes marathon in May, I was looking for my next goal to motivate me to keep running and stay fit. I love my football, and so challenge alongside the World Cup seemed like a fun idea!

I've raised money for charities before. Donating is a very personal thing, I feel, so I wanted to encourage people to donate to a charity close to their heart, but if they didn't have a charity in mind, they could support my charity, CHECT. Thankfully for me, quite a few people decided to donate to CHECT via direct donations or via my fundraising page, but I also had donations to Brain Tumour Research, Cancer Research UK and others.

I support CHECT because I had retinoblastoma when I was two, losing my left eye, so I have always kept CHECT close to my heart and doing what I can to help spread awareness and raise vital funds.

The challenge itself was rather testing at times, especially during the group stages when there were up to 6 matches a day, and also the hot weather! There were 74 goals in the space of 4 days. With shift work and being a father to two young boys, there was a lot of logistics needed in order to keep up with the running total. My wife Ellen was an incredible support during the challenge, motivating me to keep going and also making it possible to spend my spare time pounding the pavements around Lichfield. One specific morning I was due on an early shift, but it was due to be 35 degrees that day and thanks to some late-night/ early-morning goals, I went out at 4am to complete 20 km before work! That was the peak of the challenge thankfully though!

It was a lovely opportunity for me to run with members of my family and friends as they joined me on my challenge on Parkruns, etc. People who have supported me for as long as I can remember, including my sister Lucy and dad Phil, but also my best mate Josh, and two sons, Otis and Evan.



## Have your Christmas donations doubled.

**1 - 8 December**

## Take part in our Big Give Christmas Challenge!

**This Christmas, we're taking part in the Big Give Christmas Challenge between 1 - 8 December to help us raise money towards our 40th anniversary in 2027.**

Our 40th anniversary will be a special opportunity to celebrate four decades of supporting children and families affected by Rb, while looking ahead to the future and the support needed for generations to come.

Through the Big Give Challenge, we're asking you to donate to CHECT via the Big Give platform and help us reach our £10,000 fundraising target. Every donation made will be doubled by the Big Give.

Donate using the QR code, or visit www.donate.biggive.org/campaign/a05WS00000G0pirYAB

## Thank you to our amazing fundraisers

**This summer, an incredible group of individuals and teams took part in CHECT's Hospital to Hospital Challenge, covering the 122 miles between the Royal London Hospital and Birmingham Women's and Children's Hospital, either one way or as a 244-mile round trip, over the course of a month.**

And what an achievement! Together, you raised almost £11,500, smashing the £10,000 target. We are incredibly proud of everyone who took part, not only for helping us raise vital funds to support more individuals and families affected by Rb, but also for shining a light on the distances many families have to travel to access specialist treatment and care.

We are also grateful to all our fundraisers who have supported CHECT throughout the year, whether by taking on personal challenges, organising events or raising awareness in their local communities. A special thank you to those who took part in the Great North Run in September. Your dedication and support mean the world to us. A huge thank you to everyone who took part, donated, encouraged others and helped us raise awareness.




## Remembering your loved ones

**We've teamed up with Free Wills to give you the chance to create a comprehensive Will at no cost.**

Every Will is reviewed and approved by a qualified solicitor. To find out more, visit **chect.org.uk** and select 'Get Involved', then 'Legacy Giving', or alternatively, email **fundraising@chect.org.uk**.

We are deeply grateful to every-one who has chosen to leave a gift to CHECT in their Will, and to those who have raised donations in memory of someone they love. These gifts are a truly meaningful tribute, and we are touched that our supporters think of CHECT even during such a difficult time.

Our condolences and grateful thanks are extended to the families and friends of Mary Digby, Mario Felato, Steven Fuller, Maureen Firth and Wayne.