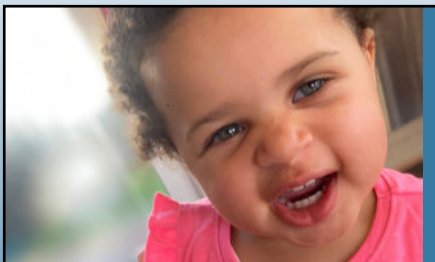


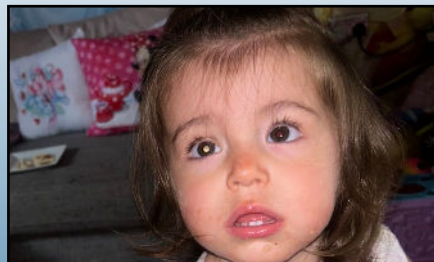


Our Festive Stars



"My daughter's Rb was mistaken for eczema"

Read Amelia's story **Page 7**



"I spotted my daughter's Rb as she watched TV"

Read Evie's story **Page 9**



"My eye never once held me back"

Read Steven's story **Page 5**

Welcome

Welcome to the winter issue of InFocus and a big thank you to all our families who submitted wonderfully festive photos for our front cover.

As always it has been an absolute honour for us to celebrate so many of our amazing members at our CHECT Champion Awards, which recognises some of our brave children at our Family Members' Days. We have also been delighted to see such brilliant awareness-raising from some of these children on the national news and radio - including the BBC and ITV!

We are thrilled to continue both our in-person and online support events across the UK. Whether it's hosting our first-ever Grandparent's online meet up, delivering a session on genetics, seeing our teens and young adults being spellbound at the Harry Potter Studios or pumpkin picking with our families, it has been great to see new friendships formed as our community joins together. We are looking forward to continuing these events in 2024.

As well as support events, we have had a number of successful fundraising events too - and we remain incredibly grateful to everyone who takes the time to help and support us. As we receive no government funding, we couldn't continue our support, research, or awareness work without you.

We were delighted that, during Childhood Cancer Awareness Month, so many of you helped spread awareness and took part in our 50km Your Way campaign where our fundraisers tackled the distance either walking, running, cycling, or skating! Turn to page 11 to see the photos.

We are really looking forward to our Christmas fundraising event in December, which you can learn more about on page 12.

It has been an honour to share so many awareness stories in the media over recent months, including mum Katherine who first spotted that her daughter Amelia's eye was causing her irritation as a newborn. You can read the story we shared as part of our Childhood Cancer Awareness Month story on page 7.

Thank you to mum Danielle for sharing her daughter Evie's story as part of our World Sight Day campaign. Evie was diagnosed with Rb after her mum spotted a glow as she watched TV. You can read their story on page 9.

I hope you enjoy what is a jam-packed edition of InFocus, filled with interviews, stories and even some colouring in for you to do. We'd love to see your colouring - why not send us a photo?

I would like to give a special mention to the amazing team here at CHECT, the staff, our volunteers and Trustees. We are a small charity that does big things in our quest to be there for anyone affected by Rb. The team do everything that they can to ensure we lessen the impacts of Rb by delivering lifelong support, funding research and driving early diagnosis. It is because of them that we can do what we do, thank you to them all.

Finally, on behalf of everyone at CHECT, I would like to thank all our members, trusts and foundations, fundraisers and supporters who have enabled us to continue our integral support, research and awareness work. We really appreciate your support.



Richard Ashton, Chief Executive

Contact us

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

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News

CHECT support events!

This autumn we kicked off our new CHECT events schedule with a visit to The Making of Harry Potter, Warner Bros. Studio Tour for our Teens & Young Adults group, an Online Genetics Evening with Dr Hay, and a Halloween-themed family day at Lower Drayton Farm in Stafford. As this goes to press, we are also planning a Scottish family day in Glasgow on 18 November and our online TYA Christmas Party on 11 December. We are so enjoying meeting up with you all - keep checking www.chect.org.uk/events for future in-person and online events as we've got plenty planned for 2024 too!



'My Rb Summary' launched!

Great news! We have a new suite of patient information now available for adults who were affected by retinoblastoma (Rb)

as children. The selection includes information on late effects; second cancers and minimising risks; having a baby after Rb, and our brilliant My Rb Summary document – which allows adults to self-populate a treatment summary to take along to future healthcare appointments. Leaflets are downloadable from the 'Adults after retinoblastoma' section on our website, or you can request a hard copy. For more information or assistance, please contact support@chect.org.uk or **020 7377 5578**.

Want to receive InFocus in a different format?

We can offer InFocus in the following formats:

- Large print (A3)
- Braille
- Electronic - PDF and HTML

If you would like to receive future editions of InFocus in a new format, please let us know on 020 7377 5578 or at info@chect.org.uk

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Page 11-12: Fundraising and events
Page 13-14: Children and TYA's corner
Page 15: Ways to help

Have your say

Do you enjoy receiving your copy of InFocus? Is there anything in particular you'd like to read about? Would you like to submit content for our blog? If so, we'd love to hear from you at info@chect.org.uk.

Thanks for your support!

A Day in the Life of a CHECT Support Worker



Lena Copley has been our Support Worker based in Royal London Hospital since October 2021. She shares with us what it's like to be a CHECT Support Worker during a day in September.

Got up earlier than usual this morning. I wanted to go for a 20-minute run ahead of the start of working day. It was a glorious morning with a spectacular, orange glowing sky and all was quiet. Already quite hot. Like most of the UK, London has seen temperatures over 30c for the past few days - hot, hot, hot!

I logged on around 8.45am and started checking text messages, responding to those whilst making notes for the daily to-do list. I then go through the inbox and can see we've had a few queries about our little CHECT penguin, Pip, who is designed to help children who will, or have, had their eye removed (enucleated). I respond to those and then go to Facebook where we have a few membership requests from international families. After signposting and responding, I make a couple of planned support calls. We have a new family, so I want to send them an email with information about CHECT, what we can do for them and signpost them to a few other charities. Then it's time to make a call to Royal London to speak with one of the Cancer Nurse Specialists (CNS). I want to update them on the progress with a couple of applications and discuss the upcoming examination under anaesthetic (EUA). By the time I hang up, I have got the information I needed to complete and submit a blue badge application for one of the new dads.

By now it's already lunchtime and after a quick bite to eat, I check for messages/emails/Facebook and respond to further support queries. I've had a message from a worried mum, so call her back straight away. I then continue to do some applications – one for a financial grant to help with travelling/hospital costs and another for white goods to help a needy family. I also make a quick call to check in on a housing letter I provided for a family with a partner charity I work closely with at Royal London.

Next, I prepare for the afternoon's Support Team meeting. At the time of writing, we were planning a TYA (teen and young adult) event at the Harry Potter Studio in Watford and also planning for an October Family Day and an online support event.

I have just realised that at the time of the October Family Day, I will have been with CHECT for two full years. Time has flown and I still enjoy my job as much as I did when I started. I consider myself lucky to be able to work with so many wonderful families and colleagues.

The CHECT support worker role is a busy one but so very interesting and varied. I think I learn something new every day and I am in awe of the specialised knowledge the medical team has. There are so many highlights - meeting the families; seeing how the CNSs work with the complicated planning to ensure that each and every child is seen at the right time; working with the play specialist and seeing how the children are crazy about her is just lovely. We all play a part in making sure families feel supported and safe and it's a privilege to be part of such a great team.

Just before I finish for the day, I follow up on our events meeting. It ends on a high note with good news from a partner charity who have agreed to help one of the families by offering a short break away.



Eddie's Wembley Experience

A big thank you to the Free Kicks Foundation for the wonderful opportunity to attend a football match at Wembley. Mum Diane tells us about Eddie and James' experiences:

They had a great time. Eddie went with his big brother (he's 20 and in the Royal Navy so it was lovely for them to have such a special day together) and they had a wonderful day at Wembley. Ed was very pleased with the result too. Many thanks for the opportunity to enjoy top-flight football in probably the best stadium in the world. They even bumped into the Three Lions. They had a great view of the game too. Thank you to CHECT for putting Eddie forward for the tickets and thank you Free Kicks Foundation for a wonderful day out.

CHECT Support

Kerrie & Megan see Harry Styles live!



Kerrie and Megan attended a Harry Styles concert, with thanks to our collaboration with the Free Kicks Foundation. Here, Kerrie discusses the experience!

Thank you so much to CHECT and the Free Kicks Foundation for such a fabulous experience. This was the first concert I've taken my nine-year-old daughter to, and what a first concert! One of the Wembley staff did say to her though that nothing will ever be quite as

good as sitting in the purple zone in Wembley just near the Royal Box, so hopefully I can manage her expectations for the future!

I was slightly nervous about navigating Wembley with no sight, but I can't say enough about the incredibly helpful staff who made it so easy. It has definitely given me the confidence to take my daughter to more concerts.

As for Harry, he really knows how to put on a show; the atmosphere was amazing. My favourite memory is the two of us jumping up and down and going crazy to the One Direction medley, in our matching pink bucket hats of course! I'm still picking feathers out of our suitcase, off bedroom floors etc, but I can definitely live with that!

James' Rb Story!

Mum Lesley tells CHECT about James' journey with retinoblastoma, and what life is like now.

James is a happy, healthy and energetic 9-year-old. He loves school, steam trains and eating (lots). In his spare time, he attends Cubs (where he has just achieved his Silver Award), swims and plays percussion in a band. He loves playing the drums and spends time outside of school climbing, abseiling and archery. We are reminded every day of our son's strength, bravery and perseverance. The first few years of James' life weren't easy, they were filled with lots of trips to the hospital.

When James was 3 years old, I noticed his left eye moving in a different direction, so we visited the GP where they examined James' eye and referred him for a squint. Over the next few weeks, I started to see more symptoms emerging. I remember his eye looking almost transparent and there were times when it looked red and sore. Because the referral date was months ahead, I decided to drive James straight to the eye hospital in Oxford where he was examined. The examination concluded that James was blind in his left eye and that he had a large tumour behind his eye. I remember the hospital not going into detail about James' condition but referring us to the Birmingham Women's and Children's Hospital where they performed an eye examination under anaesthetic and confirmed that James had

bilateral Rb (cancer in both eyes). As parents, it was difficult news to hear and digest, it felt like the four walls of the room were closing in on us. I, as a mum, was immediately overwhelmed by guilt thinking that I should have seen or done something sooner.



That day, we were also informed that because the cancer was more advanced in his left eye, it could not be saved and that to guarantee James' survival the left eye would have to be removed. It was in October, just after James turned 4 that his left eye was removed and replaced with a prosthetic implant. A decision was taken to also treat any residual tumours in the right eye with laser treatment.

James never complained or cried during his treatment, he still remains a happy boy and looks forward to celebrating his 10th birthday this year.

He doesn't think twice about his prosthetic eye and is just like any other child his age. The tumours in his right eye have not affected his vision but he continues to visit hospital for six-monthly check-ups.

Have you got news to share? We'd love to hear from you! Email us at info@checht.org.uk.

Steven's Story: From Rb to Rugby

I was diagnosed with retinoblastoma (Rb) when I was 3 months old and fortunately through the amazing skill of the doctors and my mum's awareness to spot something early on I only lost sight in my right eye.

I remember from a young age going for yearly check-ups on the eye I had sight in. I remember these days fondly as it felt like a day out from school! Taking the train with my mum and getting lunch at the hospital. I have always tried to see the positives in everything in life and I think this is because of my experience with retinoblastoma. There is always a positive outcome if you are willing to look hard enough for it.

I am very lucky to be alive and I look to put that into my daily life when it comes to taking opportunities or even just slowing down to appreciate what I do have and what I can do, rather than focusing on what I can't do or what I don't have. It's not always easy, some days are harder than others, but there is always tomorrow and another opportunity to push yourself forward.

When I was 10, I started playing rugby at Cartha QP Rugby Club. It was a challenge to begin with, like all sports. However, catching and passing with your hands are obviously a key area of the game. Having one eye my depth felt like an issue however, playing rugby and constantly working on my catching and passing skills improved my depth, both on and off the field. I am proud of the fact that I played rugby with Cartha QP through all the junior age groups into senior rugby. I am very proud that I earned the opportunity to play representative rugby for Glasgow at U16s and went on tour to France with the Glasgow Thistles. I always took for granted how I could play rugby and do a decent enough job at it. However, in 2016

I wanted to run an event to support the Childhood Eye Cancer Trust. I decided to put on a rugby game with my club and the catch was the players had to play with an eye patch. It was great fun and the players struggled slightly with their catching and their awareness

of where the opposition was and their teammates. I felt a sense of pride that I was able to overcome that challenge and play rugby for nearly 20 years now.

I wanted to help others grow their confidence and because rugby was such a big influence on me, I wanted to find a way that I could use the sport to be that driver. When I was 16, I left school to become a modern apprentice with Scottish Rugby. The two-year course taught me how to coach as well as how to develop sport in school, clubs, and communities. I loved every second of my apprenticeship and wanted to continue my career in rugby development.

Since finishing my apprenticeship at 18 I have worked with 10 rugby clubs, countless primary and secondary schools, two unions (Scottish Rugby Union & Malta Rugby Union) and coached different age grade and representative teams.

My eye never once held me back because I never let it. I wanted to find my path and I worked hard to make sure it never defined who I was.



Steven's Top Tips:

We asked Steven for his top tips on managing depth perception in the game after losing sight in one eye:

- Treat it like any skill. Your depth perception will only improve by practising it and sticking at it.
- Use different shapes and sizes of balls; tennis balls, rugby balls, footballs and big and small balls. Practice catching and throwing them with a partner or a target!
- Tennis balls are great to focus on your catch; get used to walking about bouncing them and catching them.
- You can also throw tennis balls off of a wall and practice catching them that way.
- Overall, just have patience. If you're practicing, you will improve on it!



How we talk about our Rb

We spoke to teens and young adults who have had Rb about how they broach conversations about either their prosthetic eye or lack of vision:



Danni said, "I tend to vary my response depending on the age and understanding of who is asking, I volunteer as a Scout leader and there's a wide age range of kids so if any of the young ones ask, I tend to just say that I was poorly and had to have my eye removed to make me better. Because I have a gold eye they're always interested and asking so I ask if they know about prosthetic arms or legs, which most of them do, and explain it's like that but for your eye. With the older kids I go into a bit more detail about having had retinoblastoma and it being a really rare cancer because they're old enough to understand properly what that means and the impact it had because we do a lot of disability awareness with them. With adults it really depends on how they ask and what they ask, I'm happy to answer any questions they have about my eye and Rb because I know it makes people curious because it stands out, but I've had rude comments that I just don't tolerate and decide not to answer."

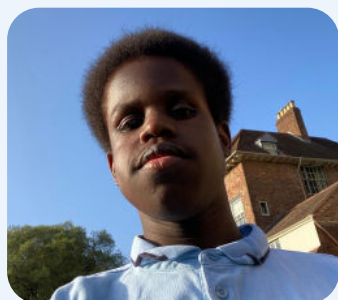


Katie said: "I personally never experienced any bullying or negative comments first-hand due to having a great prosthetic match every time; when my Rb story would come up in a conversation saying that I now have a prosthetic eye people tend to be shocked! But you can show an individual who you really are first as a person, and how strong you are by answering them positively back by asking if they would like to understand more about prosthetic eyes, living with one eye, appointments etc."

Hold your head up high, as an Rb warrior you have been through a lot since the beginning of your journey, more than some people have been through in a lifetime! Teach them to never judge the individual's visual perception, show them who you are and that you're strong enough to answer them!"



Samih said: "From my experience, I have learnt that, although people tend to ask probing and what can feel like personal questions, it is mainly out of curiosity, rather than spite or harmful intentions. It's important for parents as well as young people living with retinoblastoma to remember that yes, we might not be able to drive or do some of the things that fully-sighted people may be able to do. However, we are still our own wonderful people, and we still have something to give to the world."



Independence is a must. Learning how to be independent from a young age and how you can adapt the necessary skills such as cooking and living with retinoblastoma matters, because the more independent a person is capable of being the more they can bridge the gap between us and our sighted peers."

Would you like to speak to someone about talking about your retinoblastoma diagnosis? Contact our support team at support@chect.org.uk or call us on 020 7377 5578.

REAL LIVES

“My daughter's Rb was mistaken for eczema”

Mum Katherine had noticed her newborn Amelia had been rubbing her left eye since being born in September 2020.

Katherine said, “I was first advised by the health visitor to put breast milk on it. There was a noticeable redness on the eyelid, but the eye appeared normal – she had passed her newborn sight check and I was advised the redness could be eczema.”

Katherine said, “As Amelia was a bit premature (4 weeks), a twin (she has a twin brother Jake) and their birthweight had dropped, I'd had quite a lot of contact with the Health Visitors and had kept mentioning it. I was told to mention it at the 12-week check. As I wasn't sure that the 12-week check was with a GP, I had called the GP the day before as the rubbing was getting worse. They requested I send some pictures and thought that the redness could be a birthmark. I didn't think that this was the case, but I was told that we'd be seeing the GP the next day. It was a different GP to the one

who had suggested it might be a birthmark, but she concurred and said she wasn't concerned.”

Katherine added, “As the problem continued and it was becoming increasingly distressing for Amelia and for us trying to stop her rubbing, I contacted the GP again. They would only allow a phone call due to COVID-19 and it was the same GP as the 12-week check. She said that I should bathe her eye to see if that helped. She didn't seem to be concerned and said that they weren't seeing patients during lockdown. Amelia also had a squint in the same eye which I spoke about and the GP said that they wouldn't do anything about it until Amelia was 12 months old.”

“I was so relieved to get her back in my arms.”

In March 2021 when Amelia was 6 months old, Amelia's Grandma noticed something wasn't right with Amelia's eye during dinner.

Katherine said, “Amelia was in her highchair when my mum said, “What's wrong with Amelia's eye?”. I hadn't noticed anything about the actual eye before, but under the spotlights in the kitchen, you could see that it was protruding and looked kind of 'dead'.”

Katherine added, “We called the GP the next morning and they fitted us in that day. I had walked to the surgery with the twins not expecting to hear what I was told. The GP examined the eye and shined a light into it. She quickly told me that it could either be

a cataract, or a very rare cancer called retinoblastoma, but she thought it was the latter. She gave me a leaflet and said she was referring us under the 2-week cancer rule. I was devastated – I didn't call my family as I couldn't break down yet as I had a half an hour walk home with the babies. Two ladies stopped me to make a fuss of the babies and I remember just not being there – It felt so surreal and I couldn't believe what I had been told.”

“I couldn't bear the thought of waiting 2 weeks to be seen so I contacted my local independent optician, and he advised that I go and see him and if he was concerned, he'd refer us straight into my local hospital and we could expedite things that way which is what happened - we were seen at Leighton Hospital that evening. They were not able to confirm a diagnosis there and referred us on to Manchester Children's Hospital where we were seen a week later. Manchester confirmed that it was retinoblastoma, and that Amelia had no sight in the left eye but that we needed to be seen by specialists at Birmingham Women's & Children's Hospital for further confirmation and assessment.”

Amelia was diagnosed with a Grade E tumour in her left eye.

Katherine explained, “The first initial suggestion was to remove the eye rather than trying to shrink the tumour, but a decision would be made after the team meeting with the oncologist. Later that day,



we were brought to a meeting and the team had agreed that they would try with chemotherapy to see if they could save the eye."

Katherine added, "One week after diagnosis, Amelia was admitted to Manchester Children's Hospital to have her line fitted. The line was fitted in surgery in the afternoon and her first round of JOE chemotherapy was administered to her through the night. I slept in the bed next to her, she was hooked up with wires, it was awful to watch knowing how poorly it would make her. The next morning, she looked very pale and as soon as she woke up, she vomited. It made her very sleepy and sick."

Amelia had six rounds of chemotherapy at Manchester Children's Hospital between March and August 2021.

Katherine explained, "The tumour shrunk but Birmingham would laser it each time to prevent the recurrence. Unfortunately, the cancer started to grow again very quickly, and they needed to give chemo injections straight into the eye. She had four chemo injections but there were new areas of growth – even the consultants

were surprised at how aggressive the cancer was. I took the decision there and then to have Amelia's eye removed – she had been through enough and by then, we realised that her eye didn't look like her eye anymore and as she couldn't see out of it, at least if she had a prosthetic eye, the cancer would be removed."

One week later, the family set off from visiting friends in London to get to Birmingham for 8am after being called in by the hospital.

Katherine said, "We had Jake with us too and left at 4am to be there on time. They removed Amelia's eye at approximately 6pm on 8 December 2021 in a nearly three-hour operation. It was so awful taking her through to theatre, after everything she'd endured, and now this and I felt like she'd gone through it for nothing as she lost her eye in the end. I was so relieved to get her back in my arms afterwards and so grateful to the consultant. Unfortunately, when Amelia's prosthetic eye was first fitted, her body rejected it and she had to have a fat graft."

Katherine said, "Amelia is doing fantastically now. You really wouldn't notice that she only has sight in one eye – she has just as much confidence as Jake, if not more. Amelia turned three in September. She still has to have check-ups in Birmingham every three months. She is a superstar. She has such a wonderful, feisty and kind personality. She is always keen to try new things and make



new friends. She loves Peppa Pig, baking with Grandma, scooting to the park and helping in the kitchen."

Katherine added, "What we have all found really helpful is a local charity called The Joshua Tree where we spend a lot of time and they have offered support for all the family.

We have met lots of people and children who have been affected by childhood cancer and even two children with the same condition."

Katherine said, "Our support worker from CHECT is always so lovely and supportive in the clinic.

She makes sure that she spends time with each family to see if there is anything they need and any way that CHECT can help. She put us in touch with a charity that provided a tablet for Amelia to watch her favourite programmes on when she has to attend clinic appointments which has been great. I know that if I needed any advice or support that I can contact CHECT."



"Amelia is doing fantastically now."



A huge thank you to Katherine, Amelia & Jake for helping us to raise awareness during Childhood Cancer Awareness Month! We can't raise awareness without the help of our CHECT

families. If you'd like to share your story to help us to raise awareness of Rb, please contact info@chect.org.uk.



Mum Danielle spotted a white glow in Evie's eye during the winter.

It was 11 January 2023 and a day like any other day. I was feeding Evie lunch whilst she was watching her favourite presenter 'Miss Rachel'. I noticed a haze or a cloudy smear across her eye. I initially thought that maybe she rubbed food in her eye (she used to always rub her eye or where she had food on her hands she would rub her eye or face). I went to wipe with a baby wipe around her face and gently on her eyelid. The glaze wouldn't go. I decided to take a photo on my phone with a flash on to see if I could see what it was and a white glow would appear only in her right eye. I thought it was strange and showed my mum who said it could just be the reflection of my flash.

I went straight to Google as I had never seen this in Evie's eye before. I took more photos from different angles, and it was still there. I took a photo in a different room of Evie, with different lighting, I used my mum's phone as well as I thought it was my camera but the same happened on my mum's phone. I saw Google said 'retinoblastoma' which I read was eye cancer. I had not heard of retinoblastoma before Evie was diagnosed, or any type of eye cancer before. I

"I noticed Evie's Rb as she watched TV"

was always oblivious to cancer as it had never appeared in my family so never thought this would happen to us.

Once all the symptoms kept flagging up on Google as 'retinoblastoma', my heart sank. I then thought, Google always shows the worst thing it could possibly be. I rang the GP straight away that afternoon at 3pm and they gave me an appointment within the next hour the same day to see Evie. I took Evie down on Wednesday 11 January and the GP ran a red reflex test (shining a light on Evie's eye) to see if red would reflect. The right eye did not and my GP then sent an urgent referral to Ophthalmology to St Helier Hospital to examine Evie's eye properly and run further examinations. All I did was cry and Google and search endlessly to see if there was something else it could be other than cancer to make me feel better. I couldn't cope with cancer. It destroyed me knowing that my only child that I had longed for and took so long to conceive was unwell. I hated waiting to know if she was ok.

We were seen by St Helier Hospital on Friday 13 January the same week where the consultant put eyedrops in Evie's eye and examined Evie and also did an

ultrasound on her eye which showed a mass tumour with calcium deposits which usually would mean cancer. Our hearts sank again as this kind of told us what we knew already – it was retinoblastoma. St Helier then sent a referral to Royal London Hospital.

We went to Royal London on Wednesday 18 January, and they did an EUA (examination under anaesthetic) check and that's when the proper diagnosis happened. The consultants, the specialist nurses, and the whole Rb team came around to our room to break the news of the unilateral (cancer in one eye) Grade D retinoblastoma diagnosis of Evie. I had my mum and partner there (Evie's Dad). We relived the trauma of the gut-wrenching news that we had leading up to this point as we already knew from St Helier Hospital it was retinoblastoma. We just felt numb. I couldn't eat for a few days, I couldn't sleep. I was endlessly Googling or searching up ways to treat retinoblastoma, the success rate, the survival rate; everything.

Treatments were discussed briefly such as enucleation of the eye which we did not want. They said as it is Grade D that we could explore chemotherapy treatment but would have to discuss it with Great Ormond Street Hospital once they send over Evie's diagnosis. We had to have a Zoom meeting with the

"Evie does not look like she has gone through what she has."

Oncologist on Friday 20 January where I decided for Evie to have intra-arterial chemotherapy. Evie had 3 courses of intra-arterial chemotherapy (IAC) to start in January 2023, Feb 2023 and March 2023.

After her first IAC treatment in January, the tumour shrunk a big amount straight away. After the second IAC her tumour was already dead and stable but she still finished her course and had her third IAC. Evie was great throughout; we did have ups and downs with it all as she had to be put under anaesthetic each time and the procedure took 2 hours to do. Once the procedure was done, she then had to lay flat for 4 hours after each IAC because where they catheterised through her femur artery, they had to apply pressure to keep the wound close. She was always sick after each IAC round so she felt poorly each time but always recovered fast by the next day.

Unfortunately, by May 2023 EUA's check, it showed Evie did relapse and had two tumours growing in her one eye from seeding. We had to go through options again with

GOSH and we decided to go for another 3 rounds of IAC instead of enucleation. We wanted to try to save her eye. Evie had another 3 courses of IAC from June - August 2023 with a higher dose of chemotherapy drugs. Her tumour was stable after her first relapse course of IAC but we all decided it would be best to continue the three courses just to make sure. From her EUA by the end of August 2023, the tumour showed stable and her retina has reattached, no seeding at all. She had another EUA in September and again it showed it was stable and now we are going for 8 weekly checks.

Evie is doing great. Evie does not look like she has gone through what she has gone through. The only thing that has affected her is her confidence with people. She is scared of any adults or children she does not know and hangs on tight to myself as she thinks everyone wants to hurt her. It takes her maybe an hour or so to warm up or feel comfortable to play with strangers around. We are working on this by taking her out to soft plays or around friends and family who have children. Evie is will be two in February. She was only 11 months old when first diagnosed with Rb.

Evie has always been energetic. She loves climbing, playing in the sand – she is a water baby. What



“What really helped Evie was having us family around.”

really helped Evie was having us family around, and her favourite TV shows on her iPad such as Miss Rachel, Peppa Pig, nursery rhymes, Mr Tumble and Iggle Piggle. She loves going around my mum's house to play with Duke the dog and also the cat 'Laz' as she is a big animal lover. She loves going swimming so we would always take her swimming each weekend. We would take her to the park and see the ducks and birds. The treatment days were hard but Evie always bounced back quickly and just wanted to be on her feet and play.

CHECT have always been there, calling or texting me. Lena has been great and always offered her support and checked in every time we have been at Royal London Hospital through the good and bad times. As I haven't been able to work or go back to work, she has helped me with contacting charities for financial support. CHECT are great and I cannot recommend them enough.



Thank you so much to Danielle and Evie for helping us to raise awareness during World Sight Day and gaining national press.

Our fundraising updates!

50Km Your Way!

In September 2023, during Childhood Cancer Awareness Month, CHECT launched its '50km Your Way' Campaign. We aimed to inspire people to complete 50km throughout the month, representing the approximate number of children who are diagnosed with Rb each year. The response was amazing— supporters walked, ran, cycled and skateboarded to raise funds for CHECT and also to raise awareness of Rb. We extend our heartfelt gratitude to all participants who dedicated their time to our campaign, as well as those who generously sponsored them. Thank you!

50km Your Way



James gets a World Record for CHECT!

On the 6 August, James Utting achieved a Guinness World Record by running a half marathon in high heels to raise funds for CHECT after being inspired by a radio interview about CHECT's work.

James said, "The challenge was a half marathon taking place at Dorney Lake in Windsor – it's the 2012 Olympic Games rowing lake. I have completed a lot of runs in my time from half marathons, marathons, Ironman events and multi-day desert events and just thought that wearing high heels would make a half marathon that bit tougher, and therefore worthy of trying to raise some sponsorship. Having investigated, there also wasn't a world record for the fastest half marathon in heels for a male, (I know why now...) so thought it would be great to tie the two together for a worthwhile cause."

"It's a funny little journey and makes you really accountable to yourself and all those around you once they know what you are hoping to do. Raising money for a charity at the same time also provides you with additional support from the charity itself, something that they are experts in. It's a wonderful way to be part of a caring team. The run was interesting, the flat course was nicer to the feet than all the training runs but I have to admit that by mile 9 things were getting a tad sore! The finish time was 2:01:51, very pleased with that!"

Thank you James and congratulations from all of us at CHECT!



Thank you

We are very grateful to those supporters who have remembered our charity in their will, and to those who arrange donations in memory of a loved one. This is a wonderful tribute, and we very much appreciate the thoughts of those who support CHECT even at such a difficult time.

Our condolences and grateful thanks are extended to the families and friends of:

Adewumi Wasiu Abiola
Ian Williamson
John Wood
Patricia Young
Suki Thompson.

Getting you ready for Christmas

Can you give the gift of support this Christmas?

Get ready to embrace the season of giving & look out for the launch of our 2023 Winter Appeal.



This year we're raising much needed funds to ensure that the 50 children per year who get diagnosed with Rb, and their families, and all those affected by Rb, will continue to be supported, and are able to find warmth and joy during the chilly winter months.

Can you help us to spread the word about our winter appeal to help us raise much needed funds this Christmas? Please share our social media posts and communications, talk about Rb to your families, friends, work colleagues and other networks, and encourage people to donate. Your support will make all the difference!

Have you got your Christmas cards?



It's very exciting that we have our CHECT Christmas card scheme running again in 2023.

You can order by 5 December to get your CHECT Christmas cards, each lovingly designed by children who have had Rb. Each pack contains a mixture of 10 hand drawn cards and cost £5 (including P&P). Missed the deadline? Don't worry, we have a virtual Christmas card option too!

Visit www.chect.org.uk/other-ways-to-help/christmas/ to get yours!



Dates for your diary

Join TeamCHECT and take on a new challenge in 2024!

Whether you want to set personal goals or try something entirely new, we'd love to hear from you. You can sign up for challenges of any size – there's something for everyone. To discover our upcoming events and make a meaningful impact on the lives of people affected by retinoblastoma, visit our website: www.chect.org.uk/other-ways-to-help/events/

Important dates:

London Marathon: Sunday 21 April 2024

Come and join our cheer squad!

World Retinoblastoma Awareness Week:

Week commencing 12 May 2024.

Great Birmingham Run: Sunday 5 May 2024

Minimum sponsorship £300.

RunThrough Regent's Park: July 2024

Minimum sponsorship £200.

Childhood Cancer Awareness Month:

September 2024.

Great North Run: Sunday 8 September 2024

Minimum sponsorship £500.

Please contact fundraising@chect.org.uk for more information on these events.

Get involved

Would you like to take on a challenge for CHECT? We would love to chat to you about taking part in an event, or becoming a corporate partner.

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

Children's Corner!

Violet's mum Annalise discusses Violet's life since having her eye removed.

Violet (aka Queen V) is a very busy, confident and happy seven-year-old girl. Being diagnosed with Rb at the age of four has not stopped her from achieving many goals. Violet is a whizz at maths and is excelling within school life and auditioned for and successfully gained a lead role in the school Christmas production last year, and loved practicing for the role every day to ensure she knew all of her lines.

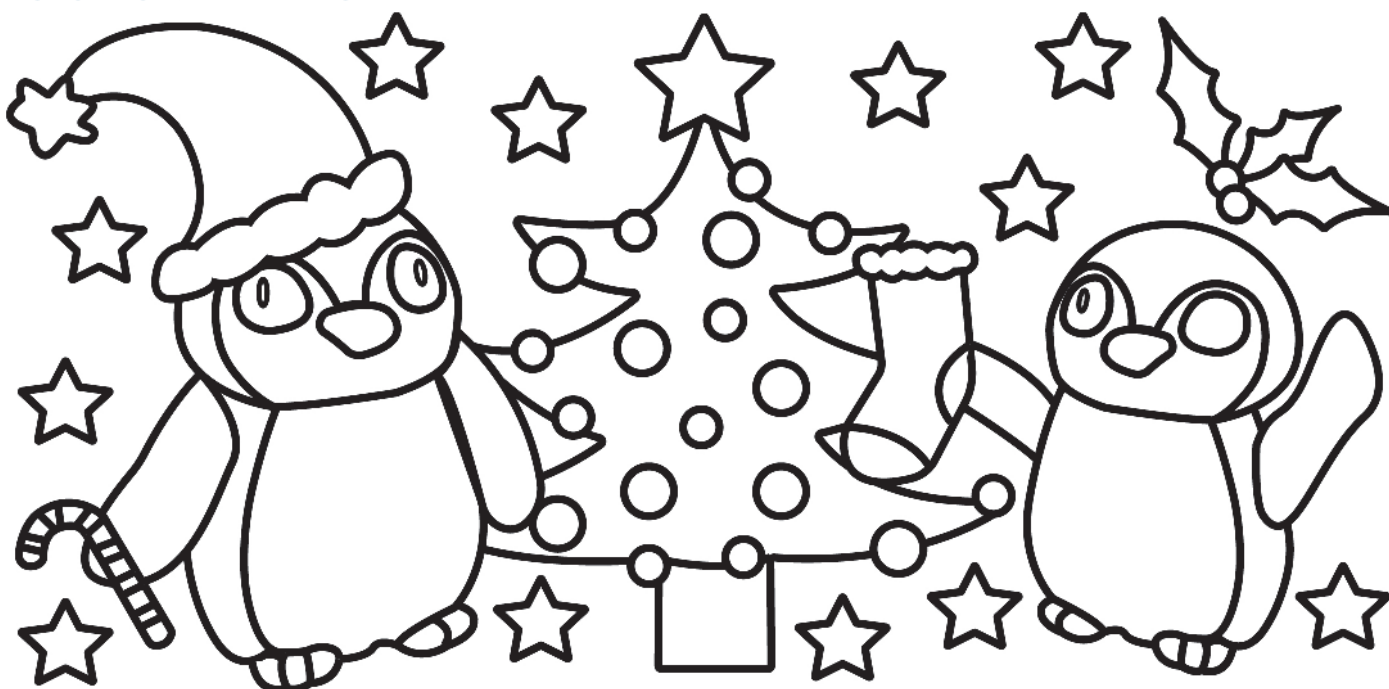
A typical week for Violet would consist of a number of activities including Brownies, swimming and gymnastics. Violet's enthusiasm for group activities is wonderful to see. Her other hobbies are riding her bike and skating, and Violet has enjoyed a skiing holiday. Violet enjoys being artistic and loves creating pieces of art using all types of materials. Violet has a strong appreciation for art and history and we visit galleries and museums when on school holidays and loves to visit her local library. This summer she took part in 'Ready, Set, Read' challenge and read 6 books in just one day to complete the challenge and gain a certificate and medal. Violet is obsessed with dinosaurs

too and loves the beach no matter the weather.

Violet has adapted to having a prosthetic eye so well and for over 12 months now has been taking her eye out independently to clean it and pop it back in with full confidence. Violet doesn't feel different to any other child in school and is very comfortable cleaning her eye if needed in the classroom with her eye pack which she takes with her. Violet has a true zest for life and laughter which has been recognised by her Headmaster at school. She received a Headmaster's Award for having such a positive and happy-go-lucky outlook on life. Violet's sense of humour is dry and beyond her years and she has a wonderful personality. Violet loves a prank too and once took out her eye, placed it on the cat's head and said, "Salem I have my eye on you." Violet continues to grow and thrive like all other children her age regardless of a bump in the road back in January 2020 and undoubtedly, she will continue to reach her goals.



Colour me in!



CHECT TYA!

Teens and Young Adults

An interview with singer & influencer Norma Night

Kelsey Ellison (otherwise known as Norma Night) tells CHECT about her life post-Rb, her new singing career and what life is like living with a prosthetic eye.

Can you tell us about how you were diagnosed with Rb?

I was two years old when my parents noticed something was wrong with my eyes. My mum initially took me to the doctors, and they didn't pick up on anything. But then she got a second opinion, and that's when they discovered it was Rb. She mentioned that my eye would look strange in photos, and I wasn't focusing as well with my right eye. I had my treatment just before my third birthday and had to have my right eye removed, and now I wear a prosthetic one.

What is life like for you now, post Rb?

To me it feels normal as I've had my prosthetic eye since I was so young! Sometimes I forget that it's not actually "normal", such as me having to adjust my balance and peripheral vision or taking care of my prosthetic. As a child and a teenager, it was quite difficult as I didn't feel like I fit in, but as I've grown older, I've really learnt how to love and live with it!

You've had experience with dancing, acting and creating music - can you tell us a bit about that and what you are currently up to?

I'm currently working on my new music project Norma Night! I started it this year and have mainly performed at queer events in London and pride events. I have new singles and music videos and I've been super excited to release them!

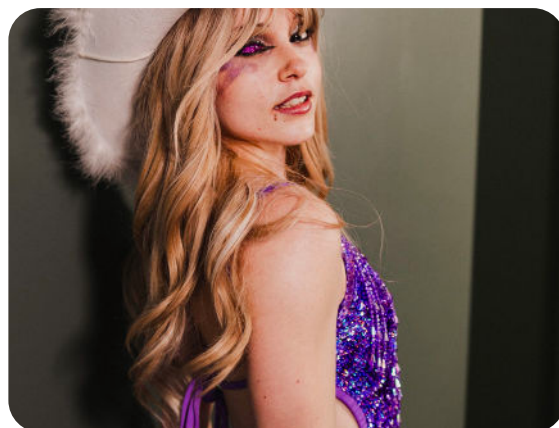


Photo credit: Kaleidoshoots

Can you tell us about your new single, what inspired you and the 'queer cowgirly pop' genre?

I've always loved singing country and folk music since I was a kid, but I also love camp pop music. So I decided to mix both together, while also involving my queer experience.

You often change your prosthetic eyes - can you tell us about the different designs you have and how you use these in your social media videos and posts?

Yes! This is only a recent thing. Up to a year ago I only used my NHS eye. But I partnered up with Eye Mkr, who's based in the U.S.A. They've made me some really cool, out there eyes! And it's really built my confidence to have fun with my prosthetics. I use them to match them to my outfits and educate others about prosthetic eyes and Rb. I have a few designs now, my favourite are my all black one, a glittery pink one, a glow in the dark green one and also one I actually got made by the NHS which is a green iris one instead of my brown natural colour. I wear that one almost every day.

What advice would you give others who have prosthetic eyes?

It's a part of you, yet it doesn't define you. But it does make you a lot cooler (in my opinion!). So, you might as well have fun with it and embrace it! Don't let the thoughts of not fitting in stop you from doing anything. In fact, not fitting in might be your biggest strength.

Did you know that we have a website and social media dedicated to teenagers and young adults who have had Rb?

Visit www.chect-tya.co.uk and follow us on Instagram at @chect_tya.

Your contributions help in so many ways



£10 funds a Pip the Penguin toy for a child who has had their eye removed. This will help them come to terms with their artificial eye.



£50 supports travel expenses for a family, to one of only two hospitals in the UK that specialise in treating Rb. This will help them manage the additional financial burden associated with cancer.



£100 funds five valuable support sessions with a dedicated CHECT support worker.



£500 funds an event to bring together those affected by Rb so that they feel supported and less isolated.



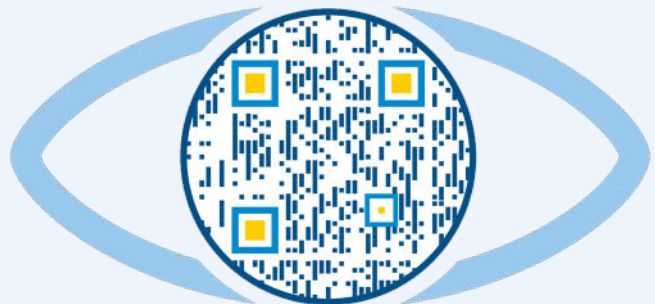
Ways to help

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

Our QR code

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

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



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



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



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



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

Please consider making a monthly donation to CHECT. Regular gifts are a fantastic way to contribute to the resilience of our charity and provide us with a reliable and dependable source of income. You can sign up at **chect.org.uk/donate/regulardonation/**.

We always enjoy receiving your thoughts and feedback. If you have any questions about your fundraising, making a donation or becoming a CHECT corporate partner then please get in touch with us at: **fundraising@chect.org.uk** or **020 7377 5578**.

Thank you!