infocus

Summer 2023

Fighting Retinoblastoma Childhood Eye Cancer Trust

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Welcome

Welcome to the Summer issue of InFocus and a big thank you to all our families who submitted photos of their children with our special new penguin, Pip, who you can meet on page 4.

Time has flown and I have now been at CHECT for over a year, and it has been wonderful to meet so many of our brilliant community and see first-hand how much our team, trustees and members get involved to support each other and help CHECT raise such vital awareness and funds.

A real highlight for me has been the CHECT Champion awards recognising some of our superstar children at our Family Members' Days. Keep a look out on our website and social media for details of our future events or drop our team an email or phone call.

The number of online and in-person support events for our members for everyone right across the membership is wonderful. From music experiences to assault courses, and slime-making to creative workshops, it has been touching to see our community join together for support, fun and friendship.

I have been fortunate to be part of a number of events myself and ran the London Marathon for CHECT back in April. You can read about our London Marathon adventures on page 11.

It has also been an honour to share so many awareness stories in the media over recent months, including mum Rebecca who spotted a white glow in daughter Isla's eye as she played with her toys. You can read the story we shared as part of our Rare Disease Day campaign on page 7.

Thank you to mum Ewelina for sharing her daughter Olivia's story as part of our World Retinoblastoma Awareness Week campaign. Olivia was diagnosed with Rb after her mum took her to her optometrist aunt for an eye test. You can read their story on page 9.

We were delighted to have such brilliant support during World Retinoblastoma Awareness Week, with many of our supporter's spreading awareness and taking part in Crazy Glasses events. You can see the brilliant pictures on page 11.

Our CHECT-funded researchers have been busy conducting crucial investigations into liquid biopsies for retinoblastoma - you can read the results of their work on page 3.

You can read the results from our 2022 Pathways to Diagnosis findings on page 5, which shows some promising results. We remain fully focussed on doing our best to eliminate unnecessary retinoblastoma diagnosis delays.

We are really looking forward to our '50km Your Way!' fundraising event during Childhood Cancer Awareness Month in September, which you can learn more about on the back page of this issue.

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 during these tough financial times.

Richard Ashton, Chief Executive

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News

CHECT support events!

We have been delighted to host a range of both in-person and online events the past year, aimed at families, teenagers and young adults and also adults who have had retinoblastoma. Our events have included an assault course in Birmingham for our TYA (teeangers and young adults), a trip to Liverpool at the Christmas markets and the British Music Experience Museum for our adult members, a trip to the North Wall in Oxford for a creative workshop for our families and also a trip to Wrexham to the Xplore! Science Discovery Centre for another brilliant family support event. We were delighted to award our young members with their CHECT Champion awards too - we have so many wonderful superstars who deserve the recognition.

We have an 'events' section on our website where you can register for our upcoming events: **www.chect.org.uk/events**

Lizzie's pupdate!

CHECT's Trusts & Foundations Fundraising Manager Lizzie and her family have recently become Puppy Raisers for Guide Dogs. Golden Retriever Ashford moved in with them at the beginning of February and is expected to live with them for the next year or so until he starts his formal guide dog training. It has been a busy few months but the whole family adores Ashford and he is making amazing progress. He gets on well with their seven-year-old pet Labrador Xanthe and their elderly cat Moomin. So far he has been on a few very short walks round the cul-de-sac they live in and has experienced his first car journey. He has also been into a shop and a café for the first time. He was incredibly calm and well behaved in the café and received a huge amount of attention! Lizzie and her family are really proud of Ashford and the achievements he's made in his first few months with them, and look forward to him changing the lives of blind and visually impaired people in the future.

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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!

CHECT Research

We hear from two CHECT-funded research projects which have both been investigating liquid biopsies for retinoblastoma.

Comparing blood to aqueous humour as a liquid biopsy for Rb

Professor Jesse Berry's project aimed to develop a liquid biopsy for retinoblastoma (Rb) using either aqueous humour (AH) or blood, to help overcome two current clinical problems: 1) our inability to directly biopsy tumour tissue from the eye; and 2) the resulting lack of measurable molecular information for diagnosis and decisions about the best treatment for the tumour.

Berry found that the AH has a higher amount and likelihood of finding circulating tumour DNA compared to the blood. However it is not impossible to find this information in blood, as 1/60 in this group showed 6p (a marker of disease) gain in the blood. This is actually a really significant finding – and as far as we know this is the first time that 6p gain has been identified in the blood. While the AH can provide important information about the risk to the child's eye from this cancer, it is the blood that can provide crucial information about the risk to the child's life. Thus, identifying 6p gain in the blood provides important evidence that there is a role for monitoring the blood for tumour DNA, as these children may be at increased risk of metastatic disease, and that in the future, it may be used to guide any additional chemotherapy treatments the child may need.

Further investigation into intra-ocular fluid as a liquid biopsy in retinoblastoma

Dr Amy Gerrish and her team have also been working with liquid biopsies, this time to discover if a patient has the heritable or non-heritable form of retinoblastoma (Rb), in a project joint-funded by CHECT and Fight for Sight. This information is vital in identifying individuals at risk of developing further Rb tumours, and possible second cancers later in life; as well as those individuals and relatives at very low risk, who can then avoid unnecessary examinations under anaesthetic (EUAs).

Having found that the analysis of cell-free DNA within eye fluid can be used as an alternative to direct tumour tissue analysis for the diagnosis of retinoblastoma, this group has now also found the best time point for collecting this fluid to maximise the chance of getting a diagnostic result. This will be essential to making this test part of the clinical service, which is planned within the next 24 months.

This diagnostic test may also contain information to identify those tumours which are more resistant to treatment, making it less likely that the eye can be saved, and so would be best managed with immediate enucleation.

Glossary of terms

Aqueous humour (AH): a clear fluid in the eye.
Biopsy: the removal of cells or tissues for examination.
Cell-free DNA (cfDNA): fragments of DNA circulating in body fluids.
Diagnosis: identification of an illness by examination of the symptoms as well as results from laboratory tests.
Heritable: can be passed from parent to child.
Liquid biopsy: a lab test done on a sample of body fluid to look for cancer cells.
Metastatic disease: cancer that spreads from where it starts to another part of the body.
Prognosis: the likely course of a medical condition.

To read the full blogs go to www.chect.org.uk/blog.

CHECT Support

Meet Pip the Penguin!

We are delighted to announce that the CHECT penguin Pip arrived in February 2023, thanks to the generosity of Phoenix Bespoke Solutions Ltd. Pip is an educational cuddly toy specifically created for children who will, or have had, an enucleation at one of the two retinoblastoma treatment centres in the UK – London and Birmingham. This fluffy friend can be used to explain this procedure by the clinical teams, or by parents or guardians at home.

Upon arrival, Pip created a lot of activity on social media, and our members were invited to vote for the most suitable name, with Pip being the winning name - and we agree it fits brilliantly!

So far, Pip has found its way to 75 young members. Here is what some families thought of their new penguin:

"Thank you so much for Pip who our daughter loves, it's amazing what you've created. Pip having a special eye makes it helpful to explain to her".

"Thank you so much for sending Pip, our son was over the moon!"

"Pip came through the post today, our daughter was so excited, we are going to take Pip to our next eye appointment".

If your child would benefit from a Pip the Penguin, please email support@chect.org.uk.

Chris' footballing experience

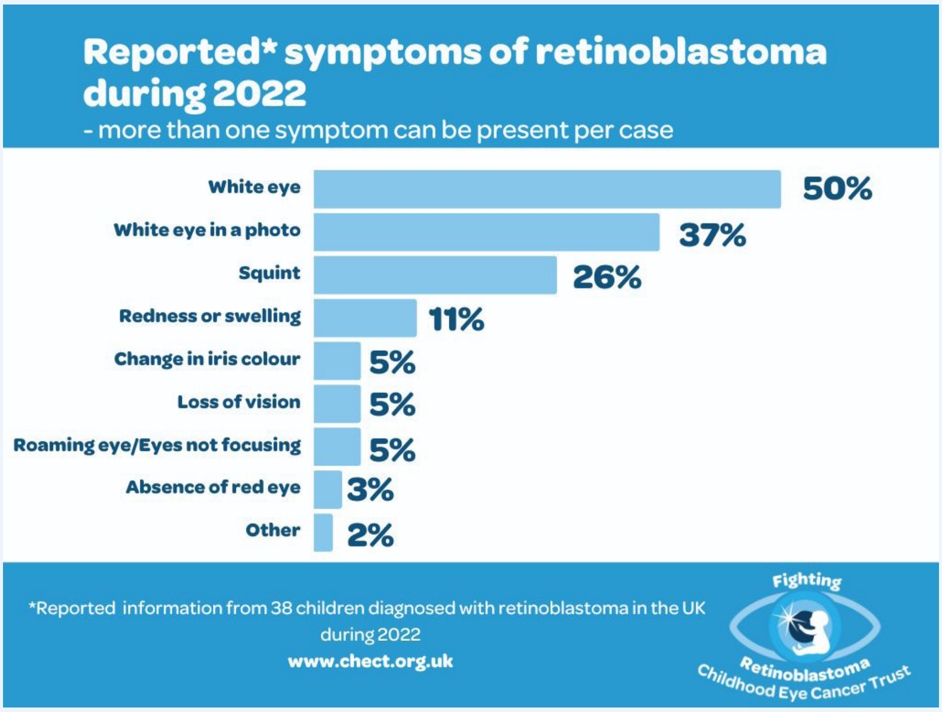
Chris talks to CHECT about his recent experience watching the Ukraine vs. England game, thanks to the Free Kicks Foundation.

"Courtesy of CHECT and the Free Kicks Foundation, my brother and I were going premium at Wembley! My previous experience at the home of football certainly could not be described as such – standing across two seats, squashed in like a sardine in the Crystal Palace ultras' section at the FA cup semi-final last year. With that memory firmly planted in my mind, I was thoroughly looking forward to a padded seat. Sure enough, the premium section did not disappoint – private concourse, plentiful leg room and even a handy cup holder. The atmosphere began to rise as we took our plush seats fifteen minutes before kick-off. Harry Kane was awarded a golden boot for becoming England's top scorer in the previous match against Italy – a standing ovation was in order (which I reluctantly took part in having never truly forgiven him for that penalty). Then the rousing national anthems, with the Ukrainian supporters in full voice and finally, kick off. A slow start for England was turned around with two quick-fire goals – another for Kane's collection and then a screamer from Saka. From then on, England never lost control of the game. A good game was capped off for us by a terrible Mykhailo Mudryk cameo - Nick Carter would genuinely have been better. Then, thanks to a cheeky premium exit, we managed to avoid a lot of the crowds on the way out. My brother and I thoroughly enjoyed our time at Wembley, thank you very much CHECT and the Free Kicks Foundation for the premium experience, it was fantastic fun!".

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

Pathways to Diagnosis 2022

Each year, we report back on families' experiences of being diagnosed with Rb in the UK: the symptoms they noticed; the healthcare professionals they saw; and how long it took them to reach one of the specialist retinoblastoma centres (Birmingham Women's & Children's Hospital or the Royal London Hospital). By recording and reporting this information, we can identify where problems are occurring, and what CHECT can do to help. Last year we were able to report back on ten years of figures.



2022 round-up

Overall 46 children were diagnosed with retinoblastoma in the UK in 2022, and we have information from 38 of these families (some children have a family history of retinoblastoma and so were diagnosed through screening). So what were families' experiences in 2022?

Although a white glow seen in the eye is still the most commonly-reported symptom, as with last year, many more families are reporting spotting a white glow in photos than has previously been the case (37% against the ten-year average of 18%). This is significant because in some cases the white glow can be seen in photos earlier than it can be observed with the naked eye, so potentially can result in earlier diagnoses. Also, it suggests that our awareness work is really having an impact: so a huge thank you to all those families who have either shared their stories in the media, shared our social media posts, or distributed our leaflets and posters in your local communities. You have all helped to make more parents aware that a white glow in the eye is something that needs to be checked out as soon as possible.

After a white glow (seen either in directly the child's eye or in a photo), squint was the next most-common symptom, noticed in just over a quarter (26%) of children later diagnosed with retinoblastoma.

As in previous years, most families saw their GP first when they had concerns over their child's eyes, but opticians and health visitors also played an important role.

And encouragingly, more GPs than ever in 2022 (two thirds) made an urgent onwards referral when they saw a child with retinoblastoma. This is such an improvement on the early years of the survey, when the figure was regularly around one third. Obviously there is still work to be done, but it is positive to see this upward trend, and especially after the pandemic year of 2020 when only 37% of GPs made the appropriate urgent referrals.

Opticians were (perhaps understandably) the best route to diagnosis, with 83% making urgent referrals. However, issues still remain here around some practices being unwilling to examine very young children, and we are working on this.

The trend is reflected in the number of medical appointments families had on average before being referred to a specialist retinoblastoma centre: over half were referred after just two appointments.

Overall, more children in 2022 were diagnosed within the recommended two-week period than since CHECT started recording these figures: 73%. This means more children getting into treatment quicker than ever before, which is fantastic to see. However, these figures don't alter the fact that some families this year also had very difficult journeys to diagnosis, which means there is still a lot of work to do in reaching our goal of eliminating all avoidable delays in the diagnosis of retinoblastoma in the UK.

We want to say a huge thank you to all of the families who take part in Pathways to Diagnosis to help us collect this important data.

Real lives: Life is a rollercoaster!

Kyle describes what life is like post-retinoblastoma (Rb).

"I was diagnosed with Rb at the age of two-years-old. I consider myself a very lucky person as I was fortunate enough to have suffered from the unilateral form which only meant losing my right eye. For anyone reading this and is battling Rb or if you are a family member of someone that is going through this, I promise you that life is beautiful, and it will get better. These hard times will mould you into a stronger and more resilient individual.

People might ask themselves why some things happen to them but unfortunately, we will never have an answer to that question. It is surely difficult to try and comprehend why our own body is fighting itself and we have no control over what's going on, except waiting and hoping for the best. Mindset and support from those closest to you is the defining factor that fuels you with energy to overcome not only Rb but any situation that occurs in your life.

As I am from Malta, I had to travel regularly to the UK for check-ups, operations and trying out different prosthetic eyes amongst other reasons. Travelling has become a part of my life because it opens your mind to new horizons. Last summer I managed to cross something off my bucket list; skydiving in Belgium! This was truly a once in a lifetime experience. Travelling and experiencing different cultures around the world will continue to be one of my main priorities in life.

Having had Rb has never halted my desire to achieve anything I wanted to. In 2021, I graduated with a Bachelor's Degree in Accountancy and Marketing before going on to do a Master's Degree specialising in Accountancy.

I'd like to imagine my Rb journey as a rollercoaster ride. The moment you step into the carriage before the ride starts, all sorts of emotions spark with fear being a dominant factor. This is the same with any cancer patients, the fear of the unknown and what could occur is a feeling that not everyone can understand. Just like a rollercoaster, you will have your ups and downs, happy and sad moments but what's most important is the final destination. Having conquered this journey myself I can assure you that all these emotions will continue to be present in my life, but ultimately it is up to me to decide what approach I take to face these challenges. Rb has taught me that anything is possible in life and if you can dream it, then you can achieve it. Having this kind of disability should not limit you from anything. Most importantly you shouldn't feel like you are less than others, but to use that energy to strive and achieve greater things. The sun always shines after the storm!".

Katie's story: Sharing my Rb story helped me

Katie describes how sharing her story for CHECT TYA - our website for teens and young adults - helped her.

"Opening up about having retinoblastoma is one of the best things I've ever done. Connecting with other families who have been, and are still coping, with Rb is beyond inspiring. Between everything, including my experience with both encephalitis and epilepsy, even though it didn't make me feel any different to any other child, it has taken me nearly 20 years to talk about Rb and share my story with the Childhood Eye Cancer Trust. It took courage to talk about it. But I thought, if I didn't, who would? Not many have heard of retinoblastoma and know what it actually is, and neither would I if I hadn't have experienced it first hand. Sharing my story has made me even stronger. Yes, I do get an off day feeling 'ughh' when my prosthetic gets sore or gungy, or uncomfortable when getting a new eye that tends to take time to get used to the socket. But that's life just part of life, and how my life will be!".

CHECT continue to support adults who had Rb as children. We connect people on social media, and facilitate meet ups to allow people to share tips, and establish friendships. We can also signpost and refer in to other support services. Contact the support team on support@chect.org.uk.

REAL LIVES

"Our daughter was playing with her toys when we spotted Rb"

Parents Rebecca and Charlotte Palul first spotted an unusual eye movement in their daughter Isla's eye over Christmas 2020.

Rebecca said, "I remember playing with Isla on the floor, and her looking down at a toy then looking up at me. When she looked up, her right eye whizzed out to the side and back again as if it couldn't focus. We also noticed her iris would sometimes wobble. Both happened only a few times, they were quite subtle things. We assumed she had a lazy eye, and perhaps needed glasses. I remember not feeling very worried about it."

Rebecca added, "Between Christmas and New Year, we phoned the GP. It was during lockdown, so we had a phone appointment. We told the GP what we'd seen Isla's eye doing. I remember the GP saying that it sounded like something might not be quite right, and she would refer us to the Paediatric Clinic at St George's Hospital in Tooting."

"Because of lockdown, Charlotte wasn't allowed in, so she waited outside for us during the in-person appointment. The GP performed a fundal (red) reflex test and noticed that while her left eye appeared normal, her right eye did not. The GP said she would refer us to Moorfields. She also said she would book Isla an MRI appointment. On the way home I remember us discussing Isla having an MRI and being really worried about her having a general anaesthetic, which looking back, shows how little I was prepared for what was to come."

> **"She's been through more than anyone should have to."**

Rebecca said, "Retinoblastoma (Rb) came up as a possible option when I googled the symptoms, but I remember us both thinking that was the worst it could possibly be, so surely it wouldn't be that. Perhaps this was us in denial."

Rebecca explained, "We went to the appointment at the Moorfields Clinic at St George's. I still thought it could just be that Isla needed glasses. Charlotte had to wait outside in the car, so Isla and I went in on our own. It was difficult trying to take in everything, ask questions and look after Isla without Charlotte there. It was equally hard for Charlotte having to wait outside for news."

"During these checks, the nurse put a pair of special sunglasses on Isla. The glasses only had one lens, on the left-hand side, so the nurse could only see what Isla's right eye was doing. Isla was sitting on my knee facing away from me, but with her left eye covered, I could see that her right eye couldn't focus on anything and was moving about all over the place. I remember being really shocked."

The nurse dilated Isla's eye before the doctor examined her eye.

Rebecca explained, "I remember her saying to me, "Unfortunately, there is a tumour in her right eye", and being completely blindsided. I cried and Isla looked at me perfectly happy probably wondering what was going on. I remember asking the doctor how bad it was, but I don't remember her reply.

"Charlotte was still outside in the car at this point. I started getting our things together to go out and find her, but then stopped and thought how can I go out and tell her that Isla has cancer? The doctor was very kind and said Charlotte could come in. Charlotte knew straightaway that something was wrong, and the doctor then explained what she'd seen."

"We went home, calling our parents on the way to let them know. Those phone calls were very, very hard to make. We had so many questions and were so grateful that one of the Retinoblastoma Clinical Nurse Specialists from the Royal London rang us that night. She spent a long time answering our questions and said they would see us the following week. That week felt very long. We both had time off work, and it snowed so we spent lots of time together playing. We tried to make things as happy as possible for Isla, not knowing what might happen next."

Six days later in January 2021, Isla's Rb diagnosis was confirmed at the Royal London Hospital. Rebecca said, "Isla had a stage D tumour in her right eye. The doctors explained that it was a smaller stage D, and because of this they hoped Isla's eye could be saved. Instead of removing Isla's eye, we decided systemic chemotherapy was the best route to take."

Rebecca added, "Before they could start this Isla needed to have a lumbar puncture and an MRI to make sure the cancer hadn't spread outside of her eye. She also had a port fitted into her chest to make it easier for the chemotherapy to be administered, and for regular blood samples to be taken. Isla and I went into Great Ormond Street six days after her diagnosis thinking she was just going to have some blood taken, and we ended up staying for four days! Charlotte again had to wait at home for updates."

Isla had her first of six rounds of chemotherapy the day after her port was fitted and had regular examinations under anaesthetic at the Royal London Hospital. It was only when Isla's parents took a photo outside of her with a flash that they spotted a white glow in her eye.

Rebecca said, "Chemotherapy was hard. Isla often got infections, so we had lots of stays in hospital for antibiotics, and she lost a lot of her hair. But the chemo did its job and she battled through chemo like a little trooper, and although she must have felt terrible, she kept smiling. She kept us all going! The tumour shrank and is now stable, which is amazing. There are some tiny tumour seeds which keep appearing and growing in Isla's eye, so she has needed to have lots of cryotherapy to treat these. Isla has had periods of quite a few months where everything seems to be looking good. However, she's also relapsed a few times and needed some more cryotherapy. She is currently still needing the cryotherapy – and although with each check-up we're hopeful she won't need any further treatment, there's no way of knowing what might happen. The unknown is difficult."

"Isla is an inspiration to us every day."

Isla has reduced vision in her right eye, which wasn't noticeable before she had her first eye check-up. Rebecca said, "Sometimes she struggles with walking down steps and her balance, but it is only when her left eye is patched to help with the vision in her right eye that you can really notice."

Isla received a CHECT Champion award from CHECT in 2022.

Rebecca explained, "Isla is so brave. She's taken everything in her stride and has just kept going! She's been through more in her first few years than anyone should have to. She is amazing. She is an inspiration to us every day. She loves Frozen, really enjoys swimming, and has just started gymnastics. Isla became a big sister to baby Theo last summer, and they adore each other. Isla is so caring with him and loves giving him kisses and cuddles."

Rebecca said, "From the beginning of our journey CHECT have been there to support us. The support workers have helped us with practical things like applying for Isla's blue badge, as well as signposting us to other organisations for a short break last year. They have also provided us with never-ending emotional support and advice.

"The staff at the Royal London have been incredible. Going there for Isla's EUAs, although stressful, is strangely something we sort of look forward to now. Isla loves the nurses and the play worker; they are like family to us now. Our local hospital, the community nurses, and GOSH have also been amazing. We saw all of them regularly when Isla was having chemotherapy, and everyone made the journey that much easier. We say often, how grateful we are for the NHS, for CHECT, and for the people that support them."

"Our family and friends have been so supportive, not only to us, but also to CHECT. Charlotte's best friend Katie ran the distance from Grantham to GOSH. Charlotte's Dad and his friends put on a golf day, and Isla's nursery made and wore eye patches to raise money and awareness."

A huge thank you to Rebecca, Charlotte and Isla for helping us to raise such great international awareness of Rb for Rare Disease Day.

“My daughter’s optometrist aunt referred her for Rb”

Mum Ewelina Skwarlo first spotted an unusual white glow in her daughter Olivia’s eye in February 2022, just after her second birthday.

Ewelina said, “One day when she was watching TV, I noticed a strange glare in her right eye. I was observing her eye in different angles as the glare was not easily visible. Oliver, Olivia’s Dad, was away for a few days in Scotland, so I was at home on my own with Olivia. I just decided to take a few photos when the glare was more visible and sent it to Oliver to see what he thought.”

“I did not think it was anything serious, but my instinct was telling me to check. I decided to send the photos to Olivia’s aunt, Laura, who is an optometrist. In the meantime, I started to search on Google ‘glare and reflection in the eye.' I came across retinoblastoma and started to read about it. I started to panic that the white glow may be retinoblastoma, which I had never heard of before. Laura confirmed an appointment and we went to have it checked.”

Ewelina said, “For a two-year-old, having an eye examination is very difficult, and Olivia had no plans on making it easy, but Laura did an amazing job to distract Olivia as much as possible to be able to check her eye. When the examination was completed, Laura confirmed there was a big chance it was retinoblastoma and she referred us to hospital as soon as possible. We were devastated, but I was still hoping it may be something else.”

Laura Leafe, Olivia’s aunt, said, “I was already concerned due to the photograph Ewelina had sent me, but I was shocked to see what I suspected to be a retinoblastoma. After the shock, I was very thankful to be an optometrist and, in the position, to be able to help at one of the most stressful times of my family’s life. I am so glad Ewelina asked about the ‘reflection.’ If I hadn’t been in this profession the diagnosis may have come much later.”

Laura referred Olivia to Pinderfields Hospital in Wakefield, where she was seen a few days later.

> **“We've started to appreciate more of what we have in life.”**

Ewelina explained, “After the examination, a diagnosis of retinoblastoma was confirmed. The very same day we had a call from Birmingham Women’s and Children’s Hospital confirming our appointment with the retinoblastoma team. I remember these few days as very difficult, we were heartbroken, but we were trying to behave as normally as possible in front of Olivia as she was as happy as usual.”

“After checking Olivia’s eye in Pinderfields Hospital Eye Centre, we started to do more research and were getting to know more about retinoblastoma and possible ways of treating it. It was very hard for it to sink in, as Olivia was no different than just a happy, jumpy girl playing around as usual. As Olivia was only two-years-old at the time, we did not notice anything other than a glare when looking deeply in her eye at a certain angle. When we were told that she couldn’t see from her right eye we were surprised as it was not noticeable at all.”

Ewelina added, “Over the past year, Olivia has been under general anaesthesia around twenty times for various different treatments. She’s undergone two

MRI scans, four sessions of intra-arterial chemotherapy (up to June 2022), five rounds of dual-agent intravitreal chemotherapy (up to August 2022), routine check-ups at least once a month, cryotherapy and laser treatments. The main tumour shrank and is under control, but there are still some small parts to treat. We keep hoping that Olivia will be cancer free soon."

Ewelina explained, "This experience changed each of us individually, but also had a massive effect on us as a family. Olivia being only two at the beginning of this journey was not really aware what was happening. Constant visits in hospital, seeing nurses and doctors and going through various procedures did have an impact on Olivia as a child. We can tell she keeps changing as she is growing up and she understands more now what is happening and that we keep visiting doctors to treat her eye. For us as parents it is a constant worry about cancer cells being under control and if there is a chance to get rid of it totally."

"Our visits and stays in Children's Oncology at Birmingham Women's and Children's Hospital for a few days had a massive impact on our perceptions of seeing the world around us. We started to appreciate more what we have in life as you never really know what it may bring. Going through this experience made us stronger as a family, as we know it is important to be strong for each other."

Ewelina said, "We cannot stress enough how important it is to observe your child and if there is something suspicious to have it checked straight away. We were in a good position having an optometrist in our family and having Olivia's eye checked quickly, but we are aware that not many places are that easy to have a two-year-old's eyes checked."

"This experience has made us stronger as a family."

Ewelina added, "The Childhood Eye Cancer Trust (CHECT) has been with us from day one when we went to Birmingham Women's and Children's Hospital, offering advice when needed and making sure we are supported. I remember at the start when we found out about Olivia having cancer it was hard to process and we were overwhelmed, but it was good to know that CHECT is there, and we can contact them whenever we need to.

"They kept checking how we are doing mentally and financially, letting us know we are not alone in this situation. Reading other people's stories who went through retinoblastoma on the CHECT website was also helpful to have a better understanding of what we may go through and relate to some scenarios. Our support worker from CHECT is such a friendly, cheerful, and kind person, she kept in touch asking how we all are doing."

"We would also like to take an opportunity to say massive THANK YOU to our employer NEXT Distribution for donating a large amount of money to support CHECT a few months ago."

Thank you so much to Ewelina, Oliver, Laura and Olivia for helping us to raise awareness during World Retinoblastoma Awareness Week. Their story ran across the international press.

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**.

London Marathon 2023!

TeamCHECT was thrilled to celebrate the achievements of our ten runners at the 2023 London Marathon, who each crossed the finish line on Sunday 23 April! We are so proud of each and every one of them, for braving the rain and for completing the gruelling 26.2-mile course, starting in Blackheath in South London and finishing on The Mall near Buckingham Palace.

CHECT staff, family, and friends were out in full force at mile 20.5 to cheer on our runners for the final stretch of the race. We were thrilled to welcome them over the finish line in St James's Park, where they received a well-deserved round of applause.

Each of our runners trained tirelessly in preparation for the event and have done brilliantly with their fundraising. Thank you to each of our runners, as well as their supporters and sponsors, for their unwavering support of CHECT and commitment of raising awareness of retinoblastoma. If you're feeling inspired and would like to join TeamCHECT for the 2024 London Marathon please email **fundraising@chect.org.uk.**

World Retinoblastoma Awareness Week!

During World Retinoblastoma Awareness Week (14-20 May), we were thrilled to see incredible support from individuals wearing crazy glasses at work, school, and home. These amazing efforts raised awareness for Rb and collected crucial funds for CHECT. We adored all your photos!

If you haven't had a chance to participate, don't worry! It's not too late to host your own Crazy Glasses Day. Visit our website to discover how you can get involved: **www.chect.org.uk/other-ways-to-help/crazyglasses/**.

Thank you

We are very grateful to those supporters who have remembered our charity in their will, and also 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: David Eustace, Rita Olive King, Mandy Chatten, William (Billy) Griffiths, Paul Castle, Margaret Annette Herdman, Jean Eason, Paula Newman and Ralph Thompson.

Festus' fundraising story

"As a family we'd never heard of retinoblastoma before our daughter, Harper-Rose, was diagnosed with the eye cancer when she was a baby.

The first sign we noticed was that Harper's eye could never focus straight forward - it was wandering off to the left and then in pictures we started noticing a white flash in her left eye even when the camera flash wasn't on.

Once she was diagnosed with retinoblastoma, Harper had chemotherapy on three occasions and she's still currently receiving laser treatment. However, she is really good and she's doing great - we still attend Birmingham Women's and Children's Hospital once every six weeks for regular check-ups and treatments.

Since my little girl Harper was diagnosed with retinoblastoma, I felt helpless but knew I wanted to do something. I got my running shoes out with a group of close friends and started running, and then we decided to run and try to raise not just money but awareness for other people who like us who hadn't heard of retinoblastoma and could miss the signs that luckily for us we didn't miss. So far, in the last 18 months, I've raised close to £20,000 for both CHECT and the Birmingham Women's and Children's Hospital, and I'm going to continue to keep raising money for them both.

I took on the Liverpool half marathon for CHECT on the 28th March. I started training by myself at first just a few miles a day, and then a few of my close friends asked me if they could start doing it with me. Before I knew it, there was ten of us, so we started our own running group called Cool Runnings which now has lots of people who are part of it.

I was meant to run the London Marathon back in 2022 for CHECT. Missing the London Marathon was tough. I'd trained hard for it, but I tore my calf and my Achilles at the same time before the event. Luckily, we still managed to raise close to £4,000 and my best friend Jama took over and ran the marathon in my place and he was amazing. The recovery was long, lonely and boring - it was just rest really and lots of physiotherapy work to get me back to running.

The advice I would give for other people looking to do a running event is do it! Get out there and run - just start slow and short and build on it. Aim for a 3k first then build up to 5k.

We want to thank the doctors that Harper sees at Birmingham Women's and Children's Hospital. They are the real heroes and deserve so much more than they get. I also want to thank CHECT and any other non-profit cancer charity who do things out of the love of their hearts. CHECT have been there from the start offering advice and helping to offer with travel expenses and trying to make a hard situation a bit easier for us. You are the heroes and anything I can do to help I'll continue to do."

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 (sporting or otherwise!). We are also keen to work in partnership with companies large and small, across a wide range of industries, to raise funds to help fight retinoblastoma. If your employer would be willing to support us in any way, we'd really love to hear from you. **Please email fundraising@chect.org.uk or call 020 7377 5578.**

Children's corner & CHECT TYA!

Natalie's creative streak

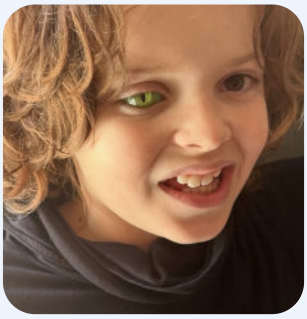
Mum Sanya describes how having bilateral retinoblastoma is not getting in the way of her daughter Natalie's accomplishments.

"My daughter Natalie has bilateral retinoblastoma but that does not stop her doing all the amazing stuff she loves. She loves to do gymnastics, horse riding, making stuff with clay, playing the violin and swimming. Natalie won second place in a gymnastics competition and we were all there to support her. She also has had horse riding lesson in the summer and is very good at it. Natalie's imagination runs when she is making stuff with clay; whether she's making an animal or making something from her imagination or she's copying something it always looks perfect. She has also been doing violin lessons since she was four-years-old and is currently eight-years-old. A couple of months ago she performed in a concert and her playing was so lovely. We are all so proud of her."

Eliza's bursary success!

Eliza was chosen to be the receiver of the Ffion Miles Music Bursary in 2022 by the CHECT board of directors. Eliza has used the funding to buy a piano – and has been using it to create beautiful compositions.

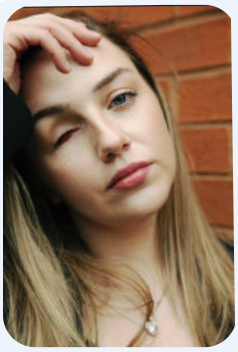
Eliza's mum Lucy said, "Eliza is absolutely thrilled with her piano, and has a renewed enthusiasm for composing as well as learning pieces with her piano teacher. Thank you CHECT so much, and most especially to Ffion's family, for the opportunity you have given to Eliza, and to everyone who will enjoy both the music she makes and the joy she takes from it."



Jude's customised eye!

Nine-year-old Jude discusses why he chose to go for a customised prosthetic eye after losing his eye to retinoblastoma.

"Losing my eye is the biggest obstacle I've had to overcome and having only one eye and dyspraxia is a challenge for me. Most of the time having a special eye is ok, I take it out and clean it once a week which I can do by myself. I first saw custom eyes on YouTube and really wanted one. Choosing a design was hard as there were so many to choose from so I researched and thought hard about a design I would like to wear for a long time. I chose two eyes; an eye that looks like the Minecraft Eye of Ender and a galaxy eye. I was so excited when it was finally time to get my new eyes. I feel good when I wear them, a few people have stared at them but my Mum and I practised what to say if someone asks me about my custom eye so I didn't feel worried. My friends think my new eyes are really cool and I like being able to change between different eyes which is an awesome skill to have. I would recommend to anyone to get a custom eye as it makes you feel stylish and unique."



From retinoblastoma to modelling!

"My names Katie and I was diagnosed with retinoblastoma at four-years-old. I'm now twenty-years-old and living in the outskirts of Glasgow. I'm currently studying events management whilst working part time as a supervisor at a local golf club.

Before I was diagnosed my mum noticed my pupil looking different, I was sent straight to the hospital to find out it was a Grade E tumour which would have to be removed to save my life. The type of treatment I had was called JOE chemotherapy to treat the cancer cells. During my treatment I visited seven different hospitals across England. Many months later I was in remission but still needed to be seen to regularly by oncologists and doctors to be on the safe side.

As soon as I got the all clear I went and saw my pony at the time. I have always loved being around horses. From an early age I have competed in many competitions and won. Having one eye, my depth perception felt like an issue, however riding horses has helped me improve my depth perception. I have always taken for granted how well I could ride with one eye.

My goal for now and the future is to help spread awareness of different disabilities and help people young and old feel more confident in themselves and in their bodies and to help prevent bullying.

After posting a picture of myself without my prosthetic eye in I felt so confident in myself which has lead me being signed with a modelling agency who focus on people with different disabilities.

My message to anyone who has been/is diagnosed with retinoblastoma is to be true to yourself and love yourself the way you are. Your imperfections are what makes you unique."

If you are a teen or young adult and would like to talk to our support workers, email support@chect.org.uk.

Colour in Pip the Penguin!

50km YOUR WAY!

September 2023

Claim a free pair of limited-edition shoelaces when you walk, run, cycle or skate to raise money for Childhood Eye Cancer Trust during Childhood Cancer Awareness Month, September 2023!

Whether you choose to walk, cycle, run or skate, lace up your trainers and take on the challenge of completing 50km, representing approximately 50 children a year who are diagnosed with retinoblastoma.

Plus, if you raise £200, you'll also get a free CHECT T-shirt!

For more info and to sign up visit **www.chect.org.uk/50km**

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/

Thank you!