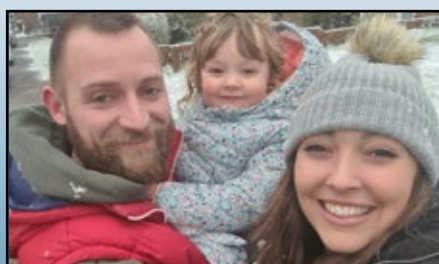




Shining a light on our Christmas Stars!



"We thought a snowball had hurt her eye"

Read Darcey-Rose's story **Page 9**



"We rang the bell nearly a year apart"

Read Bonnie's story **Page 7**



Meet Star Trek Actor Bruce Horak!

Read Bruce's story **Page 5**

Welcome

Welcome to this issue of InFocus and a special thank you to all our families who submitted the festive photos on this edition's front cover.

I am thoroughly enjoying my time at CHECT, and seeing first-hand how strong our community of members, supporters, trustees and CHECT staff team members are. Thank you to everyone for making me so welcome.

It has been wonderful to see events moving from virtual to once again in-person, and we have thoroughly enjoyed cheering on our amazing runners at events across the UK.

Another highlight has been the handing out of CHECT Champions awards to our amazing superstars at our Family Members' Days. Our teens and young adult members took part in a Bear Grylls adventure day, and we are looking forward to visiting Christmas markets and the British Music Experience in Liverpool with our Beyond Rb members this December.

We have introduced a number of accessible online events, allowing our members from across the UK to join together from the comfort of their own homes to listen to some incredible and inspiring speakers. Do keep a look out for our upcoming events which can be found on our website - www.chect.org.



uk/events - or by dropping the team an email.

Craig has now been our Head of Support for seven months, and he has been busy meeting members, generating support feedback and adding services to our ever-expanding support service. You can meet Craig and learn what he has been doing over on page 4.

It has also been an honour to share so many awareness-stories in the media over recent months, including mum Gina, who spotted a white glow in daughter Darcey-Rose's eye during a snowball fight. You can read the story we shared as part of our World Retinoblastoma Awareness Week campaign over on page 9.

Thank you to mum Lisa for sharing her daughter Bonnie's story as part of our upcoming Christmas media campaign. Bonnie was diagnosed with Rb just months after Lisa rang the bell following her treatment for breast cancer. You can read their story on page 7.

On page 5 and 6 there are two inspiring stories from Star Trek actor and artist Bruce Horak and Team GB Paralympian Simon Hill.

Finally on behalf of everyone at CHECT I would like to thank you, our members as well as our amazing trusts and foundations, fundraisers and donors who have allowed us to continue our instrumental support, research and awareness work. We know times are financially tough for all - and we really appreciate your support.

Richard Ashton, Chief Executive

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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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Crossword answers for page 14:

Answers across:

2. Hats, 5. Nutcracker, 6. Frosty, 8. Reindeer, 10. Advent, 11. Fire, 14. Cracker, 15. Hibernation

Answers down:

1. Holly, 3. Turkey, 4. Tree, 7. Santa Claus, 9. Elf, 12. Ice, 13. Skiing

News

CHECT-TYA Launched!

We are delighted to launch our new website aimed specifically at teens and young adults who have had Rb. Head over to our new website: www.chect-tya.co.uk.

We also launched our TikTok channel (@chect_uk) and CHECT TYA Instagram channel (@chect_tya). Our new channels and website have resources for teens and young adults and feature real life stories from our amazing members. Visit our website to read Katie's story and experiences at school, watch a make-up tutorial from influencer Kelsey and a video from model and influencer Olivia, plus much more!

If you'd like to get involved or contribute, please contact:
isabella.greenwood@chect.org.uk



Support events are back!

We are thrilled to be hosting both in-person and online events again! We have a new 'events' section on our website where you can register for our upcoming events:
www.chect.org.uk/events



New NIPD Testing



A new type of in-pregnancy testing called Non-Invasive Prenatal Diagnosis (NIPD) is now available for families affected by the heritable (genetic) form of Rb.

NIPD uses a blood sample taken in pregnancy from the mother's arm to look at the genetic make up of the baby.

NIPD is different from invasive prenatal tests, such as chorionic villus sampling (CVS) and amniocentesis, that are associated with a small risk of miscarriage. NIPD does not pose any risk to the baby. Head to our website to learn more about the process, the benefits it can provide, and who is eligible, or speak to our support team.

Please visit: <https://chect.org.uk/new-pregnancy-testing-technology-now-available/>

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 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? If so, we'd love to hear from you at info@chect.org.uk.

Thanks for your support!

Meet Our New SAC Chair



It's all change on CHECT's Scientific Advisory Committee this year.

In July we sadly said goodbye to Prof Lorna Fraser, who had spent six years as Chair of the SAC (the body that oversees our research). As well as bringing her immense professional expertise to the role, Lorna also brought personal experience of having had bilateral Rb as a child. We will miss her clear-sighted, empathetic approach, but are delighted to welcome our new Chair, Dr Bob Phillips. Bob is Clinical Academic Paediatric Oncologist at the University of York and Leeds Children's Hospital (in his words "basically a part-time proper doctor and part-time researcher"), who looks after a range of children and young people with cancers including retinoblastoma.

To find out more about Bob and the rest of the SAC, go to: www.chect.org.uk/research.

Professor Ohnuma: Next generation sequencing analysis of retinoblastoma samples



Although there are a range of successful treatments available for Rb, unfortunately many of these can cause some degree of vision loss for the child. In order to be able to develop new treatments, that also preserve healthy vision, we need to understand more about how Rb forms.

Cancer is known to be formed through the accumulation of mutations of important genes. It is already known that mutation of the RB1 gene is crucial for the development of retinoblastoma. To gain a more detailed picture of the gene mutations involved in Rb, we analysed whole sequences of retinoblastoma patient DNA. To our surprise we found that only two genes were mutated. This is different from other types of cancer. It is known that RB1 mutation is not sufficient on its own to initiate retinoblastoma in children. Our results indicate that additional mechanisms other than

gene mutation are required for retinoblastoma to develop.

When we examined these mechanisms in detail, we found that almost all cancer-related mechanisms are activated in retinoblastoma. In addition, we found that whilst a protein called PRELP is highly expressed in normal retinal tissues, it is not expressed in retinoblastoma. PRELP plays an important role in cell to cell adhesion (where cells interact and attach to neighbouring cells). The fact that it is strongly decreased in retinoblastoma indicates that this decrease enables the Rb cells to grow freely in the patient's eye. Our study proposes that reversing this, by activating cell to cell adhesion, may have potential as a treatment of retinoblastoma.

Preliminary data from cell cultures indicate that administration of PRELP to the established laboratory retinoblastoma cell lines inhibits cancer progression. We have now been awarded CHECT funding to explore this further, this time applying PRELP protein to human retinoblastoma tissues and examining the effect on retinoblastoma development.

If successful, we hope these findings will lead to the development of new treatments for retinoblastoma that would preserve more of the child's healthy vision.

You can read the full report on our blog: www.chect.org.uk/blog.

Introducing our Head of Support, Craig!

Hello, I'm Craig, and I commenced my role as CHECT's Head of Support in May this year. I know many of you have a long-standing relationship with CHECT and its people; and I'm really looking forward to being part of that team and getting to know you.



I live in Scotland, half an hour south of Glasgow, in Ayrshire, and will be home based there with travel to the two treatment hospitals and our office. I am a therapeutic radiographer by background and qualified at Glasgow Caledonian University. During my radiotherapy training, I spent half of my 4 years in the Beatson West of Scotland Cancer Centre. The Beatson is a world class cancer hospital and provided me with a really full training experience. As time passed however, I realised I wanted to diversify from technical treatment delivery and specialise in patient support. From there, I was appointed as a Cancer Support Specialist at Macmillan Jersey and enjoyed providing support services to islanders affected by cancer – as well living in what I still deem to be one of the most beautiful places in the world. I then returned to the UK to take up my role as Cancer Information and Support Specialist Radiographer at Macmillan Cancer Support – working across Scotland and the North of England in their mobile team. It was a brilliant job, really supporting people and their families, in their own communities, with what was most important to them. When the pandemic hit, I returned to the NHS to work in ICU for 6 months and then in public health. I was keen to return to oncology and patient support and was lucky enough to be successfully appointed to this role.

this and helping us co-produce a plan to develop our support services moving forward. I've also launched our online support offer – allowing people an accessible space to get support, meet others and keep in touch in between our family days, teen events and adult meet-ups. I have a few passions in my area of work. Firstly, the importance of high-quality information and support. I believe that in order to tailor support to someone's individual needs, you need to assess their needs holistically. Giving people time and space to be heard, and then providing them with the tools that they need to move forward is both essential and rewarding. High quality information means informed decision making, and high-quality support improves overall wellbeing and patient experience. Secondly – psycho-oncology – the impact of a cancer diagnosis on emotional wellbeing – both of the individual and their family. And thirdly, late effects. We need to be aware of long terms effects of the cancer and its treatment, and support patients with these to ensure that they live well, physically and emotionally as they move forward in life beyond their cancer diagnosis.

I think if the pandemic has taught us anything, it's that the little things really are the big things, we all value human connection, and that's why I'm over the moon to restart our face-to-face support events. These events bring people together to meet others, make friends, experience new things, learn, and most importantly have fun. They encompass the family feel that is CHECT, and I look forward to meeting you at one of them soon.

In the meantime, if you have any questions, please do not hesitate to contact me. I will focus on sustaining the high quality of our current service as well as building on that work so that we can be there for people and their families, and support them holistically with their needs lifelong.

To contact Craig please email: craig.blackwood@chect.org.uk



I've kicked off my time here getting to know the CHECT team, and the clinical teams in the Royal London and Birmingham Children's Hospital. I've been lucky enough to meet some families and have surveyed all members to build a picture of needs, what we do best and where we can improve. Thank you for participating in



Bruce Horak, who plays 'Hemmer' in Star Trek, discusses his journey with Rb and sight loss, his life as an artist and actor and how his mindset helps him overcome any obstacles.

Bruce Horak: From Painting to Star Trek

I was diagnosed when I was just over a year old. My doctor had seen Rb before and was quick to diagnose and to recommend removal of both eyes. It was at this time that my father, Carl was informed that he'd not only had Rb himself, but that he'd passed it along to me. Carl had lost one of his eyes to Rb when he was a child, but was never told the real reason why. Back in his day the word "Cancer" was only ever whispered, and his parents always told him that he'd just been sick and that was why he'd lost his eye.

When I was diagnosed, the doctor looked back into his history and discovered the truth, and also informed him about how Rb can be passed along through the genes. This devastated my father, who became depressed and almost took his own life. It was through the support of his family and friends that he found the strength not only to carry on but to fight for my vision. He and my mother insisted that the doctors find some way to save some of my eyesight.

My right eye had to be removed as the cancer had progressed. My left eye only had three small tumours on it, so I was flown to Toronto to have radiation treatment done. The treatment left me with heavy scarring on the retina, but enough that it was clear for me to see through. A cataract developed and I had surgery for that before I started school. My father and I had a very strong bond as a result of the treatments. We both had artificial eyes, so we'd go together once a year to have them polished, and that was a pretty special time.

I'm the youngest of four boys and my older brothers certainly looked out for me. They also challenged me to keep up and "didn't let me get away with anything". They taught me to ride a bike and to play soccer. I was a goalie

– the perfect position for someone with 9% vision. I only had to follow the ball and get in the way.

My family are all involved in the arts in some way so it was pretty much inevitable that I would be too. I got bit by the entertainment bug early on – making my fellow classmates laugh, etc. My art is inspired by perspective. I love seeing the world in a new way. Putting myself in someone else's shoes, getting my audience to see the world differently, these are acts of compassion and exercises in empathy, which I feel the world needs more of.

I rarely anticipate what will be an obstacle until I encounter it. I try to be open to possibilities and shift my perspective. Often, it seems like there's only two solutions but I believe that there is more than one option. I look to mentors and colleagues to find other ways through when possible. Reaching out for help requires courage and humility, and I think that's a pretty good lesson.

Being in *Star Trek: Strange New Worlds* was a dream of mine since I was very young. The producers were looking for a blind/low vision actor to play a blind alien, so I put my name in the hat for that. I was cast in late 2020 and shot the first season in early 2021. I went from doing street shows and low-budget indie theatre to doing a major series. I experienced a bit of whiplash there. Suddenly, there were a lot of people who were around to help and to make it as easy for me as possible. It was quite a trip. I had to keep it a secret for a long time, and when it finally came out the flood of support was immense. The Trek family is incredibly welcoming and I've been inundated with kind words and messages of love. It's really wonderful.

I'm continuing to paint portraits and I am working towards my 1000th one. I've moved my practice online and sitting with folks from all over the world. I'm continuing to tour my solo show, "Assassinating Thomson" in which I paint a portrait of the entire audience while I tell the story of becoming a visually impaired visual artist. It will be touring Manitoba in February 2023. I'll also be making appearances at Star Trek and Fan Conventions around the world. I'll always find ways to make my way in the world as a creative.

Image credits from L to R: Trish Lindstrom, Star Trek, Horak, Michelle Peek, Terry Manzo



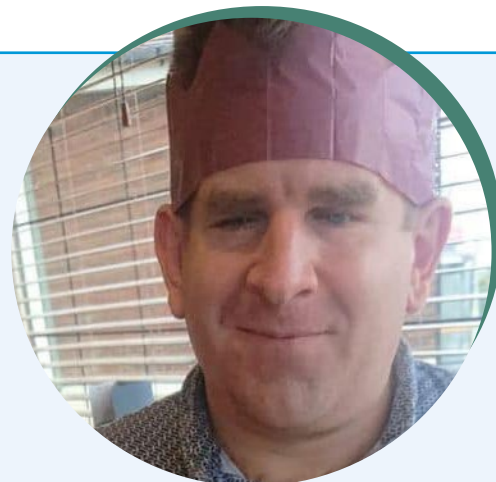
Meet Paralympian Simon Hill

Simon Hill, who played football for Team Gb in the Beijing Paralympics, talks to CHECT about his path from school football to representing Britain.

I don't remember much about the first couple of years battling retinoblastoma, so I can only describe it how it was described to me. My parents spotted some kind of discolouration in my right eye when I was less than 6 months old, and I ended up at Birmingham Children's Hospital where the diagnosis was given, and my right eye was removed when I was 6 months old.

When I wasn't having treatment, I was just like any other boy. I knew I couldn't see and that meant I was different to most other children, but I didn't have any fear about trying to do whatever they were doing – I only wish that was the case now. I wanted to ride a bike so I did, I would ride around our estate and have no more accidents than sighted kids. I wanted to play football so I played football. Looking back now I'm not sure how I did it and I'm not sure I could do it now.

Overall, being blind didn't bother me that much until I reached my teenage years. By this time I had been taken out of mainstream school and sent to New College Worcester – which was a specialist school for the blind. One thing that being at a blind school did for me was give me the opportunity to play competitive football for the first time. Although even in that setting I was still at a disadvantage, because playing as a totally blind person against partially sighted people isn't exactly a level playing field. However, I tried my best and in 2003 when I was in my final year at New College, myself and a couple of other boys were invited to go along to train with the blind England squad following a recommendation from our P.E teacher. We went along and after attending a few training camps the three of us were selected to take part in a tournament held in Buenos Aires in April 2004. Over the next six years I represented England 31 times. Unfortunately, my time was blighted with the frustration of picking up injuries at the worst possible times i.e., when there was a match coming up. I have supported West Bromwich Albion since the age of seven, and in 2006 I helped set up the West Bromwich Albion blind team who I have played for ever since and am club captain. For a few years I was representing my club as well as my country at football which was something I never imagined being able to do when I was growing up, because there just isn't the same amount of opportunities out there for blind footballers as there are for sighted footballers. It has given me a number of highlights including winning the national blind league on a few occasions with West Brom, and representing England at three European championships finishing runners up on two occasions,



and two World cups. However, the biggest highlight has to be qualifying for and playing in the Paralympics in Beijing back in 2008. Representing England at international tournaments was special but stepping into the team GB set up was another level. We were just one small group of many with different disabilities, and all competing at a range of sports. By the time you got into the Olympic village and were amongst the other country's teams, you realised just how enormous the Paralympics really is.

We spent two weeks training and acclimatising in Macau, where the facilities were certainly a step up from the football tournaments. Team GB were put in a luxury hotel, with plenty to keep us occupied when we weren't training. My favourite activity was the driving range. It was unusual because at the end of the driving range was the South China Sea, and there was a man out on the water in a boat whose job it was to collect any balls that went into the sea. I am not sure what the hotel staff made of a load of blind people being let loose with golf clubs and a basket full of balls to whack around but there were no injuries to report...

My big disappointment about Beijing apart from the fact we only managed to finish fifth, was that because our first match was at 9am the morning after the opening ceremony, it was decided that we would be unable to attend. We missed out on the experience of walking into the stadium with the crowd welcoming us, and I know that would have been an amazing experience.

We were able however to join the rest of the GB Paralympic and Olympic teams on the celebration parade through London a few months after we got home, and that was certainly an amazing experience. The number of people lining the streets, the cheering, and getting to meet the Queen at Buckingham Palace are memories that will stay with me forever.

To read more of Simon's story – and learn about his battle with mental health and struggles with living with blindness, head over to our blog: www.chect.org.uk/blog

CHECT continue to support adults who had Rb as children. We connect people on social media, and facilitate in person and online meet ups to allow people to share tips, and establish friendships. We are well connected with other organisations and can signpost and refer in to other support services. We have up to date information and can support around late effects. Contact the support team on support@chect.org.uk for more information.

REAL LIVES

“My daughter lost her eye to cancer 5 months after I had the ‘all clear’ for breast cancer”

Parents Lisa Shaw and Daryl Robson first spotted an unusual white glow in the pupil of Bonnie’s eye on the 26th December 2021.

Lisa said, “We had just had a lovely Christmas day with our family and it was Boxing Day. It was around teatime so it was dark outside and the lights were dim in the house so the Christmas lights were twinkling while Bonnie danced about the room. As she was dancing and spinning around, I noticed an odd reflection in her eye which looked like a cat’s eye that you would see in the road. I didn’t think much of it but I turned the main light on and asked her to come closer. When she came close, I noticed a cloudy film on her eye.”

Lisa added, “As it was Christmas, I thought I would go straight to the opticians on the 28th December. When I saw the cloudiness in her eye I was not overly concerned. Bonnie is allergic to animal fur so she has always itched her eyes, so I thought Bonnie had hurt her eye

from itching. Regardless of this I thought it was best I get this checked out”.

Lisa explained, “Bonnie was excited to show off her letter skills at the opticians. The optometrist covered her right eye and she read some letters. He then covered her left eye. From there I knew something was very wrong. Bonnie seemed to panic and she couldn’t focus. Her eye was moving up and down, side to side and it was like she could not see anything with her right eye. The worry in the optician’s face said it all. He explained we

needed an emergency appointment. He explained he has not seen this before but he knows what he has seen is very rare. I knew I had to quickly pull myself together and try not to worry Bonnie.”

Bonnie attended Doncaster Royal Infirmary on the 29th December for an ultrasound.

Lisa added, “During the appointments at Doncaster Daryl and I were nervous. We try not to use ‘Doctor Google’ but part of me could not help but research into the white glow. All the signs pointed to retinoblastoma. I didn’t want to believe it and I didn’t let anyone know what I was reading because part of me was hoping for a different outcome. We were asked to come back on the 30th

and then on New Year’s Eve. When we were told we need to get an emergency appointment with Sheffield, we knew this was becoming serious”.

Lisa noticed a rapid change in the appearance of Bonnie’s eyes over this period.

Lisa explained, “Her eye colour became dull and there was a little puddle of what I could only describe as a milky build up. I knew whatever this was it was getting worse and no matter what we found out we needed help. We were devastated and both in shock as the doctor at Sheffield explained it could be retinoblastoma, but we had to fight back tears as Bonnie was in the room with us.”

The family travelled to Birmingham Children’s Hospital on the 12th January.

Lisa said, “Bonnie was excited to go to a big city and stay in a hotel. We made the most of it, but we were hurting inside. Bonnie went to sleep at the hospital and while she was coming round Daryl and I were invited into a room where retinoblastoma was confirmed.”

Lisa said, “Because the cancer was grade E, a unanimous decision had been made by the doctors for her eye to be removed on the 20th January. I could not believe that my baby was going to lose her eye. Her eyes are beautiful, how would she manage without her eye?”.

Lisa said, “I asked what a prosthetic

“I am proud of us for getting through this so positively”



eye would feel like in Bonnie's eye; they explained it would just feel like a normal eye and in fact it would feel better than what she was experiencing at the time. Asking questions calmed us down and we came to the conclusion that getting this nasty tumour out of her eye was the most important thing."

Lisa bought a doctor set to help Bonnie prepare for her operation.

Lisa explained, "I went online and bought a doctor kit which was on a trolley. I borrowed a mask that they use to put children to sleep with in the hospital. We got eye patches and everything hospital-themed you could imagine for us to play with. We would explain to Bonnie how we were going to the doctors and then we would play, re-enacting what will happen at the hospital, so she understood."

Lisa said, "The day of the enucleation is by far the worst day of our lives. We were in Birmingham for five nights. Due to Covid regulations, I stayed in the hospital through the night and Daryl stayed at the hotel. I don't know what is worse, being with Bonnie at the appointments or being Daryl and waiting wondering what is going on. On the day they took off the eye patch we were so happy to go home."

After Bonnie's eye had some time to heal, she started chemo as a precaution. Lisa had experienced chemo just a matter of months before.



Lisa explained,

"I was diagnosed with breast cancer in October 2020. I was told it would probably be nothing to worry about. When I went back from my results, I knew something was wrong. When they broke the news to me, I can only describe this as someone knocking the wind out of me. I had a material face mask on, and I nearly breathed it in."

Lisa said, "After 7 rounds of chemotherapy, I was told I would need a mastectomy. I had the operation and recovered well. I then had 8 lots of radiotherapy. Although this is not nice, I have been very lucky and went through this positively. If my daughter was happy, I was happy and as long as I was there to watch her grow up is all that mattered to me. I went through this so strongly because of her. When my hair fell out, I promised Bonnie this is something to do with mummy's strong medicine and it is not something that would happen to her. I never thought in a few months' time my daughter would be facing the same experience at age 5."

"Bonnie rang the bell as a sign of finishing her treatment on the 23rd of April 2022 and I rang the bell on the 20 April 2021. I would have never imagined we would be doing this and in such a short space of time, but I am proud of us for getting through this so positively. We were determined we would not let this get in our way of living a happy life."

Bonnie's family were surprised

"I hope she knows how much we love and adore her"



with a trip to Lapland from their family and friends. Lisa said, "We can't thank them enough and can't wait to take Bonnie on this magical trip to see the real Santa this Christmas!"

Lisa added, "We also want to thank the Childhood Eye Cancer Trust who have been amazing; they're easy to get hold of, very supportive and always a friendly face. We also received a grant which helped us with expenses."

"I also want to thank the NHS. One day when Bonnie was struggling with starting her medicine the nurses promised we would do some crafts. Bonnie told the nurses it was her hamster's birthday. They got everyone on the ward involved and all the parents and children were making decorations for a hamster party - Bonnie soon had her medicine!"

Lisa said, "Bonnie is just the best thing that ever happened to us. I thought I knew what love was until I met Bonnie. I look at what she has gone through and see how she is and I could not be prouder. When she is older and reads this, I want her to know that all the times I had to hold her tight were done out of pure love and we will protect her forever. I hope she knows how much we love and adore her."

A huge thank you to Lisa, Daryl and Bonnie for helping us to raise such great awareness of Rb this Christmas.



“I thought my daughter had ice in her eye, but it was eye cancer”

Parents Gina and Michael Hickson first spotted an unusual white glow in the pupil of Darcey-Rose's eye on 9th February 2021.

Gina said, “We just saw a mass, like a cloud in her eye that would change shape depending on where her eye was directed. Initially we thought it was ice in her eye from a snowball fight. I googled it and it took me to the Childhood Eye Cancer Trust's website – which I instantly dismissed. I was still concerned so I got Darcey to pose for a picture and sent it to the GP straight away.”

Gina explained, “She had a slight lazy eye, but I put it to her vision tracking. I don't even think I mentioned it to anyone.”

Gina said, “The doctor referred us to ophthalmology. There wasn't a sense of urgency or worry. However, I made sure I didn't tell anyone what I'd seen and avoided telling my best friend as I knew she would tell me it's sinister and

I was actively avoiding anything that could suggest it was. I was genuinely concerned she would need glasses, which is so, so silly; I definitely had my head in the sand.”

Darcey-Rose had a vision screening to determine what was causing the unusual cloudiness in her eye.

Gina explained, “When looking through her right eye, Darcey was able to identify every animal and loved the game. When we covered the right eye you could immediately see she was blind in that eye. Her whole body language changed, she became withdrawn and she was trying to find a way to see again.”

Gina added, “When she then had a scan, in the room there were posters on the wall with visuals on what to look out for, and how different eye conditions are seen on the screen. I found the cancer image and just held my breath. The right eye on the scan was clear and the left eye had a huge black mass. When we left the room, a woman came and gave Darcey a toy; I looked at Michael and told him to prepare himself as Darcey's got cancer. We went into the room to be told she “potentially has a rare

eye cancer but they can't diagnose as only the specialists can”.

Gina explained, “We broke down. Michael was playing with her on the floor, I was sick in the corner. Our world fell apart. Everything stood still but was also blurry around us”.

On the 19th February, Darcey-Rose attended Moorfield's Eye Hospital, where retinoblastoma was confirmed. She then began the first out of six rounds of chemotherapy on the 1st March 2021 at Great Ormond Street Hospital before going into remission.

Gina explained, “Covid meant I had to drive my baby to London alone and do everything on my own. She didn't get to have her dad and it was just us, the amazing nurses and the unknown. It was especially tough for Michael. He wasn't allowed to support his wife or his daughter and had to have lots of extra shifts. He was given the news his daughter had cancer, and then because of our circumstances outside of the diagnosis he had to work harder to support us and due to the pandemic, he wasn't allowed physically to support us or her during treatment.”

In September 2021 she needed laser and cryotherapy treatments, and in January 2022 it was decided she needed to restart chemotherapy.

Gina said, “It was devastating

“She is just the funniest sass pot we have ever met.”





to watch her go back through it 11 months later. Before the chemotherapy started we just cuddled in bed and I watched her breathe."

On the 23rd March 2022, the family were given the news that she had gone into remission.

Gina explained, "We had a 4-6 weeks wait until the next check to see if the cancer had gone, and even then it would still be frequently monitored. But for that day, she was in remission again, she had regained more sight, she was safe. And now mummy and daddy could breathe for a little moment. Darcey has always responded unusually to all of her treatment. It's a running theme in conversation that the "less expected side effects and reactions" aren't less expected. And the usual isn't something we see."

Gina said, "On the 15th June 2022 we were told Darcey-Rose could either have chemotherapy injections in her eye or have her eye removed, as they had found more cancer in her eye. We did consider both options and as the direct injections would be done under anaesthetic, she wouldn't know any different to her normal treatment. So we cancelled our mini break to Scotland, crashed Darcey's holiday with her grandparents at the caravan, and just tried to forget in-between consultations."

"We booked in the chemotherapy for the 29th June. Her vision was better and worth fighting to save. She was incredible, she went down happy and we went off to the cafe for a coffee, expecting it to go well. But after 20 minutes my phone rang, and we were told to come back. When I saw we ran, we sprinted."

Gina explained, "Her tumour had spread around the retina, the chemotherapy wasn't an ideal choice anymore. When they said they were going to have to remove her eye, and the choice was taken, I felt pure fear. The scariest part for me was explaining to her that her needed to have the operation – I was scared she would be scared. The play specialists had props and toys to explain how she was poorly like this Dino was poorly. So to stop her body being poorly we were going to take her poorly eye and give her a special one to make her better. We answered her questions and she breezed through it."

Gina added, "The operation went really well. The clinician fitted a prosthetic eye. Darcey-Rose did really well and understood why she needed a special eye because of her poorly one."

Gina said, "She is just the funniest, sass pot I've ever met. She makes me laugh every day. She's so clever, and inquisitive. She made every trip easier with her sheer zest for life. She loves sports and also horse riding, despite only having vision in one eye".

Gina said, "The Childhood Eye Cancer Trust has been amazing support throughout all of this time. Our support worker is always checking in on us and sorted out a few grants for us which have been invaluable. We were not entitled

"She made every trip easier with her sheer zest for life"

to much financial support. We couldn't take furlough as key workers in the pandemic, and we were not entitled to benefit support either so it really did financially become quite tough. I remember one point having the petrol station phoning to let us know the petrol was being delivered when there was a shortage, as they used to open one pump for us and let us fill up so we could get to London for appointments."

Gina added, "The play specialists both at Great Ormond Street Hospital and at the Royal London Hospital have been our guardian angels. We learnt how to access dolls, medical play, distraction play, had normality, and built relationships. And most importantly, she learnt about the next stages in her treatment and reducing procedural anxiety."



Thank you so much to Gina, Michael and Darcey-Rose for helping us to raise awareness during Childhood Cancer Awareness Month. Their story ran across the national 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 2022!



TeamCHECT had an amazing day at the 2022 London Marathon! Thankfully the threatened rain stayed away, and the sun shone on our 11 wonderful runners as they set off on the 26.2 miles to The Mall, near Buckingham Palace. CHECT staff were at mile 20.5 to offer jelly babies and cheer them on along the way, when they might have been feeling a little weary – and then we welcomed them home in St. James's Park, just past the finish line. We were thrilled to be joined by some of the runners' friends and family at both points. It was an emotional afternoon, and we are so proud of our team. Everyone did brilliantly, from their training and heroic on the day performance, to their fabulous fundraising. And to make the event extra special, CHECT runner Phil not only achieved a personal best but proposed to Darcie at the end! A huge thank you to all our runners and of course their sponsors and supporters – and a big shout out to our corporate partner Vision Express colleague Katie, who raised funds for CHECT and the Macular Society from her run, too.

If you would like to take part in the 2023 London Marathon or virtual marathon in April, please email fundraising@chect.org.uk.

Have you got your Christmas cards?

Order by 5 December to get your CHECT Christmas cards, all designed by children who have had Rb! Each pack contains a mixture of 10 amazing cards and costs £5 (including P&P). Visit www.chect.org.uk/other-ways-to-help/christmas/ to get yours!



Up for a challenge in 2023?

Are you making a New Year's Resolution to run more, get fitter, or challenge yourself to something you have never done before? If so, we may be able to help! Browse the 'Get Involved' section of our website for UK wide events big and small, from running events to skydives! Check out all our events at chect.org.uk/other-ways-to-help/events/

TCS London Marathon Sunday 23rd April

Having read about our amazing runners in 2022, the TCS London Marathon needs no introduction! And it is back to being an April event in 2023. Starting at Blackheath, passing through Greenwich before crossing the Thames over the iconic Tower Bridge, the course continues through central London, winding around Canary Wharf and along Victoria Embankment before finishing on the Mall in front of Buckingham Palace. Join #TeamCHECT in this world-famous event! **Minimum sponsorship £2,000**

Or do it your way! For the virtual TCS London Marathon you have 23 hours, 59 minutes and 59 seconds to complete 26.2 miles on a route of your choice. All participants receive an official London Marathon T shirt and medal upon completion. **Minimum sponsorship £100**



Great Birmingham Run Sunday 7 May

Now established as the second biggest half marathon in the UK, Birmingham comes alive with thousands of runners pounding the streets, encouraged by on-course bands, entertainment and, of course, cheering crowds. Recruit a group of enthusiastic runners and tackle it together – the more the merrier!

Minimum sponsorship £300

New for 2023! Birmingham Running Festival Sunday 21st May, Sutton Park, Sutton Coldfield

In response to the growing success of the RunThrough Regent's Park we are introducing a new sister event for the Midlands! Choose between a 5k, 10k or Half Marathon distance – the perfect opportunity for running with friends and family. Sutton Park is one of the largest urban parks in Europe, with open heathland, woodlands, seven lakes, wetlands, and marshes. Enjoy the captivating scenery, and spot the cattle and wild ponies grazing on the land. Minimum age: 11 for 5K, 15 for 10K. 17 for Half Marathon.

Minimum sponsorship £200

RunThrough Regent's Park Sunday TBC July

Now a firm fixture in the CHECT calendar, join our mighty team running a 5K or 10K through this amazing Royal Park, past the grounds of Winfield House, the second largest private garden in central London. The flat course offers a great opportunity for a chip timed personal best. And afterwards you can have a picnic and hang out with the rest of TeamCHECT, or visit ZSL London Zoo. Even if you don't run yourself, please come along to cheer on our team. We are looking forward to seeing both regulars and new faces to this fantastic event! Minimum age: 11 for 5K, 15 for 10K. **Minimum sponsorship £200**

Great North Run Sunday 10th September

Join 56,999 others in the largest half marathon in the world. You'll run through Newcastle city centre, across the iconic Tyne Bridge (perhaps glimpsing the Red Arrows passing overhead) and after having been entertained by bands and cheered on by thousands of supporters, finish on the coast in South Shields. **Minimum sponsorship £500**



To find out more about any of our events, or if you want to go one step further and organise your own event (sporting or otherwise), our Fundraising Manager Diane is here to help - email fundraising@chect.org.uk to chat through ideas, or call 02073775578.

Children's corner & CHECT TYA!



Finn the Buddy Dog

"This is Finn he is 2 years old, he is a labradoodle, I am Harvey and I am 7.

I wanted a guide dog because of my eyes, but we ended up with Finn who is a buddy dog. That is because he doesn't like to wear a harness.

I like to take Finn to the park, I throw the ball for him and I have to fetch it! We do lot of recall training, where I make him sit and stay, then I walk away and blow my whistle three times for him to come.

I really love Finn and we have lots of fun."

William's Time at School

William, who is in Year 5, has written about his school life:

"My name is William. I study in Year 5 in West London. At school I play football, basketball, the game 'it' and so much more. Also in PE every year we have sports days, we do shooting, skipping races, throwing and other sports. When my eyes hurts I go to a teacher and put in my eye drops. Nothing has stopped me from achieving my goals. I really appreciate Royal London and Moorfields for helping and keeping my eye healthy."



Daisy's Pink Eye!

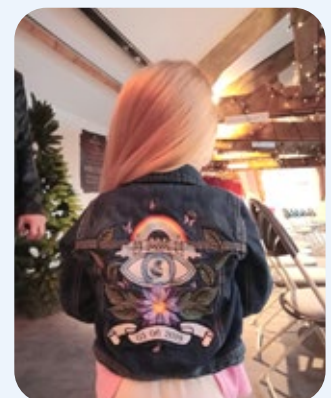
Daisy had her eye removed (enucleated). She has always wanted a pink sparkly prosthetic eye since she was two-years-old, and now, aged eight, is delighted to show the world her new special eye!

Mum Alysia says, "Daisy was 14 months when diagnosed and just over 2 when she had her eye removed, she said she wanted a pink sparkly eye because pink is her favourite colour and she loves sparkles like a unicorn and she feels like a superhero with her eye".

Meadow's Customised Jacket!

We love this customised jacket that Meadow wore to our Newcastle Family Support event this year!

The jacket features Meadow's retinoblastoma diagnosis date, her birth flower, the CHECT logo with the hospital above it, 5 butterflies that signify her family, and the butterfly with the halo above is lovingly for Meadow's grandad who sadly passed away.



Megan's Golden Eye!

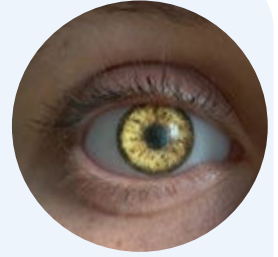


Megan shares with us her Rb story, and why she decided she wanted to have a golden prosthetic eye.

I was diagnosed with retinoblastoma at three-months-old, by the time I was one I had gone through six rounds of chemotherapy and cryotherapy, two blood transfusions and had my right eye removed.

I have never been embarrassed or felt weird for having one eye as I have no memories of not having it. I have been very lucky at school and throughout my life with everyone being so understanding or curious.

I don't necessarily hide the fact I have one eye, but I haven't been obvious with it either! I have been fortunate enough to always have such brilliant prosthetics that unless people ask about why my eye doesn't move, they don't notice!



However this year, I had an idea to have something different, so when having my new mould done for my prosthetic I asked about different designs you could have, I never knew how many different designs can be done! So I did some research and found a beautiful golden design, it looked as though there was a glowing light in the eye.

I wanted to have something different to show how beautiful a disability can be, and to show how proud I am to be different. I really think more young people should have it advertised to them as I really think it could boost a lot of people's confidence!

Solve the clues!

Katie from CHECT's TFC has created a Christmas crossword, can you solve the clues? Also, why not colour in the pictures and share them with us on social media! P.S answers are at the bottom

Across

2. You & Santa wear these to keep your heads warm (4)
5. Title of a famous Christmas story and ballet about a present which comes to life (10)
6. The name of a snowman in a favourite winter song, also a description of weather, mostly on cold mornings (6)
8. Leave milk and a carrot out for this animal on Christmas Eve, especially for a special red-nosed one! (8)
10. Type of calendar you open every day in December until Christmas. You might even get a treat behind the doors! (6)
11. Gives warmth inside on a snowy day (4)
14. You might pull these at Christmas and receive a toy, a joke and a hat (7)
15. Many animals such as hedgehogs do this over winter- it may look as though they are sleeping (9)

Down

1. A spiky plant often used on Christmas wreaths (5)
3. You might eat this for Christmas dinner, also the name of a county (6)
4. You might decorate this plant near Christmas with lights and baubles (4)
7. He might come down the chimney on the 24th of December (5,5)
9. A creature such as Dobby from Harry Potter, also Santa's traditional workshop helper (3)
12. Frozen water (3)
13. A winter sport in which you whiz down slopes (6)



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:

Marshall Browning
Mabel Grazebrook
John Fallowfield
Madie Key
Mabel Brand
Valerie Jakeway
Gay Fuller
Olivia Norfolk

Valerie Malin
Michael Jeffs
Jeff Maughan
Deborah Mortimer
Kate Lyon
Ciss Randall
Audrey Allen
Matt Evans



Recommend us to your employer!

We are 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.

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!