infocus
Summer 2022

Fighting
Retinoblastoma
Childhood Eye Cancer Trust

Crazy Glasses for Rb Week!

Thank you, Lesley!

Lesley reflects on her time at CHECT **Page 4**

How a Polaroid photo revealed Elijah's eye cancer

Read Elijah's story **Page 7**

How AJ's Rb was spotted as he took his first steps

Read AJ's story **Page 9**

Welcome

Welcome to this issue of InFocus and a special thank you to all our families who submitted wonderful World Retinoblastoma Awareness Week photos for our front cover.

It has certainly been a busy six months since the last InFocus! We have seen our amazing community come together to raise awareness, holding brilliant events and sharing content on social media. Our Awareness Week story on page 9 features AJ, whose parents spotted a cloudiness in his eye the day he took his first steps. The family also held a brilliant charity evening to raise funds and raise awareness - a huge thank you to all involved!

We bid a sad farewell to our wonderful support manager Lesley in March, who has worked at CHECT for just under ten years. You can read Lesley's reflections on page 4. We've also had to say a very sad goodbye to the late John Hungerford, whose contribution to the Rb community is warmly reflected via an outpouring of thoughts and memories on page 5.

We've had many families share their awareness-raising stories in the media over recent months, including mum Annabel, page 7, who spotted her son Elijah's white glow in a Polaroid photograph and who kindly shared her story for Rare Disease Day.

I would like to take this opportunity to offer CHECT's huge congratulations to the inspiring Rb team at Birmingham Women's and Children's Hospital, who have just celebrated their 20 year anniversary! You can read more about this on page 3.

We are delighted that in-person events are once again taking place – it has been wonderful to see all your photos from challenges and fundraising events that you've kindly held so far this year – we can't wait to see many more of you in-person at the London Marathon on 2nd October.

In line with the relaxation of Covid restrictions, we are planning an array of member events across the country - keep an eye out for more information.

I have loved reading the delightful adventures of Zain, Xavi, Mohamed and Eliza in our Children's Corner on pages 13-14 - what talented members we have!

2021 marked ten years of gathering information from newly-diagnosed families, which we call Pathways to Diagnosis. You can read the interesting results of this survey on page 3.

As ever, we are so very grateful for your continued support – it is only with the support of incredibly generous individuals and companies and some wonderful charitable trusts that we can continue to make a difference to the lives of those affected by Rb.

Sadly, it is now my time to pass the honour of being chief executive of this very special charity to my successor, as I look to begin my retirement at the end of June. Working for CHECT for almost seven years has been such a privilege. I have met so many incredible people and families, and been humbled and inspired by your resilience, your energy and your generosity. CHECT will always hold a very special place in my heart. I am very pleased to be leaving the charity in good health, with a committed board of trustees and an inspiring and talented staff team.

With very best wishes for the future,

Patrick

Patrick Tonks, Chief Executive

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News

Exciting research announced!

CHECT is delighted to announce our latest new research project, which has been fully funded by the Clive Richards Foundation. Headed up by Professor Shin-Ichi Ohnuma at University College London, the project aims to form the basis for a possible new treatment for Rb. Although current methods are extremely effective at treating retinoblastoma, many children are left with some level of visual impairment.

Previous research by Professor Ohnuma (also funded by CHECT) has identified a potential new candidate for vision-preserving Rb treatment: a gene known as PRELP. His team has found that whilst PRELP protein is highly expressed in normal retinal tissues, it is not expressed in retinoblastoma. Preliminary data from cell cultures indicate that administration of PRELP to the established laboratory retinoblastoma cell lines inhibited cancer progression.

Now, Professor Ohnuma wants to confirm that these results have clinical application, by applying PRELP protein to human retinoblastoma tissues and examining the effect on retinoblastoma development.

If, as expected, the study shows that administration of PRELP is a practical approach for inhibiting retinoblastoma progression, the next step will be to demonstrate the effectiveness of PRELP as a treatment for retinoblastoma in clinical trials. The advantage of such an approach over some current methods is that only affected cells will be impacted by the treatment, with no expected toxicity to surrounding normal, unaffected retinal cells, thereby preserving more of the child's vision.

We are enormously grateful to the Trustees of the Clive Richards Foundation for so generously funding this project.

The Ffion Miles Music Bursary

If you or your child have a love for music, you could be the first to benefit from The Ffion Miles Music bursary – in memory of the late Ffion Miles.

Ffion was not only known for her love of music, but her passion towards helping those who had retinoblastoma and/or who had a visual impairment. Please contact support@chect.org.uk stating what you would spend £1000 on if you had £1000 to spend on something that encourages your love for music. The member that is chosen to benefit from this singular annual award will be chosen by the CHECT board of trustees. The deadline for applications is 15th July 2022.

Please visit chect.org/blog for more information and T&C's.

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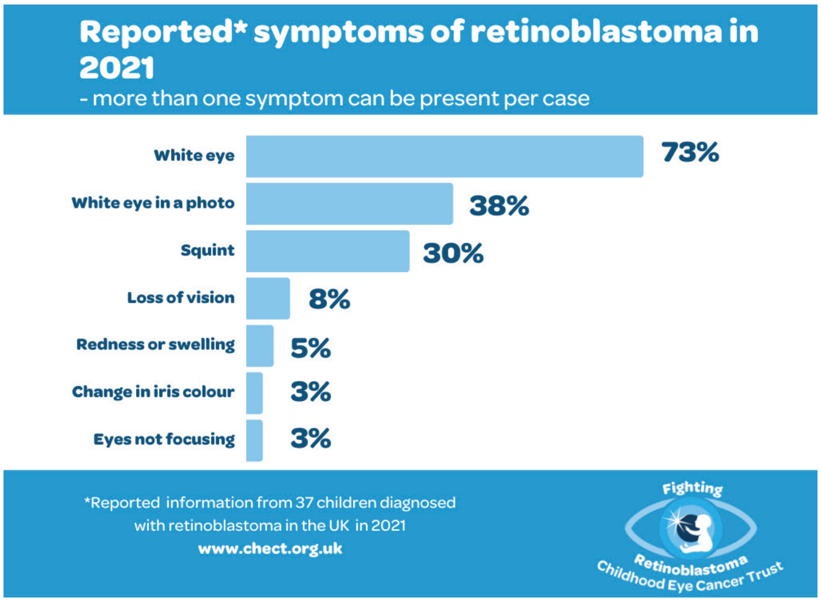
Do you enjoy receiving your copy of InFocus? Is there anything in particular you'd like to read about? If so, we'd love to hear from you at info@chect.org.uk.

Thanks for your support!

Pathways to diagnosis



Reported* symptoms of retinoblastoma in 2021

- more than one symptom can be present per case

*Reported information from 37 children diagnosed with retinoblastoma in the UK in 2021

www.chect.org.uk

2021 marked ten years of gathering information from newly-diagnosed families that we call Pathways to Diagnosis. This survey helps us to shine a light on parents' experience, and to identify areas for improvement.

Overall, referral rates seem to have recovered from the impact of the pandemic, with over a half of children with retinoblastoma receiving appropriate urgent referrals, and just 8% waiting more than six months. Of course there is still a lot of room for improvement, but it's an encouraging recovery from the previous year when just over a third (35%) received urgent referrals and 24% waited over six months. White eye continues to be the most common sign, with more parents than ever reporting this as a symptom, either seen in a photo (38%) or in their child's eye itself (73%). Previous awareness of Rb had fallen slightly amongst newly-diagnosed families however since 2019, suggesting perhaps that there just has not been much space for talking about non-Covid related health issues in the last two years. For more information, visit **chect.org/blog.**

The Birmingham Rb Service 20th Anniversary

We would like to say a huge congratulations to all those who work on the Rb ward at Birmingham Women's and Children's Hospital who are celebrating their 20th anniversary this year. Here Sister Maureen McCalla, a Retinoblastoma Nurse Specialist at the hospital, discusses the Birmingham Rb Service's 20 years.

In 2002 we began a journey that has lasted more than 20 years with a number of the team having worked together for more than 10 years.

We are multi-disciplinary, with a mutual respect for each other as well as a keen sense of learning.

At the very beginning we agreed that ours should be a gold standard service where the patients were central and the support, care and treatment was an individualised pathway along which we would walk beside the families. We devised our own patient information literature and unique teaching aids. We pushed the boundaries of innovative treatments as well as becoming the leading light in genetics.

We have treated and supported our families and now we are treating and supporting the next generation for some of these families. We've had to say a final goodbye to some of the children, parents and grandparents along the way. We have had generous support from our families as well as fantastic financial support for our service and the hospital. We have had a number of great Christmas family parties and residential weekends away for groups of children devised and led by our play specialists.

The last 5 years has seen the most change in staff as well as an increase in the number of staff since the beginning of the service and it's only fair to pay homage to all those who were there in the beginning and on whose shoulders the current service stands. Some of the original team have stood the test of time and are still members of the team. The service continues to be child and family focused, the challenges are there to be overcome and the new team continues to grow and learn whilst still remaining a team at all times.

Thank you, Lesley!

Lesley started her career at CHECT as a support worker and has helped hundreds of people in so many different ways since she joined back in 2012. Lesley was instrumental in growing the range of support we offer as a charity and was the natural person to become our first ever support service manager. In her almost 10 years with the charity, Lesley has been integral in shaping the way we provide support. Lesley reflects on her time at CHECT.

I can hardly believe I am writing this as I retire from CHECT. While reflecting, I must start by saying that my predecessors had laid an incredible foundation of supporting families for me to build on and I truly hope that my successors will feel the same. I was so impressed that they knew so many people and so much about each family, and I have loved building on the absolute cornerstone of our work – individualised support. Emotional support, signposting, help with finances, introducing families to others in similar situations were the bulk of the support work.

I know that I have been so fortunate to be a part of two amazing teams. To be integrated with the Rb team at RLH as well as the CHECT team has been quite incredible, I have made lifelong friends in both teams.

The other, much larger team, has been the CHECT members, from tiny babies, sometimes only days old, to people who were diagnosed with Rb many years before the charity existed. Through a child’s early, school and teenage years and into adulthood. There have been tears and laughter, fun and outings, all contributing to an amazing wealth of relationships and experience.

I’ve been in the most privileged position of meeting parents on the day their child was diagnosed with Rb, offering what support they could manage at that time, knowing that I would likely go on to know them well and that this was the beginning of an often very long relationship with their family.

Speaking to adults who had been affected by Rb and perhaps wanting support around having a new baby and all that may bring, possibly bringing their brand new baby for screening or treatment. Ensuring adults have the appropriate follow up and support for their own Rb where needed. Working with some amazing teenagers, having fun days out and forming the CHECT Teen Focus Council to meet the needs of this age group. Being able to offer support to whole families has meant the joy of getting to know siblings, grandparents and family friends too.

CHECT members have also taught me so much, particularly around the issues of visual impairment. Watching children running around and growing up to achieve amazing things, and seeing their parents' joy & pride has been such a delight.

It has been great working together with different members of the clinical team to provide complementary support including visual impairment resources, local psychology contacts, teenage support, financial information and much more, supporting each other to find what works best for families.

I’ve loved receiving messages from parents telling me what their children have been doing and achieving, pictures drawn for me, seeing photographs as they grow and hearing the funny, touching things they say in the way only children can. There are many such memories and I can’t relay them all, but receiving a message from one mum saying that her two-year-old was playing with her doll who had a poorly eye and said, “’Hi I’m Lesley, please to meet you, I make everyone feel happy!”, brought a big smile and a tear to my eye. Being in a crowded room at a member’s weekend hearing a little voice shouting loudly across the room “LESERLEY!!!” made my evening. Having various names: Granny Lesley, Milk Lesley, Zezley Yoghurt Lady was very special.

So, it’s goodbye and a huge thank you so much to all of you who have allowed me the privilege of being a part of your family’s Rb journey and the joy of getting to know you. I will take you all with me as I embark on the next phase. ***Love, Lesley***

A Tribute to John Hungerford

We are extremely sad to inform our members of the passing of Consultant Ophthalmologist John Hungerford, who not only helped many people who had retinoblastoma (Rb) and actively assisted with fundraising as the trust established itself, but was also key in the development of new approaches in the treatment of Rb.

Libby Halford, a former CEO of CHECT wrote: "Almost forty years ago when CHECT (formerly The Retinoblastoma Society) was a fledgling support group, John Hungerford not only gave his time and expertise on the clinical side of things, but helped to organise the use of a small office within Barts and gave us access to the wards – an extraordinary privilege. He then supported Jenny, our first National Coordinator/ Support Worker.

"I recall taking my own daughter to a new prosthetist when she was about 10. She looked into my daughter's socket and said 'Ah! She must have been a John Hungerford patient – I can always spot his work – so neat and tidy.' The knowledge that John Hungerford was in there, fighting for your child, was immense. As a parent and as a CEO I have many memories of this extraordinary man and I am pleased to have known him, in so many ways".

John was also at the forefront of pioneering treatments. Today we try to avoid radiotherapy but his work on lens-sparing radiotherapy 35 years ago was a huge step forward in the management of Rb and its side effects.

His work was also celebrated in the 2012 25th Anniversary edition of our InFocus magazine, where the late Dr Judith Kingston, another pioneer in the world of retinoblastoma, reflected on the work she did alongside John and radiotherapist, Dr Nick Plowman.

She said "In 1984, Mr Hungerford, Dr Plowman and I as paediatric oncologist, all newly appointed consultants with enthusiasm to change things, set up a close working relationship with the aim of improving the outcome of children with retinoblastoma."

"Our achievements together during the twenty-year collaboration were substantial and included the development of a lens sparing radiotherapy technique, the introduction of chemotherapy as adjuvant (additional) therapy for children with adverse histology, the introduction of chemotherapy as primary treatment for intra-ocular disease to avoid the use of radiotherapy in babies and very young children and the use of orbital implants to improve cosmetic outcomes."

Dr Plowman remembers John's pioneering work on radioactive plaques: "John and I were appointed to Barts around the same time, and over the 25 years we worked together he became a very good friend, and was always an extremely good opinion. One of his main contributions to the development of Rb treatments was his work with radioactive plaques as a first line basis for treatment. His work in this area went on to influence globally the use of radioactive plaques for eye tumours."

John Hungerford was also a passionate advocate for ensuring the voice of the families affected by Rb was heard and valued by the hospital teams; as such he was a strong supporter of CHECT not least in its role as the representative voice of the patients.

Laura Crawford, who had retinoblastoma, said, "He was a wonderful man. And a silly thing – every time I travel over, or near, the Hungerford Bridge in London, I think of him (when I was little I thought it had been named after him, I think my Mum thought it should have been!)."

Yvonne Hungerford, John's widow, said: "Throughout his working life John was totally dedicated to his patients. Through his experience and research he worked not only to save life and sight but to improve the quality of life of those who suffered from Rb. A committed family man himself, he was always mindful of the stress suffered by families but also how much they can contribute to the future of their loved ones. He regarded the work of the trust as a key contribution to this. My daughter and I are putting together a book, not of condolences, but of memories of John, little vignettes from those who met him."

If you wish to contribute to the book, please email **info@chect.org.uk.**

We wish to pass on our deep condolences to John's family, friends, colleagues and all who encountered him; it is most certain that John has left a legacy which helped to shape the future of retinoblastoma treatment, and changed the lives of many patients and families of those with Rb.

Thank You, Geneticists!

We wish to say a huge thank you to the geneticists who do such significant work. Here, Dr Elisabeth Rosser and Dr Trevor Cole reflect on their experiences.

Dr Elisabeth Rosser

I started as a consultant in clinical genetics in Great Ormond Street Hospital on 1st February 1997 and retired on 31st January 2022 – after exactly 25 years. I must confess that I had very little experience of retinoblastoma when I began, and I spent my time for the first few months seeing families who came to clinic and also reviewing the notes of everybody who had been seen in the unit. This gave me a really useful overview of the experiences that patients had had over the years.

Routine genetic testing was not possible when I started but improved over the next few years. The time to get results has decreased from many months to several weeks and we are fortunate to have such a dedicated and knowledgeable team of scientists who never give up on anything!

One of the very special things about genetics is that it allows you to see a family for many years. I have now managed testing for new babies for a number of people whom I first met when they were babies themselves. It is always lovely to catch up with families when the children are teenagers and to hear how well those children are doing. Today's teenagers are very impressive creatures! I have been very privileged to work with an amazing team of dedicated, knowledgeable people for 25 years. I have also learned a great deal from so many families and hopefully have been able to use what I have learned from colleagues and families to benefit other colleagues and families.

Dr Trevor Cole

I became a consultant in adult cancer genetics in Birmingham in 1992, later moving to my other area of fascination and passion: childhood cancer genetics. In time, working with colleagues in the Birmingham retinoblastoma team, we put forward, and had accepted by the national commissioners, the case for a second national Rb service in Birmingham. One might say the rest is history but that would be simplistic.

As the last of the three original Birmingham retinoblastoma consultants to retire I have had the privilege of working with a wonderful team of medical and non-medical colleagues - one of the many reasons I loved working with the retinoblastoma service.

The second and most important reason I have enjoyed my time with the retinoblastoma service are the children and their families. The strength of the children, the wonderful support and resilience of the families and their willingness to work with the retinoblastoma team is both awe-inspiring and humbling. For me one of the most rewarding parts of my job was meeting the children 15 years later and seeing very positive young adults wanting to understand their condition, succeed in their life and have their own families. They are amazing.

What have I been able to give back to the families? I hope, some time and support, to understand the complexities of the underlying genetics and how they can use this knowledge to achieve some of their own goals. For my part I will always look back on my time working with retinoblastoma families as the most enjoyable and rewarding part of my career. I wish you all well and good health for the future.

Dr Cole and Dr Rosser are being succeeded by Dr Foster at Birmingham Children's Hospital and Dr Hay at the Royal London Hospital. Go to chect.org.uk/blog to read the full article, and to meet our new geneticists!

REAL LIVES

"A Polaroid picture helped reveal the eye cancer that cost our son his eye"

A mum and dad are urging other parents to look out for the tell-tale signs of eye cancer after their 14-month-old son lost his eye through retinoblastoma.

Dad Tom Byrne, from Brighton, spotted an unusual white glow in his then eight-month-old son Elijah's eye – a common sign of eye cancer which is often only seen in certain light.

Mum Annabel Byrne said, "Tom first spotted the white glow in the summer of 2020. Later, I took a video of Elijah climbing up the stairs and Tom said, 'There's the white glow I've been talking about. I'm worried because I can see it really clearly'".

The parents were unaware of the signs and symptoms of retinoblastoma, and findings from a recent survey by CHECT found that only 19% of parents surveyed had heard of the cancer, and a decline in parents being concerned about their child's eyes.

Elijah had a white glow in his eye

Annabel said, "I saw a TikTok video of influencer Jarrett Stod removing his artificial eye and explaining that he'd had retinoblastoma. You never think something like that will happen to your child".

In January 2021, a month after seeing the TikTok video, Annabel had the sudden urge to find her old Polaroid camera.

> **"You never think something like that will happen to your child."**

Annabel explained, "I was so keen to find it, I was going crazy as I just really wanted the camera to work. I rushed to get the last film in the shop and then rushed out again when I realised it needed batteries. Everyone in my house was looking at me like 'What's going on?'".

"The first photo I took on the Polaroid you could see the white glow in Elijah's pupil so clearly, and although Tom had told me that he had seen a glow, I didn't realise something was wrong until then. The white glow really alarmed me because it was so clear and everything else in the picture was so dark apart from the glow, and after talking to a family friend, I took Elijah to hospital the next day."

"Elijah looked up at me as he ran around the ward and I could see his eye glow in the light. When the doctor examined him, he said, 'I'm really sorry, but I think your son has retinoblastoma'. He explained that someone from the children's ward would see him ASAP. I calmly replied 'Ok, lovely thank you', because I didn't know what retinoblastoma was."

It wasn't until the specialist at The Sussex Eye Hospital mentioned about Elijah going to Great Ormond Street Hospital for Children (GOSH) that Annabel realised the severity of the situation.

Annabel explained, "I remember the word 'cancer' and that's it. I just felt so numb and floppy and had to leave. My whole world stopped; I couldn't even process it. I rang Tom and said, "Elijah has cancer' – he didn't believe me at first but then immediately left work to come to the hospital. I was holding onto my 14-month-old boy who hadn't a clue, smiling away. I was his comfort and I needed to step up. It was by far the hardest moment I've had to deal with, and I had to keep our family together and strong."

Annabel adds, "We both felt so bad. I felt bad for not listening for the past six months and Tom felt bad for not doing anything, but we didn't even mention it. We knew that he was being seen now and that's all that mattered."

Two days later, the family went to Moorfields Eye Hospital where Elijah was diagnosed with retinoblastoma. The next week, Elijah's MRI revealed that the cancer luckily hadn't spread outside of his eye. On the 16th January, the parents were given the choice of Elijah having chemotherapy, or having his eye removed.

Annabel explains, "If Elijah had gone through chemotherapy there was a chance he would still need his eye removed or the cancer spreading. While parents who choose chemotherapy are so strong, Tom and I looked at each other and we just knew that having his eye removed was the right thing to do for Elijah."

The morning of Elijah's operation at the Royal London Hospital, Annabel felt emotional and tried to hold back the tears.

Annabel said, "I'd never been so scared when we went to collect him - I scooped him up and didn't want to let go. Tom and I are both very grateful for each other, we were each other's backbone."

"The day after the operation, Elijah was happier but wanted lots of cuddles – he bounced back to normal within a week. He was given an artificial eye – which he is amazing with! Elijah is now at an age where he is aware and likes to play with it. When I catch him, he always giggles because he knows he's being cheeky. We have a box of all the artificial eyes he's had so far; he loves looking through them and explaining they're his 'old eyes'. It's so nice to see him be that way."

After Elijah had his eye removed, he attended an event hosted by influencer Olivia Deane, who had also had retinoblastoma.

"I don't want to wrap him up in cotton wool"

Annabel explained, "Olivia is an inspiration; she gave me that spark of confidence to not care what people think. I wanted to come across as a strong mum and not care about other's opinions, but I did care. You just want to protect your children at all costs, and you don't want people saying nasty things. My confidence around it is definitely growing."

Elijah now gets seen for a check-up at the Royal London Hospital every six months, but he was able to ring the bell for being cancer-free on the 4th January 2022 – exactly a year after he received his diagnosis.

Annabel said, "We were thrilled because it's such a lovely thing to do, especially as it was a year anniversary. We helped him ring it and it was a lovely atmosphere."

Elijah with his mum

"Elijah is the most amazing, funniest, bravest, cheekiest, gorgeous, polite little boy! He loves animals, being outside and horse riding. As he has one eye you just want to protect it, but I don't wrap him up in cotton wool. I want him to go out and be himself. I believe he can do anything a child with two eyes can do."

In a message to other parents, Annabel said, "Trust your gut. If you're worried, book a doctor's appointment. It's a few hours out your day that could save your child's life."

Elijah's Great Great Aunt, Ash, has very kindly shaved her hair for CHECT.

Annabel explained, "I'm so happy Ash chose to do this for CHECT as they've helped our family hugely - not only financially, but mentally, and offering help whenever it was needed. Thank you Ash"

"We also want thank all the health professionals who helped with diagnosing and treating Elijah".

A huge thank you to Annabel, Tom and AJ for helping us to raise awareness of Rb. Their story was featured in The Sun as part of our Rare Disease Day campaign.

If you've been affected by retinoblastoma and want more information, please either contact our support team at **support@chect.org.uk** or visit our website **chect.org.uk**

We spotted our son’s eye cancer the day he took his first steps

A mum and dad from Bolton are urging other parents to look out for the tell-tale signs of eye cancer after their 11-month-old son lost his eye through retinoblastoma.

Parents Natasha and Alex Finney first spotted an unusual cloudiness in their then eleven-month-old son AJ’s eye in November 2021.

Natasha said, “While changing AJ's nappy, he cried a lot. When he got up, taking his first steps in the process we were over the moon, but then we noticed a cloudiness in his eye and decided to get him into the doctors that day. We weren't aware of retinoblastoma before AJ was diagnosed, so we wouldn't have known any typical signs or symptoms of it”.

Natasha explained, “Although AJ had a visible squint quite early on, we weren't concerned as Alex and his mum also have a slight squint, so we assumed it was hereditary. Since AJ’s diagnosis, we have discovered that a squint is the second most common sign of retinoblastoma”.

Natasha said, “I was at work while Alex took AJ to the doctors so when he rang and said that he needed to take AJ to the hospital, I panicked.”

AJ was referred by the hospital to a specialist eye hospital the next day, where he had vision tests, pressure readings and ultrasound scans. The consultant revealed that they thought it could be retinoblastoma.

Natasha explained, “They warned us not to Google it, but on the way home, Alex and I decided that we needed to know more so we went straight to the NHS website to search what retinoblastoma was; the standout word was "cancer." Our hearts sunk lower than we knew was possible, we were devastated”.

The following week, the family travelled to the specialist retinoblastoma ward at Birmingham Women's and Children’s Hospital to have AJ’s eyes examined under anaesthetic.

> **“It took us a while to digest what we were being told.”**

Natasha said, “The confirmation of AJ's Rb diagnosis was immediately after – and we weren't really given any other option other than removal of his right eye, purely due to the size of AJ's tumour. Alex and I were devastated, and it took us a while to digest what we were being told.”

The day before his eye removal, AJ turned one. Due to travelling to Birmingham the next day, the family celebrated on his thirteenth-month birthday instead.

Natasha said, “On the day of the operation, we met with AJ's surgeon, and he explained the procedure and really put us at ease. AJ's operation took around three hours, which felt like the longest three hours of our lives! The surgeon performing AJ's procedure came to see us once it was done and told us that it had been a success which was a huge relief! When we collected him from recovery, it was bittersweet as we were so excited to have him back with us, but equally it was hard to see him all bandaged up.”

Natasha added, “AJ's recovery went really well, although it was tough because we stayed in the hospital for five days with him, working shifts between us as we were only allowed one hour per day together with him due to covid restrictions.

“Unfortunately, as AJ had been teething and snotty on the day of his operation, his eye socket became infected. His implant – which we nearly mistook for a bouncy ball – and his clear conformer which he had in his eye before his artificial eye, had fallen out. After another hospital trip, it was determined that AJ needed to have a dermis fat graft in April 2022, where they took some fat from another part of his body and inserted this into his eye to fill the socket space where the implant once was."

Natasha explained, "At first, I found it really difficult to accept that AJ would be going through his life partially sighted because whenever we were out together, the first thing that people would notice was 'his beautiful eyes' and although I knew that he would always be beautiful to our family, I became conscious that it wouldn't be the first thing people noticed about him anymore. However, even now, people will comment on AJ's beautiful eyes as well as his cheeky smile. As long as we know that AJ is happy, we are happy too."

Natasha said, "People who are aware of AJ's artificial eye are in awe of how alike it is to his left eye. On three separate occasions, kind strangers have also noticed a difference in his eyes and asked about them and been amazed when I've explained that one is an artifical eye. There has been however, one occasion, not long after his clear conformer had been fitted when a little girl commented on AJ having a "magic eye" - which I thought was beautiful. She then told her mummy and when questioned what she meant, the little girl said he had a normal pretty blue eye and a magic white eye as well. I was disgusted that the mother's response was 'eurgh'. I would encourage people to think about what they say because you never know what a family has been through and how your comments might affect them in a negative way."

AJ's left eye is monitored for tumours, and so far he has received the all-clear. Natasha said, "We feel extremely lucky that this is the case and that his left eye doesn't need any further treatment at the moment but are extremely vigilant for any signs of changes within his left eye. When his vision was checked last, his left eye's vision came back very strong but having vision in one eye only hasn't seemed to affect him too much, but he bumps into door frames from time to time!

"He is very much a lefty now - choosing to do almost every one-handed task with his left hand but as this is the side where he has vision, we can understand that and are constantly tweaking our parenting to suit AJ's needs, such as sitting him on our right knee to do peekaboo on his left hand side".

Natasha added, "As a one-year-old, AJ is a happy little boy who is now up on his feet, walking around everywhere and developing a cheeky, contagious personality day-by-day. He loves to clap hands and make a mess of the front room by emptying his ball pit, launching three balls across the room at a time - all 300 of them! He always has a smile on his face, especially learning new Makaton signs."

Natasha said, "At the end of World Retinoblastoma Awareness Week, we hosted a local charity evening where all proceeds were split equally between CHECT and Bolton Wanderers In The Community".

AJ with his family

> **"As long as we know that AJ is happy, we are happy too"**

Natasha added, "We are forever grateful to the entire Rb team at Birmingham who have held our hand, been a shoulder to cry on, been a listening ear and been factual, yet sensitive, with us throughout. We would also like to thank the team at CHECT for also being the best support for us while we've been going through the most difficult time of our lives and for always being there at the end of the phone, just to listen and offer advice."

In a message to other parents, Natasha said, "There are so many different scenarios when it comes to Rb and the treatment that AJ has received is completely different to that of other Rb warriors that we are now in contact with. The Rb community is strong and there is always someone there to chat to whenever you're feeling lonely, worried or anxious".

A huge thank you to Natasha, Alex and AJ for helping us to raise awareness of Rb. Their story was shared in The Daily Mail, The Sun and Chat Magazine as part of World Retinoblastoma Awareness Week.

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**.

Crazy Glasses for Rb Week!

As you will have seen from the cover of this issue of InFocus, our families had a wonderful time marking Rb Awareness Week 2022 with a Crazy Glasses event! We are very grateful to everyone who took part, and had fun along the way.

From school to the workplace, at home and even in the pub, you can hold a Crazy Glasses event anywhere, anytime. And you do not need to stick to Rb Awareness Week, either – we encourage our supporters to hold a Crazy Glasses event throughout the year.

All you need to do is wear a pair of wacky specs for a day and donate £2. If you would like to, you could also organise other activities, like a bake sale, charity breakfast or raffle, to boost fundraising even further. We can provide collecting tins, balloons, CHECT leaflets and other merchandise – head over to our resources page at **chect.org.uk/chect-merchandise/** to order yours.

If you'd like to buy a pair of glasses, you'll probably find cheap novelty ones in your local discount shop or online. However, we've put together some free resources so you can download, print and design your own pair at home – find them at **chect.org.uk/other-ways-to-help/crazyglasses/**. If you hold a Crazy Glasses event of your own, do share your photographs with the hashtag #CrazyGlasses. We love to see them!

Could CHECT be your workplace's charity of the year?

If your company would like to support us in any way, we 'd really love to hear from you. Please email Diane Emery, our Fundraising Manager, at **fundraising@chect.org.uk** or call 020 7377 5578.

Summer's here, let's get moving!

If Crazy Glasses aren't your thing why not take on an outdoor challenge?

With summer here we have lots to choose from on our website: **chect.org.uk/other-ways-to-help/events/**.

From the Scottish 10K to the Cheltenham Half Marathon, via the Gower Triathlon and many more in-between there is sure to be an event near you. Or if you have always held an ambition to jump out of a plane – we can help you there as well! With airfields across the UK, you can enjoy the exhilarating and unforgettable feeling of a skydive, flying through the clouds from over 10,000 feet at up to 120mph. Your jump will be free if you raise a minimum of £450 in sponsorship money. Please email **fundraising@chect.org.uk** for more information.

Meet Marvin the Mole, Vision Express' New Fundraiser!

As you may have seen in stores and on social media, the lovable Vision Express mascot Marvin the Mole is now raising vital funds for both CHECT and the Macular Society.

After joining the Vision Express team in 2021, Marvin has proved to be a hit with the public, prompting the high street optician to bring him to life in the form of a soft toy. Better yet, 100% of all profits raised from the sale of Marvin will help those affected by retinoblastoma and people living with macular disease. The fluffy mascot went on sale both online and in Vision Express stores at the end of March, and people are loving offering Marvin a new home.

Vision Express Product Development Director Will O'Connor explained: "We received so much positive feedback from our customers and our colleagues following the launch of Marvin in 2021 and it became really evident that Marvin has quite a fan base! We wanted to bring him to life in our stores in a way that would support the communities in which we operate. I am proud that the business has committed to donating ALL profits from the sale of Marvin to our charity partners and the sale of Marvin will help more people to experience the joy in vision."

We are delighted to be continuing our partnership with Vision Express and this exciting new Marvin the Mole initiative. It will help us to raise vital funds and at the same time raise awareness of retinoblastoma and the importance of early diagnosis. Marvin encourages us all to book routine eye tests, and in particular, parents to make sure their children have regular checks.

To purchase your own Marvin, visit the Vision Express website to buy online, or find your nearest store.

We'd love to see your photos of Marvin! Please tag us on social media and use the hashtag #MarvinandMe or email **fundraising@chect.org.uk** to share your photos of him in his new home.

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:

Brian Thompson
Mrs A C Berryman
Clive Hart
Debbie Macey
June Lambert
Kathleen McLucas

Children's corner

Zain's first bike

Mum Nadia shares the excitement her son, Zain, age 4, has at receiving his first bike from Cyclists Fighting Cancer after having his right eye removed.

When Zain cycles, he faces no difficulties despite having monocular vision – he is a master of his bike and has a such a good handle over his speed and breaking. He is so happy when he is on his bike – he has lost all interest in cars and his other toys as he just wants to be on his bike! Every day he goes to nursery on his bike and all the staff clap and cheer him on, which makes him even happier.

Xavi's trip to London

Xavi was diagnosed with retinoblastoma two days after he celebrated turning two years old. Now age six, Xavi goes for a check-up every six months and is due to have squint surgery in August. Here Xavi tells us about his trip to London with his sister Rosa.

In February half term Mummy took me and my sister Rosa to London. We stayed in a big hotel, and we had a delicious breakfast every morning with coco pops, chocolate croissants and lots of strawberry jam. We also had lots of beds to jump on in our room!

We did lots of exciting things like getting a boat to Greenwich, going to the Natural History Museum, and climbing 311 steps to the top of the Monument. Mummy also took us to Build a Bear and I chose Pikachu and Rosa chose Eevie. I love London and I can't wait for to go back again soon!

Eliza's Equestrian Enjoyment

Eliza, who had bilateral retinoblastoma and had an enucleation, has written about her love for horse riding.

My name is Eliza and I am eight years old. I have a special eye since I was one-years-old. I do like participating in a lot of after school activities. One of my favourite things I love is horses and horse riding. I have been riding for three years now. I go horse riding once a week where I live and have lessons with my sister. I often ride ponies and my favourite ponies are Munchy and Beauty who are well behaved and easy to ride. So far I have been able to walk, trot and canter with the ponies and I really enjoy it. I am hoping I will be jumping soon and I am very excited. When I ride a pony I wear my glasses to protect my eyes.

Mohamed's Posed for Poetry Success!

Mohamed, who had his eye enucleated aged three after being diagnosed with retinoblastoma, is now aged eight and has a strong love for poetry. Mum discusses his achievements and shares a poem that inspires him:

Mohamed has a poetry competition every year called the Poetry Slam, and he loves to participate in it.

Last year he surprised everyone and went to the last and final stage. This year he was reluctant to stand in front of everyone. Therefore, I promised him if he just tried, he will be the best and will be awarded whatever he likes. He has chosen VR Goggles – which are very expensive! Again he surprised everybody and reached the final stage after hot competition.

Mohamed has chosen this piece of poetry by Barbara Vance because he feels that it represents himself, and he likes the message that although life is full of ups and downs, we should always try and find the satisfactions in life.

Why Me? – Barbara Vance

If you have to ask Why me?
When you're feeling really blue
When the world has turned against you
And you don't know what to do

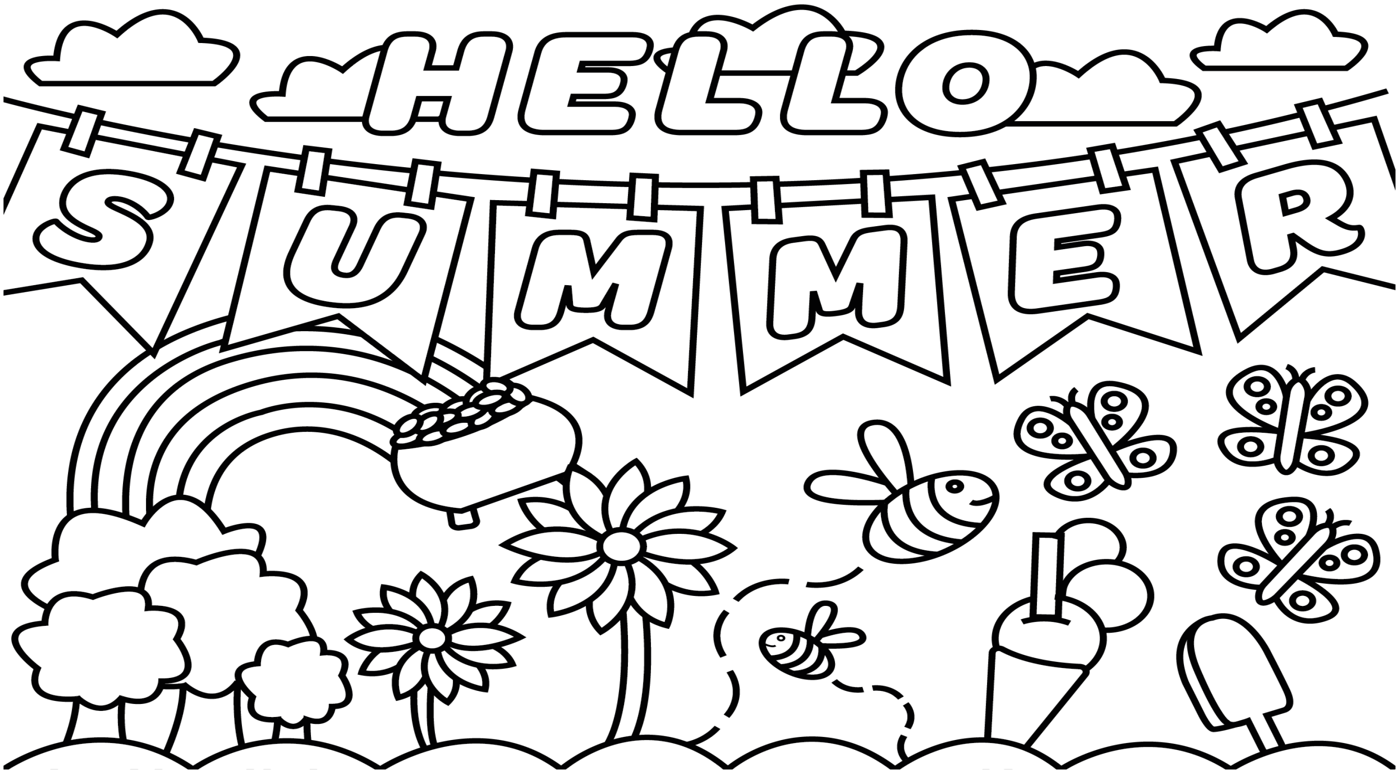
When it pours colossal raindrops
And the road's a winding mess
And you're feeling more confused
Than you ever could express

When the saddened sun won't shine
When the stars will not align
When you'd rather be
Inside your bed
The covers pulled
Above your head

When life is something
That you dread
And you have to ask Why me? . . .

Then when the world seems right and true
When rain has left a gentle dew
When you feel happy being you
Please ask yourself, Why me? then, too.

Colour me in!



What's on...

Virtual London Marathon ***2nd October 2022***

Join in with the largest single fundraising event in the world! Runners have 23 hours, 59 minutes and 59 seconds to complete a marathon on a route of their choice. Do it your way! Design your route along landmarks that are important to you, or invite friends and family to complete a section of the route with you. Participants will receive an official London Marathon T-shirt and medal upon completion (as well as a CHECT vest!). Minimum sponsorship £200

Great North Run ***11th September 2022***

Join 56,999 others celebrating the return to the city to sea route of the largest half marathon in the world. You'll take in the sights of Newcastle, run across the iconic Tyne Bridge and finish on the coast in South Shields, hopefully spotting the Red Arrows along the way. Minimum sponsorship £500

To find out more about any of these events, or others that we have planned for the year ahead please call Diane Emery on 02073775578 or email fundraising@chect.org.uk

Other ways to help

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.

CHECT

BOPP

*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!