

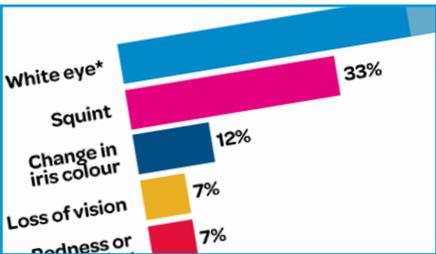
infocus



THANK YOU
for taking part in the
2.6 Challenge!



DON'T DELAY!
The story of a mum who spotted her child's cancer in a flash photo.
Page 5



RB DIAGNOSIS PATHWAYS
The latest Rb figures from our yearly report.
Page 4



I REMEMBER MY RB TREATMENT
Diagnosed at nine, a teenager recalls her Rb experience.
Page 7

WELCOME

For most of us our day to day world has changed hugely, for some of us it has been turned upside down. I hope that you and those close to you are finding your own way through the unusual and testing circumstances we find ourselves living in.

As you can see, this edition of InFocus has been produced in digital format only. As a small charity, we are seeing the significant financial impact of the pandemic and the resultant lockdown. This digital issue is one example of where we are minimising expenditure to ensure that we are able to continue providing much needed support and maintain our efforts to raise awareness.

This May saw World Retinoblastoma Awareness Week and thanks to our wonderful families and their work with us and with the press, we were able to reach over 3 million people as part of this year's campaign. Now, perhaps more than ever, we need to encourage anyone who has a concern not to delay and not to be deterred from seeking help from a medical professional if they

suspect anything is wrong with their child's eyes – sadly, cancer does not stop for COVID-19.

A huge thank you to all of our incredible members and supporters who took part in the 2.6 Challenge.

We've really enjoyed seeing your photos, many of which are on the cover of this issue of InFocus, your videos and finding out what amazing ideas you have come up with to help us through what is a financially difficult and testing time.

Since the end of March, all of the CHECT team have been working remotely, adapting to new ways of communicating digitally with one another and with our CHECT families. I was lucky enough to be able to join one of our Zoom Story Time sessions with some of our families led by our support workers Lesley and Sarah. It was wonderful to see all those smiling faces, enjoying the session and almost always, listening intently!

Lesley and Sarah are available as usual both online and directly via phone. Please don't hesitate to contact them at any time. Despite the fact that we may not see you in person for a little while, rest assured everyone at CHECT will not stop being there for everyone affected by Rb.

With very best wishes for you, your families and all those around you.



Patrick Tonks
Chief Executive

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New postcode!

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

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NEWS

INFORMATION LEAFLETS

We are pleased to announce that we have updated three of our information leaflets for parents:

- 'Just Diagnosed',
- 'Enucleation' and
- 'Chemotherapy'.



As well as including the latest information, these leaflets feature stories and tips from families who have already gone through the process.

Thank you so much to all the families who took the time to share their experiences with us - we know other parents always find these stories incredibly helpful. They are now available to view and download at: www.chect.org.uk/resources

BUSINESS AS USUAL (ALMOST)

Like many, many people, our CHECT staff are all working remotely from home at the moment, continuing to raise awareness and support families affected by retinoblastoma. Here we all are on our weekly Zoom call saying hello from our living rooms and kitchens!



WANT TO RECEIVE THIS MAGAZINE IN A DIFFERENT FORMAT?

This edition of InFocus is online only. For future editions, we will be offering InFocus in the following accessible 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.

CONTENTS

- Page 2-4: News
- Page 5-8: Real lives
- Page 9: A week in the life of a support worker
- Page 10: Teenage update
- Page 11: Research
- Page 12: Members day moments
- Page 13 -15: Fundraising and events

HAVE YOUR SAY

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

Thanks for your support!

STORY TIME WITH LESLEY AND SARAH

As CHECT support workers Lesley and Sarah are unable to visit the hospital clinics at the moment, one way that they are able to be in contact with families is by holding story telling sessions via Zoom.

This is a great way of keeping in touch with young members, their parents and siblings - and for the children to see Lesley and Sarah and each other too.

Each 20-minute session is mainly aimed at children up to the age of seven, but anyone is welcome to join.

Lesley said: "We both find it is a real highlight of our working week and have enjoyed sharing stories, celebrating birthdays of the children - and occasionally favourite toys - together!".

If you and your children would like to join in any of these sessions, please contact Lesley or Sarah for details: www.chect.org.uk/your-support-worker.



▲ Young CHECT Member Amber taking part in Story Time.

WE NEED YOUR STAR PHOTOS!

Can you help? We're looking for a UK-based child who has been affected by retinoblastoma to be the cover star of our new batch of thank you cards.

Photographs should include a happy pose such as smiling, jumping or giving a thumbs up! We send thank you cards to donors, supporters, volunteers and companies. The image may also be used within thank you emails, on CHECT thank you certificates and in CHECT marketing materials.

If you have a suitable (high resolution) photo that you would be willing to be used for these purposes, please send it to us at info@chect.org.uk by 1st September 2020.

This picture of young CHECT member Taigh was one of the photos chosen last year



PATHWAYS TO DIAGNOSIS 2019

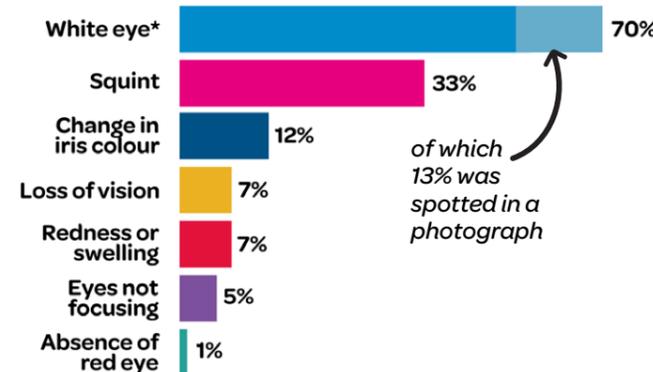
Each year we collect information about the journeys UK families take to reach an Rb diagnosis for their child.

Since 2012, this 'Pathway to Diagnosis' information has been gathered by our support workers with the agreement of families who have had a new diagnosis and no prior Rb family history. This information informs the work that CHECT does, in particular our awareness raising.

Symptoms

Our data shows that a white glow in the eye is the most commonly first-noticed symptom of retinoblastoma. Whilst a glow can sometimes be spotted in flash photos, it is far more commonly spotted in the child's eye itself, often in dim lighting.

Reported symptoms of Rb (more than one symptom can be present per case)



Awareness

In 2019, **28% of our newly diagnosed families had heard of Rb** before they had a diagnosis.

5 out of 7 of these families had heard about it through Facebook, and 6 out of 7 were diagnosed at an Rb Centre within a week of seeing their first health care professional.

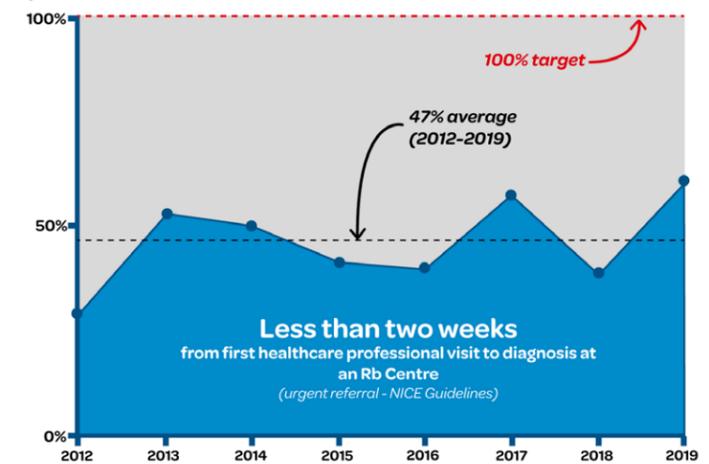
For a rare condition this is great progress, and we'd like to thank all our members for sharing our posts over the years - helping us to raise awareness.

Thank you!

Referral rates

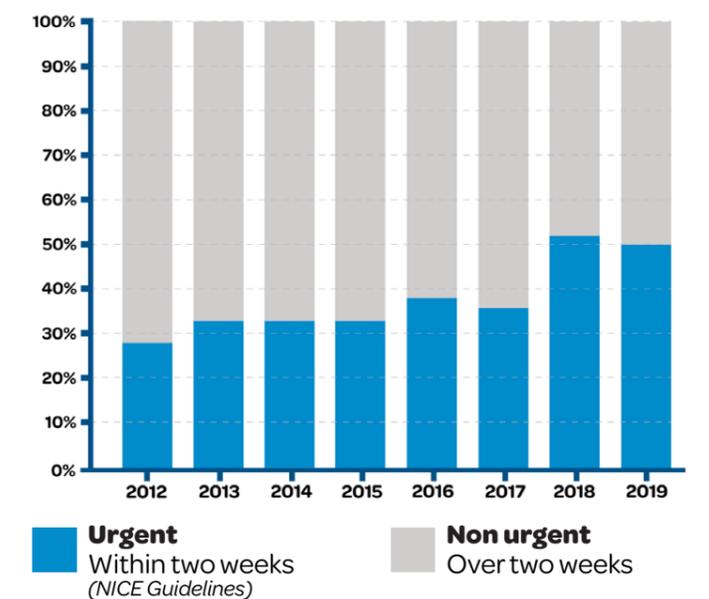
In 2019 we had our highest urgent referral rate on record with 60% of children having taken less than two weeks from their first healthcare professional visit to being diagnosed at an Rb Centre. However, there is clearly much room for improvement to reach our target of a 100% urgent referral rate for children who display the symptoms of Rb.

Urgent referrals across all UK healthcare professionals:



We also continue to work with GPs (the most common first port of call for parents) who have also been showing an average increase in urgent referral rates since 2012, with the last two years being over 50%.

Urgent vs non-urgent referrals made by GPs for children with Rb in the UK:





“DON’T DELAY”, SAYS MUM WHO SPOTTED HER CHILD’S CANCER IN A FLASH PHOTO.

Parents Shelby Simkins and Ryan Denham teamed up with CHECT during World Retinoblastoma Awareness Week, at a time where parents may feel anxious about seeking medical advice due to the pressures of COVID-19.

Dela-Rose Denham was just five months old when she had her life-saving operation to remove her eye, after a cancerous ‘white glow’ was spotted in a chance flash photo.

Mum Shelby mentioned Dela-Rose’s squint at her six-week check. However, as squints are common in babies, the parents were told that they shouldn’t be concerned. It was only when Dela-Rose was about three months old

when Shelby took a flash photo that she spotted something unusual in her baby girl’s eye.

Shelby said: “By chance, she was lying back on Ryan’s knee when I snapped a photo on my phone. We noticed that one of her eyes was red and the other was silver. We thought that it was likely to be the light reflecting off her eye because of the odd angle the photo was taken at, so we didn’t think too much about it, but it was always in the back of my mind.”

Around a month later in September 2019, Dela-Rose had a routine appointment with her GP. The GP acknowledged that her squint was rather pronounced, which was no cause for immediate concern, but suggested that the couple take Dela-Rose to be seen by an optician for a thorough check after Shelby mentioned what she had seen in the photo.

After a visit to the opticians, Dela-Rose was then referred to an ophthalmologist. The specialist, who found that Dela-Rose’s left eye didn’t fixate

◀ **The photo which first captured the white glow.**



or respond well to light, further referred the couple to a consultant at Dover Hospital. It was at this point that Shelby and Ryan realised that something could be seriously wrong.

Shelby said: “In those two weeks between seeing the ophthalmologist and the consultant, we had noticed that Dela-Rose’s left eye had started to develop a sort of glazy haze, which was now becoming more noticeable.

“People say you shouldn’t Google symptoms because it only makes you worry, but we had been. We were hoping it was just a cataract – but when we realised it could be something as serious as eye cancer, I felt sick to my stomach.”

After further examination by the consultant at Dover Hospital, tests revealed the news that the couple had been dreading – Dela-Rose had retinoblastoma and that she would need to be seen urgently by the specialist Rb team at The Royal London Hospital.

Shelby said: “Ryan and I went into shock and we just sat down outside the hospital together – we couldn’t believe what we had heard. I thought I’d mentally prepared myself for the worst, but were both absolutely heartbroken.”

Within an hour, The Royal London Hospital had called the couple to arrange an urgent appointment for the following week.

Shelby said: “I broke down in tears on the phone to my mum – ‘It’s just not good news’ I told her. We desperately wanted someone to fix what was wrong with our baby girl.”

At the Royal London Hospital, Dela-Rose’s eyes were examined under general anaesthetic where they could thoroughly check the tumour’s progression. The cancer was only in one of her eyes and hadn’t spread any further.

Shelby added: “I kept wanting to know why my child had this cancer, what was the cause. We were told that it can happen to anybody’s child unexpectedly and they’re still not really sure why – you don’t have to have a family history – it’s just if you’re very unlucky.”

The hospital staff spoke with the couple about possible treatment options. As Dela-Rose’s tumour was large, they decided to have the affected eye enucleated.

Shelby said: “It was such a hard decision to make. We decided

that as Dela-Rose didn’t have good vision in that eye anyway as the tumour was so large – we just wanted it gone. Chemotherapy and cryotherapy wouldn’t have saved her vision and she could have gone through all that treatment and still had to have her eye removed if it didn’t work.”

Dela-Rose had the surgery on 30th October 2019. The couple stayed overnight with her in the hospital and were allowed to take her home the next day.

“Everything happened so quick. We were absolutely heartbroken, but also so relieved that our daughter’s cancer had finally been removed.”

Thankfully, Dela-Rose quickly recovered from her operation and in February she received her first artificial eye.

Shelby said: “We’re really happy with her eye and she’s taken to it very well. I’m so impressed with how it looks; they’ve done an amazing job.”

“I look back to this time six months ago – I can’t believe how quick the whole process was. Now she’s a really lively, talkative one-year-

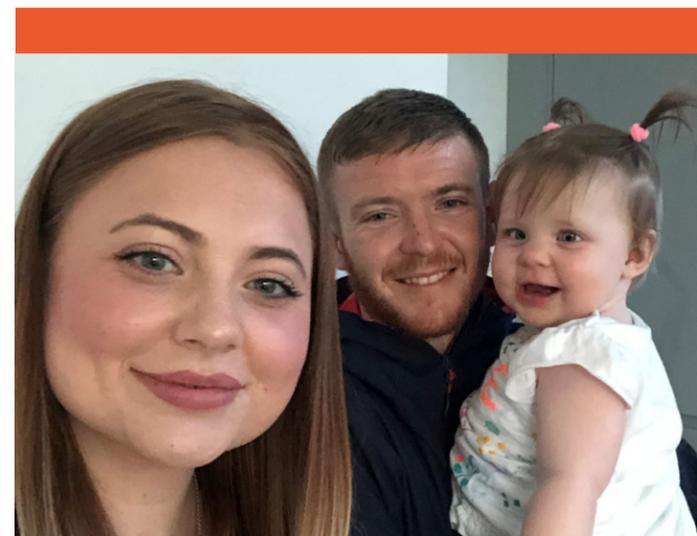
old who certainly keeps us on our toes!”

In a message to the public, Shelby says: “Please don’t delay in getting your child seen if you feel something isn’t right. I felt like I was a hypochondriac, worrying for no reason and didn’t want to be a burden on the NHS.

“Just go get them checked out. In reality you’re not bothering anyone – take notice of your gut feeling. I’m so glad I mentioned my concern to our doctor, because that led us to being able to catch it early enough and not waste any time.”

Patrick Tonks, Chief Executive of the Childhood Eye Cancer Trust said: “COVID-19 is deterring many people from seeking much-needed medical advice, and we are concerned about the delays this may cause in getting undiagnosed children the urgent treatment they may need.

“Cancer doesn’t stop for a pandemic. Now more than ever, we need to raise awareness of eye cancer symptoms – the most common being a white glow in the eye and a squint.”



A huge thank you to parents Shelby and Ryan for helping us to raise awareness.

This story was picked up by the press during World Retinoblastoma Awareness Week and was published online on websites the Daily Mirror, The Sun and Yahoo **reaching over 500,000 people.**

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

◀ **Shelby, Ryan and Dela-Rose with her new artificial eye.**



REAL LIVES

“WHEN THEY SAID I WAS GOING TO LOSE MY EYE, I WAS ALMOST RELIEVED...”

Eloise Patterson was nine years old when she was diagnosed with Rb. Unlike so many children, she is able to remember her diagnosis and journey through treatment. Now aged 16 she tells her story:

I remember having these ‘black floaters’ in my vision. Most people get them when they look at a bright light, but I had them continuously - bug-like wiggly lines.

We then noticed that in flash photos taken of me, one of my eyes would go silver and the other would go red. We ended up at the Royal London where they diagnosed me with retinoblastoma, which normally only affects babies and younger children.

When I was told that I had cancer, I was like - “ok”. Being only nine at the time, I didn’t really know what cancer meant - it was just something which I had heard mentioned on TV.

I went to school the next day and casually told my friends “Hey, by the way I have cancer”. And they were like “Sorry? What?”. “Yep, I have cancer”.

My friends were really great, they were all open about it - including my class at school. When I finally got my head around my cancer, I explained to my classmates about my treatment ahead.

One of my teachers, who previously had cancer, also offered to lend a friendly ear if I ever needed someone to talk to.

“Chemo was weird”

My mum had a friend who was recovering from cancer and she was brilliant - she’d come around to the house and talk to me about it. She told me that she had so many cravings during chemo and that she went through a phase of constantly eating Magnum ice creams!

She was right. During my own

chemo, I had the weirdest cravings, mainly for sirloin steak and bacon sandwiches. I ate SO many bacon sandwiches.

Chemo was weird. I decided to have the port instead of a Hickman line mainly because I loved going swimming, and I wouldn’t be able to get a Hickman line wet. I also had to have blood tests once a week before school. When it came to having chemo sessions, I would always make sure I did a cartwheel first before they hooked me up to a drip for six hours! Of course, you can’t do cartwheels once you’re hooked up to a chemo drip.

One of my funniest memories was when my friend came to visit me. Obviously her mum had said something to her along the lines of - “be prepared, she’ll be lying in bed and she’ll look really ill”. Anyway, she comes onto the ward and the first thing she sees is me flying towards her on a drip! I was in the middle of a race against one of the nurses whilst another nurse was wheeling me along!

Afterwards was the worst part of chemo - not during - you just feel steadily more and more tired. Sometimes I wouldn’t eat for two or three days because I’d just throw it straight back up, so I also lost quite a bit of weight too.

We all stayed in the UK during my treatment, choosing to holiday

at my grandparents’ house in Southampton. I think back on that time and remember it being an awesome summer actually, even though we had to go to hospital fairly regularly whenever I got an infection.

“Infamous chemo curl”

When I started chemo and lost my hair, I never once had an issue with people being mean or asking why I was bald - which I’m really glad about because I imagine that would have been hard to deal with. I feel that if I hadn’t been so open about it at the start and tried to hide what was going on, there would have been a different reaction.

Chemo was pretty bad, but not completely horrible. At least my hair loss turned out to be good for Halloween when I dressed up as Golum! That was an awesome costume and hands down the best one I have done to this day.

The Little Princess Trust gave me a really cool wig made of real hair that looked just like my own. However, I didn’t really like the feel of wearing wigs, they just didn’t seem like they were mine, so I chose to wear a headscarf instead.

Four years later I ended up donating my hair back to the Little Princess Trust. I also raised around £4,000 for the charity and had a stylish buzzcut. When I had finished chemo and my hair started to grow back, I got the infamous ‘chemo curl’ which everyone had been telling me about - basically I had an afro for six months which then eventually grew out. It looked good though!

Chemo didn’t really stop me from

doing anything - maybe for the couple of days each time after a chemo session - but I kept up my gymnastics, football, netball, swimming - everything I had done originally. I didn’t really like having to stay indoors all day feeling like a sick patient.

Some unfortunate news

A couple of months later, the hospital got in touch to say that they wanted to see me. They told me that the chemo, which I had to try and save my eye, hadn’t worked as well as they had hoped and I was going to have to lose my eye.

I wasn’t that phased to be honest, because I thought there was a chance that they were going to tell me that I might die. So, when they said I was going to lose my eye, I was almost relieved - I thought it was going to be so much worse.

My parents’ reactions were what hit me the most. I was ok with the fact that I was going to lose an eye, but my mum was in tears. My older sister Grace asked if I would be able to cry properly with an artificial eye (which you can!). Grace was great. She didn’t want to treat it like it was something to get upset about.

Throughout my Rb journey, all the medical staff I’ve spoken to always made sure to involve me in everything. They never looked past me - they talked to me directly, asked me questions - what I thought, how I felt. That was so helpful because it made me feel that I wasn’t being blindsided by anything, and of course, my parents always spoke to me about what happening too.

The hospital staff showed me

pictures of people who had artificial eyes - asking me if I could tell which one of their eyes wasn’t real. I think I got one correct out of about five, and at that point I knew it wasn’t going to be that bad, and that they were going to make me an eye that looked realistic.

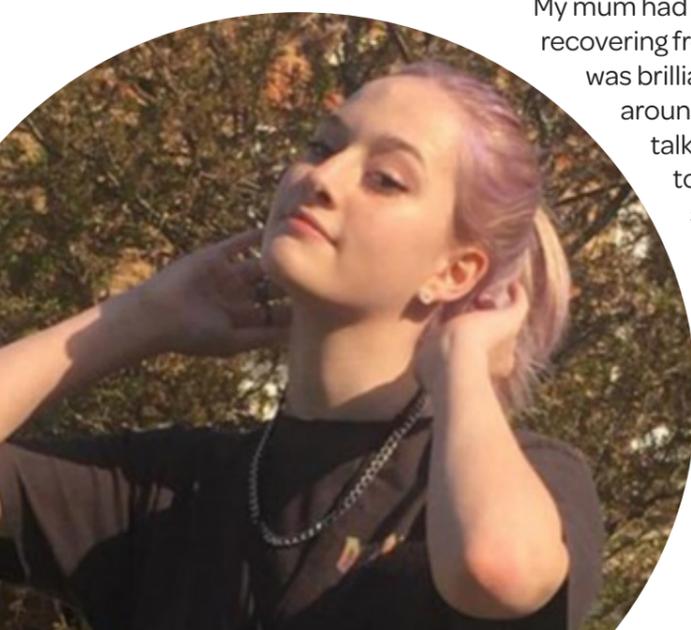
Life with an artificial eye

In the end my artificial eye did take a couple of tries to get perfect, but the one I have at the moment is really great. I also have a rainbow coloured one which I wear at special occasions! I have a bunch of different eyes around the house somewhere.

Having an artificial eye hasn’t disadvantaged me in anyway. Except, maybe trying to do winged eyeliner - but I’ve even mastered that now! I do tend to joke about it, and not shut it down, which relaxes people and makes things easier. I’m also looking forward to learning to drive soon and I’m starting to consider my options for uni in a couple of years’ time.

If anyone does notice my eye, they just assume I’ve got two different coloured eyes and they think that’s cool. Obviously I have moments when I hate it and feel paranoid that everyone is thinking about my eye - but then I talk to my friends who are genuine when they say that they didn’t even realise I had an artificial eye when they first met me, and they certainly don’t notice it now.

My advice to others who have gone through Rb or who have an artificial eye, is not to worry about what people think - people don’t notice it as much as you think they do. You build it up in your head that it’s terrible, but it really isn’t.



A WEEK IN THE LIFE OF A CHECT SUPPORT WORKER

Sarah Turley, who joined the CHECT Team in October 2019, is our part-time Support Worker based in Birmingham Children's Hospital. She shares with us what it's like to be a CHECT Support Worker during these unusual times.

Six months after starting my role, I never could have predicted that my working week would look as different as it does now. COVID-19 has changed all of our lives and made us readdress the ways in which we communicate with one another.

Initially it was very challenging not meeting families face to face. Being unable to chat and see with my own eyes how everyone is feeling has meant that as a Support Team, Lesley (Support Service Manager) and I have had to get creative – and more technological!



Monday

After checking emails, texts and voicemails from the weekend, I read our Facebook messages and contact an anxious parent in response to some concerns they have about their child. I then phone a family about a Macmillan grant we have previously discussed, and then complete an online form requesting for help with funds for travel and kitchen equipment.

Next is a call to Lesley about our upcoming Teen Focus Council meeting in June. I message the group on Facebook to schedule a pre-meeting around their ideas and to draft a brief agenda. The teens are quick to reply and enthusiastically agree to meet up online during the week.

Tuesday

Occasionally we receive enquiries from families outside of the UK. This morning I received one such enquiry and was able to message the family with some information about where they might find support locally to them.

Every week I have a meeting with staff from Birmingham Children's Hospital via Zoom which is led by their clinical psychologist. These catch-ups allow me to understand how EUA and outpatient appointments are working whilst I am working from home,

as well as talking through ideas to help support our families.

I then contact families who have been in for an appointment to see how they are and if there is any support I can offer – information about online shopping slots, suspending bills and furlough information are discussed, as well as starting to research some benevolent funds to help families who need urgent financial help.

I've got ten minutes to choose a book for 'Storytime' and to think of a simple craft idea for our children to try their hand at. We have nine families online today – with lots of siblings. It's the highlight of my week so far - lots of waving, smiles and great listening!

Wednesday

I catch-up with a family I had called earlier on in the week, who are currently shielding, to see how they are coping with isolation. We use the GOV.UK website to enlist them for priority online shopping.

We also discuss how to keep their child occupied during chemotherapy and EUA appointments now that there is no longer access to toys within the hospital. I am able to tell them that the Play Worker will be on site for support.

Next, I attend our weekly Zoom meeting with the whole CHECT team – it's great to see the team and hear some encouraging words! Both Lesley and I stay on to talk to our Teen Focus Council (TFC)

about inviting teenagers from the Birmingham Children's Hospital service to join us on Zoom – they come prepared with great ideas.

Thursday

Following our meeting, I draft some documents for the teens to look at and amend. I contact more families by phone, text and email to check in and help with any practical things they may need, as well as referring to other services or charities.

I then join 'The Health Based Youth Workers Conference'.

Here, I get to talk to other Youth and Support Workers about how they are providing support, sharing good practice and some great online resources – this is very helpful when thinking about creative ways to work with families and young people whilst we are unable to be face to face.

Friday

This morning I have a long chat with one of our long-standing members, I am able to signpost them to a great local service for some information.

I then attend Birmingham Children's Hospital's Multi Disciplinary Team meeting with all of the clinical staff. It's a great way of keeping in touch with the Rb team and remaining connected with the hospital even when working remotely.

For our final 'Storytime' of the week, we have a birthday! A rowdy Zoom rendition of the 'Happy Birthday' song, staggered and out of tune finishes my working week off perfectly!

Both Sarah and Lesley are still available by phone, text, email and Zoom for support with anything, even if it's just a chat. www.chect.org.uk/your-support-worker

TEEN FOCUS COUNCIL UPATE

Written by CHECT Teen Focus Council Member Harry Harrison

During the Coronavirus lockdown, the Teen Focus Council (TFC) have been keeping in touch via a Facebook messenger group. In May we held a Zoom meeting to discuss ways to get more teenagers involved and ways that the TFC (which now has its new logo confirmed!) would still be able to remain active and involved in CHECT whilst we were all at home. We've also decided to hold a full Zoom meeting later on this month.

Furthermore, CHECT support worker Sarah will be contacting Birmingham-treated teens about the benefits of taking part in our teenage activities, such as making friends who've also had Rb. So, please tell mum and dad to keep an eye on their email inboxes! CHECT is currently in the process of editing a short video, where TFC members tell you a little about what we do, which will be available soon on the TeenFocus website:

www.teenfocus.co.uk



CONGRATS, THEO!

TFC member Theo Sergiou has won a Rotary Young Citizens Award and was interviewed on the BBC! He is also the London representative on the UK's Youth Parliament and is passionate about reducing knife crime. Rb left Theo partially sighted, but that hasn't stopped him from achieving amazing things and having such an inspirational attitude towards cancer.

Catch his interview on Youtube: <https://youtu.be/9Wf8LujKmHQ>



CHECT RESEARCH

MEET THE NEW SCIENTIFIC ADVISORY COMMITTEE PARENT MEMBERS

As you may remember, last summer we created two new positions on our Scientific Advisory Committee (SAC) so that we could involve CHECT parents more in the charity's research activities.

We were overwhelmed by how many of you expressed an interest, and we were delighted to have so many suitable applications. Meet our new members Pippa and James, who joined the SAC for their first meeting in November 2019:

Pippa Branch



My daughter was diagnosed with retinoblastoma in March 2018. Before this point, like so many parents, I had never heard of retinoblastoma. Despite her unilateral Rb diagnosis, genetic testing has since shown she carries the Rb gene.

I hope that with my recent experience as a parent of a child receiving treatment for Rb, that I am able to offer an alternative, non-medical or scientific perspective to the SAC. My interest in research stems from my daughter's treatment and the genetic nature of her diagnosis. I was also a primary school teacher for 19 years and therefore I hope that this experience will also help to offer an educational insight into discussions about research.

PROJECTS UPDATE

We were delighted in 2019/20 to be able to award a record number of research grants to a range of projects, including a PhD study for the first time in many years.

Sadly, the financial impact of coronavirus on charity fundraising has meant that we have had to postpone these new projects for the time being.

We will continue to support research projects currently underway, and very much hope we will be able to renew our commitment to the postponed studies next year.

James Morley-Smith



I've spent over 20 years originally as a software engineer and am now leading an international design team in a global tech company, creating hardware and software solutions helping frontline workers from retail staff to nurses and doctors. My work requires me to fully understand the needs of users through research and observation.

I'm the father of four boys, the second youngest of which was diagnosed with Rb when he was four months old. After receiving almost all the treatment available, he unfortunately had to lose both of his eyes by the age of six. Now 12 years old, he is thriving. However, his journey gives me an understanding of the impact of Rb and - combined with my work - hopefully brings a unique layperson's perspective to the SAC.

MEMBERS' DAY MOMENTS

Members' days are a great way to meet other families who are or have been affected by Rb and to nominate your child for a CHECT Champion Award.

In January of this year, CHECT families enjoyed an enchanting day out at Discover Children's Story Centre in London. A special thank you to our volunteer photographer Kathleen Holman, here are just a few photos she captured from the event.



CHECT CHAMPIONS

As ever, our CHECT Champions have inspired and amazed us with their outstanding bravery coping with the impact that cancer has had on them and their families. The latest CHECT Champions to receive their certificates are (from left to right):

- Laura Slavkova
- Natalie Slavkova
- Clark Northfield
- Kaloyan Iliev
- Sebastian Burrell





DARE TO TAKE PART IN OUR LATEST CHALLENGE?

Throughout August, all are invited to join us for our new and exciting fundraiser - the CHECT "Dare-A-Thon".

The sheer scale and impact of the COVID-19 pandemic means that now more than ever we need our amazing supporters to help raise vital funds to help us continue our work and support families affected by Rb – and perhaps have a little fun at the same time.

Your friends and family can get involved, too – by making a donation in order to 'dare' you to do something you have never done before! How about wearing fancy dress for your next Zoom call or eating a mouthful of crackers and then trying

to whistle? And for children - wearing your socks on your hands for the day or even doing mum's makeup? If you feel particularly daring, you can accept a challenge every day during August - or if one challenge is enough, that's fine too!

We want you to have as much fun and to be as creative with your dares as possible – however, please avoid anything that makes anyone feel uncomfortable or which may pose a risk to someone's safety.

Don't forget to share your videos and photographs with the **#CHECTdare** hashtag, or email them in to us at info@chect.org.uk so that we can share them to inspire others to take part.

Please register via our website www.chect.org.uk/dare or email info@chect.org.uk for your CHECT Dare-A-Thon pack, containing lots of ideas to try.

CHECT SUPPORTERS STEP UP IN TIME OF NEED

For many charities, including CHECT, the COVID-19 pandemic has had a catastrophic effect on their ability to raise much-needed funds due to the cancellation of thousands of events and the loss of billions in income through fundraising.

The 2.6 challenge was a national campaign to help support charities during this difficult time – launched on the 26th April to mark what should have been the day of the London Marathon.

What can we say...our CHECT supporters truly delivered! We loved seeing all your creative ideas – a lot of photos of which have been featured on the cover of this magazine. It means an incredible amount to us and has helped us to

continue to provide support for families affected by retinoblastoma during these especially challenging times.

So, from everyone at CHECT, a huge **THANK YOU!**

Speaking of the London Marathon, with this year's event postponed, ten of our CHECT runners instead took part in a virtual marathon relay doing 2.6 miles each. When one sadly couldn't make it, CHECT Chief Exec Patrick stepped in - and our Support Worker Lesley made a welcome addition to the team, too! Well done all - we salute you!

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:
 Julie Cooper
 Sheila Geddes
 Brenda Holt
 David Hughes
 Mary Alexandra Jacobs
 Neil Preston



WHAT'S ON...

RunThrough Regent's Park (virtual) 11th July 2020

RunThrough Regent's Park always attracts our biggest team of CHECT runners, and this year we are proud to have been chosen as the run's official charity partner!

This event has now been changed to a virtual race. This means that runners can complete their chosen distance (5km or 10km) at their own time in their local area whilst adhering to social distancing guidelines. You will still receive an official medal and goody bag upon submitting your time and proof of your run to RunThrough. We have some virtual runners already and we would love to welcome you to TeamCHECT!

CHECT Dare-A-Thon August 2020

Get creative and challenge yourself and others to do dares throughout August to raise vital funds for CHECT. www.chect.org.uk/dare



To find out more about these events, or others that we will be planning in the future, please contact Diane Emery on **020 7377 5578** or at diane.emery@chect.org.uk

OTHER WAYS TO HELP



We've been helping families affected by Rb for over 30 years but we don't receive any government funding so we rely on public donations to pay for our work.

If you would like to make a donation, you can do so by:



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



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

AMAZON SMILE

We know that during this difficult time, many of us are shopping online much more. If you are buying from Amazon, we would be enormously grateful if you could sign up to AmazonSmile and add CHECT as your chosen charity. It doesn't cost anything extra and CHECT will receive 0.5% of your purchases. So far we have raised over £400 from this initiative – visit smile.amazon.co.uk to sign up.



CO-OP COMMUNITY FUND

If you are a Co-op member, or are thinking of signing up – you can now choose CHECT to benefit from Co-op donations. However, you must use the link: chect.org.uk/coop. We will receive donations until October 2020, so please help us raise as much as possible in the coming months!

