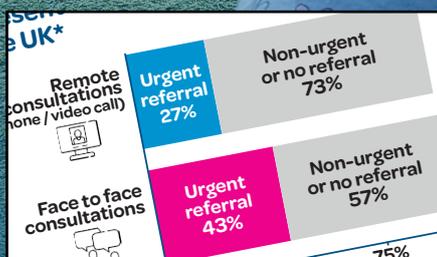


## Parental intuition proved correct

Read Katherina's diagnosis story on page 7



### Rb diagnosis pathways

The latest figures on Rb symptoms and referral rates from our yearly report. **Page 3**



### The international super team of Rb scientists

Find out about the team of researchers working to tackle Rb and second cancers. **Page 4**



### Children's corner

Read stories from our young CHECT members and enjoy a fun colouring in activity. **Page 13**

# Welcome

## Welcome back to InFocus!

After such a challenging period for so many individuals and families, it feels like we are about to enter more hopeful and positive times, I do hope so.

After a year-long hiatus being digital-only to conserve costs, we're pleased to be able to provide this edition of InFocus in print as well as online. Like so many charities, the pandemic has made us take stock of our resources and indeed our services to members, therefore on page 2 we're asking for your feedback on the future format of the magazine. We'd love to hear your thoughts.

As a charity, the last twelve months have been such a challenging time. Back in January, we tried something completely new, reaching out to a UK audience of virtual, digital fundraisers – some of whom had never heard of retinoblastoma before, let alone our small charity – challenging them to do 2021 Squats in a month (as featured in InFocus Winter 2020). The response was overwhelming!

Whilst there are still challenging times ahead, this event, along with the fundraising efforts of our members and the generous contributions from some amazing trusts and foundations, has helped make up for our lost income due to the pandemic. This ensured that we have been able to continue to offer support to all families in the UK with a retinoblastoma diagnosis and to re-start our suspended research programmes.

What is more, we've made some new friends and supporters along the way.

For Rare Disease Day (28th February) and World Retinoblastoma Awareness Week (9th-15th May) we raised awareness of the signs and symptoms of retinoblastoma

amongst the general public and health care professionals on social media and in the press. We are extremely grateful to CHECT member Rada and her family, for sharing their story with the media during World Retinoblastoma Awareness Week. The story, which was featured in the Mirror online and other news outlets during May, can be read on page 7.

Our feedback from families gathered in our latest 'Pathways to Diagnosis' results suggest that the pandemic has had a significant impact on delays in the diagnosis of children – sadly 2020 has seen the lowest urgent referral rates since 2012 for children presenting with retinoblastoma symptoms. In our key messaging, we're now frequently urging parents to insist on a face-to-face appointment with their GP if their child has symptoms of Rb, or to seek an alternative medical professional to avoid delay. You can read a summary of the key findings on page 3.

Very sadly our former trustee and friend, Ffion Miles, passed away earlier this year. Many of you will fondly remember Ffion from our Members' Weekend and Beyond Rb trips. A tribute to Ffion can be read on page 10.

It will be wonderful, we hope, to see events opening up again and everyone at CHECT sends good luck and a huge thank you to our runners in the London Marathon. This year's event is taking place in October. You can meet the team on page 11.

Finally, I hope the weeks and months ahead are calmer and kinder to all our families and to the wonderful NHS teams in London and Birmingham whose vital work is so important to us all!



**Patrick Tonks, Chief Executive**

## Contact us

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

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Page 5-8: Real lives

Page 9: Interview with an Rb rugby star

Page 10: Tribute to Ffion Miles

Page 11-12: Fundraising and events

Page 13-14: Children's corner

Page 15: What's on



## The passing of philanthropist Clive Richards

It is with great sadness that we report the death of a wonderful supporter and friend of the Childhood Eye Cancer Trust, Mr Clive Richards.

We send our thoughts and best wishes to his wife Mrs Sylvia Richards and family.

We are extremely grateful to the Clive & Sylvia Richards Charity, and to Mr Richards personally, for their kindness and generosity in supporting CHECT's work. Mr Richards' support, advice and wisdom will be greatly missed.

## News

### CHECT Scientific Advisory Committee thanks Iain for six years of service

This year we are saying farewell to Iain Riddell, who is stepping down as a lay member of the CHECT 'Scientific Advisory Committee' (SAC), having been in post since 2015.

The main responsibility of the SAC is to oversee CHECT's research activities: assessing applications to our annual funding round and monitoring the performance of CHECT-funded projects.

As the first person to hold this post, Iain has done a great job making sure the voice of adults with Rb is central to CHECT's research discussions.

We were delighted with the response to our call for a member to take over this role, and look forward to welcoming Cath McParlin as the newest lay member on the SAC.

## Have your say on the future of InFocus

We're glad we've been able to resume producing InFocus in print in 2021. However, we would like to consult you, our readership, to gather your thoughts on the future content of the magazine and if we should we continue to offer a print option or go fully digital\* instead.

*\*Accessibility is crucial to CHECT; therefore, we will always continue to provide braille, HTML and large A3 print versions of InFocus for our members with a visual impairment.*

The survey can be completed at [chect.org.uk/infocus](https://chect.org.uk/infocus). Alternatively, reply via post with the form below to: *Childhood Eye Cancer Trust, Royal London Hospital, Whitechapel Road, London, E1 1FR.*

Your name: \_\_\_\_\_

Your email: \_\_\_\_\_

I would prefer InFocus in the following format:

Printed only     Online only     Both print & online

Do you have any general thoughts on InFocus magazine? *Eg, Is there anything else we should introduce or leave out of the magazine? (Feel free to continue on a separate piece of paper!)*

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Please let us know your thoughts at:

 [chect.org.uk/infocus](https://chect.org.uk/infocus)

We'll be closing the survey 1st September 2021



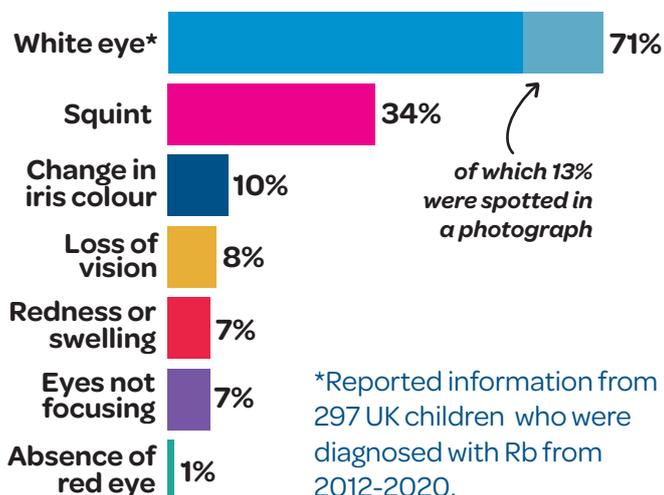
# Pathways to diagnosis

Since 2012, '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.

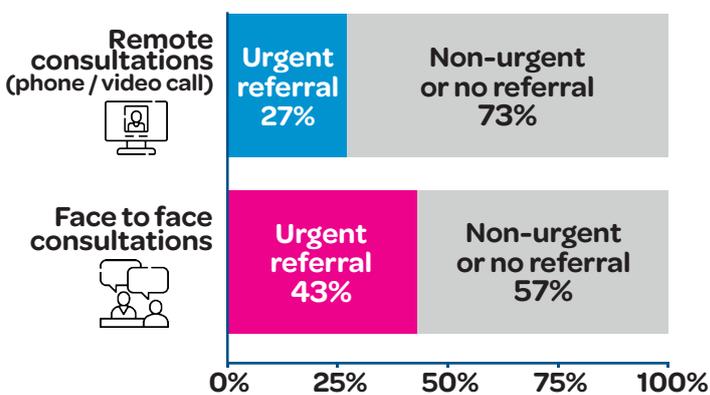
The pandemic has clearly had an impact on urgent referral rates in 2020 which have been at their lowest since 2012. Our feedback shows that families were far more likely to get an urgent referral from a GP if they had a face-to-face consultation vs a remote one when presenting with symptoms of Rb - the most common of which being a white glow in the eye. Therefore, as a charity, we have focused our awareness messaging to encourage families to seek in-person appointments and to consult an alternative medical professional if unsatisfied to avoid delays in diagnosis..

## Reported symptoms of Rb in the UK\*

- more than one symptom can be present per case.

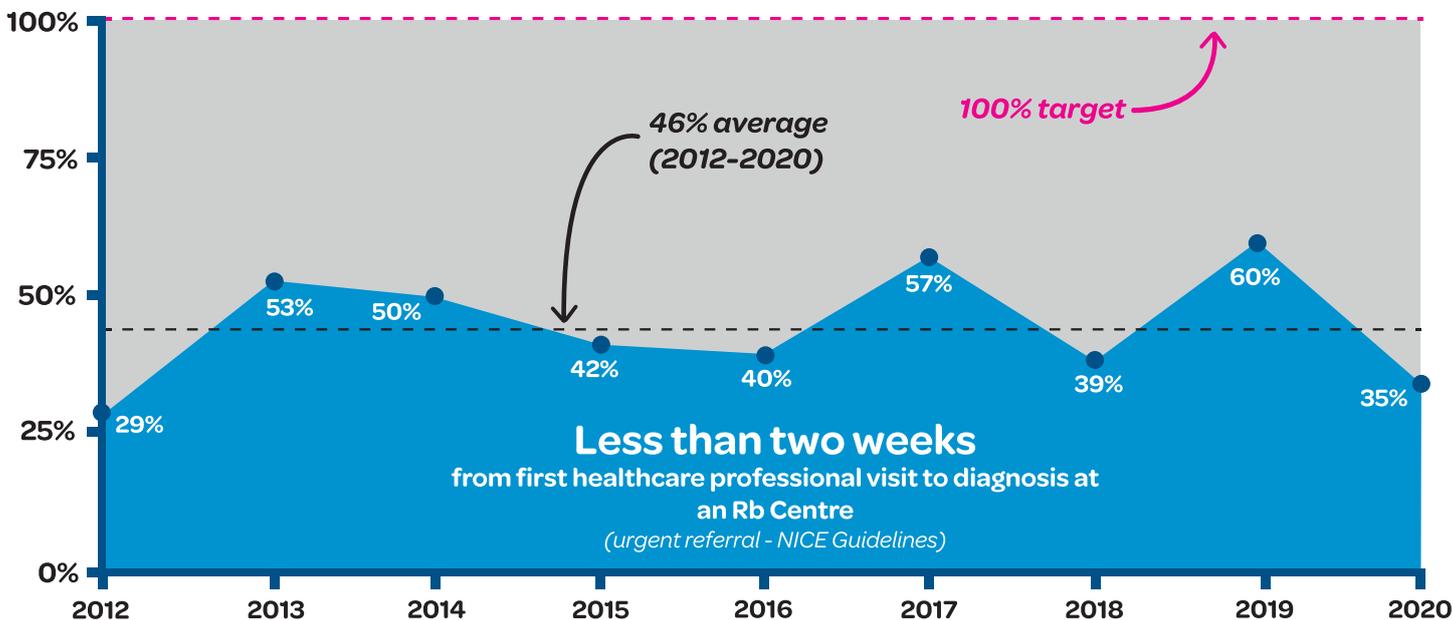


## Referrals by GPs in 2020 when presented with symptoms of Rb in the UK\*



## Percentage of urgent referrals for children with eye cancer in the UK\*

(across all healthcare professionals)



\*Reported information from 297 UK children who were diagnosed with Rb from 2012-2020.



# Explained: The International Retinoblastoma and Second Cancers Consortium (IRISC)

▲ Researchers gather for the 2018 IRISC kick-off event.

**This article – written by Dr Helen Jenkinson, Consultant Paediatric Oncologist at Birmingham Children's Hospital – explains the latest research project which aims to gain a better understanding of second cancers in Rb patients:**

Following successful treatment for genetic retinoblastoma in childhood, it is known that some patients are at risk of developing a second cancer later in life.

Researchers around the world are working together to try and gain a better understanding of which retinoblastoma patients are particularly at risk of developing such a second cancer. In 2018, the first meeting of the International Retinoblastoma and Second Cancers (IRISC) consortium was held in Amsterdam.

The study, led by Professor Annette Moll, Professor of Ophthalmology and Dr Flora van Leeuwen, Professor of Cancer Epidemiology at the VU University Medical Center Amsterdam, aims to set up an international database of second cancers after retinoblastoma (Rb) from participating centres around the world which represent at least 14 countries including Netherlands,

UK, France, Germany Spain, USA and Canada. By establishing the world's largest ever cohort of patients who have developed secondary cancer, it is hoped that the following research questions will be answered:

1. What effect does chemotherapy have on the risk of second cancer and is this risk different for intravenous, intra-arterial and intra-vitreous chemotherapy?
2. What effect does radiotherapy have on the risk of second cancer and does this risk vary with the type of radiotherapy used?
3. Is the risk of second cancer influenced by the type of RB1 genetic mutation and what effect does treatment have on this risk?

If the study identifies radiotherapy or chemotherapy protocols which are associated with a higher risk of second cancer, it may be possible to adapt or avoid these treatments in the future to reduce the long term risk. It may also be possible to identify certain genetic mutations which also carry a higher risk of second cancer. This knowledge will allow doctors

to develop personalised follow-up care based upon an individual's unique treatment and genetic characteristics.

Early detection and the use of low-risk treatments could substantially reduce long-term second cancer risk and improve the quality of life for patients with retinoblastoma.

## The risk of second cancers

People who are known to have the heritable form of retinoblastoma carry an alteration in their Rb gene which predisposes them to other cancers later in life.

This is not the case for patients with non-heritable or non-genetic Rb.

You can find more information about second cancers and advice on the CHECT website [chect.org.uk/adults-after-rb](http://chect.org.uk/adults-after-rb).

If you have any queries about second cancers, would like to arrange genetic testing / counselling, or discuss follow-up care in adulthood, our support workers are on hand at **020 7377 5578** or available via email:

Lesley Geen (The Royal London Hospital) [lesley.geen@chect.org.uk](mailto:lesley.geen@chect.org.uk)

Sarah Turley (Birmingham Children's Hospital) [sarah.turley@chect.org.uk](mailto:sarah.turley@chect.org.uk)

# “Rb has not stopped me from achieving my goals and living my life to the full.”

**Louise shares how her retinoblastoma has not held her back, but also how important it is to be aware of the risks of adult second cancers.**

My Rb journey started back in November 1973. I was eight months old when my Mum noticed my eyes were watering a lot and that I had a slight squint.

Mum took me to the GP who dismissed it as a regular squint and that I would grow out of it. Luckily for me, my mum was not happy with this diagnosis and wanted a second opinion – so off to Norfolk and Norwich Hospital we went. It was there we met Mr James who knew immediately that something wasn't right, so he urgently referred us to Moorfields in London.

Soon after I was diagnosed with bilateral retinoblastoma and went through brachytherapy (also known as plaque radiotherapy) and cryotherapy. They managed to save my right eye

but the left one had to be removed.

Weirdly, I can remember the ward I was on and that I was in a cot with another baby who also had had their eye removed – and obviously I remember the wonderful Mary who had the most amazing playroom for us all!

After my operation, London became my family's second home. Back and forth for check-ups to Moorfields and then to St Barts – which were not always the most pleasant of visits – but the staff were so lovely and supporting to my family. However, it was always greatly improved by a trip to Hamleys afterwards for me and also my brother who tagged along with visits. One of my fondest memories of these trips to London was having my picture taken with a monkey!

So then came the artificial eyes, I'm not going to lie, in those days they were not the best matches – but that did not matter very early on in my childhood. I went through primary school with some wonderful name calling to which I would respond to by taking my eye out and then watching people run away! As a result, this sometimes meant that I ended up in the headmaster's office! I had one close friend who had my back and she got me through the tough times.

When I started secondary school, my confidence was really hit as my eyes were still not a great match. On one of our trips to Barts, we mentioned the issues I was having and was put in contact with ocularist Paula Gladden.

I have to say she turned my whole life around and boosted my confidence – I got an amazing eye made and I'm still seeing her to this day for regular check-ups and replacement eyes.

Secondary school had its challenges and sports was my biggest one, but it did not stop me. Catching anything that was thrown at me had its issues, but with a little bit of practice I overcame this.

I was told by doctors not to do contact sports or sports that involved objects at high speed that could injure my eye – so I took up horse riding.

When I left school, I worked with horses and trained to be a riding instructor – my confidence just grew and grew. I had various jobs within the horse industry over the years and loved every minute of teaching people to ride, train and compete with their horses. Now I have a “sensible” job working for the NHS as a dispensary manager in a GP practice, but I still train horses in my spare time.

In 2006 I was getting recurrent eye infections in the artificial eye socket



◀ **Louise and her brother holding a monkey after a hospital visit to London.**

so I went back to Moorfields to get it checked out. It became apparent that my eye socket was starting to droop (the same as other parts of your body do as we get older!).

It was also recognised that I had never had an implant put into my eye socket when they removed my eye all those years ago. So, I underwent surgery to have an implant put in and my bottom eyelid lifted. It was a much bigger operation than I thought, but so worth it. My eye now moves better, and the socket is a lot healthier.

But it wasn't until I was in my twenties that I was informed about the risks of developing a second cancer in adulthood. Since then, second cancers have always been in the back of my mind, therefore I decided that I was going to live my life to the full including travelling to many countries.

Finding an adult follow-up clinic proved quite hard and getting a GP to refer me was even harder as they really did not have any knowledge about the adulthood risks having had Rb as a child.

Even in 2018, when I had a lump come up on my leg, it took me a whole year to get a referral to dermatology to get checked out as it

“did not look suspicious”. Finally, I did get a biopsy and was diagnosed with a rare naevoid malignant melanoma.

More operations followed, and I have been left with a scar that I now refer to as my ‘shark bite’, but I have now been cancer free for three years. I am also now monitored regularly every six months to make sure all is well.

So Rb has certainly had an impact on my life, but looking back, Rb has not stopped me from achieving my goals and living my life to the full.

Yes, I do find some things still challenging and I get frustrated. I still bump into things and bash into people that approach from my left side, but I now have ways of dealing with these issues. My friends are “trained” to walk on the correct side of me and people I know tend to understand that they will get ignored if they stand in my blind spot!

Yes, you are taking a risk by expecting me to catch something thrown towards me, and no, I have never seen the left-hand-side of my nose and my balance is not great – but these are only minor issues.



▲ Louise has a passion for horses and still rides today.

I have some amazing friends and family who have helped me throughout my life to conquer all those little issues that come along but I am now a lot more open about telling people about my eyes, and you will be amazed by the amount of people who want to find out more about it!

I have recently taken up paddle boarding which has pushed my balance to the limit, but I am loving it, and continuing to live my life to the full.

▼ Louise has recently taken up paddle boarding



## Information available

If you've been affected by retinoblastoma and want more information on second cancers, please visit our adults after Rb page: [checht.org.uk/adults-after-rb](https://checht.org.uk/adults-after-rb).

Whilst we understand that although the topic of second cancers is an important one, it can be upsetting or concerning. Our support workers Lesley and Sarah are also here to help. You can call them on **020 7377 5578** or email them directly:

- Lesley Geen (The Royal London Hospital): [lesley.geen@checht.org.uk](mailto:lesley.geen@checht.org.uk)
- Sarah Turley (Birmingham Children's Hospital): [sarah.turley@checht.org.uk](mailto:sarah.turley@checht.org.uk)

# “I felt like the worst mum in the world because I couldn’t settle my baby and no one could tell me why.”

**A mother’s intuition proved correct after GPs assured her that her baby girl was healthy. Thankfully an auntie spotted an unusual ‘white dot’ in her eye which led to a swift diagnosis.**

Mum Rada Hristova, from Kent, had been worried about Katherina since she was three months old, as she would not stop crying and seemed to be in constant pain. GPs assured the mother that her behaviour was likely due to wind or that she was simply “a sensitive baby”.

Unconvinced, Rada knew deep down that there was something not right with her little girl and persisted with trying to find out the cause of Katherina’s discomfort.

Rada said: “I felt like the worst mum in the world because I

couldn’t settle my baby and no one could tell me why.”

Then at six months old – just days after Katherina’s most recent GP examination – Rada’s sister-in-law Dessie spotted something in Katherina’s eye.

Rada said: “She rushed into the room and was crying and shaking. She said she’d seen a ‘white dot’ in Katherina’s eye and had heard previously that this could be a sign of something serious. We Googled it and the scary diagnosis of eye cancer came up.”

“Although neither of us could see the white dot again, I then noticed that Katherina’s eye looked dull in comparison to the other one which was bright and shiny.”

Rada and her partner Lyudmil took Katherina to A&E. Having examined her eyes, doctors urgently referred the family to Maidstone Hospital Eye Clinic.

**“I still couldn’t believe that my daughter had cancer.”**

◀ **Katherina and dad Lyudmil before her operation.**

It was there that the parents received the devastating news that Katherina was found to have had a large tumour in her eye – so large that she was already blind in that eye.

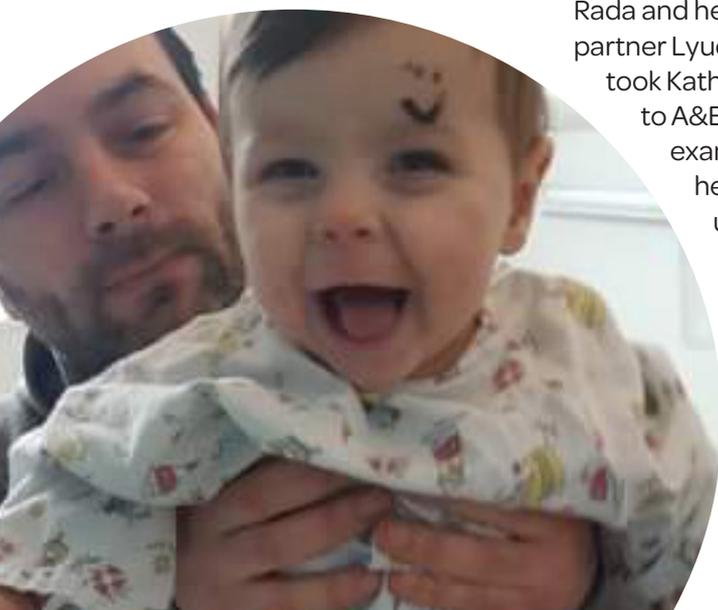
Their fears were confirmed – their daughter had retinoblastoma, a rare eye cancer that typically affects babies and young children. The family were immediately referred to the Royal London Hospital specialist retinoblastoma centre.

“Even though it made sense, I still couldn’t believe that my daughter had cancer. When you picture a child with cancer, the child looks ill. However, aside from all the crying, Katherina otherwise looked like a healthy child.”

Katherina’s left eye was removed a few days later to stop the cancer from spreading.

“The staff at the Royal London Hospital were absolutely amazing and they talked through everything with us, reassuring us that everything was going to be fine.”

“I was scared to see her after the operation – I was still in shock about what she would look like. But the moment they took off the bandages and revealed



the temporary artificial eye they had in place of her eye, my mum reassured me that my little girl was still 'perfect'.

"I kissed Katherina on the forehead and told her that 'when she wakes up, she will be more perfect'."

In what was a huge relief to the family, after her operation, Katherina's pain immediately stopped.

"It was like something had changed my little girl. She suddenly stopped crying, started smiling and would sleep like a normal child. You could see that she was finally happy."

Another blow came to the family when smaller tumours developed in Katherina's remaining eye. Thankfully these could be treated with cryotherapy (freezing).

The now happy and energetic Katherina has since been fitted with a proper artificial eye, designed to perfectly match

her other, and is currently attending regular check-ups at the hospital. The family are also looking forward to celebrating her second birthday in the summer.

Rada added: "I'm forever grateful to my sister-in-law for spotting Katherina's tumour. Dessie – thank you for saving my daughter's life. Had the cancer been left any longer, it may have been a different story.

"I really want to thank support worker Lesley who saved my mental health. She was there when times were hard. I'd also like to thank Mr. Ashwin Reddy, Dr Sagoo and the Rb Team for saving my little one's life. You are all amazing. Thank you so much!"

To mark World Retinoblastoma Awareness Week back in May, the Childhood Eye Cancer Trust urged parents to be aware of the most common symptoms of eye cancer – a white glow in the eye and a squint – as well as to seek an alternative opinion from a health care professional if



▲ **It was Katherina's aunt Dessie who first spotted her tumour**

**"Dessie – thank you for saving my daughter's life."**

they are not satisfied.

Patrick Tonks, Chief Executive of the Childhood Eye Cancer Trust said:

"Symptoms of retinoblastoma must be examined urgently in person by a GP or an optician.

"We know GP services have been under huge pressure this year, but we urge parents to trust their intuition and seek additional help from another healthcare professional if they are not satisfied.

"Avoiding delay with a retinoblastoma diagnosis can help save their child's sight, eyes and even life."

**"You could see that she was finally happy."**



## **A huge thank you to Rada and Katherina for helping us to raise awareness of Rb.**

Rada's story was picked up by the press during World Retinoblastoma Awareness Week and was published in the Daily Mirror and local press reaching an audience of over a million people.

We can't raise awareness without the help of our CHECT families. If you would like to share your story to help raise awareness of Rb, please contact [info@chect.org.uk](mailto:info@chect.org.uk).

◀ **A smiley Katherina and mum Rada**



◀ Will in his York City Knights kit

# An interview with rugby star Will Jubb

**Will Jubb was diagnosed with Rb at two years old and had his right eye enucleated. However, playing with one eye has not held him back from a successful rugby career.**

**Nowadays, Will plays as a hooker for the York City Knights professional rugby league team.**

***When did you decide that you wanted to be a professional rugby player?***

Well I didn't actually originally play rugby, I used to play football. My brother played rugby and I would always go along to his training. My dad coached him, so I used to join in a bit. One day I just decided I was going to give it a go myself, then I just sort of fell in love with it from thereon and have played ever since.

***How has your Rb journey been?***

It was my mum who took a picture – and your eyes are meant to flash red in the camera flash, but my right eye went white. So she and took me to the doctors and after more tests I ended up being diagnosed with Rb. I was whizzed down to London to have my eye removed.

For the next few years, I had to go back down every now and again to make sure everything was alright. It was obviously very hard for my mum and dad, but we got through that and we're all good!

***How's your depth perception when catching and throwing?***

I suppose in a way, because I can't remember seeing with two eyes or knowing anything different, I find it easy. The fact that my dad and brother were always playing games and throwing to me, I guess I learnt to adapt. It's all I know.

***What was life like growing up with an artificial eye?***

When I was younger it was harder on my mum. Especially when I first had my operation because you just have a clear eye whilst they're making your proper one.

But obviously young children are very much 'say what they see', so it was probably hard on my mum, whereas I was a bit blasé about it all. I didn't really know what was going on, I just wasn't bothered.

Growing up I've always been open about it with all my friends. At school everyone knew, and I would just laugh and make jokes about it. I've never really had any issues, which is lucky, but I think that's more because of how I was so open and happy to talk to people about it. It's sort of just been a part of me and I've been happy to go along with it.

***Do you have anything that you'd like to say to young people who are feeling self-conscious because of their artificial eye?***

You've got to get your own head around it at first, but the best way to go about it is to just be open and honest about it. I think the more

you're like that, the more it helps both yourself and other people to just deal with it.

Also, the artificial eyes nowadays are absolutely fantastic and are a perfect match – it's really hard to tell the difference. People don't even realise half the time.

***How does it feel to have made it as a professional rugby player?***

I still don't see myself as having "made it" properly. I just want to try get better and do the best I can. That said, it's a nice feeling to be able to do what do what you love and be able to play in the stadiums. It's brilliant. I've been to Canada, France, and all over. It is a great feeling to be able to play in front of the fans.

***What do you do outside of rugby?***

I'm currently doing a PhD in Fisheries Science at the University of Hull. I also volunteer for the Wilberforce Trust in Yorkshire – they've got a section called 'Club Wilbur', which I'm an ambassador for, and they run events and activities especially for children with a visual impairment. It's really great.

We get all the kids involved - getting them out and about doing things and showing them that there are lots of things out there that they can do.

The events also help their families, siblings get involved too so we can have a really good family day out.

# A tribute to Ffion Miles

## We are extremely sad to inform our members of the passing of our former trustee and dear friend Ffion Miles.

Many will remember Ffion for her fun nature, passion for music and fierce intelligence. She was a real people person with lots of friends, including CHECT Members, members with whom she enjoyed our Beyond Rb outings, member's weekends and developed some very special individual friendships. We are sure that lots of you will remember Ffion performing in the 'Rb band' as lead singer at CHECT members' weekends.

Ffion was diagnosed with Rb as a baby which left her with a little vision in just one of her eyes. However, she never let her Rb or visual impairment hold her back and achieved an absolutely incredible amount in her lifetime. A diagnosis of osteosarcoma (bone cancer) in her knee in her teenage years was another setback, but thankfully it wasn't long before she was living life to the full again.

Ffion graduated with a Law degree from Cardiff Law School before gaining a master's degree in Politics at Aberystwyth. She soon landed a role at the BBC between 2008 and 2016 as their Ability Rep for Wales. She had a passion for rugby and loved to travel around the world. In 2016 she embarked on a solo trip to Australia and Tasmania where she was interviewed to promote

access and inclusion for disabled supporters in sport. Ffion travelled to Canada with The Welsh Choir using her beautiful singing voice. She has passed on her passion for singing to her young nephew.

As CHECT was a charity close to her heart, between 2010 and 2016 she volunteered her time as one of our trustees, providing invaluable advice and guidance to our Board. She was also a treasured member of our 'Beyond Rb Group' and the wider Rb community.

Ffion continued her career at the BBC becoming a researcher for shows such as Bargain Hunt, the One Show and Casualty. She was also an Assistant Producer for BBC Wales and a Feature Writer for the BBC's Welsh language news service and Radio Wales/Radio Cymru News. Somehow Ffion even found time to sing live on the rugby pitch before a Wales game!! The last live rugby match she attended was with her parents, when they saw Cardiff play.

Throughout her life Ffion was passionate about the rights of people with a disability, particularly visual Impairment. She also advocated for children with a visual impairment to have access to braille or other technology that would support their learning and leisure.

Ffion was a wonderful daughter and devoted aunt. She had friends everywhere! They would always comment what a fantastic friend



▲ Ffion enjoying a sailing trip.

she was and how she always had something interesting and exciting to talk about. She was a brilliant storyteller and shared her love of books with her niece and nephew, with whom she had a close relationship.

As well as rugby and music, Ffion loved all things Harry Potter, the Pointless TV show (which she was very good at!) The Archers, Anne of Green Gables, and much more.

Ffion was admitted to a hospital close to her family in Wales for six weeks over Christmas and the New Year where unfortunately her condition deteriorated and palliative care was organised for her in her home. Ffion spent her last days at home with her family and very sadly died on January 17th.

Ffion's life was celebrated with a small funeral, due to COVID restrictions, but there were over 100 people outside the church who came to pay their respects.

We shall miss you Ffion, your tireless energy and your personal, informed insight which has helped guide the charity's work.

**The CHECT Team**

# A bumper #TeamCHECT Marathon year

Good luck to all our wonderful #TeamCHECT London Marathon runners!

After last year's public race was postponed, the event has been rescheduled for 3rd October 2021. Many of our runners are able to join in via the Virtual London Marathon, meaning we have a record number of runners taking part!



Georgina Barnard



Vicki Brader



Emma Calder



Sheila Fox



Thomas Gorman



Helen Harrison



Conor Horrigan



Sam MacLean



Ben McKnight



Will Randall



Hayley Richley



Andrew Sanderson



Iain Seath



Claire Stuart



Emily Taylor



Mike Taylor



Jamie Tubby

If you'd like to join #TeamCHECT, we still have two remaining places for the Virtual London Marathon. (min £200 sponsorship).

Contact [fundraising@chect.org.uk](mailto:fundraising@chect.org.uk) ASAP to secure your place!



Lisa Tubby



Amy Turfrey



Heidi Turfrey



Hugo recovering from his operation

## Dell colleagues inspired to raise funds after Hugo's Rb diagnosis

Three-year-old Hugo was diagnosed with retinoblastoma in March this year and is currently undergoing further treatment after the enucleation of his left eye.

In support, mum Sarah-Jane's colleagues at Dell rallied to raise funds for CHECT.

Tom Murray, *VP GBO Storage Specialties EMEA* and Blaithin Keating, *Business Operations Director, EMEA TLA* at Dell Technologies said:

"As a parent, it's something you never want to hear - your child is sick.

"When we heard Sarah-Jane's beautiful energetic boy was diagnosed with retinoblastoma, we knew we had to do something. We wanted Sarah-Jane to know she and Hugo were in our hearts but we also

wanted to do something practical.

"So we set up a fundraising page on the Dell charity page and asked employees to donate what they could.

"The initial ask was for people to donate their daily / weekly / monthly commute - the money they may have spent on train tickets, a daily coffee, bus fares etc. But people gave way more than this.

"There was an outpouring of generosity. Not only did we see Dell employees donate, but we saw families get involved, doing their own mini fundraisers for Hugo.

"We often underestimate the kindness of others and this was the most powerful message we wanted to give Sarah-Jane and Hugo."

## 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](mailto:fundraising@chect.org.uk) or call **020 7377 5578**.

## 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:

**Eileen Bayliss, Judith Godfrey, Mary Kirman, Ffion Miles, Marion Nash, Penelope Norris, Arlene Rigden and Jill Wagstaff.**

# Children's corner

**Welcome to the children's corner, a new and exciting part of this magazine where we feature your poems, pictures and stories. There is also a fun colouring in page for you to enjoy. We hope you like it!**

**Young CHECT member Suri (age 10) was born with bilateral Rb. As a result of having chemotherapy as a very young child, he has had to visit Great Ormond Street (GOSH) for a hearing test. He kindly shares his experience with us.**

I have been through many hospital appointments since the age of – well, since when I was born – but the lockdown hospital visit was a lot different.

I had to go into GOSH, or the Great Ormond Street Hospital, for a hearing test during lockdown. Because I went through several rounds of treatment for retinoblastoma, the doctors wanted to make sure my hearing was working perfectly. I was supposed to have this done a few years ago, but it just came together now...

Lockdown hospitals are very different and strange, because it's way too quiet and full of social distancing signs. At first, I felt very anxious because I hate eye checkups

and body scans. But I was glad to hear that all I needed to do that day was a hearing test. I waited in the patients' room until I got called out to do my 'practical sound test' by someone called an 'audiologist'. I scurried along across the hallway to the sound examination area which was filled with wires and data and charts, all to check my hearing.

At first they put on some headphones to check my hearing was working and then they played different sounds and noises. I had to press a button every time I heard a sound. TRUST ME, THEY WERE REALLY LOUD. But soon very quiet. From 20Hz to 20,000Hz. The audiologist said I could hear the normal sound range very well and was impressed with my results from the audiometry test.

I then had to sit absolutely still for my next test, which was called 'auditory brainstem response'. They put in earplugs and make you listen to all types of sounds. They then measure the signals from my brain. The hardest part was staying still! I had to move my tongue!

Then afterwards I told them I didn't have any pain and I was allowed to go home quickly. It was a fun session and it was nice to have no waiting or queueing at GOSH. I then got ice cream before we got on the train back home so it was a fun trip!



*If you have a poem, picture or story about your Rb that you would like to share, please ask a parent to send it to us at: [info@chect.org.uk](mailto:info@chect.org.uk).*





Colour me in!

# What's on...

## Virtual London Marathon **3rd October 2021**

Two places left! Runners have 23 hours, 59 minutes and 59 seconds to complete a marathon on a route of their choice. Participants will receive an official Virgin London Marathon T shirt and medal upon completion. Join 49,999 other virtual runners in the largest single fundraising event in the world.. **Minimum sponsorship £200**

## Skydiving **Multiple dates in 2021/22**

Ever fancied the thrill of a skydive? We've teamed up with Skyline Parachuting to offer you this once in a lifetime experience whilst raising valuable funds for CHECT. Multiple locations available – get in touch for your information pack.



To find out more about these events, or the fantastic selection of new events we have just added, please contact Diane Emery on **020 7377 5578** or visit our website **[chect.org.uk/events](https://chect.org.uk/events)**.

# 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.



## A new, simpler way to donate

Please show your support by helping us to trial our brand new QR code! We have teamed up with BOPP\* to offer this super quick gift option, which we hope will transform the ways in which our supporters can donate.

Simply scan the QR code on your smartphone and follow the instructions to **make a £2 donation** (you may need to enable QR codes in your camera settings). Your gift will come straight to CHECT, without having to download an app. You see exactly who you are paying and give your consent to your bank, via your own banking app – please rest assured that we do not receive your bank details. **Thank you!**

Scan me to donate £2



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



visiting our website: **[chect.org.uk/donate](https://chect.org.uk/donate)**



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

Want to share your feedback of BOPP? Let us know at: **[fundraising@chect.org.uk](mailto:fundraising@chect.org.uk)**

\*BOPP is:  
· Regulated by the FCA  
· Licensed PISP and AISP