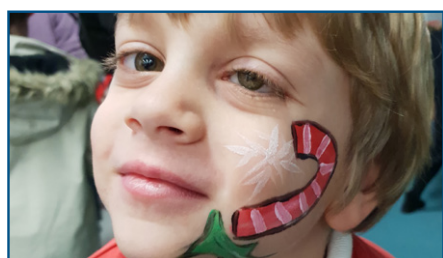




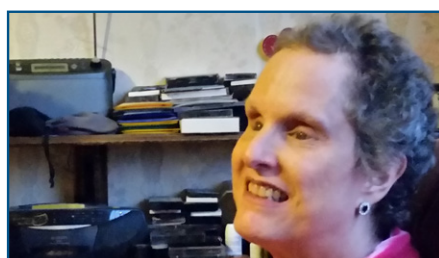
THANKS FOR YOUR PHOTOS!



A CHRISTMAS TO LOOK FORWARD TO

A LITTLE BOY'S JOURNEY
THROUGH TREATMENT.

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RB ISN'T SOMETHING TO BE AFRAID OF

A SECOND GENERATION RB
SURVIVOR SHARES HER ADVICE.

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CHECT IN PARLIAMENT

WE RAISED AWARENESS OF RB
WITH YOUR LOCAL MPS

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WELCOME

Welcome.

Firstly, thank you to all of our members who submitted a photo for our festive front cover featuring children who have been affected by Rb. We simply couldn't decide which one to choose – so we chose them all!

A lot has happened in the latter half of 2019 including the well-deserved retirement of Julia, our much-loved Birmingham Support Worker after being with us for over 16 years.

We're pleased to welcome Sarah, our new Support Worker who you will be introduced to on page 4.

Recent months have seen our members get together at our regional members' days in Bristol, York, Scotland and Leicester. We're already planning next year's events, and we're excited to finally reveal our Members' Weekend which will be taking place at PGL Liddington on 18th-20th September 2020 - a date for your diaries!

We've had many families share their moving awareness-raising stories in the media including the story of mum Laila who found out just a few days before Christmas that her son Noah would have to have his eye enucleated - a time that should have been full of celebration and festive cheer.



We simply wouldn't be able to exist without your ongoing support - our fundraisers have taken on many challenges and organised events throughout the year - everything from a sponsored haircut, to cycling from London to Paris to raise funds for CHECT.

May saw us engage with MPs in parliament, encouraging them to spread awareness of Rb in their constituencies. September marked Childhood Cancer Awareness Month, which saw many people hosting events and spreading awareness of Rb in their local community and online.

We are also very pleased to announce the funding of two new Rb research projects and that we have welcomed two of our CHECT parents to our Scientific Advisory Committee.

So as we come to the end of the year, I wish you all a very Merry Christmas and a wonderful 2020. Thank you for your continued support - together we will keep making a difference to the lives of those affected by Rb into 2020 and beyond.

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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NEWS

RESEARCH UPDATE

CHECT continues its commitment to research by funding two new projects. One, led by Professor Lako of Newcastle University, is developing human lab models of Rb which can be used to test current and future chemotherapy drugs to assess their impact on healthy, surrounding cells - and so minimise damage to vision from treatments such as intra-arterial chemotherapy.

The other, led by Professor Berry from the Children's Hospital Los Angeles, is looking at whether liquid biopsies (useful in Rb where a normal biopsy is only possible after enucleation) are possible using blood rather than fluid (aqueous humour - AH) from the eye. It has already been proved that liquid biopsies can be carried out using AH, but if it were possible to use a blood sample instead, this would be a much less invasive procedure.

WANT TO RECEIVE THIS MAGAZINE IN A DIFFERENT FORMAT?

We offer InFocus in the following accessible formats for our members:

- **Large print (A3)**
- **Braille**
- **Electronic versions – PDF and HTML**

If you would like to receive InFocus in a new format, please get in touch on

020 7377 5578 or at **info@chect.org.uk**.

LAY PARENT MEMBERS APPOINTED TO SAC

Following our call in the last In Focus for parent volunteers to sit on CHECT's Scientific Advisory Committee (SAC), we were overwhelmed by the response.

Whilst it was a challenge to shortlist from so many strong applications, we were delighted to put James Morley-Smith and Pippa Branch to work immediately at the November SAC meeting!

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HAVE YOUR SAY

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

Thanks for your support!

MEMBERS' WEEKEND 2020

Save the date! We're so pleased to finally reveal that our next CHECT Members' Weekend will be held Friday 18th - Sunday 20th September 2020.



Following your feedback, we have upgraded our choice of venue and selected the adventure holiday centre 'PGL Liddington' near Swindon. This event promises to be a fantastic weekend for all CHECT Members and their families.

The weekend, which is suitable for all ages, will be an opportunity to meet others who have been affected by Rb and to have fun.

The schedule is full to the brim with fun and challenging outdoor activities as well as indoor ones too. There will be fencing, archery, climbing, a disco and a live band to name just a few.

Tickets - which include all overnight accommodation, food and activities - will be available to purchase from February 2020.

Visit chect.org.uk/weekend for more information.



NEW BIRMINGHAM SUPPORT WORKER

We are delighted to welcome Sarah to the team! Sarah will be based at Birmingham Children's Hospital. Her working days are Monday, Wednesday and Friday.

Sarah Turley

Support Worker

sarah.turley@chect.org.uk



Hello, I'm Sarah! Becoming a CHECT Support Worker is a new adventure for me, and I am excited to meet and get to know you all.

I join you from University Hospitals Birmingham, where I was the Teenage Cancer Trust Youth Support Coordinator for ten years. I very much loved this job and helped to build a service which reflected the needs and likes of the teenagers and young adults I worked alongside.

My previous role saw me engaging young people and their families in support, activities and education, as well as consulting them on decisions which affected their cancer services. I have also worked within Child and Adolescent Mental Health Services (CAMHS) and Youth Services for many years, so I have a keen interest in child development and physical and mental health.

Alongside my work, my passions include my family and friends, horse riding, climbing and good books.

FAREWELL, JULIA!

When Birmingham Support Worker Julia first began at CHECT, she was just one of two members of staff – the other being the CEO!

Over the past 16 years Julia has not only seen the charity grow, but has played a big part in its development, particularly of the support given (by the then Retinoblastoma Society) to children and families facing the challenges of an Rb diagnosis.

Until early 2013, Julia planned, organised and ran our member's days completely on her own. These days have become a much-loved part of CHECT's calendar, providing opportunities for members to meet together and share their experiences of Rb, to feel supported and less alone. She has also particularly supported our adult members after Rb, known as our 'Beyond Rb' group, building relationships, providing events often involving good food and much laughter.

She has also been a much loved and respected colleague, whom we will all miss. But probably the greatest impact that Julia has had in those 16 years, has been through the support she has given directly to CHECT members, young and old. Here are just a few of the messages that you sent in:

"Thank you for all your help and support through the tough times. Hope you enjoy your retirement exploring the world and pottering in your garden growing the best veg ever."

"A lovely lady who will be missed by many parents. She wiped some tears for me and the hugs she gave were amazing."

"I remember the atmosphere changing as this ray of sunshine walked in. This vibrant, caring soul who genuinely cared and had time for everyone."

"You were so calm and reassuring and spent loads of time talking to us. You distracted me with normal conversation, and stopped me from being such a wreck! Your presence was really reassuring, and you made our very regular trips easier to deal with."

"It has been a privilege and a pleasure to know you, often talking to you made everything seem better and those small moments of 'normality' remain with us."

"We always found your kind words reassuring at such a difficult time. When it came to day clinic we looked forward to a catch up in the waiting room and a good giggle to while away the worries."

"One of the first people we met in our journey. A lovely friendly and reliable face during the one of the worst times of your life. People like her deserve a medal."

"Every time we were in BCH it was always lovely to see such a smiley face. You always showed interest and compassion for each person you met."

"Thank you for organising some great days out for families over the years. I always felt that you knew all the families so well, and really cared about what was happening for everyone."

"We'll always be grateful for the support you gave us. Having that familiar friendly face who knew you and greeted us made the whole experience that bit more bearable."



“FINALLY WE CAN HAVE THE CHRISTMAS WE’VE BEEN DREAMING OF”

Christmas is supposed to be a time of joy and celebration, but for Laila Gaudry and Ollie Blanks it was the moment they discovered that their little boy had to have his eye enucleated. Here Laila, tells their story...

After the worst year of our lives, we were busy planning the best Christmas ever – a new chapter for us all. Our son Noah had been diagnosed with retinoblastoma in the summer and those difficult months of chemotherapy were finally coming to an end.

Tests had shown that his tumour was shrinking and we thought we’d saved his eye.

So, when we went to the retinoblastoma clinic a few days before Christmas Day we were full of hope because we could see the light at the end of the tunnel. I knew it wasn’t good news when the doctor shut the door and pulled up a chair.

He explained that Noah’s tumour had grown substantially and the best option was enucleation. After everything Noah had been through, I couldn’t believe it. What was meant to be a good bit of news before Christmas had turned into a nightmare.

An unusual glow

It all started in 2017, when Ollie noticed that Noah’s left eye looked odd. A couple of weeks later he noticed it again. The first thing that Google came up with was retinoblastoma and after reading about the white glow, he got his phone out to take some pictures with a flash. We were horrified when one showed the white reflection.

We called 111 and got an urgent doctor’s appointment that night but we were sent home and advised to contact our

GP to request a referral to the local eye clinic. There, initial tests showed that Noah had very little sight in his left eye.

Three days later we saw a specialist eye doctor and the word retinoblastoma was finally mentioned. We looked at each other as we fell apart. The doctor made an urgent referral to The Royal London Hospital. While we waited for Noah’s appointment we just kept telling ourselves that as long as it hadn’t spread, we would get through it.

At the Royal London the diagnosis was confirmed – it was a grade D tumour and it was felt that the best course of action was chemotherapy. The doctors stressed that Noah may still face enucleation if the tumour didn’t respond to treatment but we felt a wave of relief coming over us as we’d prepared ourselves for the worst case scenario.

A few days later we celebrated Noah’s fourth birthday, making it as special as we could before he started his treatment. We knew we had a long journey ahead.



Noah's treatment

Noah would need six cycles of chemotherapy. The path was always going to be hard but life threw some extra challenges at him from the beginning – he had an allergic reaction to the medication and developed a fever. But as time went on there were fewer complications and the tumour was responding well.

As Christmas approached we felt the end was in sight. The chemo had done its job and it was going to be the best Christmas of our life, something that would give the kids enough happy memories to counter all the anxieties and uncertainty of the last few months. Ollie and I went to see the kids' nativity together and it felt so wonderfully normal as we all cooed and teared up at the children.

So when we learned that Noah needed surgery, I had an anger and heartache raging inside me that our little boy had fought so hard. But I also wanted the cancer gone and I knew that once his eye had been removed it couldn't hurt him anymore.

A new start

Noah had his enucleation on 27th December. Under advice from the Rb team and other parents we let him have his Christmas and didn't tell him until Boxing Day. I think he was a little confused about what to

expect but he took it very well.

Noah had his temporary prosthetic fitted four weeks later and I was truly amazed at how good it looked and how well he coped. At his first check-up post-surgery he was given the all clear.

Noah is now six years old and doing really well. His big brother Jake is so supportive and they're inseparable – best friends and partners in crime. I'm relieved Noah had the surgery rather than going through more treatment and it was the right decision for our family.

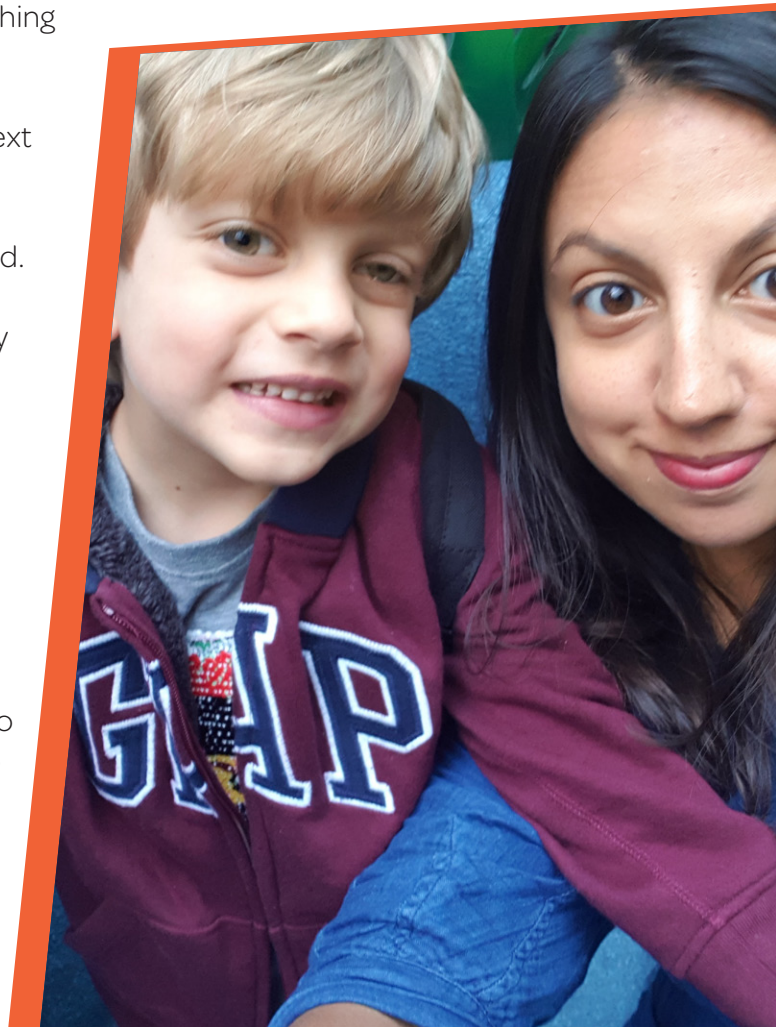
Last year we moved to Eastbourne and it felt like a fresh start. Everything is moving forward and Ollie and I are getting married next year. Christmas is approaching and we're really excited. We'll spend the day with my family in London and there are lots of new additions to the family so it'll be wonderful to see the 'new generation' together.

We're also going to Lapland thanks to a wish granted



by the charity Rays of Sunshine. We haven't told Noah yet as we want to surprise him. Life is so much better and I hope our story can help other families to know that there really is light at the end of the tunnel.

▼ Noah with mum Laila



“RB ISN’T SOMETHING TO BE AFRAID OF – I GREW UP THINKING IT WAS”

US-born Eve Smyth is a 62-year-old second-generation Rb survivor living in Scotland. She shares her advice, as well as her fascinating story of growing up blind and how she managed to find the strength to adopt after tragically losing her son to trilateral Rb.

My mother was born in 1922. At first her family were told that a cat scratched her eye, but as it deteriorated, doctors realised it was something serious. It wasn’t long before she lost her first eye. A radium plaque was a method used then to treat the tumours, but this wasn’t enough to save her remaining eye – so she became totally blind.

Mum went on to achieve a doctorate in psychology at a time when not only was it rare for women to achieve such a high qualification, but education and everyday life was far less accessible for those with a visual impairment.

Unlike the convenience and accessibility that comes with today’s electronic braille and other digital technology, my mother would have to lug a large open reel tape deck around university. They were huge things with two big reels on top.

She would always try to hide her blindness – I’m not sure how that’s even possible! She would never ever ask for help – I never understood why.

When she decided to have children, doctors didn’t realise that Rb can be hereditary. As a baby, my father said he could see something in my eye.

Doctors found I had very little vision because of the tumours in my eyes. My bilateral diagnosis and advancement of tumours meant that doctors didn’t want to take a risk, so I also had both of my eyes removed, just as my mother had before me.

My mother was told to never have any more children – so instead she adopted, and I grew up with three adopted siblings.

Childhood

Growing up blind, my dad didn’t want me to carry a cane. However, my stepmother thought I should have one – and she won! I mean, I would look a lot more blind and draw more attention to myself if I were to fall off the train platform!

My mother taught me braille. Her friends would read children’s books aloud and she would copy them. I read everything in braille I could get my hands on – no matter what it was. Not just stories – complicated information, anything!

Because my mother never tried to get assistance, I feel she was prevented from doing a lot of the things in life that I have done. My advice is to get assistance if you are struggling – never stop doing stuff just because your senses are playing up!

Adulthood and having children

In the 70s I was part of a travelling singing group working with the Churches of Christ. We flew from the US to Scotland which is where I met my husband.

We were in a room having a cup of tea with people the group had only just met. I was a bit shy back then, but I used to tell a lot of jokes. To break the ice, I asked if anyone would like to hear a joke about an Irishman – but before I could start, a man with an Irish accent shouted from the back of the room ‘No!’. At the time I didn’t know he was there – we’ve been married 39 years since!

After marriage and settling in Scotland, we talked about having children. We had genetic counselling and it was estimated that there was a 50% chance that our child would have Rb.

Then, in 1982, Matthew was born. He was examined immediately and doctors couldn't find any sign of any tumours. But then, after a follow-up, they found some in both eyes. At first the tumours were frozen, then treated with radiotherapy. However, they discovered that he also had a brain tumour – it was extremely rare and they didn't have a name for it back then, but it's now known as trilateral Rb.

Sadly, Matthew passed away when he was just four years old, he would have been 37 this year.

I was told not to have any more children, so I thought 'forget that'! Later on, we decided to adopt. Having grown up with adopted siblings, I was no stranger to adoption. It was tricky to adopt at first, my GP and health visitor were against it because I was blind. However, my social worker helped us push to get approval. We asked for a child with a sight problem because that's what we already knew.

So in 1990 we adopted Chris, who had Coloboma – a gap behind the pupil which doesn't close up – which left him partially sighted. Now aged 30, he had to have his eye removed due to glaucoma and replaced with an artificial one – although it's not such a big deal to him, having had a mother who had two of them! He now has a little five-year-old boy who, unfortunately, has inherited the condition. Hopefully he won't have any complications.

As well as having Rb, I have severe asthma, which has had a large impact on my life. I've done a lot of work for Asthma UK and the Asthma UK Centre for Applied Research – everything from being a public speaker to sitting on committees.

I've also had breast cancer in both breasts, and have been clear for two years now. After this I decided to also work with Cancer Research and the Royal College of Physicians.

I'm also on a couple of patient steering groups – I find medical research fascinating. With the experiences I've had, I can lend a patient's perspective as well as one of a disabled person. I do somehow find myself speaking for disabled people sometimes. Using my life experience, it's good to help influence various organisations for the better.

Advice for others

If there's something you want to do – go for it. Rb isn't something to be afraid of – I grew up thinking it was. The survival rates now are amazing and research has helped treatment have come along in leaps and bounds.

Life as a blind person isn't that bad. Weird stuff occasionally happens, but then weird stuff happens in life anyways and that's all part of the game. My advice to parents of children with a visual impairment is to encourage them to be independent, but not be afraid to ask for help if they ever need it.

Technology and awareness are so much better than they used to be, but it can only get you so far. I was taking the train once with my fully sighted friend. We realised that we were in the wrong carriage when the train split off and headed in the wrong direction. My friend was the one who was panicking – whereas if you're a blind person, in a world that's not geared for you, you learn to keep your head. You pretty much always have a backup plan.

I simply called National Rail who explained how to get back onto the correct train. Nowadays I have my smartphone. You just think 'I can do this. I'm in a situation where I simply have to work things out'.

It's easy to understand why some parents want to assist with everything, however it's also important to encourage children to take a few risks every now and again. Coming from the opposite angle was my Dad – if I couldn't do things the exact way he did – he thought I shouldn't do it. I remember struggling with giant scissors-my response was to use a shorter pair of scissors. Make adjustments to make things work.

The main thing is that life is too short – you have to run with it and sometimes it's stressful, things occasionally go wrong. Let them get on the wrong train once in a while.



MONOCULAR VISION: PROTECTING YOUR CHILD'S EYES

When children and young people have monocular vision, it's even more important to preserve their eyesight. But that doesn't mean that they have to miss out on all the fun of sports and activities. Zishan Naeem, Lead Orthoptist for Retinoblastoma Services at The Royal London Hospital, gives some tips on eye safety and using protective eyewear.

Monocular vision relates to having useful vision from one eye only – this could be the case for children who have both eyes (where one eye has poor vision and the other eye has good useful vision) or children who have one eye only. Therefore, it is vital to preserve their vision, and it is strongly advised that protective eyewear such as protective glasses or sports goggles should be used.

"It is strongly recommended that contact lens wearers also wear appropriate eye protection."

Sports goggles can be worn as a means of protective eyewear when participating in certain kinds of outdoor, extracurricular or sports activities. This is especially the case when it is felt that there may be some form of hazard to your child's eyes – in particular outdoor activities in which stones or debris could enter the seeing eye. We advise your child should avoid excessive contact-sports in order to minimise the risk of injury to their seeing eye.

Obtaining protective eyewear

Your child should attend a local opticians to obtain protective eye wear. High street opticians usually have a selection of goggles, which may well need to be ordered in. If your child does not have a prescription, then sports goggles should be purchased with **polycarbonate** lenses. This is a stronger material used for the lenses and will add to the protection of your child's seeing eye.

If a prescription has been found, then you will be issued with a pair of prescribed glasses, again with **polycarbonate** lenses. These can be worn

with a sports band.

Stronger, durable frames must be chosen, and these can be recommended by the dispensing assistant at the opticians.

Contact lenses will not protect the eyes, therefore it is strongly recommended that contact lens wearers also wear appropriate eye protection.

If there are any concerns or queries about protective eyewear, then please do not hesitate to contact the orthoptist from the Rb team. Your CHECT support worker may be able to provide advice and support in situations where the cost of sports goggles may be prohibitive.

For more information on taking part in sports and activities, have a look at our at school or nursery section at:

chect.org.uk/in-schoolnursery

You may also find our leaflet on monocular vision useful:

chect.org.uk/monocular



RAISING AWARENESS OF RETINOBLASTOMA IN PARLIAMENT

CHECT hosted a Parliamentary Drop-In Session back in May during Retinoblastoma Awareness Week 2019 to engage MPs in raising awareness of Rb in their constituencies.

It was the first time we have ever held an event like this. Back in December 2018 we were approached by CHECT member Hannah Matin, who works in the office of Paul Farrelly MP, to suggest we hold such an event. Thankfully Hannah was able to secure us a room at the centre of Westminster.

Over the Easter break we asked CHECT members to write to their MPs on our behalf, to share their experiences of Rb and to encourage them to attend the Drop-In. We are so grateful to all of you who took the time to do this

– it really paid off. Almost 40 MPs attended, including the Parliamentary Under Secretary of Health (Seema Kennedy), the Shadow Minister of Health (Sharon Hodgson), and the Shadow Minister for Disabled People (Marsha de Cordova).

In addition to chatting with CHECT members and trustees, MPs were encouraged to have their photo taken with our interactive #HaveYouCHECT banner to share on social media with suggested awareness messaging. Over a third of those who attended have done so, some with hundreds of thousands of followers!

We also talked to MPs about the importance of sharing information on Rb signs and symptoms and referrals with key healthcare professionals

in their constituencies - in particular GPs, health visitors and opticians.

Thank you so much to all the wonderful CHECT members, without whom none of this would have happened - from Hannah's help, support and original idea, to everyone who contacted their local MPs, to those who supported us on the day.



John Baron MP with Hannah Matin ▲



Peter Down MP with Christopher Payne ▲

CHECT TEEN FOCUS COUNCIL

The TFC met for a second time this year in August where they discussed and shared ideas about improving the TFC's presence on social media, the TFC website (teenfocus.co.uk), having their own exclusive CHECT TFC logo, peer support, mentoring and future socials.

Getting involved with the CHECT TFC and teenage events are a great way for teenagers to meet others their own age who have been affected by Rb.

If you or your child would like to be involved, please contact Lesley Geen CHECT Support Worker on 020 7377 5578 or at lesley.geen@chect.org.uk

CHECT RESEARCH:

TARGETED ANTIBODY-DRUG CONJUGATES FOR RB THERAPY

The latest report from Dr. Gail M. Seigel, in collaboration with Dr. Dhavalkumar Shah at the University of Buffalo.

Our research addresses an urgent medical need to develop new anticancer drugs specifically developed for Rb that can preserve vision and minimise side effects. The drugs that we are developing are called ADCs (antibody-drug conjugates).

ADCs are designed to specifically kill Rb tumour cells while sparing normal surrounding cells. They have several advantages over current chemotherapy drugs - because they are very small in size and delivered directly to the tumour, the ADC exists in a small area around the tumour itself. This lessens the chance of negative side-effects throughout the body. Also, since they remain intact at the site of the tumour longer than other kinds of drugs, fewer doses need to be administered to the patient. Therefore, targeted ADCs will not only provide a better treatment option for Rb patients with improved potency and safety, it will also be more convenient.

During our CHECT funding

period, we have made significant progress in the development of targeted ADCs for Rb. For one, we have manufactured and analysed new, more powerful ADCs and demonstrated that these drugs effectively kill Rb cells. In addition, we have used a new retinal imaging system which allows us to both measure the effects of ADCs on the growth of Rb tumours, and to calculate how often the drug should be given for maximum effect.

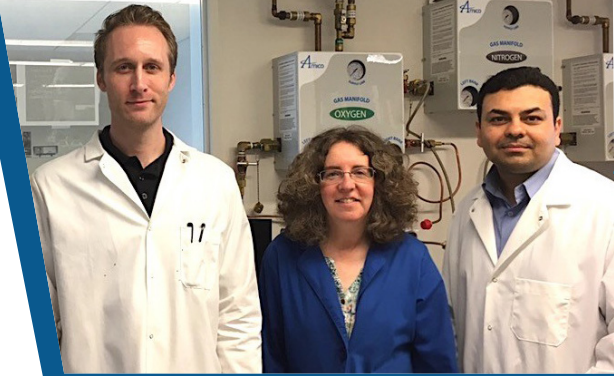
One other important aspect of the ADC is the target. The target is a marker, or landmark, on the surface of the Rb tumour cell that is unique to Rb and not present on surrounding normal tissues. The target allows the ADC to find the tumour cell and stick to it. Once the ADC sticks to the tumour cell, it is swallowed by the cell and detonates a toxic molecule that kills the cell from the inside. This is a very precise and elegant method of killing just the tumour cell and not the surrounding normal cells.

The target(s) we choose are very important. For this study, we have looked at two targets, called HER2 and EpCAM. Part of our study was to see how many Rb patient samples

have enough of this target for the ADC to be effective. The answer is that many, but not all Rb tumours have HER2 and EpCAM targets. We also checked to see whether normal cells adjacent to the tumour might have these targets, which could cause the ADC to kill them unintentionally. For these reasons, we are always on the lookout for new targets on Rb tumours so that we can develop personalised treatments to benefit the maximum number of Rb patients.

We are excited to report that we have leveraged the support from CHECT to obtain additional funding from the Developmental Studies Hybridoma Bank at the University of Iowa so that we can identify new targets on the surface of Rb cells for potential ADC therapies. So our Rb research continues thanks to you, the many supporters of CHECT. For that, we are very grateful.

A longer version of this article is available at chect.org.uk/blog. Read the full report at: chect.org.uk/previous-chect-research.



▲ Dr. David Bussing, *postdoctoral fellow*;
Dr. Gail M. Seigel, *Principal Investigator*;
Dr. Dhaval Shah, *Co-Principal Investigator*.

MEMBERS' DAYS

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.

Since May, we've held four members' days- with two Beyond Rb river cruise events taking place in York and Bristol, as well as family days out to Blair Drummond Safari Park in Scotland and the National Space Centre in Leicester! Here are just a few photos from our family days out.



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:

- **Ethan Warman (5)**
- **Charlie Earp (4)**
- **Piper Colledge (2)**
- **Harry Somers (7)**
- **Jack Colledge (4)**
- **Arwen Somers (5)**
- **Amy Colledge (7)**
- **Heidi Corcoran (4)**



YOUR SUPPORT MEANS SO MUCH TO US

2019 has seen some amazing feats and some brilliant events - both small and large - all in support of CHECT. So a huge thank you to you, our members and supporters.

We're a small charity and we have been helping families affected by Rb for more than 30 years, but we don't receive any funding from the government and so rely on public support to fund our vital work. However you choose to support us, thank you – we are extremely grateful. Here are just a few pictures of what some of you have been up to this year!



CHECT IS NOW PART OF THE CO-OP LOCAL COMMUNITY FUND!

If you are a Co-op member, or are thinking of signing up – you can now choose us as your charity. However, you must use the link: chect.org.uk/coop.



We will receive donations until October 2020, so please help us start raising funds!

COULD CHECT BE YOUR WORKPLACE'S CHARITY OF THE YEAR IN 2020?

We would love to work with your employer to raise funds for CHECT. If your company has a Charity of the Year do please nominate us. If not, we can offer a variety of activities and events that your colleagues can join in with, have fun and support us at the same time. If you would like to discuss this or need supporting information please email Diane Emery, our Fundraising Manager, at diane.emery@chect.org.uk or call on **020 7377 5578**.

CHECT CHRISTMAS CARDS

Congratulations to the winners, and thank you to every child who entered our card competition. We loved all your designs so much that we've made all entries available to send as an e-card too. Our Christmas cards are available to buy online now at: chect.org.uk/christmas.

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:

Gordon Maundrell
Anna Meers
Graham Haywood
Clive Bravery
Sandra Ann Baker
Paul Lines
Reg Webb
Cacilia Franziska Henthorn
Margaret and Ernie Burrell
Muriel Williams
Alan Castley
Alice Welsby
Linda Nugent
Stephen Beatty



CRAZY GLASSES DAY

A Crazy Glasses event can be held on any day during the year. All you need to do is wear a pair of 'crazy glasses' for a day and donate £2.

You could get your school, nursery or office involved. We've put together some free resources so you can download, print and have a go at creating your own.

Find out more at:
chect.org.uk/crazyglasses.



WHAT'S ON...

Join fellow CHECT supporters in raising funds while taking on a personal challenge – and having fun!

Hampton Court Half Marathon **23rd February 2020**

Run over a fast, flat course with definite PB potential. Runners enjoy the closed road loop around the picturesque village of Thames Ditton, the iconic three mile stretch of the Barge Walk beside the Thames and full views of the magnificent Hampton Court Palace where Henry VIII will be waiting to cheer you on. *Minimum sponsorship £250*

RunThrough Regent's Park **TBD June 2020**

Choose a 5km or 10km flat course running past London Zoo and the grounds of Winfield House. If running isn't your thing, then why not join us to cheer along our team? Afterwards, there's the opportunity to walk through the elegant flowerbeds in the Avenue Gardens and Queen Mary's Gardens, or hire a rowing boat. *Minimum sponsorship £200.*

Great North Run **13th September 2020**

Join 56,999 others celebrating the 40th anniversary 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 020 7377 5578 or email her at diane.emery@chect.org.uk

WE NEED YOUR 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.

Please use this form to donate to CHECT. Alternatively you can donate online at chect.org.uk/donate. Thank you.

Return to: Childhood Eye Cancer Trust, Whitechapel Road, London, E1 1FR.

Now you can simply text 'CHECT' to 70470 to donate £3

TITLE	FIRST NAME		
	SURNAME		
BILLING ADDRESS		TEL	
		EMAIL	
		POSTCODE	

Please accept my donation of:

£5		£10		£20		£50		Other (please specify)
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<input type="checkbox"/>	I enclose a cheque made payable to the Childhood Eye Cancer Trust
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Please debit my:	Maestro		MasterCard		Visa Debit		Visa Credit	
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CARD NUMBER:																	
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SECURITY CODE (last three digits on the signature strip of your card)			
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Valid From: (if applicable)	/	Expiry	/	Issue number (Maestro only):	
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SIGNED	DATE
	/ /

How would you like CHECT to contact you? post ☐ email ☐ phone ☐ text ☐
Update your preferences at chect.org.uk/consent. View our privacy policy at chect.org.uk/privacy