

infocus



HITTING THE HEADLINES

How your amazing children are helping to raise vital awareness of retinoblastoma...
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WELCOME

Welcome to the latest edition of InFocus. As we end the current financial year, 2018 marks the beginning of our new three year strategy developed to ensure we maintain a clear focus on and continue to help all those in the UK who are impacted by Rb.

Our core objectives of support, awareness and research will continue to form the bedrock of our work, along with our role as the 'voice of the Rb community', helping us to influence service providers where appropriate, to bring about improvements to service delivery for anyone affected by Rb.

On February 28, Rare Disease Day, we published the latest figures from our Pathways to Diagnosis data to raise awareness of Rb. Findings show that white eye continues to be the most common symptom reported by parents, but the data has also highlighted the importance of a squint as a symptom. These 'pathways' help us to ensure the most helpful information is available to parents.



Thank you to all the parents who have taken part in these conversations with our support workers Lesley and Julia.

In March we issued our latest call for new research projects and are looking forward to reviewing the applications over the coming weeks. We aim to select the next project(s) in the summer.

I would like to take the opportunity to say a huge thank you to Oliver Comyn who, after almost seven years, has stepped down as our Vice Chair, Chair of the Scientific Advisory Committee and trustee. Oliver and his family have made the exciting decision to move to New Zealand and we wish them health and happiness in their new adventure. We welcome two new trustees Sahar Parvizi and Rob Downes who have joined CHECT's Board. We also welcome back our Communications Manager, Natasha Boydell, and send our thanks to Louise Soler who stepped into the breach while Natasha was on maternity leave.

Finally, as we go to print our intrepid London Marathon runners are preparing to undertake the challenge of a lifetime. We thank them for their dedication to both their training and fundraising, we hope they had an amazing day and are now fully recovered!

Patrick

Patrick Tonks
Chief Executive

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NEWS

RB AWARENESS WEEK

Retinoblastoma Awareness Week runs from 13-19 May and we will be launching our latest awareness campaign for 2018. As in previous years, we need your help to spread the word, follow the #RbWeek campaign on Facebook and Twitter, and remember to share our posts so we reach as many people as possible!

From fundraising at schools and work, to bake sales and crazy glasses days, our supporters have also been busy planning their own events for Rb Awareness Week 2018. It's not too late to hold your event, check out our website chect.org.uk/rbweek for quick and easy fundraising ideas.

We are really looking forward to hearing what you will be up to, make sure you send us your stories and tag us on your social media posts.



GLOBAL'S MAKE SOME NOISE

Following last year's selection as a beneficiary charity of **GLOBAL'S MAKE SOME NOISE**, in addition to the coverage in both London and Birmingham, helping to raise awareness of the signs and symptoms, we were amazed and delighted to receive an incredible £93,000, which will be awarded over the next two years.

Global's Make Some Noise is the official charity of Global, the media and entertainment group. The charity unites some of the UK's best-loved radio stations – Heart, Capital, LBC, Classic FM, Smooth, Radio X, Capital XTRA and Gold – to raise money and give a voice to smaller charities. With a special thank you to the amazing, expert kayaker, Gemma Hill, our heartfelt thanks go to the whole Global team for their support in raising vital funds and awareness of retinoblastoma.



SAILING

Over recent months, we have been in discussions with the **Ellen MacArthur Cancer Trust** who run sailing trips for children and young people who have or have had cancer, to share experiences and help rebuild self confidence and self esteem. We are delighted that they have reserved two places for CHECT for 2018.

In 2017, CHECT Champion, Ernie Brown was chosen to undertake a leg of the Round Britain trip and sailed into London under Tower Bridge. Ernie says "It was the best thing ever. It was so much fun, I'd recommend it to anyone."

For more information and to read about Ernie's excellent adventure visit chect.org.uk/EMCT

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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 natasha.boydell@chect.org.uk.

Thanks for your support!



VISION EXPRESS

CHECT has been a proud partner of **Vision Express** since 2010 and the company has played an invaluable role in helping us to raise awareness of retinoblastoma, as well as generating significant funds to support our work. Vision Express was also the first optician in the UK to roll out our Opticians Protocol to ensure a quick and effective referral if Rb is suspected.

Our young ambassadors have once again been busy opening new stores following Vision Express's acquisition of over 200 Tesco Opticians. If your child would like to be a CHECT Ambassador and attend a special event in your area, please get in touch; email info@chect.org.uk or call us on **020 7377 5578**.

In early September a group of around 30 staff will take part in the fourth Vision Express **#Ride4Sight** to raise awareness and vital funds for our charity. Made up of both experienced and novice cyclists, the intrepid team will take on a challenging 200 mile route as part of the celebrations of Vision Express's 30th anniversary.

In other news we were thrilled that Rob Carmichael, Senior Marketing Manager - Research & Corporate, joined us at the Hampton Court Half Marathon – seen here with his dad Jeremy and CHECT CEO Patrick with his son Sam.

See page 14 for more charity partnerships.

JOIN THE TEENAGE TEAM

We are looking for budding writers and photographers to contribute to our **TeenFocus** website.

From gathering story ideas, creating blogs or vlogs - this is a chance to have your say, spend time with other young people affected by Rb and have a great experience to put on your CV – helping you to stand out when applying for college, university, work experience or jobs.

For more information and to put your name forward, please email natasha.boydell@chect.org.uk with details of why you'd like to get involved and what area you're particularly interested in.



MEMBERS' DAYS

We hold members' days throughout the year in regions around the UK to give families the chance to meet others affected by retinoblastoma, chat to CHECT staff and enjoy a day out away from the stressful hospital environment.

THE NEXT MEMBERS' DAYS ARE:

Spring 2018 Museum of Rural Life, Scotland
Summer 2018 Moor Valley Park, Dorset
Autumn 2018 Venue TBC, London
Spring 2019 National Railway Museum, York

Our members' days are subsidised, helping to keep costs low. To come to one of these events, you'll need to be a member of CHECT, which is free. To find out more or book your place on one of our upcoming members' events, please call us on **0207 377 5578** or email julia.morris@chect.org.uk

RARE DISEASE DAY

Little **Logan Brown** helped get retinoblastoma in the headlines in February!

To mark Rare Disease Day, CHECT published its latest **'Pathways to Diagnosis'** figures, which showed that one in ten babies and children in the UK have to wait more than six months to be diagnosed with retinoblastoma.

Information collected from conversations with families with a child who had received an Rb diagnosis in 2017, found that 11% of children had a delay of at least six months from their first visit to a GP or other health professional to being seen for specialist assessment.

The National Institute for Health and Care Excellence (NICE) guidelines state that a child should be referred urgently and seen within two weeks if retinoblastoma is suspected.

In 2017, 57% of children were referred urgently for specialist assessment and were seen within the recommended two weeks, up from 40% in 2016. However, 43% of children waited longer than this, with 11% waiting over six months. Many families have to make several visits to their doctor or other healthcare professional before the appropriate tests are carried out.



One of those children was Logan. He was diagnosed with retinoblastoma in August 2017 at the age of two, after his parents had noticed a white glow in his left eye while Logan was playing.

The following morning Logan's mum, Hayley, tried to get an appointment at a local opticians but, despite explaining why she wanted an appointment for her son, was told that Logan was too young to see, so immediately made an appointment with the GP.

Eleven weeks after his GP made a referral, Logan was diagnosed with unilateral retinoblastoma at The Royal London Hospital. The following week Logan had his left eye removed, the operation was successful and Logan required no further treatment.

Hayley said: "It was really hard, we now know retinoblastoma is really rare and not every health professional will have seen it, but we were so worried, we could see the

white glow more clearly each day and it was horrible thinking that something was wrong but not knowing for sure".

Thanks once again to all the parents who have taken part in these conversations with our support workers Lesley and Julia.

"It was horrible thinking that something was wrong but not knowing for sure"



ACT NOW

Tell us how you would like to hear from us

As you will by now no doubt be aware, a new piece of EU legislation is coming into effect later this month, the General Data Protection Regulation or GDPR. This is bringing the biggest change to UK data privacy laws for 20 years.

Here at CHECT we want to make sure that we have an up to date record of your details so that we only send you news and information in the way that you want to receive it.

To do this, we are asking you to take 30 seconds and visit www.chect.org.uk/consent, or complete the form on the back page of InFocus, to tell us how we can contact you going forward. Obviously email is the easiest and quickest way for us to communicate with you. If you would like to keep receiving news and updates by email, we need you to tell us so that we are communicating in the way you want after 25 May 2018.

CHECT will never pass your details onto third parties or share them with other organisations without your permission (unless required to by law), other than to those engaged in the delivery of our services and then only for a specified purpose. You can read a copy of our full Privacy Notice on our website (which tells you exactly how we use your personal information), or call or email us and we will send you a copy.

You can always contact us at any time to change the way we communicate with you if your circumstances change, or to let us know that you no longer wish to receive our news (call us on **020 7377 5578** or email info@chect.org.uk).

“We appreciate this feels like one more thing to do when you are already so busy, but it’s really important that you take just a moment to let us know that you want to carry on hearing from us. We really value being able to contact you, and hope you feel the same!”

Patrick Tonks,
Chief Executive



A STEP BACK IN TIME

Recent investigations of hospital and other historical records by member Iain Riddell show how cases, treatment and discussion of retinoblastoma, then known as 'glioma of the Retina', can be traced back to Victorian times.

The earliest likely patient recorded as having retinoblastoma was a boy called Edward Cann, who succumbed to tumours in both eyes having been discharged from Great Ormond Street in November 1860. As did William Samways, aged two, in 1876, who was examined but deemed unlikely to benefit from treatment. In contrast, Hannah Blackwell who was 'cured' in 1882, went on to raise many children and migrated to Canada with them.

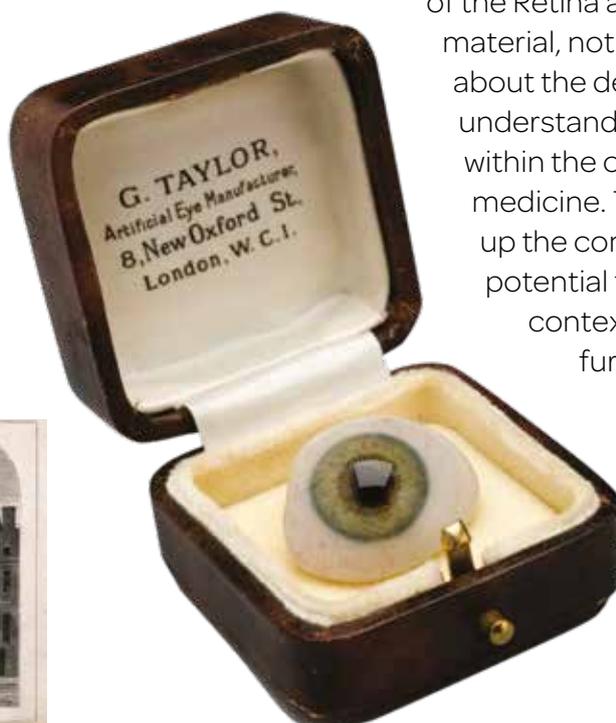
It is worth noting that by the 1920s the anonymisation of patient case studies was standard, so there is only a small number of decades where identification of individuals is possible.

A lengthy research paper by C. Devereux Marshall from 1897 is a rich resource for case studies. It also captures the tensions and developing processes of the medical profession alongside the dilemmas and forces that Rb brought upon the family.

The question as to whether glioma is likely to appear in more than one member of the same family is of the utmost importance to the anxious parents...

A century ago Dr A Hill-Griffith based in Manchester, England reported on two families' experience of glioma of the Retina. He was treating children for Rb, the two mothers of whom had themselves received treatment for Rb in the 1870s/80s. One of the children, Florence Jones, had a double enucleation before she was two in 1914. Hill-Griffith discussed his work with three generations of the one family and two generations of another, which made him consider whether some tumours of the eye were heritable. Hill Griffith signed off his report 'These hereditary cases seem to show an abnormal tendency to affect several members of the family, and also to implicate both eyes.'

These old records regarding glioma of the Retina are a rich resource of material, not least as they tell us about the development of the understanding of the condition within the context of the history of medicine. The records also open up the complex task of identifying potential family lines and family contexts that could throw further light on what it meant to be a family affected by Rb in the past.



Right: Glass eye, in London 1901. Credit: Science Museum, London.

Left: Great Ormond Street in 1872. Credit: Wellcome Collection.



A COMMON BOND

Friendships forged out of shared experiences, particularly those which involve hardship, are often the ones which endure the test of time. Retinoblastoma was the catalyst for one such alliance when, in 1977, three families found themselves brought together to undergo treatment for the disease at St Bart's Hospital, London.

Retinoblastoma patients were admitted into the care of the hospital for prolonged periods of time, up to a year for many children, with occasional visits home at weekends. As St Bart's was the only centre for treatment in the UK, many parents became semi-permanent residents on the ward – it is little wonder that bonds were made and friendships forged.

Three toddlers who raced up and down the hospital corridors on push-along bikes were; Zoe Weeks, Lamorna Parrott-Pentreath and Matt Holt.



ZOE'S STORY

I was born in the summer of 1976, the youngest of three children. My parents first noticed my eyes didn't look right when I was a few months old, luckily our GP at the time recognised the signs of a rare childhood eye cancer called retinoblastoma and sent my parents to St Bart's Hospital, London, as a matter of urgency.

On the Radcliffe Ward, my parents met other anxious parents watching their babies going through radical treatment to remove the cancer. I had my left eye removed, my right eye has been left with very limited vision and I have been registered blind since a child.

My parents became friends with Matt's and Lamorna's parents who were also having treatment for Rb. My mum remembers us all, in our prams, going for walks through the busy London streets in between our treatments. Over the years our parents have shared many letters, Christmas cards and photos updating each other of our progress as we grew from babies into adulthood.

With the help of CHECT's Facebook group for survivors of retinoblastoma, Matt, Lamorna and I, now adults with families of our own, managed to find each other on social media. We have had many great chats and moans between the three of us on social media, as our journeys continue after Rb, with new diagnoses accruing as we get older.

In May 2016, I finally got to meet Lamorna again at a fundraising event for CHECT at the O2 in London, where we climbed over the O2 Dome with other survivors of Rb! I also managed to meet up with Matt in September 2017, for the CHECT 30th Anniversary Weekend in Buckinghamshire.



**Left: Lamorna as a child.
Below: Matt as a boy.**

It was amazing to meet up with them both, be it on separate occasions and we seemed to just have so much in common. We are planning for the three of us to meet up this year together which I'm very much looking forward to!

LAMORNA'S STORY

Funnily enough it was Zoe's mum who got me in contact with Zoe through social media. Zoe was already in touch with Matt, so I became the missing link. Zoe and I reunited in May 2016 (which was rather emotional after all these years!). We met in London as we both raised money for CHECT walking over the O2; unfortunately Matt was unable to make it.

It's amazing how well we get on and we have developed a very strong bond which is rather unique! We all share the same sense of humour and often email each other regarding problems or just generally checking in on each other.

MATT'S STORY

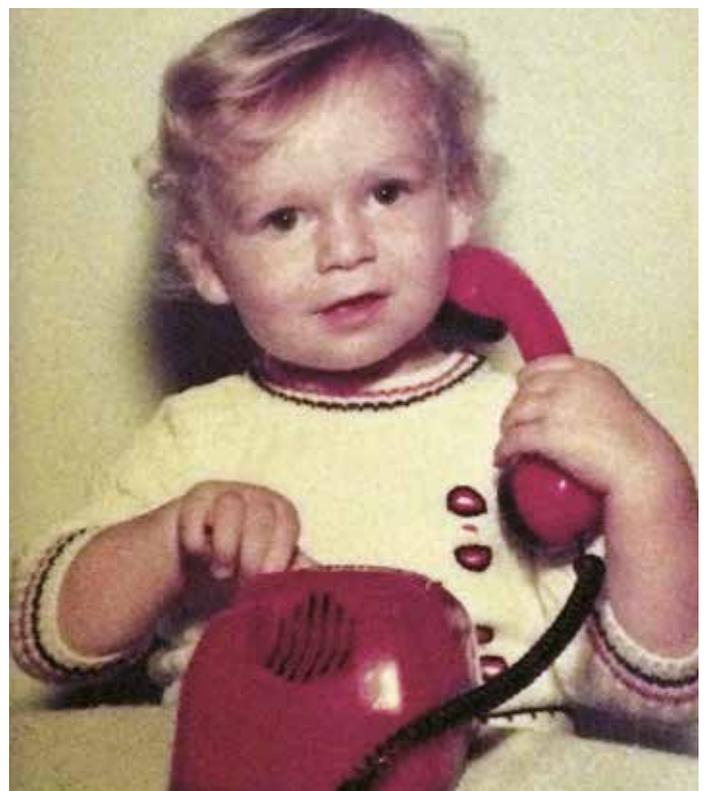
My mum swapped Christmas cards with Zoe's and Lamorna's parents throughout my childhood and adolescence. It was the only contact the families had for many years and yet the snippets of news in those cards told stories of difficulties, challenges, successes and accomplishments which resonated strongly with my own experiences growing up with the legacy of Rb.

As a teenager, I proactively avoided anything to do with retinoblastoma until, in my mid-20s, the birth of our first son George (who unfortunately inherited the disease) prompted a thirst for knowledge and a need to re-engage with the Rb community.

Email and then later social media played a key role in reconnecting, first with Zoe and later with Lamorna. Since then, mainly using group chats, we've all three shared many stories, anecdotes and 'living with Rb hints and tips' - it feels like a sort of exclusive Rb club!

We all live quite far apart and meeting up in person has been a challenge. In September last year Zoe and I finally met at the CHECT 30th Anniversary Weekend. I must admit neither of us recognised the other (unsurprising as Zoe was wearing a nappy the last time I saw her ... and so was I for that matter!). But within minutes it was as though the intervening 40 years had never happened. I met Zoe's amazing family, including her guide dog Revel, and we spent a happy few hours talking about the paths our lives have taken and the many 'Rb bridges' we've both had to cross.

I'm certain that it won't be long before we meet up again, hopefully with Lamorna too, so we can have a proper reunion!



UNDERSTANDING AND OVERCOMING BARRIERS TO LIVING WITH AN ARTIFICIAL EYE

by Dr Deanna Gibbs

Dr Deanna Gibbs, Research Consultant for Nursing, Midwifery and Allied Health Professionals at Barts Health NHS Trust and Principle Investigator of the research project.

From reports and feedback from parents, we recognised that there was a gap in the support and information provided for families whose child experiences a diagnosis of retinoblastoma and enucleation. In order to improve services, this research project, funded by the Childhood Eye Cancer Trust, aimed to explore some of the experiences of children and parents who have experienced enucleation, and identify what strategies work to instil confidence and coping.

These experiences have been analysed and loosely grouped into themes.

PARENT VIEWS

Entry into the world of retinoblastoma

Parents shared experiencing a range of emotional responses - including fear, anxiety, shock, denial, self-blame, and distress. Parents were conscious of the stress that this event placed on them, often needing to make treatment decisions in a quick time frame. The speed of the process of the diagnosis and surgery meant that once the initial medical intervention had passed, they focused on trying to regain a sense of normality for their family.

“You have got to take in a lot of information in an emotionally heated situation”

PARENT VIEWS

The importance of specialist support

Parents identified a range of elements they perceived assisted them and their children. These included accessibility of staff to clarify information and seek support as needed; developing relationships with members of the team; and receiving specialist procedural preparation and support for their child.

PARENT VIEWS

A family learning to cope

Families spent time adjusting to the ongoing care and follow-up for their child following their enucleation. For many, this was focused on the practical management of their child’s eye with both the initial conformer, and ultimately with prosthesis fitting.

PARENT VIEWS

Navigating school

Parents described concerns about both the practical management of the prosthesis if it came out at school/nursery, and managing the social-emotional response of their child and their peers in relation to the artificial eye. Some parents directly used the information provided by the retinoblastoma team to shape and support their conversations with their child’s teacher/school. Others sought direct contact between the Rb team and the school to ensure adequate transfer of suggestions and resources, or to address emerging concerns.

CHILD VIEWS

The importance of preparation and play

Most of the children were too young at the time of their enucleation to recall their experience, and their memories focused on the importance of play programmes and preparation that they received throughout their hospital journey.

“I think it’s also the case that Charlotte sees her play workers that she has met and known for years, it’s like a routine which is nice for her and she feels comfortable there.”

CHILD VIEWS

Positive reinforcement and hospital support

The children expressed the value of positive reinforcement for adjusting to living with their artificial eye – both from an internal (making their parents feel proud) and external (participating in the ‘wishes programme’) perspective. Having the opportunity to meet other children living with an artificial eye was also highlighted as a positive benefit.

CHILD VIEWS

Support and openness at home

Children described how they managed their eye at home. Some families focused purely on the practical issues, such as when the artificial eye needed cleaning, while others talked more openly about the eye in general and feelings surrounding this.

Some of the children and their families approached their artificial eye in a light-hearted way, and helped to make this a normal and accepted part of their daily life.

“I suppose for me I want to be normal, and for me being normal is that we acknowledge it. I don’t want Stephen to feel any shame in it.”

CHILD VIEWS

The importance of good school support

All of the children talked about challenges that they faced at school which included concerns about their eye falling out, when to clean it, who to go to if something happens and support from their peer group.

They also spoke about comments from other children - some had a level of resilience and managed these as jokes, while some were more upset and took the comments personally. The children placed importance on knowing who to go to and feeling support at school, especially when they knew there was a plan in place.

Finally, parents also shared how they and their child had adapted to their treatment so far, and challenges they anticipated arising in the future.

We are currently collaborating with parents to identify innovative ways in which we can develop resources and the retinoblastoma service to provide the best possible support for children and their families. Options to be considered in the future include child-designed, co-written and directed short films describing various stages of the hospital experience (eg hospitalisation, prosthesis fitting); development of an app to enable easily accessible information about living with an artificial eye for children and families; and enhancing our current physical resources (eg eye-care kits, procedural support toys etc) based on feedback and suggestions.

The full final report will shortly be available at checht.org.uk/research



A WORLD OF BOOKS

By Lesley Geen

Some parents have told us their child is not always getting the same opportunities as their peers to access books in different formats; this can obviously have an impact on their desire to read from an early age. At CHECT we have been exploring resources to help your young readers to access books to feed their imagination. Many of these organisations also have resources for teenagers and adults.

ClearVision is a postal lending library of children's books designed to be shared by visually impaired and sighted children and adults. Their books all have braille, print and pictures. This allows children with little or no sight to share books with their sighted friends and family, and adult braille readers to enjoy stories with sighted children. There are over 14,000 books in the collection, catering for children from birth until they're independent readers.

They add lots of new ClearVision books each month to make sure the collection is up-to-date and children with a visual impairment can enjoy the same titles as their sighted friends.

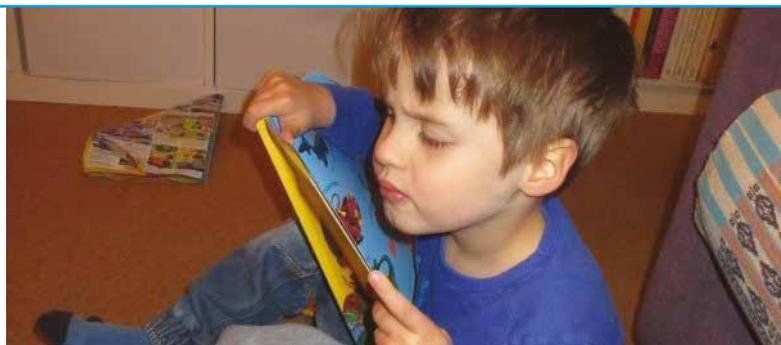
www.clearvisionproject.org

Young Calibre Audio Library is a national charity providing a subscription-free postal service of unabridged audio books for young people with sight problems, dyslexia or other disabilities, who cannot read print.

There is a one off joining fee of £20, but thereafter you will have access to as many of their audio books as you want

www.youngcalibre.org.uk

"The more that you read, the more things you will know. The more you learn, the more places you'll go."— Dr. Seuss.



Bookshare[®] is the world's largest accessible online library for people who have a visual impairment. More than 425,000 people in 70 countries have access to Bookshare's collection of 611,337 titles. Books can be downloaded free of charge, but you will need to ask your school or VI teacher to register with the Bookshare, to enable you to access the library.

www.bookshare.org

RNIB Talking Books service is absolutely free, providing access to over 25,000 fiction and non-fiction books for adults and children.

Talking Books has been one of their most loved services for more than eight decades, and they now offer more formats and titles than ever before.

www.rnib.org.uk/talking-books-service

Guide Dogs' CustomEyes service produces tailor-made large print books for children and young people up to and including age 25 with a visual impairment or dyslexia. They support blind children and young people across England, Northern Ireland, Scotland and Wales.

You can choose from over 4,000 large print books with new titles being added monthly. Books available include picture books, fiction, non-fiction, Oxford Reading Tree, GCSE and A Level English texts and textbooks, plus revision guides for Key Stages 2, 3 and 4.

www.guidedogs.org.uk/customeyes

Don't forget your support workers are always on hand to help with any questions you may have. Your VI teacher may be able to suggest other resources too.

THANK YOU!

Donations in memory of a loved one are a wonderful tribute and we 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:

Vera Madden
Leslie Ketteringham
Betty Jenkins
Carol Minogue
Paula Joan Ferry
Peter Nixon



The family and friends of Pippa, Dan and Seb Burrell have been such super supporters over the last year. Activities already undertaken include the London Marathon, coffee and cake day, doughnut sale and an Elvis Tribute night at AFC Portchester! Pippa, Alex and Denise will be tackling the Superhero Run in Regent's Park in May.



We were very sad to hear of the death of **Helen Shingler** in June of last year. Helen was in contact with CHECT for many years and contributed an article to InFocus in 2013 as she was about to become 21, on her experiences of Rb when growing up.

In February, staff from Hesley Group, where Helen worked, organised a charity ball in her memory, and funds raised were kindly split between CHECT and Teenage Cancer Trust. The event was a very special celebration of Helen's life, and we were privileged to be a very small part of it.

Many CHECT staff met Helen and we were all struck by how determined and cheerful she always was, with a beautiful smile. We remain in awe of Helen's energy, her drive and her spirit.

Linda Rogers planned the perfect fundraiser in December: 20 friends brought along food to add to her own, and her husband was designated drinks monitor! One friend brought her husband by mistake but luckily the two men discovered they were soul mates with a shared interest in trains. All had a wonderful time and raised over £600 for CHECT.

We are extremely grateful to **Roisin Lynch**, who with her husband **George** has been fundraising annually for CHECT for 24 years, since her son David was diagnosed with Rb. Each year they and a hardy bunch of supporters brave the waters of Lough Swilly, Co. Donegal for a Christmas Day Swim! This year Roisin, David and George rallied a great crowd and raised £1,550!

Lindsey Scales and Mathew Pringle hosted a fabulous celebration party for Joshua in October and raised a wonderful £2,000.

Hayley Brown and her family have undertaken a number of fundraising activities recently – and have yet more planned! Hayley's niece Katelyn started off with a cake sale at her school Christmas Fayre, and others joined in with a Christmas party at the local community centre. Hayley is now planning more schools fundraising with Katelyn and niece Chloe, as well as more family adventures, including the 5K Inflatable Obstacle Run Peterborough!

PARTNERS IN CHARITY

We were thrilled to see such a fantastic team from BIRMINGHAM OPTICAL turn out for the Great Birmingham Run in October. These heroes added over £4,000 to their impressive fundraising total last year – smashing their £10,000 target.

We are proud to be their Charity of the Year again, and Birmingham Optical now aims to raise £12,500 to support CHECT in 2018. They already have an impressive array of fundraisers lined up – Chief Operating Officer Arran takes on the London Marathon, a marvellous Tough Mudder team is raring to go and Chief Executive Steve Fleming will tackle the Coast2Coast in September. Thank you Birmingham Optical – we really value your support.



KID'S PRAISE THEATRE WORKSHOP very kindly chose us as their Charity of the Year 2017. The children performed 'I Believe' at Middleton Arena in November and collected an amazing £120. Musical Director Kathryn Thomas said: "The performance went exceedingly well and we are very proud of all involved. Two groups of children had a bucket each, one group were pirates and the others fairies... and were competing for the most change! They are over the moon to have done so well." Thank you to all involved, and especially to Kathryn for nominating us.

We would like to say a huge thank you to **MILL HILL SCHOOL**, who are supporting CHECT this year. The Charity Committee arranged a fantastic Unplugged Evening in November, where we heard some of the amazing musical talent within the school.

We were also proud to hear pupil Theo and CHECT Support Worker Lesley discussing the help that CHECT offers, in a special Q&A session. Thanks to pupils, staff and parents, the evening raised a superb £1,128.

We were grateful to be one of the chosen charities of the Original **Hampton Court Half Marathon** again this year. Our team of volunteer marshals and goody bag / water providers had a fantastic day, which was surprisingly mild for February.

Our special thanks go to Peter Wedderburn and the team at KBC Special Events for choosing us and for the wonderful donation of £1,971.50.

#TeamCHECT runners included **Ashley Williams**, who was supporting us for the first time. Ashley is a serving soldier in The Royal Welsh, Army Sportsman of the Year 2014/15 and Commonwealth Light Fly Boxing Bronze Medallist 2014.

We loved meeting Ashley and look forward to working with him again!



We are thrilled to be the chosen charity for 2018 of **Evolutio**, one of the leading NHS, self-funding and private ophthalmology providers in England.

The team kicked off their programme of events with a quiz and raffle in February, followed by amazing 'Row For Retina' and 'Spin For Sight' day.

Evolutio are also working with us on awareness raising – a great partnership all round!



Thank you too, to Chris Willis. In December each year her church, Trinity United Reform Church in Upminster, invites nominations for Charity of the Year.

This year Chris successfully nominated CHECT, as her great nephew Jude was diagnosed with retinoblastoma in 2014.

BARBER SHOW

We're very excited to be involved with Barber UK 2018, which is being held at the Birmingham NEC on 20 and 21 May.

CHECT Ambassador and barbering educator Alison Scattergood (who was awarded TES Further Education Teacher of the Year earlier in 2018) along with Super Supporter Mike Taylor, co-founder of the British Barbers' Association, will be taking over two stages at the show, raising awareness and funds for CHECT.

Thank you Mike and Alison, for all your hard work and dedication – we are really looking forward to the event.

GET INVOLVED...

RB WEEK 13-19 MAY

Rb Week is almost upon us – but there is still time to get involved!

CRAZY GLASSES

Join in with schools, companies and individual supporters in holding a Crazy Glasses event. More fun than a dress down day, invite your colleagues, fellow pupils and friends to get together and see who can design / make / wear the craziest glasses – or hold a virtual event online (please share your photographs with us, too). Find out more from Diane at **diane.emery@chect.org.uk**



ADD 25% TO YOUR FUNDS

Did you know that if you hold a cash collection for CHECT, and pay the coins and notes directly into our bank account, we may be able to claim Gift Aid from the government – meaning an extra 25% on funds raised.

Rb week is the perfect opportunity to launch an appeal – we can send you a CHECT collection tin, leaflets - and a paying in slip to use when depositing donations. Email diane.emery@chect.org.uk for your tin.

WHAT'S ON...

Join fellow supporters on one of our fantastic fundraising events and wear your CHECT running vest with pride!

Runthrough Regent's Park *Saturday 7 July 2018*

Choose 5K or 10K runs past London Zoo and the grounds of Winfield House, the second largest private garden in central London. The flat course offers a great opportunity for a chip timed personal best.

If you don't want to run, why not join us to cheer along our team? And afterwards you can walk through the elegant flowerbeds in the Avenue Gardens, see more than 12,000 roses in Queen Mary's Gardens, or hire a rowing boat and join the ducks on the boating lake.

Great Birmingham Run *Sunday 14 October 2018*

Now established as the second biggest half marathon in the UK, Birmingham comes alive with thousands of runners pounding the streets, encouraged by on-course bands, entertainment and, of course, cheering crowds. Be part of Team CHECT taking in the sights of the Cadbury Factory at Bournville and Edgbaston cricket stadium.

London Marathon *April 2019*

It's never too early to think about joining in with this iconic event. CHECT places are highly sought after so if you would like to run alongside 40,000 other dedicated individuals, get in touch for your application pack now!



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

GDPR CONSENT

New General Data Protection Regulation (GDPR) taking effect in May 2018 will change how charities can keep in touch with supporters.

If you would like CHECT to continue to contact you, please take a couple of minutes to complete this form or visit chect.org.uk/consent. Please tick all ways in which you agree for us to contact you.

Please complete the form in **BLOCK CAPITALS** in as much detail as possible.

TITLE	FIRST NAME			
	SURNAME			
ADDRESS		TEL		
		EMAIL		
		MOBILE		
		POSTCODE		

HOW WE KEEP IN TOUCH

How would you like us to contact you (please tick **ALL** that apply)?
By ticking these boxes you confirm that you are 18 or over.

EMAIL	<input type="checkbox"/>	PHONE	<input type="checkbox"/>	POST	<input type="checkbox"/>	TEXT	<input type="checkbox"/>		
Signed						Date	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

Please return to: Freepost Plus RTCK-JKAT-ZAKA
Childhood Eye Cancer Trust, Royal London Hospital, PO Box 59 Whitechapel Road, London, E1 1BB. Tel: 0207 377 5578 / Email info@chect.org.uk

The information which you provide in this form will be processed in accordance with the Data Protection Act 1988. By signing this form you agree to your personal information being made available to a limited number of employees of the Childhood Eye Cancer Trust and selected volunteers engaged for database work, subject always to compliance with the data protection legislation. We will not pass your information on to third parties without your consent (unless required to by law). If you have previously agreed to us using your personal information for direct marketing purposes, you may change your mind at any time by writing to or emailing us. Please refer to the website for further Privacy information.

