

infocus



BRING RB OUT OF THE DARK

It's time to shine a
spotlight on Rb.

For years, retinoblastoma has been shrouded in darkness. Too many children are left in the dark because some or all of their vision has been stolen. Parents and other health professionals are in the dark because not enough people know about this cancer.

It's time to shine a spotlight on Rb. SEE PAGE 14.



IN MEMORY

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WELCOME

Welcome to the May edition of **InFocus** and our new look newsletter. It was great to receive your comments and suggestions following our readers' survey in December, and the new design is a result of your helpful feedback. I very much hope that you enjoy reading the latest news and hearing from some of our wonderful families and members.

January saw the terribly sad news of the death of Dr Judith Kingston, who passed away after a short illness. Dr Kingston was an extraordinarily well respected and much loved Paediatric Oncologist who will be missed so very much. You can read more about 'Dr K' and the incredible impact she had on the lives of children with Rb on pages 6 and 7.

It's been a busy few months here at CHECT. We welcomed two new members to the staff team – Natasha

Boydell as Communications Manager and Lizzie Smalldon as Trusts and Foundations Manager.

I'd also like to take this opportunity to give a warm CHECT welcome to Ravi Gupta who has joined us as Treasurer on the Board of Trustees. As always, our amazing members and supporters took on many different personal challenges to raise money and awareness. They include Cathy Woodstock, who tackled the Sahara Desert Trek and our London Marathon team. We also had a fabulous group of runners and volunteers at the Hampton Court Half Marathon for the first time. My son Sam and I ran for CHECT and we were delighted to be part of such a great day.

A big thank you to our friends and supporters at Vision Express, Wunderman, Sackers, Thompsons and BBMV, who have helped with everything from fundraising to creative ideas for greater awareness, use of meeting rooms and redecorating our office! Huge thanks to every one of you for so generously giving up your time to support us in so many ways.

With thanks for all your continued help and support.

Very best wishes

Patrick

Patrick Tonks
Chief Executive

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NEWS

INFOCUS GETS A MAKEOVER

Welcome to your new look InFocus.

As you'll see, we've given the newsletter a bit of a makeover and we really hope you like it.

We want to make sure that InFocus is as useful, informative and enjoyable as it can be to the people who matter the most – you. With this in mind, we held our readers' survey at the end of last year to get your feedback. This was invaluable in helping us to understand what you liked, and didn't like and plan for future editions.

In the new look InFocus we've included all your favourite features, including personal stories about people affected by Rb, latest news and research, as well as practical tips and ideas on how to get involved with CHECT. Thank you to everyone who took the time to fill in the survey – we really value all of your comments.

We're also incredibly grateful to Mike McCoolle from McCoolle Creative, who so generously volunteered his time for free to give InFocus its new look. We hope you agree he's done a fabulous job. Thank you Mike!



VISION EXPRESS VIPS

Well done to all of our fabulous junior ambassadors who were guests of honour at Vision Express store openings across the UK over the last few months.

Vision Express often invites young CHECT members to be VIP guests when it officially opens new or refurbished stores. They're really fun days out for all of the family, plus a great way to raise awareness of Rb as the events often get reported in the local media.

If you'd like to be a Vision Express VIP guest, email natasha.boydell@chect.org.uk and we'll get in touch if there's an event being held near you in the future.



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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!



RARE DISEASE DAY AWARENESS

Gorgeous little Ezmai Hopkins helped to get retinoblastoma in the headlines on Rare Disease Day in February.

To mark the international awareness day, CHECT published its latest figures, which showed that in 2015 one in five babies and children had a delay of at least six months from their first visit to a health professional to being seen at a specialist eye centre.

One of those children was Ezmai. Her mum, Stephanie Beasley, first noticed there was something wrong with Ezmai's eye when she was nine months old but she wasn't diagnosed with Rb until she was two, despite several visits to health professionals. Just a week later, in October last year, she had her left eye removed to stop the cancer spreading.

Stephanie, from Tamworth, says: "My instincts told me there was something wrong with Ezmai but I felt no one believed me and that I was going mad. I want all parents to be aware of Rb and its symptoms. Get them checked out if you have any concerns and if you feel something's wrong, don't give up."

Stephanie and her family are now fundraising for CHECT. Their story, along with CHECT's news report, was published in local and national newspapers and websites across the UK, reaching millions of people and raising vital awareness of Rb.

You can read Ezmai's story at chect.org.uk/blog.

JOIN THE CHECT TEENAGE NEWSROOM TEAM

Calling budding writers, editors, photographers and designers: we're producing a new, digital edition of our popular TeenFocus newsletter and we need your help.

This summer we're recruiting a group of teenagers for a week's work experience at our office in Whitechapel, London. You'll work on the newsletter at every stage of production – from gathering story ideas to developing the design of TeenFocus, which will then be sent to our teenage members and their families and promoted on social media.

Not only is this a chance to have your say and be involved in the newsletter, you'll also get to 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.

The newsroom will run in August 2016. 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.

If you'd really like to take part but you can't make it to London, or you aren't free in August, please get in touch as we have some limited opportunities to get involved remotely.

NEW BABY JOY

We're delighted to announce the happy arrival of Chiara Áine Calvo, whose mum Rachael Tuley you may remember from the last edition of InFocus.

Rachael was diagnosed with bilateral Rb at nine weeks old. She had her right eye removed and her left was saved by targeting the tumours with radioactive plaques. When she was 37 she met the love of her life and Chiara was conceived by pre-implantation diagnosis (PGD).

Rachael says: "When I wrote my story for the last edition I was 30 weeks pregnant. At 36 weeks, I was admitted to hospital with pre-eclampsia after a routine check revealed dangerously high blood pressure levels, protein in the urine and excessive swelling of my legs and feet.

"One day short of 37 weeks, on 6 December 2015, Chiara entered our lives by emergency c-section, weighing 5lb 15oz. A healthy and serene baby, cord blood confirmed that she was free of the retinoblastoma gene."

Rachael adds: "The sun continues to shine on us: I recently discovered that our little star is the Centre for Reproductive and Genetic Health's first ever PGD embryo to be biopsied three times and result in a live birth. We therefore feel even more blessed to have her in our lives."

Huge congrats to Rachael and Davide on the new arrival. You can read Rachael's full story at www.checht.org.uk/blog.



EARLY YEARS AND VI LEAFLET

CHECT's latest information leaflet – *Early years and visual impairment (VI)* – is now available.

For many parents the news that their child has eye cancer is accompanied by the discovery that they have a visual impairment, which can be very distressing. Children with a visual impairment may have difficulty seeing facial expressions, moving around their home, watching television, interacting with their friends and, when they're older, reading.

This leaflet gives practical information and suggestions on supporting your child to maximise their remaining vision and other senses at this early stage of their life, as well as providing pointers for navigating the benefits system.

It includes information on:

- **Registering your child as blind or partially sighted.**
- **Applying for Disability Living Allowance (DLA) for children.**
- **Making the most of your VI/sensory team.**
- **Support at school.**

It also has an extensive resource section on topics such as play, special educational needs, financial help and VI organisations across the UK. We hope it will be an invaluable resource for any parent of a young child with a visual impairment.

You can download the leaflet at checht.org.uk or ask your CHECT support worker for a copy. Find out more about the educational support available to families affected by Rb in our article on pages 12 and 13.

AMAZING DEDICATION

When a bright young consultant started working at St Bartholomew's Hospital in the early 1980s, she had no idea that her work over the next 35 years would revolutionise the treatment of retinoblastoma worldwide and, quite simply, transform lives.

That consultant was **Dr Judith Kingston**, or Doctor K as she came to be affectionately known by those she met, cared for and worked with throughout her extensive career.

Dr K passed away in January after a short illness and she will be greatly missed by many, but her memory remains in our hearts forever. Her impact was felt in so many ways – from sitting by a poorly child's bedside and making them smile in the darkest of times, to improving treatment options for thousands of young people with retinoblastoma.



Revolutionising Rb treatment

Mr John Hungerford was another young consultant who joined the St Bart's team within a few months of Dr K. At the time, children with retinoblastoma rarely saw a paediatrician. Rb was seen as an ophthalmological condition and no one really thought about the fact that they were also children with cancer.

Dr Kingston, along with Mr Hungerford and Dr Nicholas Plowman, set out to change that and to improve outcomes for children with Rb. Together they developed a "lens sparing" technique which dramatically improved the quality of life for children needing radiotherapy, and introduced chemotherapy as a primary treatment option to avoid the use of radiotherapy and other treatments in babies and very young children. They also introduced orbital implants to improve the cosmetic appearance of artificial eyes.

Mr Hungerford says: "Cobalt plaque treatment for Rb had been predominant since the 1930s. If the other eye was healthy, eyes with extensive tumours had been removed until external beam radiotherapy arrived on the scene. I inherited the first generation of children who had received this new method and found severe



© Mike Abrahams / Alamy Stock Photo

facial deformity and other permanent side effects.

"At this time, the treatment of Rb was largely confined to surgeons but I quickly realised that Judith's knowledge and deep understanding of chemotherapy in children might be fundamental to a new approach."

Initially, the doctors expected that chemotherapy would only be used for large and multiple tumours, but now many children with Rb are treated predominantly by this method. This has given them a better chance of keeping the affected eyes and significant vision, as well as improving visual appearance.

Mr Hungerford adds: "The world of expertise in retinoblastoma



is totally agreed that Judith's contribution has been paramount to the current worldwide treatment of this tumour in thousands of children every year."

Caring for families

Despite her incredibly busy schedule, Dr K was absolutely devoted to her patients. Lesley Geen, CHECT Support Worker, said she was constantly inspired by the "amazing dedication" that Dr K had to the children and their families, from the point of diagnosis for as long as they needed her.

She says: "I remember one day she was so pleased that the small baby of a parent she had treated some years before smiled at her. It gave her the greatest pleasure to still be involved. She, too,

had the kindest smile and this was shared constantly with her young patients – they loved and trusted her, literally with their lives."

Pelham Allen and his wife Janet first met Dr K in 1986 when their son David was diagnosed with trilateral Rb. He says: "Judith was a truly wonderful woman: a beacon of hope for families facing terrible fears and pain. She combined deep expertise in her discipline, extraordinary devotion to her patients, a wonderful ability to empathise with and comfort affected families and, above all, a spiritual calmness that brought peace to frightened parents facing their worst nightmare.

'It's difficult to imagine how anyone could have done it better'

Supporting CHECT

Shortly after David was diagnosed with Rb, the Allens set up the David Allen Retinoblastoma Appeal, which subsequently merged with the Retinoblastoma Society to become what is now CHECT.

Dr K was one of the main forces behind CHECT from the very start. Joy Felgate, who was Chief Executive of CHECT from 2011 to 2015, says: "She completely understood the value of the work undertaken by CHECT in relation to awareness raising and campaigning, in addition to the support offered to families in clinics and on the ward.

"She also recognised the role the support workers play in supporting the medical staff involved in the care and treatment of people affected by Rb. Dr Kingston said that CHECT support made her job easier and that she felt confident about referring patients and parents to the support worker knowing that they were in good hands."

Joy adds: "She was a huge advocate for CHECT, always had time for CHECT staff, new and old and once said that when she retired from the NHS she would quite like to come and work for CHECT. She will be greatly missed by so many families and all the CHECT team."

Farewell to a saint

Dr K will be so terribly missed by all of us but her legacy will live on in the children she has already helped and the ones who will be helped in the future by her work.

As Mr Allen says: "She gave her all for as long as she could. Few of us will reach the end of our lives knowing that we devoted every minute of every day of a long working life to the cause we were most passionate about.

"I hope she will be smiling. We all know where saints go, and there is no doubt that Judith was a saint."

If you would like to talk to anyone, please feel free to call your CHECT support worker on 0207 377 5578 or the Rb nurses at the Royal London Hospital on 0203 594 1419.



RESEARCH AIMS TO HELP PARENTS OF CHILDREN WITH RB

Nicole Beddard wears her first ever artificial eye in a ring – a symbol of her determination not to let retinoblastoma stop her from achieving anything. She says it's a great conversation starter.

But it's taken a long time for Nicole to feel confident enough to hold her head up high. She was three months old when she was diagnosed with bilateral retinoblastoma and to save her life she had many forms of treatment – her left eye was removed and her right eye was subjected to cryotherapy, radiotherapy and a radioactive plaque was inserted to get rid of five tumours.

When she was five, she was given the all clear, only for a cataract to start forming in her remaining eye three years later.

Above: Nicole as a baby with her parents.
Right: Nicole now

Nicole says: "Throughout my childhood, teenage years and the beginning of my adult life, I struggled with different things – for 10 years of my life throughout school, college and my undergraduate degree I covered half of my face, over my left eye, as I had become ashamed of what I looked like.

"At the end of university I realised that it doesn't matter what people think; all that matters is your own happiness. I have the wonderful support of my family and friends that make me proud of who I am and what I have gone through."

Nicole adds: "My cataract has not once stopped me from achieving anything and I go for yearly appointments to the opticians who are rather shocked at how good my eyesight is under the circumstances."

Now aged 24, Nicole is studying for her master's degree in health psychology and clinical skills, and she wants to help people who are going through what she and her parents did.

She says: "I know it's a scary process and when I have children I may have to go through the same as my parents."

SHAPING THE FUTURE

Nicole has begun a new research project and has been speaking to parents of children with Rb, learning more about their experience of going through diagnosis and treatment. The aim is to see if there is any more support that can be put in place for parents.

Nicole says: "There is a great need for research into this topic. I fundamentally want to spread awareness of Rb and help those who are affected by it, which means that the research, expectantly, will be published."

If you're interested in contributing to Nicole's research, please email her at NicoleBeddard@gmail.com by the end of May.



It doesn't matter what people think; all that matters is your own happiness.

ARTIFICIAL EYE SERVICE SURVEY – THE RESULTS

Thanks to all of you who took part in our survey last year to discover more about the artificial eye care service members receive from different providers around the UK.

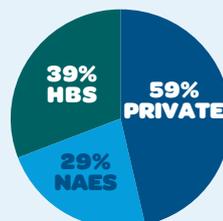
We had a great response: so much so that we kept the survey open much longer than initially planned. Over 300 of you shared your views, two thirds of whom were using NHS services, with a third using private services. The majority of you receiving NHS care were using the National Artificial Eye Service (NAES), and the others were accessing hospital-based services (HBS).

In response to the survey, Helen Lever, Operational Manager of NAES, said: “Our website www.naes.nhs.uk now offers the option for anyone to contact us directly using a query form. We have also implemented a telephone recording system which has enabled us to address any concerns raised from patients or carers if they feel that our service to them has not met the standard we expect. If you have any concerns about the way your query was handled, please let us know (if possible with the date and time of your call).”

Helen added: “If anyone has a specific comment regarding our service, I would encourage them to contact us directly – please be assured that any concerns raised are acted upon immediately by a member of our Management Team.”

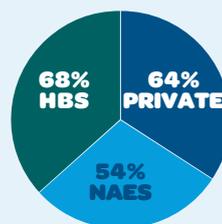
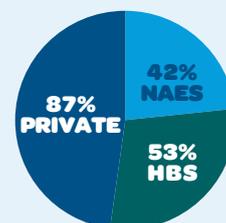
Patrick Tonks, Chief Executive of CHECT, said: “It’s very important to us that our members’ voices are heard and that we are able to represent your views and opinions. We are grateful to everyone who took the time to participate in our survey and we hope that the findings will help to improve services in the future.”

Keep up to date with the latest news and research at www.chect.org.uk.



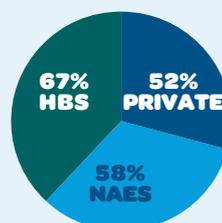
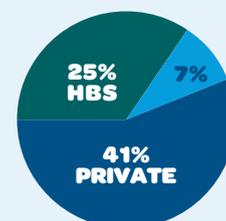
Those using **private** services were more likely to be given routine appointments within six weeks

Private services were best able to offer urgent appointments within three weeks



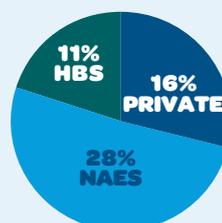
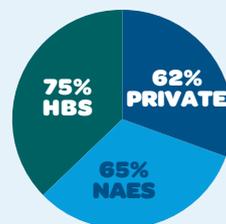
HBS users were happiest with their booking experience

NAES offers the most local options, with 68% travelling less than 20 miles. 25% of hospital visitors and 41% of private patients travel more than 50 miles for their clinics compared to just 7% of NAES users.



Those using **HBS** were most likely to have a regular prosthetist

When asked to rate the **overall service** (Good or Excellent)



28% of all NAES users said that they had experienced **negative change** in the last three years, compared to 16% of private and 11% of HBS patients.

MY EYE? WHAT ABOUT IT?

Mum **Melanie Cassidy** reveals how, with the help of some cuddly friends, her son Edward took to his new eye like a duck to water...



Edward was 19 months old when he was diagnosed with unilateral Rb. A week before the operation to remove his right eye, I was met by a lovely lady from CHECT, who gave Edward a toy dinosaur called Dino with a very special "magic" eye that could be removed.

Just a few hours after his surgery, Edward was happily playing with Dino. He also had a favourite teddy who, along with Dino, had a bandage over his eye. When we were discharged, Edward and pals had the bandages removed and they all had their eye drops administered.

Dino and Teddy always went first and they were always happy with it, so Edward was too. It's a brilliant way to demonstrate to your child that the toy is making the same journey as them and that they are not alone.

Only a couple of weeks later Edward removed his conformer. The first time this happened, I was a little perturbed by it and off we went to our local emergency eye department, where they kindly put it back in and showed us how to do

it ourselves if necessary. Of course the whole gang came along, and again Teddy and Dino were not bothered by it so neither was Edward.

When this happened again, a mere two days later, I realised that I'd have to deal with it myself and, without making a fuss, I just popped it back in. I took Edward's lead – I couldn't let my emotions get the better of me when he was so unfazed by it. At the age of two he was showing a strength that I could only copy.

When Edward went to get his artificial eye fitted he happily removed his conformer. We were told to clean his new eye regularly and of course we practised on Dino first. Luckily Dino never cries or gets upset, so Edward decided he wanted to clean Dino's and his own eye himself. From then on, Edward always cleans his eye at bedtime along with brushing his teeth, and it's part of the normal, daily routine.

Edward hasn't always been a perfect angel. He once thought the lady at the check-in desk at Manchester Airport would like

to see his eye in more detail and gave it to her with his passport! Fortunately I managed to retrieve it before the lady fainted.

Edward is 10 now and spends more time in front of the mirror than I do. He has beautiful thick, curly hair which he spends fruitless hours trying to tame.

And his eye? Well what about it? He says it's just like me wearing glasses – "no big deal" – and I really think that's the secret of our success.

The Childrens' Eye Cancer Foundation in Germany, KAKS, offers free elephant cuddly toys to families affected by Rb around the world. "Elli" has a magic, removable eye, just like Edward's old toy Dino. If you'd like to order an Elli, please email info@kinderaugenkrebsstiftung.de



"demonstrate to your child that the toy is making the same journey"

MEMORIES OF AN RB SURVIVOR

Iain Riddell, lay member of CHECT's Scientific Advisory Committee, reflects on how childhood memories are shaped by the realities of Rb...

Among the mass of childhood memories rises the parental decision on a regular basis that an exciting family trek was required. So the four of us – parents, older brother and I – would set off with the dog.

These walks always seemed like a massive waste of time, which is not to say I didn't enjoy or appreciate the act of walking. Right through my 20s you would find me happily trekking, headphones and sunglasses on, eye flicking about – right, left, up, down.

Their purpose was partly that they were uplifting and illuminating. Only in adulthood did it twig that family walks were mostly about concentrating on uneven surfaces, mud edges, tree limbs reaching out to snatch glasses away, accidentally walking into parked cars. Yet, oddly, walking represented independence. A-level maths tuition meant nearly two hours of walking through Cardiff's back pathways once a week in all weathers. This was preferable to having to navigate

the bus system and its series of exhausting visual challenges.

Following an operation six years ago to replace my surviving eye's lens that was lost to cataracts in 1981, I have got back onto bicycles. Cycling was abandoned in my early teens, partly as I kept going into lampposts and signs.

The replacement of my internal lens after 29 years brought along something called peripheral vision. I discovered I no longer needed to point my nose directly at whatever it was I wanted to see, nor did I have to tip my head to ensure that the bifocal line distorted the bus information while trying to dodge through a crowd. The abandonment of heavy bifocals and months of physiotherapy helped realign the nerves, reducing my shoulder, neck and arm pain, and I gained 1.5 inches of height as the hunched shoulders for which I was noted from primary school were no longer required.

While skiing in Saalbach after new year, I was reflecting on the disparity that Rb and Rb treatment has caused in visual ability. One day, I was crawling across a basic slope unable to see the difference between up and

down, or notice significant mounds of snow ready to hurl me from my skis, utterly reliant on hearing and skill to keep me on my feet. The next, I was whizzing past the majority of folk, hurtling down steep black runs with a certain flare as the ambient light had produced some striking contrasts on the pitches. I wondered what level of determination would overcome these realities of Rb.

As I peeled out of the layers of ski gear in the evening, I wondered how many of the life defining choices so far taken were shaped by the consequences of adjusting to the realities of Rb and Rb treatment?

Read the full article by Iain on the CHECT blog at www.chect.org.uk/blog.



"Cycling was abandoned in my early teens, partly as I kept going into lampposts and signs."

ADVICE



PARENTS AND CHILDREN NOW HAVE A CHANCE TO BE HEARD

Marie Lloyd is a Qualified Teacher of Children and Young People with Visual Impairment, and mum to Daisy who had retinoblastoma. She outlines the educational support available to families affected by Rb and how recent changes in the law could affect you...

There has been a massive shift in culture towards children with a disability or special educational needs in England. Families now have a voice and a chance to be heard.

In 2014, the introduction of a new Children and Family Act in England led to the biggest educational reforms in a generation, with new legislation and legal duties for education, social care and health. Reforms are taking place in Wales and Northern Ireland, and Scotland is reviewing its situation.

This will have an impact on children with health needs or visual impairment after retinoblastoma. The SEND Code of Practice 2014 is there to support a broad

range of needs including sensory impairment (VI) or physical needs.

Your child doesn't need a Statement of Special Educational Needs (SEN) or Education Health and Care Plan (EHCP) to get the support they need at their place of learning, and all schools, including academies and free schools, have a legal obligation to make any "reasonable adjustments".

Previously this came in the form of School Action or School Action Plus but these have now been replaced with a new, single approach – Assess, Plan, Do, Review.

Clear targets are set for your child with identified support and intervention.

Their progress is monitored and reviewed regularly with parents, usually every term. If your child's needs are more complex or exceed a certain amount of funding, an EHCP will be requested instead of the old SEN Statements. All existing Statements will be converted to EHCP by 2018.



SUMMARY OF THE MAIN CHANGES

- Education, health and social care all work together to produce ONE plan rather than each doing their own. All information is centralised with coordinated assessment.
- The guideline is 20 weeks (not 26) from request of EHCP to final issue.
- Parents and young people can now request EHCPs, not just professionals.
- The whole process should be person-centred, tailored to you and your child.
- The age range is 0-25 (rather than to 5-16).
- All local authorities offer an Independent Parental Support and Advice Service to help you through the process.
- It will be easier for parents and young people to appeal the EHCP, and this can be in the form of mediation or tribunal.

If a young person stays in further education or an approved apprenticeship, the EHCP can be requested or stay in place, helping to ensure that young people are picked up by Adult Services (16-18 plus) and their needs are still met.

In every case, an Assessment Coordinator is appointed to act as a key point of contact. Parents and young people can choose this person or even do the role themselves. They work with the family and professionals involved and gather all the information needed to write the plan. You should feel more supported without the need to repeat yourself and speak to lots of people.

A PERSONAL APPROACH

EHCPs are outcome-focused, based on the aspirations of the young person. It's about what the family and child want to achieve and aspire to in school and life. Outcomes are usually linked to age – for example at college a young person may want a particular career and to live independently; in KS2 outcomes may be around SATs and transition to secondary school.

Personal budgets are part of an EHCP. This is an amount of money identified by the

local authority needed to deliver particular parts of the provision and is paid to the family or young person to give them more control and choice. My local authority identifies personal budgets for transport and short breaks. Yours will have its own areas of provision for this.

All local authorities and schools have worked with parents and young people to produce a list of services (in one place!) and support available locally. Mine can be found at portsmouthlocaloffer.org and is a good example. All young people with a visual impairment should now have a qualified teacher of visually impaired children and you should speak to the SENCo or your local authority if you don't have one.

MORE SUPPORTIVE

As a mum to a young person with Rb who had a double enucleation, I have found the new system much more personalised and supportive of her needs. As QTVI, I have been an Assessment Coordinator and written plans and I have found this very rewarding because it is about getting it right for the child and involves much closer working with the family.

Hopefully you will all benefit from the reforms too. Remember, knowledge is power so I hope that reading this has helped you.

FUNDRAISING



IN THE DARK

World Retinoblastoma Awareness Week

marks the beginning of our campaign to shine a spotlight on Rb and we need your help.

Rb Week runs from 8-15 May and there are lots of ways that you can get involved, from fundraising to raising awareness. And please don't worry if you can't take part during that week – anything we can do to make more people aware of Rb throughout the year is really important and we're grateful for any help that you can give us.

Here are some of the activities going on:

- Get dressed or do your makeup in the dark and get friends to donate to "dare" you to put a photo on your Facebook or Twitter profile. #InTheDark
- Have a sponsored sleepover in the dark – camp out in the back garden for the night or, if it's too chilly for children, make a camp in the living room.
- Ask children to do a painting or drawing blindfolded to see what it can feel like to have a visual impairment. Send us a photo and we'll feature some of the artwork on our website.
- Distribute awareness leaflets in your local area, for example doctors' surgeries, baby clinics, children's centres, community and church halls, photography studios and anywhere else you can think of!
- Ask your school, club or work to have a bake sale or wear black for a day.

To find out more about any of these activities or let us know what you're up to, visit chect.org.uk/rbweek, call us on 020 7377 5578 or email us at info@chect.org.uk.

IN MEMORIAM

A gift in a will or a donation in memory of a loved one is a wonderful tribute and very much appreciated. Our condolences and grateful thanks are extended to the families and friends of:

Colin Thomas Palmer
Joan Marjorie Sedgwick
Edith Blackabee
Harold Edwin Harper
Daisy Hindmarsh
C Radford

TREK FOR CHECT

A team of 17 people from motor manufacturer **Parvalux** took out of office socialising to the extreme after they trekked 26 miles through the New Forest in aid of CHECT.

James Edwards was part of the team who took part and helped to raise £722. He said: "We were treated to some spectacular scenery and perfect weather for walking. With all levels of experience among our group it was certainly a challenging event and except for some blisters and stiff legs we all came through relatively unscathed."

James adds: "While the last few miles were tough, the support of those who had sponsored us and the knowledge that the money we had raised was going to such a worthy cause pushed us over the line."





FAMILY AFFAIR

When **Tina** and **Simon Treadwell's** son **Taylor** was diagnosed with Rb, Tina rallied her family, friends, work colleagues and businesses to help raise awareness and funds for both CHECT and the two local hospitals where Taylor was receiving treatment.

Simon did a parachute jump, Tina's sister got her work involved in fundraising, the local Co-op had collection pots, and a friend's New Year's Eve party raised funds too. So far **CHECT has received around £10,000 from the Treadwell family**, which will go a long way towards helping other families affected by Rb.

CHARITY DRIVE

Thanks to **Richard Nightingale**, Men's Captain of **Oakland Park Golf Club**, who chose CHECT as his charity of the year.

Through a number of fundraising events, including the Captain's Drive In, annual charity match, charity bunker and caddying for people during wet weather when trolleys were banned, Richard has helped to raise hundreds of pounds for CHECT.



HIGHLIGHTS

MARATHON MAGIC

Dad and daughter duo Kevin and Lizzy Porter ran the Brighton Marathon in February and smashed through their target, raising **£1,135**.

BIRTHDAY GIFT

Thank you to Isaac Stevenson and his parents, Jed and Selam, who asked friends and family to donate to CHECT in celebration of his fifth birthday – they raised **£315**.

HAMPTON HALF

Seven runners and 11 volunteers helped to make Team CHECT's debut at the Hampton Court Half Marathon a success and raised **£3,197**.

CHRISTMAS E-CARDS

Thanks so much to everyone who sent a CHECT Christmas e-card – not only did you increase awareness of Rb, you also helped to raise **£1,600!**

AWARD WINNING FUNDRAISER

A Vision Express store manager has been awarded for her incredible commitment to charity after she helped to raise **£17,000** for CHECT.

Judith Crowe, who manages the York branch, took gold at the Corporate Engagement Awards for coordinating charity activity across 17 stores, motivating team members, organising events and helping to raise awareness of Rb.

Jonathan Lawson, CEO at Vision Express, said: "It's fantastic for Judith's efforts to be celebrated on a national stage. She has worked tirelessly alongside her store manager role to drive forward the aims of the charity partnership with CHECT, and has inspired those working with her to raise a phenomenal **£17,000** in donations. We're extremely proud of her achievements."

WHAT'S ON...

Join Team CHECT and have fun at the same time by signing up to one of these fabulous fundraising events throughout the year...

Great Newham London Run – 10K 17 July 2016

Have your very own Olympic moment as you cross the famous finish line that saw Olympic greats Usain Bolt and Mo Farah race across in 2012.

London to Paris Bike Ride 20-24 July 2016

Take on this 300 mile ride for a truly unforgettable experience.

Great North Run 11 September 2016

We have charity places available in this half marathon, which is the world's largest with 56,000 runners

TrekFest: The Peaks – 25km to 100km 3-4 September 2016

Choose from a number of different routes, all in one of the UK's most gorgeous national parks.

Snowdon Trek 24-25 September 2016

This trek in the heart of North Wales comprises breathtaking scenery and rewarding trekking.

Angkor Wat, Cambodia 5-13 November 2016

Trek over hills, through valleys and dense forests, ascending to the upper plain of Kulen Mountain.

Inca Trail, Peru 11-20 Nov 2016

One of the top 10 trekking trails in the world and a popular charity challenge deep in the Andes Mountains.



If you would like to take part in any of these events, please call Fiona Heath on **020 7377 5578** or email her at **fiona.heath@chect.org.uk**



WE NEED YOUR HELP

We've been helping families affected by Rb for nearly 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 for your support.

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

TITLE	FIRST NAME		
	SURNAME		
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 / postal order made payable to the Childhood Eye Cancer Trust
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Please debit my:	<input type="checkbox"/> Maestro	<input type="checkbox"/> MasterCard	<input type="checkbox"/> Visa Debit	<input type="checkbox"/> Visa Credit
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Valid From: (if applicable)	/	Expiry	/	Issue number (Maestro only):	
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SIGNED	DATE
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From time to time we may wish to communicate with you by phone or email. If you would like us to do this, please tick this box: [] For more information, please call us on 020 7377 5578.