

# infocus



## ON THE AIR

Teenage members of CHECT got a VIP tour of the famous Global radio studios in London and discussed the launch of our exciting new Teen Focus Council. Read about their adventures on page 3.



### HELPING HAWWA

HOW THIS BRAVE LITTLE GIRL INSPIRED A LOCAL COMMUNITY

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### NEVER GIVE UP

ANGIE'S DETERMINED JOURNEY TO BECOME A MUM OF FOUR

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FOR BROTHERS AND SISTERS OF CHILDREN WITH CANCER

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# WELCOME

## Welcome to the latest edition of InFocus.

The last few months have been as hectic as ever with some wonderful work with our teenagers, a really well attended and fun day out with over 80 people at Colchester Zoo, a Beyond Rb get together at a vineyard in Surrey, the selection and grant award to our latest research project, and the publication of our Impact Report to name just a few. We have been looking back on all the things that we have been able to achieve thanks to your support and making plans for our future. You can read more about this in the Impact Report, which you'll find on our website at [chect.org.uk/publications](http://chect.org.uk/publications).

While our core aims of support, research and awareness remain the same, we are always looking for new, innovative and where possible, better ways to help us achieve them. With this in mind, we are planning to carry out a members' survey, so we can find out more

about what is most important to you, what you think we're doing well, what we could do better, and anything else we could be doing to support you. All of our members will receive a copy of this survey and we would be grateful if you would take a few minutes to complete it as your opinions are incredibly important to us.

We would like to say a special thank you to the team of 30 cyclists who took part in the epic Vision Express Ride4Sight event in September – and to the young CHECT ambassadors who went along to support the riders. You can read more about this on page 15. Yet again we have been inspired by the amazing efforts that our supporters have gone to – from taking part in running events, to organising a Crazy Glasses Day, to giving awareness-raising media interviews. Thank you to each and every one of you.

*Patrick*

**Patrick Tonks**  
*Chief Executive*



## CONTACT US

CHECT office hours are Monday to Friday, 9am-5pm.

CHECT, Royal London Hospital, Whitechapel Road, London E1 1BB.

 /CHECTUK  
 @CHECTUK  
T: 020 7377 5578  
E: [info@chect.org.uk](mailto:info@chect.org.uk)  
W: [www.chect.org.uk](http://www.chect.org.uk)

## OUR TEAM

**PATRICK TONKS**  
Chief Executive  
E: [patrick.tonks@chect.org.uk](mailto:patrick.tonks@chect.org.uk)

**JULIA MORRIS**  
Support Worker  
Mon, Wed & Fri.  
T: 0121 708 0583  
E: [julia.morris@chect.org.uk](mailto:julia.morris@chect.org.uk)

**LESLEY GEEN**  
Support Worker  
Monday to Friday.  
T: 020 7377 5578  
E: [lesley.geen@chect.org.uk](mailto:lesley.geen@chect.org.uk)

**PETRA MAXWELL**  
Information & Research Manager  
E: [petra.maxwell@chect.org.uk](mailto:petra.maxwell@chect.org.uk)

**NATASHA BOYDELL**  
Communications Manager  
E: [natasha.boydell@chect.org.uk](mailto:natasha.boydell@chect.org.uk)

**DIANE EMERY**  
Fundraising Manager  
E: [diane.emery@chect.org.uk](mailto:diane.emery@chect.org.uk)

**LIZZIE SMALLDON**  
Trusts & Foundations  
Fundraising Manager  
E: [lizzie.smalldon@chect.org.uk](mailto:lizzie.smalldon@chect.org.uk)

**HAYLEY DOBSON**  
Office & Finance Manager  
E: [hayley.dobson@chect.org.uk](mailto:hayley.dobson@chect.org.uk)

**BETH LARDNER**  
Admin Assistant  
E: [beth.lardner@chect.org.uk](mailto:beth.lardner@chect.org.uk)

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**Printed by Fine Print (Stockport) Ltd. Telephone: 0161 484 2244.**  
Our continued thanks to Fine Print (Stockport) Ltd, for their ongoing support which enables us to produce this newsletter in full colour.

Design volunteered by [mccoole-creative.co.uk](http://mccoole-creative.co.uk)

# NEWS

## CHECT TEENAGERS GO GLOBAL



Nine teenage CHECT members had the opportunity to go on a VIP tour of the Global radio studios in London, home to stations like Capital, LBC and Heart. The group saw first-hand what goes on inside the studios and chatted to some of the presenters. One of the teenagers who attended, 16-year-old Harry Harrison, said: "The day was amazing. We all managed to meet new friends and reunite with old ones. It was great and we all look forward to the next day out!"

This event was made possible thanks to Global's Make Some Noise, the official charity of Global, who chose us as one of their beneficiary charities last year. As well as giving us an amazing grant of £93,000 which will be awarded over the next two years to support families affected by retinoblastoma, the Global team have given us some fantastic media opportunities to raise awareness of Rb.

Thank you to Beth Holman for providing the fabulous photo on the front cover of this edition.

*"The day was amazing. We all managed to meet new friends and reunite with old ones. It was great and we all look forward to the next day out!"*

## TEEN FOCUS COUNCIL

We are in the process of setting up a Teen Focus Council for our younger members. The aim is to better support teenagers affected by Rb and give them a voice within the charity.

If you or your child would like to be involved in this, please get in touch with Lesley Geen, CHECT support worker, on **020 7377 5578** or [lesley.geen@chect.org.uk](mailto:lesley.geen@chect.org.uk).

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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](mailto:info@chect.org.uk).

**Thanks for your support!**



## HAWWA'S STORY

A family from Peterborough donated an amazing £5,000 and helped to raise vital awareness of retinoblastoma after being inspired by baby Hawwa Amel Hussain.

Hawwa was diagnosed with Rb earlier this year, aged nine months. Her mum Aaliya Ahmed-Hussain took her to the GP after Hawwa developed a squint. She had also noticed that Hawwa's eye had a glassy look to it that was getting worse.

Hawwa has lost the sight in her left eye and is currently undergoing treatment. Aaliya said: "Despite everything she's been through, Hawwa is still smiley, bubbly and full of life. She is a typical mischievous baby who is always on the move."

Hawwa's granddad Shabir Ahmed is the manager of Peterborough Cars and the taxi company joined the family in raising funds.

During the World Cup football tournament each of the 160 drivers, office staff and some customers donated every time England scored, as well as the company donating each time England made it to the next round, raising £2,870. Aaliya has also been asking for donations and has raised £2,130.

Hawwa's story featured in the Peterborough Telegraph and on ITV News in August. Thank you so much to Hawwa, her family and the local community for their amazing support.

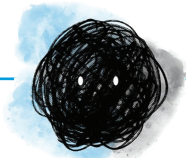


## VISION EXPRESS AMBASSADORS

So far this year, an amazing 33 young CHECT members have attended Vision Express store events as VIP guests, helping to raise awareness of retinoblastoma.

Thank you to each and every one of you, we hope you had a fabulous time. If you'd like to be a CHECT ambassador and represent us at Vision Express store events, we'd love to hear from you. Call us on **020 7377 5578** or email [info@chect.org.uk](mailto:info@chect.org.uk).





## ALICE AND DOT

On World Sight Day in October we launched a new campaign to raise awareness of Rb. Developed by the digital agency Wunderman and illustrated by artist Peter Clayton the campaign, which featured characters Alice and her 'Uninvisible Friend' Dot, aims to teach parents about the symptoms of Rb.

There was a lot of activity around the launch - a Dot blimp flew in London's Old

Spitalfields Market, and Vision Express put a 'Dot' on the lenses of the children's glasses in its Oxford Street store. Digital displays told the story of the Uninvisible Friend, and Alice Taylor, aged three, was the face of the campaign. The story also featured in the national media and on Mumsnet.

Thank you to Wunderman, Vision Express and everyone who helped to make this campaign a success. See it at: [www.uninvisiblefriend.com](http://www.uninvisiblefriend.com)

## YOUR COPY OF INFOCUS

### Are any other formats of InFocus available?

Yes, we offer InFocus in the following formats:

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

If you would like to receive InFocus in a new format, please let us know by calling us on **020 7377 5578** or emailing [info@chect.org.uk](mailto:info@chect.org.uk).

*I completed a GDPR form to say I wanted to receive CHECT communications by email. why am I receiving InFocus via post?*

All of our members are entitled to receive a postal version of InFocus. However, if you would prefer to receive an electronic version in future that is no problem. Just let us know on [info@chect.org.uk](mailto:info@chect.org.uk) or **020 7377 5578**.

search  
**UNINVISIBLE FRIEND**  
[www.uninvisiblefriend.com](http://www.uninvisiblefriend.com)



# ALL I WANTED WAS TO BE A MUM

All her life, **Angie Campbell** had dreamed of being a mum and having a large family. But after being diagnosed with a genetic form of retinoblastoma as a baby she knew that her path to parenthood wouldn't be straightforward.



**She shares her remarkable journey over the last 18 years to realise her dream...**

As I grew up all I wanted to do was be a mum. I had no idea that the cancer I had as a baby would mean that this simple life plan would turn into an 18-year-long traumatic and emotional journey.

My firstborn boy Kieran inherited my mutated gene and had to endure 20 months of active treatment to save his eyes. This had a devastating impact on both Kieran and myself. I knew that I didn't want him to be an only child, but also knew that going through that again was not something I was strong enough to do.

When Kieran was two years old, a conversation with Dr Elisabeth Rosser gave me hope that I could have another child and not pass on my gene. She referred us to University College Hospital (UCLH) and we began the process of pre-implantation genetic diagnosis (PGD). It sounded so easy and an answer to my prayers. I had no idea that it would take four years of trauma before I would meet my second son.

We were the first people in the UK to go through the PGD process for cancer and therefore had to go through the battles for funding, the Human Fertilisation and Embryology Authority (HFEA) approval process, the huge media exposure and the wait for the team at UCLH to develop the techniques needed to carry out the treatment. It was excruciatingly difficult but we were very lucky that the treatment worked first time and I had a healthy baby boy, Cameron, who did not inherit my faulty gene.

My path to motherhood had been so challenging and heartbreaking in so many ways and over so many years. I felt extremely blessed to have my two boys who were both healthy and happy, but also sad that I would not get the large family I desperately wanted. I decided to become a foster carer – I may not be able to have any more children of my own but I could be mum to many vulnerable little ones that needed my love.



Little did I know that this decision would lead to me meeting my youngest son. Dane came to me at two days old and was loved unconditionally from that moment on. He officially became my son at the age of two when we were unable to find adoptive parents for him, but I believe he was always destined to be my boy.

So I was a mum to three beautiful boys and time was healing a lot of the old wounds. My eldest was 17 and I was a very different person to the 23-year-old that nursed her son through cancer. My husband and I decided to try for one last child.

We did this with the full understanding that the baby may inherit my gene but I had reached a place in life where I was OK with that. We had an amniocentesis test when I was 16 weeks pregnant and it was only a few days later that we received the most amazing call to let us know

***“My path to motherhood had been so challenging and heartbreaking in so many ways and over so many years.”***

that our baby did not inherit my gene and that we were having a little girl. The relief and joy were truly overwhelming. Millie arrived and completed our family in March this year.

Looking back, it feels as though my whole adult life has been spent trying to achieve this family but I cannot think of a better use of my time or energy. I may not have taken the conventional route to get here but I have the four children I dreamed of and I love every second of the chaos and noise.

*If you'd like more information about having a family after Rb, please visit our website at [chect.org.uk](http://chect.org.uk) or speak to your support worker.*



# ESTABLISHING AN ENHANCED RETINOBLASTOMA REGISTRY

By **Helen Jenkinson**, Consultant Paediatric Oncologist in the Retinoblastoma Service at Birmingham Children's Hospital and **Paul Davies**, Head of Registration at NCRAS West Midlands and South Central, Public Health England...

Every year, the retinoblastoma (Rb) teams from Birmingham and London meet with NHS commissioners. At the meeting clinicians, nurses, commissioners and analysts discuss differences in referral, diagnosis and treatment at the two centres. Understanding these differences is vital to improving the services and care provided to children with Rb in the UK.

Making comparisons between the centres can be frustrating and time consuming as both centres collect and analyse their results in slightly different ways. After one such meeting, we agreed how much better it would be if the data was collected centrally and from that initial idea an exciting and ground-breaking project emerged.

In 2015, with the support of a generous grant from CHECT, we started to design a unique national Rb register in partnership with Public Health England's National Cancer Registry which collects information on all cancers treated in England. The Rb register is set to replace existing Rb data systems used in the UK; improving and standardising the way we collect data.

The register will use the full range of data already collected by the cancer registry and Rb clinicians will be able to audit and enrich their patients' cancer registration records with data specific to the diagnosis and treatment of Rb. The resulting gains in consistency, completeness and data quality will make reporting to commissioners much easier.

## BENEFITS OF THE NEW REGISTER

This approach to develop a register within a well-established, world-class cancer registration service will mean that the information will be entered and stored securely, undergo careful quality control for accuracy and will still be available in decades to come – providing lifelong monitoring of the incidence of second primary tumours and other potential late effects.

There are numerous benefits of this approach not only to patients with Rb but those with other childhood cancers or rare diseases too. These include:

### 1. CLINICAL AUDIT

To be able to better assess the quality of Rb services being provided, which could include the effectiveness of treatment plans and the short and longer term health and wellbeing of patients after they have finished treatment.

### 2. PATIENT CARE PLANNING

To provide treatment timelines, end of treatment summaries and individualised care plans which help patients to understand their diagnosis, the treatment they have received and the potential problems they may encounter in the future, along with advice on how to stay healthy as they get older.

### 3. RESEARCH

Access to anonymous data will allow research teams to understand more about the causes of retinoblastoma and investigate new and innovative approaches to treating both the disease and its late effects.





The Rb clinical teams and representatives from NCRAS and CHECT met for an initial workshop in 2015 to discuss and debate what information should be collected on each patient. As we expected, we started off with a very long list of information and this has gradually been refined and revised to make sure that the data collected is necessary, appropriate and manageable for the busy clinicians who will be entering it into the database week by week.

Once the final list had been approved, it was sent to the NCRAS IT development unit in Cambridge for the team

there to create the platform in which it will be stored and the clinical portal through which the clinical teams will be able to add new data and review the patients under their care. Each Rb centre will only be able to see information on patients registered at their own centre although anonymised data will be available to clinicians on all patients registered in the database on request.

The clinical portal has now been developed and is currently undergoing testing by the clinical teams to iron out any potential problems before the system goes "live" later this year.

The National Cancer Registry has the government's permission to collect and use sensitive personal data on cancer patients without consent, for medical purposes and in the public interest.

If you want to find out what information the cancer registry may hold on you or your child, please contact [FOI@phe.gov.uk](mailto:FOI@phe.gov.uk)

Anyone can opt out of cancer registration without it affecting the care they receive from the NHS.

You can find out more about the cancer registry at **[www.ndrs.nhs.uk](http://www.ndrs.nhs.uk)**.

# LOOKING AFTER YOURSELF

When your child is diagnosed with retinoblastoma, so much energy goes into looking after them and the rest of the family that it can be easy to forget to take care of yourself. But, as **Lesley Geen**, CHECT support worker, explains, this is important too...

Finding out that your child has cancer is truly devastating. Coming to terms with learning that they will need difficult treatment when they, usually, are well and happy is not easy. But as parents you do whatever you have to, to look after your precious child.

However emotional and exhausted you are, you get up early for hospital appointments, wake in the night to check on your child when they call out, if they are unwell, or just need an extra cuddle. You just keep going. You organise care for siblings, play dates, sleepovers, granny and grandad care, anything to help them also feel special and important

to you, despite their day to day life changing too.

*“Accept help if you can, sharing practical things can make life a little easier.”*

But what about you? How can you look after yourself? Do you even have the energy or desire to at this point?

You will have plenty of people to support you – hospital teams (play specialists, nurses, doctors to name a few), your CHECT support worker, other charities, as well as your family and friends. Accept help if you can, people like to help and sharing practical things can make life a little easier.

Talking therapies can be a great help. There are people that you can talk to, perhaps a counsellor or psychologist. But what if you don't have the energy for that? Well, that's fine. In fact, whatever works best for you and your family is fine.

There may come a time when it would really help to find someone to speak to about what you, your child and your family have been through and the impact of that. This can be during treatment or it could be well after treatment has ended, when you may experience waves of emotion about the diagnosis and treatment, or even feel as if you have been hit by a sledgehammer as it all comes back to you.



You may ask, why now? Why, when treatment is finished and my child is well, should I need to talk about it? Well, at the beginning you have to use your energy and emotions to get through the treatment phase. Now, you have the time to allow these feelings to surface. This is normal. It can be considered a strength to ask for help at this time. It's certainly not a weakness.

You can talk to your CHECT support worker or Rb team about the best way to find this help. At the Royal London Hospital there is a psychologist on the Rb team who you can speak to on the telephone or meet at the hospital. Birmingham Children's Hospital can also offer psychological support for parents – ask your Rb team for a referral.

You can speak to your GP, or your CHECT support worker can often help you to find counselling support locally. **Please don't be afraid to ask for help, at whatever stage you are.**



# Q&A WITH NAES

**The National Artificial Eye Service**, part of the NHS, makes up to 5,000 bespoke artificial eyes a year for people of all ages, from babies to pensioners.

We spoke to **Helen Lever**, Operational Manager and **Ken Barratt**, Production and Quality Manager, to find out more about the service and its new scheme to prioritise orders for children...

## **Tell us about the service**

The National Artificial Eye Service manufactures and fits ocular prostheses (eg artificial eyes, conformers) to all eligible patients in England. We also manufacture for our colleagues in Wales and Northern Ireland.

We have a purpose-built manufacturing laboratory in Blackpool, where all orders from the Orbital Prosthetists (OPs) are sent. We have 18 Ocular Technicians (OTs) who make the eyes and 20 OPs who treat patients at either one of our 18 main centres or an outreach clinic linked to the main base. We produce 4,500-5,000 artificial eyes a year for

individuals ranging in age from newborn babies to older people who have been with us for all of their lives. The service actually originated during the First World War for injured soldiers returning from the frontline.

## **What's involved in the process of making an eye?**

Every eye is different and requires a number of skilled processes to manufacture and fit. First the patient will meet an OP, who will take an impression of the eye socket using a special moulding material. They will convert the shape into a wax replica and send this with a detailed specification into the lab.

A plaster cast is made which is used to produce an acrylic copy of the shape. The OT will paint the iris to the individual specification using oil paints. Once dry, a watercolour stain is added to the sclera (white of the eye) followed by silk embroidery thread to create the natural vein effect. A clear acrylic lens is moulded over the top to create the cornea and seal it.

The eye will be sent to the clinic for a final polish before being fitted and minor adjustments can be carried out if needed. If it's not right, it will go back to the lab as a priority, where a technician will carry out any remedial work required. We are currently working to a 96% first time success rate. All

OTs and OPs undertake training programmes, developed by the NAES over many years, which can take up to a year to complete.

## **Is there anything you do differently when the patient is a child?**

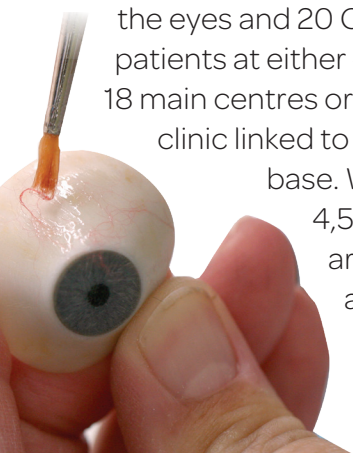
Children are treated as a priority across the service. In April we launched a new scheme, which means that their order forms are identified as soon as they arrive at the lab, enabling them to be prioritised out of the hundreds of orders we receive each month, and fast tracked.

It is very important to us that children get their bespoke eye as soon as possible because we need to keep pace with their growth. A child will need a replacement eye much more often than an adult and will need to be seen more regularly, possibly every three to six months.

An adult may have their eye replaced approximately every six years, but will attend for regular checks and aftercare annually.

## **Who can families contact if they have any comments or concerns?**

Phone the helpline: **01253 951131**  
Email: [naes.naesinfo@nhs.net](mailto:naes.naesinfo@nhs.net)  
Fill in our website contact form: [www.naes.nhs.uk](http://www.naes.nhs.uk)



# I CAN'T IMAGINE MY LIFE WITHOUT GOALBALL

**Kelsey Trevett**, 16, was introduced to goalball during the 2012 London Paralympic Games. Since then, the sport has had a huge impact on his life, as he explains...

As a blind teenager, it can be difficult to find a sport-related activity that is fully accessible: the mainstream games of football, cricket and rugby were, after all, hardly designed with the blind in mind.

Goalball is the first, and only, sport designed with the intention of being played by blind and visually impaired athletes, but that's not to say it can't also be played by sighted people too. Today, it is a Paralympic sport, and has received a spike in interest in the UK since the 2012 London Paralympic Games – where I was introduced to the sport.

## What is goalball?

The basic objective is to get a basketball-sized ball into the opponent's goal, past the three players on the other team. While it is not a contact sport – the ball is thrown, bounced or rolled – it is still very physical, as the main aim is to get in front of the ball, to prevent it reaching the goal behind you.

All players are blindfolded, to put everyone on (quite literally) an equal playing field. As the sport is played indoors, the court is made tactile, by using string and tape to mark out the lines. The bells within the ball allow for it to be heard by all players.

I started playing regularly when I was 11 years old, training with a club in Winchester. I've gone on to participate in tournaments across the country, as well as attending several talent camps. Goalball has been a huge part of my life, by both filling my weekends with an activity I enjoy, and by being the starting point of some of my closest friendships.

Additionally, it has so many advantages for players when off-court. It has increased my confidence in movement no end – navigating independently and unaided on court was a new, and frankly terrifying, experience for me; it has, however, undoubtedly increased my confidence off the court too, in day-to-day situations. I travel around the country training and participating in tournaments. Goalball really fuelled my want for (and confidence in) independent travel. Nowadays, I regularly travel by train both for goalball, and for social events and work experience opportunities.

From a social perspective, goalball has been wonderful for me. Being part of a sports team was something I had not experienced before, and the atmosphere and tone of the group is always so warm and welcoming. Goalball has given me the skills and opportunity to reach for my potential, both on and off the court. I can't imagine my life today without it – I'm sure it'd be very, very different.

For more information, visit the Goalball UK website: [goalballuk.com](http://goalballuk.com)

*"It has increased my confidence in movement no end."*



# SUPPORTING SIBLINGS

**Dr Jennie Robertson, Clinical Psychologist, offers advice to parents and carers on how they can support the brothers and sisters of children with cancer...**

Siblings of children living with cancer can experience a range of emotions – anxiety; anger; jealousy; guilt; grief; and feeling left out or alone. They can also continue to have a number of other emotions, including those that are not cancer-related.

There is no “right” way to support siblings and no one can do everything all of the time but there are a number of strategies that you might find helpful:

**COMMUNICATE** Acknowledge a sibling’s feelings and give them chances to express them (including unflattering things about the unwell child). Be wary of minimising their concerns. Understand that children have different coping styles to adults and that siblings may have different emotional styles. They may wait until treatment is over before expressing their feelings and may not always want to talk about their emotions.

**EDUCATE** Give age-appropriate information and remember that this is an ongoing process of repeating and updating plans and medical information as the child’s developmental capacities change. Consider educating the sibling’s teacher and classmates. Use a variety of techniques (books, videos, verbal explanations, visual aids) and messengers (partners, medical staff).

**NORMALISE** Avoid differential treatment of your children whenever feasible and keep routine in place where possible. Avoid casting the sibling into a premature parent role. Ensure they have time together with the unwell child to normalise their relationship.

**BUILD A SUPPORT NETWORK** Take advantage of other adults who offer to help. Encourage contact with other siblings who can understand their situation. Take advantage of sibling programmes and camps.

**CREATE A BALANCE** between the focus on cancer and a distraction from it. Redirect attention to the sibling tactfully when others focus only on the unwell child. Try to include a gift for siblings every time the unwell child is given a present.

**PLAN AHEAD** Predict absences of the unwell child and parents/carers whenever possible. When separations are necessary, leave siblings with the same person as much as possible, a person he or she is comfortable with and trusts.

**HAVE 1:1 TIME** Spend as much time as you can with the sibling and ensure it’s “individual” time. Let them know that you need and love them and recognise their own strengths and accomplishments. When you cannot be with them, write letters/notes, make videos, and talk to them by phone or text.

**INVOLVE THEM** in the child’s care. Include the sibling in the cancer community so that they get the opportunity to see where the child is treated and explore medical experiences. Try to keep them involved in the process by giving them something non-threatening to do.

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■ It might sound paradoxical, but there are many positive possibilities for siblings of children living with cancer, including maturity; compassion; empathy and awareness of people’s problems and differences; resilience; knowledge; a positive outlook; strengthened relationships with others; enhanced self-esteem; coping skills and problem-solving abilities; and temporary perks (eg free tickets to events!).

If you feel you or your children might benefit from further support, speak to your CHECT support worker.

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**Dr Jennie Robertson** is a Clinical Psychologist working in the Retinoblastoma Service at the Royal London Hospital. This advice is adapted from *Living with Childhood Cancer: A Practical Guide to Help Families Cope* (Woznick & Goodheart, 2002).

# 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:

**David Weir**  
**David George Bradshaw**  
**Joy Wilkinson**  
**Dick Fuller**  
**Justine Duffy**  
**Ted Pernet**  
**Gordon Brader**  
**Steven Crossley**  
**Hilda Maundrell**



One of the hottest days of the year saw a magnificent bunch run around Regent's Park. Once again the Quest Institute put forward their fantastic team, joined by CHECT CEO Patrick Tonks, Office and Finance Manager Hayley Dobson, and CHECT member Magda Lodge. With just under £7,000 raised, we'll be doing it again next year – so sign up for **RunThrough Regent's Park** now to join in the fun.



It was officially the hottest **London Marathon** ever! This year our fantastic runners Gemma, Lou, Matthew, Paul, Ben, Arran, Jo, Emily, and Helen braved the searing heat to all finish as heroes and raise a magnificent £34,500.

**Hannah Dowling**, together with intrepid friends Vikki and Leanne, raised £1,552 from their skydive in April. Hannah really enjoyed the experience but says that her feet are firmly back on the ground for the time being!

If you would like to take on a similar challenge, do get in touch. We can help you to arrange a tandem skydive at any one of 19 airfields across the UK.

To raise awareness and funds for CHECT, **Liam and Fiona O'Reilly** attempted to drive from Newcastle to Nürburgring in Germany and back in 24 hours. Despite being stuck at the Channel Tunnel for four hours with no water or toilets, Liam said it was one of the best experiences they have ever had. Without the delay they would have completed the trip with 15 minutes to spare, raising £570.

Massive congratulations to **Gemma Cotton** and **Nicky McQueen** who both celebrated their weddings this summer and gave CHECT pin badges to their guests as wedding favours, and to Dean and Shirley Alldis, who asked guests to donate to CHECT in lieu of wedding presents.

InFocus Autumn/Winter 2017 reported how **Ethan Burn** had successfully pitched CHECT as Charity of the Year at his school, Carshalton All Saints. After a wonderful three terms of fundraising the last charity event saw Ethan and his fellow pupils lay an enormous CHECT logo in coins across the playground. We were thrilled to receive a cheque for £1,588.58 as a result of all their hard work.

**Mike Taylor, Alison Brightwell** and their teams pulled out all the stops in May at Barber UK. Held over two days at the NEC Birmingham, the show featured two CHECT branded stages, a raffle and auction, raising awareness and a fantastic £6,000. Patron Darren Harris visited and was treated to a special CHECT hairstyle, performed live on stage!

## NEW YEAR, NEW CHARITY OF THE YEAR?

In 2018 we have been lucky enough to partner with schools and companies as their chosen charity – a fantastic way to raise both awareness and funds for CHECT. We greatly value our relationships with Birmingham Optical, Essilor and Evolutio, among other generous organisations. We were very kindly chosen by Trinity United Reformed Church in Upminster, and they have been raising funds for us in a variety of ways, including donating all proceeds from their regular lawn sales.

If your work, church or school is looking for nominations for a new charity to support in 2019 do please think of us. We will be happy to talk to them and even if they are not looking for a new charity partner, they may want to join in with Crazy Glasses.

If you need any information to support a nomination please contact Diane Emery, our Fundraising Manager, on **020 7377 5578** or **diane.emery@chect.org.uk**.



## RIDE4SIGHT

In September a team of riders from Vision Express, along with CHECT patrons Darren Harris and Bryan Steel, and Chairman Ian Ellington cycled 300km over two days in a bid to raise £30,000 for CHECT.

The 30-strong team took on a gruelling circular route from the Vision Express head office in Ruddington, Nottinghamshire, to the Peak District, climbing altitudes of up to 3,000m. The determined cyclists stopped at Vision Express stores along the way and were met by CHECT ambassadors who went along to cheer them on. Staff at head office also supported the event by taking part in a static bike challenge.

This is the fourth Ride4Sight that Vision Express has organised and as we go to print, this year's event has almost reached their goal of £30,000. Thank you so much to Vision Express and all of the cyclists who took part and helped to raise such a phenomenal amount for CHECT.

## AMAZONSMILE

Do you shop on Amazon? Are you using AmazonSmile? This is the same Amazon you know, with the same products and prices, but by using this service, 0.5% of your purchase can be donated to CHECT every time you shop, at no extra cost to you. Visit **smile.amazon.co.uk** to find out more and sign up.

## CRAZY GLASSES

Since May we have seen schools, workplaces and nurseries hold a Crazy Glasses Day to raise funds. It's a really fun and simple way to support us.

If you'd like to join in the fun, you can find out more at [chect.org.uk/crazyglasses](http://chect.org.uk/crazyglasses). Please let us know you're planning to hold one so that we can send you leaflets, posters and balloons. You can organise a Crazy Glasses Day at any time of year.



# WHAT'S ON...

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

## Santa Run 5km or 10km, Victoria Park, London

**Sunday, 2 December 2018**

Grab your free costume and join the largest Santa Run in London for some festive fundraising. With a children's fun run before the main challenge the picturesque route is pram and wheelchair friendly and the flat paths make it perfect for beginners or those looking for a chance to beat their personal best. £25 registration fee (£10 for children)

Minimum sponsorship £100

## RunThrough Regent's Park July 2019

Choose 5km or 10km 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. Minimum sponsorship £200

## Great North Run September 2019

Join 49,999 others at the largest half marathon in the world. You'll get to take in the sights of Newcastle, run across the iconic Tyne Bridge and finish on the coast in South Shields. 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](mailto: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](http://chect.org.uk/donate). Thank you.

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

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 <b>Childhood Eye Cancer Trust</b>
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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
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How would you like CHECT to contact you (please tick all that apply)? Post  email  phone   
 Update your preferences at [chect.org.uk/consent](http://chect.org.uk/consent). View our privacy policy at [chect.org.uk/privacy](http://chect.org.uk/privacy)

