



CHECT Champions receive their awards at the Liverpool meet up.



Children take part in the craft activities at the Members' Day in Bath

Members' Days

Here at CHECT, we really love getting out and about in the community and meeting up with our members face to face and the past few months have seen four fantastic Members' Days take place at a variety of locations throughout the UK.

We kicked off the summer with a visit to Colchester Zoo in June and our biggest Members' Day ever! Everyone attending had a really 'wild' time especially during a very special hands-on animal experience in the Kalahari Theatre.

Next up was a trip to the West Midlands with a day out in Dudley, where families visited the zoo and took a step back in time as they entered the 11th century castle. A picnic on the lawn was a very civilised way to end the day.

CHECT's next stop was North Somerset in August, when we

held a Members' Day at the Holburne Museum in beautiful Bath. Our families enjoyed visiting the museum's exhibits from Renaissance treasures to masterpieces by Gainsborough, and then we got stuck in to making some very special art of our own with a bit of glue and quite a lot of sparkles!

Autumn began with a trip to Liverpool's fabulous World Museum in October. Families spent the day exploring the interactive galleries and we also enjoyed a fun 'creepy-crawlies' session and a very informative dinosaur talk, featuring genuine prehistoric poo!

Members' Days really are fantastic events and a great chance to meet other families affected by Rb as well as an opportunity to chat with a member of the CHECT team. It is also where we hold CHECT Champion award presentations

- to see this year's wonderful champions, visit our blog at [**chect.org.uk/blog**](http://chect.org.uk/blog)

Dates for future Members' Days are detailed below - we'd love to see you there so either wait for your invitation or call development manager Matt on 07821 649965.

Upcoming events

- **Saturday January 23**
– **Techniquet, Cardiff**
- **Saturday February 20**
– **Noah's Ark Zoo Farm, Bristol**
- **Saturday March 12**
– **National Museum of Scotland, Edinburgh**
- **Saturday April 23**
– **Bockett's Farm, Surrey**

infocus



How technology is helping to fight retinoblastoma - see page 4

First ever teenage weekend is a hit!

A group of CHECT teenagers got the chance to share their experiences and make new friends for life at our first ever young people's weekend.

Eight teenagers from across the UK attended the event, at St Mark's College in Essex, in July. Activities included fun team exercises (like the popular bungee run and wet sponge throwing contest!), and a chance for everyone to talk about their personal experience with Rb and the challenges they face.

We know it can sometimes be hard for young people affected by Rb, who may have to tackle issues around self-confidence and visual impairment. Over the next three years we plan to extend our work with teenagers, making sure they get the support they need at this critical time in their lives.

Our teenage members have told us they had a fabulous time at the event, and you can read all about it, in their own words, **on page six**.

E-cards spread festive cheer



Feeling festive? Why not send one of our Christmas e-cards to your loved ones and help raise money for CHECT?

There are several designs to choose from, including some beautiful photos of children affected by Rb and their siblings. There's also a Christmas cartoon painting of reindeers by one of our young supporters.

For a donation to CHECT, you can pick your favourite



design, add your own personal message and email the card to all your family and friends. To see the designs and send your personalised e-card, please visit chect.org.uk/chect-e-cards

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News from the office

I am delighted to introduce myself to you as one of the new members of the CHECT team. After more than four years as chief executive Joy Felgate left CHECT at the end of September to follow her other dream – running holiday cottages in southwest France. I was lucky enough to work alongside Joy for a few weeks before she left, which was incredibly valuable in helping me begin to understand our work supporting individuals and families affected by retinoblastoma.

My first weeks have been wonderfully busy. Before I even joined CHECT I was one of the fortunate thousands taking part in this year's Great North Run. I ran with one of my three children, my eldest daughter Annie, and we both finished tired, muscles aching but thoroughly elated. A huge thank you to our team of eight who took part to raise valuable funds for CHECT. I look forward to doing it again in 2016.

I have visited both the Birmingham Children's Hospital and the Royal London Hospital to see first-hand the work of the specialist Rb teams and also how our support workers are such an important and integrated part of the help available. I was privileged to be able to meet some of the children, their families and the staff at both centres and I look forward to doing this on many more occasions in the future.

Recent months have seen our first ever teenage weekend which you can read about on page six, and which

proved to be a great success. It has been really inspiring to hear what some of the teenagers felt they got from the experience. I have also had the opportunity to meet the team at Wunderman, our partner and renowned digital advertising agency who produced the posters and video promoting Rb awareness. This campaign attracted more than 1.1m YouTube hits and won a host of awards, including the Grand Prix at the recent DADI awards celebrating digital innovation.

My first few weeks have reinforced what I saw in my meetings with staff and the Board before I joined CHECT: a focused charity, with a wonderful, supportive membership, working hard to raise awareness, drive developments in research and provide vital support for those affected by retinoblastoma.

I look forward to helping to continue this work and to meeting as many of you as possible over the coming weeks and months.

Patrick Tonks



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newsletter are those of the
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Fighting Rb in 2015 and beyond



It's been a busy year at CHECT! A few months ago we came to the end of our first three-year strategy, which was developed to help us achieve our aim of preventing sight loss and death as a result of Rb, through raising awareness, funding research and supporting those affected.

Here are some of the things we've achieved since 2012 with your amazing support:

- 100% of families were offered support following a diagnosis of Rb and throughout their child's treatment.
- We provided more than 2,000 hours of support to around 525 families each year (more than 6,000 hours in total since 2012).
- More than £8,500 was given in grants for 40 families facing financial difficulty because of the expenses related to their child's treatment.
- In our feedback questionnaire 100% of you who responded said you felt CHECT support helped you in your experience.

We're really proud of our achievements so far, but there's a lot more work to do and we won't rest until more and more people – from parents to healthcare professionals – know about Rb and its symptoms so that children are diagnosed and treated as quickly as possible.

Looking forward

We've now started on the second of our three-year strategies and here are some of the main

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 take just a few minutes to fill in our quick online survey on our website

www.chect.org.uk/survey

Your feedback will be used to improve future editions of the newsletter and to make sure it's as helpful and enjoyable as possible. Thanks for your support!

things we'll be focusing on in 2016 and beyond:

- Making sure families and individuals affected by Rb have access to appropriate counselling and psychological support services.
- Supporting young Rb survivors who sometimes struggle with self esteem issues, relationships, visual impairments and bullying.
- Finding ways to reach and help families who are feeling isolated and concerned outside of the hospital setting.
- Campaigning for quicker diagnosis and more treatment options for children with eye cancer.

Make sure you don't miss any of our news and announcements – subscribe to our blog at chect.org.uk/blog. You can also find us on Facebook or Tweet us at @CHECTUK

Technology to

It's difficult to imagine that, only five years ago, smartphones and apps were largely in their infancy – a far cry from their widespread use today. Thankfully, given the rate of technological innovation, these devices are now not only part of everyday communication, but are starting to play a role in the early screening of potential visual impairment, including Rb.

Here, we provide an overview of three exciting emerging technologies.

CRADLE

CRADLE (Computer Assisted Detector of LEukocoria) is a free app initially launched in October 2014 that scans photos for signs of leukocoria, or white eye, which can be a key indicator in screening for Rb and other eye diseases. The technology basically detects white pupils or area reflexes in digital pictures or digital video frames.

The app is available for iPhones and Android devices and is designed to be used by parents or relatives of children, and also by paediatricians, clinicians and other healthcare professionals.

CRADLE has particular relevance for individuals in 'resource light' settings, ie those without specialist diagnostic technology like an ophthalmoscope. The app was developed by

CHECT member JOSEPHINE CARR takes a look at how the latest digital imaging technologies are being used in the battle against retinoblastoma.

chemistry professor Bryan Shaw and computer science professor Greg Hamerly, after Dr Shaw's three-month-old son was diagnosed with retinoblastoma.

CRADLE uses what's called machine learning – a way of training a computer to do something by example, to spot a white reflection in photos. Using photos of children with retinoblastoma, compared to photos of healthy eyes, the app has been taught to screen for potential risk factors.

Dr Shaw and his colleagues are currently running clinical tests in hospitals in the US, where side-by-side comparisons between CRADLE and screenings performed with an ophthalmoscope are being undertaken. The aim is to determine which method is more effective in screening for leukocoria in Rb. The team is also developing a desktop version of the app, which they hope to get into doctors' offices.

CHECT spoke with Dr Shaw, who said: "We know that Rb is a very rare condition, and the likelihood of a paediatrician coming across it is rare, which means giving clinicians a technology that

is extremely usable is imperative.

"In the majority of cases, white eye will be a reflection off the optic nerve, but in my opinion, every single occurrence of white eye in a picture needs to be reported if we are going to get to the right diagnosis as early as possible."

Peek

The Portable Eye Examination Kit (Peek) aims to enable a non-expert with minimal training to carry out eye-health checks and help prevent and diagnose blindness.

It is particularly for use in low-income countries where the cost and logistical headache of transporting specialist equipment to remote locations has proven prohibitive.

The technology works by adapting a smartphone with clip-on hardware and an app, for a high degree of portability, flexibility and ease-of-use. It can be used to diagnose blindness, visual impairment, cataracts, glaucoma, macular degeneration and diabetic retinopathy, among others.

fight Rb



The Volk
Eye Check

With Peek, the camera lens of a smartphone is used to carry out a cataract test, while basic vision is assessed using a shrinking letter on the screen.

Images captured can be assessed in-app or securely uploaded, while geotagging enables follow-up treatment where and when a condition is diagnosed. Peek currently has patents pending.

IRISS, Volk Eye Check

IRISS Medical Technologies provides advanced diagnostic-assistance devices and technologies in ophthalmic and eye data solutions.

IRISS has, to date, developed three applications for ophthalmologists and optometrists, as well as paediatricians and GPs. Its Volk Eye Check is a handheld device that was originally designed to be an early detector of squint.

The company currently has FDA and CE approval and from the same device has recently developed a new module for the specialist contact lens market.

While screening for squint, which is the second most prevalent indicator of potential Rb, the Volk Eye Check does not currently do red / white eye reflex. However, IRISS is in the early stages of discussion for a potential NHS study with Mr Ashwin Reddy at the Royal London Hospital, to see whether the technology might be able to identify additional clinically relevant factors.

● **Keep up to date with latest news and developments about the diagnosis and treatment of Rb at cheet.org.uk/blog**

New look CHECT website

We've just launched our new website to provide people in the UK and around the world with even better support, information and advice about Rb.

The site is now more visual, interactive and user-friendly, so that new and returning visitors can find the information they need quickly and easily.

It's also mobile-friendly, so you should find it easier to access on your smartphone or tablet.

There's a new resources section full of advice about topics like diagnosing and treating eye cancer, support for adults with Rb, information for healthcare professionals and the latest research.

We've kept popular features like the blog and information about ways that you can get involved with CHECT.

We hope you enjoy taking a look around and if you have any feedback we'd love to hear it – email us at info@cheet.org.uk

'Remember – you

Following our first teenage weekend away, young CHECT members TOR MOORE and LEXIE EDWARDS share their thoughts on how the event went...

"Usually when CHECT events are organised they are specifically aimed at families – so being the first teenage residential trip away we were naturally sceptical. The idea of spending a whole weekend with people we had never met before dampened our moods and a fun weekend didn't seem realistic.

Most people arrived late on Friday evening and sat down for dinner with their families. As parents began to leave it was nice to see who the CHECT teenagers on this weekend were. We got to know a bit more about each other as we played the name game (where you say your name and something you like beginning with the first letter of your name).

After we were all acquainted, we learned who we would be spending the next two nights with and went to our rooms, for a good night's sleep.

Team bonding

The following morning, we woke to a bright blue sky. We got dressed and headed to breakfast, where we found out what the day's activities would be. We walked out to the field and entered a large marquee, which contained a huge, inflatable



Forging new friendships at the teenage weekend

bungee run. Initially, we felt quite apprehensive as we weren't quite sure what to expect. However, we soon discovered how hilariously fun it was – and really quite challenging!

After this, we put on some blindfolds and got into two teams. This next game gave the partially sighted people an insight into what it would be like to have no vision at all, and let us tell you we were hopeless!

The people with the least amount of vision were at a definite advantage having had to cope with it for so many years. We each had a length of drainpipe which we needed to connect to one another's in order to pass a tennis ball smoothly down without letting it fall. We had to repeat this three times and luckily our

team won! We quickly snapped a smug victor's photo as the losing team exchanged looks of defeat.

We then sat down for a quick talk about medieval archery. It was fascinating to see how heavy the armour and bows they used to use were. However, luckily for us, we used much more modern bows which were a lot lighter.

The next activity was the funniest. Members of each team were put into the stocks where we threw soaking wet sponges at everybody. It was much harder than you may think to aim for a person's face, much to our annoyance, and we didn't manage to hit anybody square on.

Time flies

After lunch we all relaxed in the

are never alone'



Left: Team bonding with the bungee challenge

Bottom left: Sharing a joke in the lounge



After breakfast, some of us took part in a video where we shared our personal stories about our experiences with retinoblastoma, while the others designed a CHECT coat of arms. Once lunch had ended we all began to depart and say our sorry farewells, all sad to see the end of a fabulous weekend.

Looking back, we never thought we'd make so many lovely friends with whom we share such a close bond, but now all eight of us are in contact via social media. We have all shared our stories and everyone had something different to say because, like we are always told, everyone is unique.

We really feel our confidence has improved and you must always remember you are never alone. Not only is there a great support system through CHECT, but there are also people who have gone through the exact same things. We are both so excited for the next teenage weekend whenever that may be."

glorious sunshine and then played some team games. The day had gone by so quickly due to our constant laughter and fun that we were shocked when it was dinner time. The phrase time flies when you're having fun definitely applied to this weekend.

After dinner we sat in a circle and played the bongo drums, and Lexie played the guitar while Josh sang a heart-melting rendition of Ed Sheeran's I See Fire. We then toasted marshmallows around the fire and had another round of songs.

When it got dark, we went inside where we all excitedly belted our hearts out to High School Musical. There was so much laughter as we sang, making silly Snapchats of each other, that there was not one face in the room which wasn't smiling.

Once again bedtime was soon upon us and the thought of leaving the following day saddened us all.

Saying goodbye

The next morning everyone was surprisingly cheerful for 8am!

'The Rb odds were s

I was diagnosed with Rb at nine weeks old, in 1976, with no prior history of the disease in the family. I was my mother's first child, and so she assumed the constant howling owed to the fact I was simply a whingey baby.

My grandmother spotted that my right eye appeared milky and glazed. I was referred to hospital and my eye was removed immediately. Further investigation revealed that I had bilateral retinoblastoma: the eye that was removed carried one tumour, while my left eye carried three. I was treated at St Bartholomew's Hospital in London and, miraculously, they managed to save the left eye by targeting the tumours with radioactive plaques. Had the tumours been left undetected for any longer, I would certainly have died.

I started out life with some very poor artificial eyes, but by the time I went to school (with the potential for mockery and bullying horrors that this entailed), my parents, on a low income, decided to save and send me to have my eyes made privately. I have been with my specialist since I was three.

Childhood years were punctuated with the odd insult, but I'm grateful to my parents for teaching me to be resilient and proud, and the teasing never affected me. Surprisingly, when I went to an all-girls' secondary school, my peers were more interested in understanding why my eye looked slightly different ("Do you have a lazy

eye?") than insulting me. I was the class clown, sociable, and well liked, so it was a huge relief to be spared from the unpleasanties I had anticipated.

And so from school, I obtained a first-class honours degree in Hispanic studies at King's College London. I then went on to study a Master of Philosophy in European literature and culture at the University of Cambridge, and received a distinction. Upon graduating, I became employed in the university's senior administration and have been there (in various roles) ever since.

The years passed by and I busied myself with home-ownership, world travel and a healthy appetite for socialising. Retinoblastoma didn't feature in my life at all, apart from the inconvenience of visits to London for new eyes every four years or so. And then the love of my life appeared, when I was 37. I no longer entertained the idea of having children when we met, although I was aware of pre-implantation diagnosis (PGD) and had this in the back of my mind if I ever did wish to start a family.

Fate took me to the lovely genetic consultant Dr Elisabeth Rosser, and I obtained a referral to the Centre for Reproductive and Genetic Health (CRGH) by the skin of my teeth: I met Elisabeth one month before my 38th birthday (and almost didn't as I felt unwell that day and Elisabeth had been misinformed about our appointment, so had to travel



Rachael aged 15 months

My

back across London to see me). If I had seen her beyond my birthday, I would not have been referred and our hopes of trying for a PGD (or even natural – given what we know now) conception would have been erased.

Blessed with NHS funding for up to three attempts, I started PGD IVF treatment in January 2015. Only three eggs were collected in the first round, as the surgeons couldn't access my left ovary, and only one of those was Rb-free. It didn't

stacked against me'



Rachael with her fiancé Davide Calvo

Story by Rachael Tuley

develop to blastocyst stage by day five and implantation failed.

I began my second attempt in March 2015. On Easter Monday, 11 eggs were collected – only one was healthy and Rb-free AND made it to blastocyst. Our miracle baby decided to stick and I'm now 30 weeks pregnant and feeling blessed, privileged and lucky to have been given the chance to bring a baby into the world. The odds were stacked against me with retinoblastoma (tumours in

both eyes, and yet they saved the eye that had three).

The odds were also stacked against me with PGD IVF (my hormone levels weren't great, and I was already starting out at a disadvantage with my advanced years). Nevertheless, I have been lucky and I'm convinced that with determination, Rb need not define your existence, but indeed, enhance it. It has made me even more driven to live a full life and pursue my dreams.

Finally, I will be forever grateful to the NHS for saving my life, giving me a good life, and for enabling me to bring a new Rb-free life into the world. And to my parents, for making me resilient and tenacious.

● **Would you like to share your story? We'd love to hear from you – email Natasha Boydell, CHECT's communications manager, for details at natasha.boydell@chect.org.uk**



Drew Murray windsurfing

Drew's story started when he was 16 months old. I took him to his paediatric GP because his right eye just didn't seem right – the iris was much darker than the other one and he seemed to get very close to things on the right hand side.

The GP told me there was nothing wrong but I asked for a referral which came along three weeks later, for Drew to be seen in five months time.

I knew there was something wrong and nobody would listen. What I didn't know was that my baby boy was going blind in that eye, something which I can never forgive myself for.

I kept on at the professionals and kept getting ushered away.

Drew's

by

I'd heard of Moorfields Eye Hospital and I saw online that there was a paediatric A&E, so off we went. Within two weeks he'd had his right eye removed, three general anaesthetics, his Hickman line in and had started chemo. He also had a shadow in his left eye (now seven tumours). We truly felt our world had imploded.

Drew was an absolute star. He did very little complaining, lots and lots of vomiting and yet he still always managed a smile.

Drew's five years old now and up until our last EUA we had

Cardiff weekend for Beyond

The Beyond Rb group was set up for adults who have had Rb to socialise together and discuss shared challenges. The group meets regularly and FFION MILES reports back from their latest weekend away in Cardiff.

We chose to break the ice at our latest Beyond Rb meeting with a picnic at Wales' very touchy-feely-smelly outdoor National History Museum, before escaping the sudden and torrential rain by seeking cover at a Turkish restaurant. We then got down to discussing which issues we'd like CHECT to help tackle. We agreed as a group that research - both



Members of the Beyond Rb group meet up in Cardiff

medical and psychosocial - into the after effects of being treated for Rb is lacking. It is only on Facebook that many of us have realised that we're not unique or unlucky in the problems we

face. We're adults who've had treatment as children, but often not been told much about its consequences. As we all seek care locally for various issues with our treated eyes, there is

s Story

Jennie Wisdom

never made it longer than three weeks between visits. Most of those were with cryotherapy, laser therapy and once radiotherapy.

This hasn't stopped him – he plays lots of sports including golf, tennis, football, swimming, windsurfing, kayaking, horse riding, ice-skating, gymnastics and he loves running and running and running.

Getting his prosthetic eye to fit has proved a huge challenge but we're getting there. My little star is not going to let this beat him or stop him doing things.

Rb group

little opportunity for the sharing of knowledge between medical experts or continuity of care. We also discussed the challenges of having a prosthetic eye, both physically and emotionally. We were agreed in our wish that our experiences be professionally documented and studied on the road to greater understanding and continuity in the care of adults with Rb.

● **If you'd like to speak to others who've had Rb, or help us organise another get-together, please find us on Facebook – search for Beyond Retinoblastoma.**

Sharing experiences of cancer creatively

JTV Cancer Support creates videos for cancer patients, made by cancer patients – particularly young people.

Last year CHECT was fortunate enough to receive funding to produce a series of 12 short films based on a variety of aspects of Rb.

This has resulted in a specialised and established CHECT channel on the JTV website and we now have the first films available for you to see.

What does the JTV project mean for CHECT members?

This is a fantastic opportunity for young people to express views or share experiences about growing up with Rb, while having a lot of fun.

These short films, video diaries or vlogs can be based on anything from treatments and prosthetic appointments to relationships, learning to drive, an artificial eye, personal achievements or anything you can think of.

This is an ideal way to communicate with other people in a similar circumstance. The channel will provide valuable support and a resource for young people as well as other age groups. Ultimately every

film made belongs to the filmmaker and you can be involved in the editing process, and decide whether your film can be shown fully on the website, or who you would like the audience to be.

At our teenage residential weekend in July, the first films were made by several young people talking about their personal experience as well as a great film about the weekend. You can find these films by visiting www.jtv cancersupport.com and clicking on the CHECT channel.

Making a film is simple and can easily be done using a smartphone. You can then upload them to the JTV website editing suite, where professionals will edit them in consultation with you.

Why not team up with family members or friends to create something unique about your own experience? By creating a video you could be giving invaluable support and advice to someone who is feeling the same as you.

If you would like to get involved or have ideas for films, please email our support worker Lesley Geen at lesley.geen@chect.org.uk who will be happy to talk you through the process.

Meet the team...

I am very pleased to have been given the chance to serve as a trustee for CHECT.

At 18 months old I was diagnosed with unilateral Rb, leading to the loss of my right eye.

Years later, when meeting other families who had been affected by Rb it became clear to me that many would have benefited from proactive support and information, both at the time of treatment and beyond, lessening their immediate and longer term trauma.

CHECT provides this, as well as

Alex Brebbia Trustee

increasing awareness in order to catch the tumours earlier and assisting with research into Rb.

For these reasons, and the work they undertake with Rb survivors, I sought to become involved.

I do not have medical training but am a qualified chartered accountant and my day job involves me sitting on the boards of medium-sized



companies, helping them to grow and to make strategic decisions.

It is this knowledge which, combined with my personal experience, I hope will be of some value to CHECT as the charity continues to perform such an essential role, despite being relatively small.

Martin offers invaluable support

We'd like to say a huge thank you to volunteer Martin Payne, who has generously donated two days a week of his time to help the CHECT team over the last few months.

Martin (*pictured right*) who works as a department manager for Waitrose, was given six months' leave as part of his long service benefit package and, rather than spend it lying on a beach, he decided to put his skills to good use and support CHECT instead.

Martin and his wife Vicky have fundraised for CHECT in the past after their son Christopher was diagnosed with Rb seven years ago. Since volunteering

with us he's provided invaluable support for a number of projects, and inspired Waitrose to fundraise for us too. Now it's time for him to go back to work and we'll really miss having him around the office.

Last year 127 volunteers gave up 835 hours of their time to support the work of CHECT, from providing office support to raising funds and awareness, and we are so grateful to each and every one – we couldn't do it without you.

To find out more about volunteering opportunities, email Matt Croxall, our development manager, at matthew.croxall@chect.org.uk





FUNDRAISING



Kelly Castling (centre) with a £6,000 cheque from Carla Rowley and regulars at The Grapes at Hexham



From left: Mark Baggot, Stephen Poundall, Rafael and Lucia Baggot

The Great North triumph

This was the second year that CHECT secured places in the Great North Run in Newcastle and the lovely Baggot family kindly agreed to be the faces of CHECT this year. A big thank you to our runners, Matt Pells,

Stephen Poundall, Vicki and Phil Brader, Kelly Castling and Andy Sanderson who raised over £8,000 and also to Patrick and Annie Tonks for raising awareness in CHECT t-shirts.

Freemasons raise £1k

Many thanks to Paris Williamson and her father Jason who received, on behalf of CHECT, £1,000 from The Lodge of St Cuthberga No 622, who meet in Wimborne.

Paris has recently been treated for Rb with great success. The money was raised through a summer BBQ and fish and chip cruise around Poole



Harbour as part of an ongoing commitment to support charitable causes. Paris and Jason are pictured with Geoff Knights, from the lodge.



Bridge walk

Jan Fairbrass, who works for Vision Express in Grimsby, took part in the Thames Bridge Walk in September. She said: "The atmosphere was like a carnival, with total strangers chatting along the route, there was a real buzz in the air. A fantastic day out in London with a difference. What a great way to have fun and see new sights while raising awareness and money for a great cause." Well done Jan!

FUNDRAISING



Terri's marathon effort

Terri Dunn ran the Waterside Half Marathon for CHECT with family and friends and raised an amazing £1,300 - a fantastic effort Terri! Pictured are: Kevin Dunn, James Dunn, Terri Dunn, Michael Jackson and Tom Simpson. Front row is Kian Dunn, aged three. Kevin McLaughlin also ran but is not pictured.

Olivia's fabulous fundraising

Thank you to young member Olivia Hards who raised more than £900 for CHECT through her school, Fareham Academy.

Her grandmother Kay tells us: "It was a lovely day, the sun came out and a great time was had by all, with a DJ providing music, cake stall, candy floss, ices, an inflatable obstacle course, raffle, and lots of stalls run by different year groups and tutors. They also had a non uniform day and Olivia gave talks to students to tell them about CHECT and why it was important to raise awareness of Rb." You're a star Olivia!



Fundraiser Olivia Hards

● **Heather Grainger held an afternoon tea in aid of CHECT and two other charities each benefitting by £400. Thank you so much Heather!**

Katy's

Rb ambassador Katy Bishop braved scorching temperatures and steep ravines to raise funds for CHECT...

I always wanted to see the Grand Canyon but I never thought I would. And not for a second did I think I would go because of my son's cancer. But that is what happened.

Owen was diagnosed in 2010 aged 10 months, and is now a thriving six-year-old, full of fun and joy, and he makes me proud every single day. As most parents of a child with cancer will know, we immediately wanted to do something to aid the fight – not just ours, but everyone else's too. I guess the biggest part of it is that it gives you something else to focus on. Something positive.

So we started fundraising. We did golf days, raffles, cake stalls, carrot walks and fun day events for the community. Since 2010 we've raised more than £15,000. It's all been rather hard work but we've had awesome fun along the way.

This challenge was completely different from everything else. I was flying halfway across the world to trek through the unknown. It was simply mind-blowing. I had to raise £2,600 but I've already achieved around £6,000! Leading up to the



FUNDRAISING

s big adventure



event, myself, my brother-in-law and the local community did many challenges and all the funds raised went towards the total for this trek. It's been amazing.

We started with a trek in a hot, dusty ravine to acclimatise to the heat and terrain. It was around 45 degrees and the going was tough. The group struggled a little, concerned at what we had let ourselves in for, some more than others, but we supported each other along and got through it.

The next day we made an early start to the canyon. Once you descend the 'Hilltop' the only means of transport are feet, be it yours or mules. There really are no words to describe what you see. The photos cannot quite bring to life the true majesty of the canyon. The canyon descends down from 5,200ft to 2,800ft, most of that initially on the first mile and a half so the first bit of descent is steep and tricky. Then the canyon becomes flatter and

unbelievably, more lush.

We trekked eight miles toward our campsite and through the Havasupai Indian Reservation. The tribe has tight control on tourists, allowing only a certain number in who must abide by their strict rules. I expected the tribe to be living in teepees but they live as we do, with modern facilities and wi-fi!

We trekked for three days through creeks and up falls. We visited Beaver Falls and jumped off into the turquoise water. Learning to trust your feet when you're on a small ledge – it doesn't always come easy. But that's what's so great about going in a group. Everyone has their strengths and weaknesses and we are able to support each other along.

The last day saw us up and out by 6am and we were in Las Vegas celebrating later that night. There was talk of the Canadian Rockies next year - watch this space!

Katy Bishop in the depths of the canyon. Below - enjoying the falls



● **Feeling inspired? Would you like to take part in a fundraising challenge for CHECT? Visit chect.org.uk/fundraise to find out how you can get involved.**