



Our Christmas Stars!



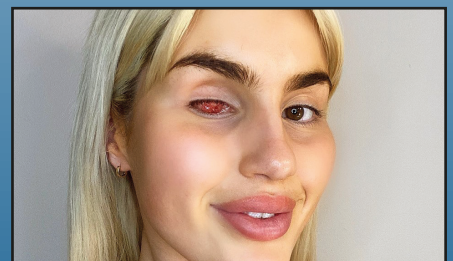
Meet our new support worker!

Meet Lena, the newest member of our London-based support worker team **Page 3**



How Imogen nearly missed her parents' wedding

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How I learned to love my eyes

Influencer & model Olivia Deane discusses body confidence **Page 9**

Welcome

Welcome to this issue of InFocus and a special thank you to all our families who submitted some wonderfully festive photos for our front cover.

2021 has continued to be a really difficult year for many. Whilst lockdown restrictions have eased, the financial climate remains extremely challenging, particularly for smaller charities such as CHECT. We are extremely grateful to all the individuals, organisations and families who continue to help and support us throughout. While life for many is returning to a version of normality, we know that this is not the case for all.

Adapting to the new ways of working that COVID made so many of us adopt, we have downsized our office space to allow for a more hybrid approach combining home and office-based working to increase our effectiveness and at the same time reduce costs. We are extremely grateful to all the wonderful volunteers who gave up their time to help with moving and decorating and to Beth, our Office and Finance Administrator, who led this important project.

I would like to take this opportunity to welcome our new support worker Lena Copley to the team. Lena joined at the end of September and alongside Lesley, will be providing families with our much-needed support at the Royal London Hospital. You can learn more about Lena on page 3.

We are also delighted to have been able to welcome the new, CHECT-funded PhD researcher Nicola O'Donnell to our offices. Nicola is undertaking an important PhD which we hope will be of great value to teenagers and young adults who have had Rb - see page 4 for more details.

As ever, we are so extremely grateful to all the individuals and families who share

their stories in the media to help raise awareness including Lorna and Mike on page 5 - who, after spotting daughter Imogen's white glow, ensured that she received the diagnosis and treatment she urgently needed. The hospital team put on a wonderful celebration for the family after Imogen needed to go to hospital the day of her parents' wedding.

Our diagnosis story on page 7 features Evie - who has coped tremendously well during a difficult year. Evie was diagnosed and had her eye enucleated after quick-thinking parents Kara and Ryan noticed that her eye had a white glow.

We also are proud to have Olivia Deane as the face of our World Sight Day 'Love Your Eyes' campaign. Olivia - featured on page 9 - is doing great work in advocating body positivity - having modelled for Vogue Portugal and appearing on Katie Piper's podcast.

We are also extremely grateful to Kitty Woodstock - who was talent-scouted from a YouTube video to become the face of an NHS England Childhood Cancer Awareness Month social media campaign. Kitty's video was extremely successful in helping us to raise awareness of retinoblastoma.

After a long postponement, the London Marathon commenced - with the brilliant TeamCHECT stepping up to the challenge and taking part in both the physical and virtual marathon - helping us to break a record for the number of runners for CHECT - thank you all.

As ever, we are so very grateful for your continued support - you enable us to continue to make a difference to the lives of those affected by Rb. I wish you all a very happy Christmas and 2022!



Patrick Tonks, Chief Executive

Contact us

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News

CHECT has moved!

CHECT has changed office location – but don't worry, we are still here to help you!

We are changing the way we work as we enter a post-lock-down world.

After many years in the same office, the recent experience of remote working, the Covid limitations that remain in place and the costs involved, led us to change our office arrangement. Following consultation with staff, we moved our office in August from the 5th floor to the 1st floor of the same building on Whitechapel Road, close to the Royal London Hospital.

We moved to a smaller office at a reduced cost and have

changed our office setup to enable a blended approach to working where staff have greater flexibility to combine working from home with working from the office. We will continue to maintain the highest levels of support, information and access for all our wonderful members and for anyone who has been affected by Rb.

We want to say a huge thank you to our volunteers Adam, Paul and Louise from the Royal Bank of Scotland, and Louise's husband Bob. We also wish to thank Kelly from Taylor Woodrow, Josh who volunteered his time and Charly from the Royal College of Paediatrics and Child Health who helped with taking down shelves, moving furniture and



Our volunteers in action!

doing some great DIY jobs. We also wish to thank Beth Lardner – our Office and Finance Administrator – who did a great job in managing the move.

We've had many great memories in our old office and look forward to making many new ones in our new office.

If you need to get in touch, please continue to call us on 020 7377 5578.



Kitty did a great job in an awareness campaign for the NHS

Kitty's NHS campaign

A big well done Kitty Woodstock, who recently featured as the star of a social media campaign for NHS England and the NHS Improvement Service, discussing her journey with retinoblastoma, and the signs and symptoms to watch out for. The video reached over 80,000 people, including members of the public and the medical community too. A big thank you to Kitty and mum Cathy – we look forward to seeing many more videos from YouTuber Kitty!

Want to receive InFocus in a different format?

We can offer InFocus in the following formats:

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

If you would like to receive future editions of InFocus in a new format, please let us know on 020 7377 5578 or at info@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? If so, we'd love to hear from you at info@chect.org.uk.

Thanks for your support!

Meet Lena: CHECT's New Support Worker



▲
Lena Copley has joined the support team

Hi everyone! I am Lena and I have recently joined the CHECT team as a Support Worker, alongside Lesley, at the Royal London Hospital.

For the past 15 years my working life has been spent in the charities sector, beginning with Save the Children, then the Living Earth Foundation and most recently as a Care Support Worker with the Great Ormond Street Hospital team of Young Lives vs Cancer (formerly CLIC Sargent).

Although born and bred in the far north of Sweden, I have been a north London resident for many years where I enjoy the views over London, running in the local parks and spending time with my family and friends.

I am delighted to have joined the CHECT team and I am so looking forward to getting to know you all.

You can contact Lena by emailing lena.copley@chect.org.uk or calling 07706919996. Lena works Mondays, Wednesdays and Fridays.

Charitable Trusts Help Fund Our Support Work

We are extremely grateful to all the charitable trusts and foundations helping to fund CHECT's work.

Some of our funders have awarded grants for specific elements of our work, including Sarah's role and support work based at Birmingham Women's and Children's Hospital (BWCH). The Eveson Charitable Trust and the Lord Austin Trust are both regular funders of this work, and we are delighted to have their continued support. The William A Cadbury Charitable Trust has recently awarded CHECT a second grant. We are very pleased to be a new recipient of a generous grant from the James Tudor Foundation. Finally, we are grateful to Contact/Pears Foundation/DCMS for two emergency Covid grants over the past year, enabling our

continued support work with our Birmingham families.

CHECT has to fundraise for 100% of our running costs, including all of our support work at BWCH and at the Royal London Hospital. We rely on the kindness and generosity of many charitable trusts every year to help us fund this work. Thank you so much to all of CHECT's funders, past and present.



Sarah Turley with Jessica Neale ►

Opportunity For Young People to Help Shape Future CHECT Support!

Nicola O'Donnell has just begun a CHECT-funded PhD which will ultimately lead to new support resources being developed to help young people who have had Rb transition to adulthood. We took the opportunity to ask her some questions!

What is your background?

After gaining a MSc in Health Psychology, I worked in roles which allowed me to work with young people to create psychoeducational resources, or interventions, for various health conditions.

What is the PhD about?

My PhD project is focused on developing a resource/s to support teenagers and young adults who have had Rb. Essentially, this means that I am interested in hearing from young people how having had Rb might have impacted them as individuals growing up in terms of their psychological and social needs (identity, forming friendships and relationships, self-confidence etc).

What are you hoping to achieve?

Short-term, I am hoping to connect with young people and families who have personal experience of Rb. I would love the opportunity to talk to these individuals and find out what they think is missing from current psychological support for young people when living beyond cancer



▲ Nicola O'Donnell with Petra Maxwell, CHECT's Information and Research manager

diagnosis and treatment, and what they think would be helpful to have.

Longer-term, I hope to use the above experiences (as well as the evidence-base) to develop a psychoeducational resource for young people who have had Rb. I don't know yet exactly what this will look like – it could be a leaflet, a workshop or even a video! I will be led by what young people tell me would be helpful for them, and they will also be involved in developing the resource. Once we have designed an intervention, I hope that we can test this out to see if it's helpful, and if so, I would love to roll this out as an option to all young people who have had Rb.

How can CHECT members get involved?

There will be many times during my PhD that talking to CHECT members would be really helpful to my project. There will be specific tasks (like attending a focus group, or designing a project logo) that I would love CHECT members to get involved in. There may also be a need for more general involvement throughout the three years of the PhD, so please do get in touch at any time by emailing me at nrv503@york.ac.uk if you would like to help out!

You can read the full interview on the CHECT blog chect.org.uk/blog/

Psychoeducation

Psychoeducation is an evidence-based tool or process which helps patients and their loved ones to better understand and cope with illness.

“We spent our wedding night in hospital with our daughter”

Mum Lorna Lloyd, from Barry in Wales, spotted an unusual white glow in her then 8-week-old daughter Imogen's eye.

Lorna said, “Her right eye looked milky white in certain lights. At first it was only some of the time, but very quickly it was visible more often than not. By the time she was diagnosed, her right eye was also larger than her left and appeared to be bulging. Looking back, her left eye had an obvious squint, but being first time parents, we assumed it was a normal part of our newborn baby's eyes developing.”

Lorna added, “Somewhere in the back of my mind I could recall something about a white glow being a sign of retinoblastoma. I'm not sure whether we were naive or in denial by this point, but you never really want to believe it could be the worst-case scenario.”

Imogen's parents Lorna and Mike booked a doctor's appointment straight away after noticing the symptoms, and luckily their GP urgently referred Imogen.

Lorna explained, “After being referred, I was looking at some obvious masses in her eyes on the ultrasound screen. Her right eye didn't even show different masses - it was all just

white. The consultant broke the news that Imogen had bilateral retinoblastoma - cancer in both her eyes.”

Lorna recalled, “I remember feeling absolutely devastated that our tiny baby could be facing something so huge, and absolutely furious that it was happening to her, and to us. The rest of the appointment was a blur, but I remember feeling like my heart had physically broken and trying desperately to take in all the consultant was telling us.”

Imogen and her parents travelled to Birmingham Women's and Children's Hospital (BWCH) a week later to meet with the specialist retinoblastoma team and have laser treatment. Her consultant disclosed that Imogen's right eye, which she could only see light through, had a complete retinal detachment, and her left eye had multiple tumours which were obscuring her vision. The family were told that her best option was to start systemic chemotherapy as soon as possible, which they started last December over the Christmas and New Year period.

Despite treatment, which included radioactive plaque therapy where Lorna and Imogen had to isolate due to Imogen contracting MRSA, it became apparent that her tumour was still too large for her retina to settle on its own. Imogen's consultant asked a retina reattachment specialist to look at her right eye but unfortunately, he deemed her main tumour too tall to manually reattach her retina.

Imogen had three courses of

intravitreal chemotherapy injections, and while the treatment appeared to work at first, signs of activity started again only a few weeks later. While Imogen was under anaesthetic for further treatment, her consultant found that her tumour had started to calcify and respond to the combination of treatments Imogen had endured over the months.

Lorna explained, “We were amazed - although slightly cautious - we were used to having the rug ripped out from underneath us by this point! After Imogen's first birthday, tests showed her eyes were stable - needing only a small amount of laser treatment - so we were able to breathe a sigh of relief.”

Lorna added, “A hospital trip in October brought more amazing news; the retina in her right eye had spontaneously reattached itself! Upon hearing those words I promptly burst into tears of disbelief and relief. Our girl finally had a run of good luck, and an attached retina means a smoother treatment journey for her.”

The family are full of praise for all the teams who have worked with Imogen during her retinoblastoma journey to date, however, as Imogen was diagnosed with retinoblastoma during the Covid pandemic, the family often struggled to cope with the effects of the Covid measures in place.

Lorna explained, “Covid has massively impacted our treatment journey, in multiple ways. The obvious and most impactful restriction has been the one



parent rule - aside from our initial Birmingham appointment, and the occasional time when Mike has been allowed into a meeting to discuss bad news, all of Imogen's hospital appointments have been attended by me alone whilst Mike has to wait in a hotel room across the street, or sit in his car in hospital car parks.

"Covid has also had an impact on physical support from family and friends. During one of the darkest times of our lives, our family have been forced to watch from the sidelines, unable to provide the practical support needed to allow us as parents to solely focus on our sick child. They have been forced to go months without seeing Imogen as the risk of Covid was too high for her as she was immunosuppressed, alongside local and national lockdowns prohibiting travelling. Mike's parents were able to drop food parcels on our doorstep and wave at Imogen through the window, which was a real lifesaver, whilst my parents who lived too far to be allowed to travel provided comfort and support via video calls, but it's hard to think about how different it could have been if Covid wasn't an issue."

Imogen's parents were originally due to get married in April 2020, but this was postponed due to Covid and the national lockdown.

Lorna explains, "We decided to go ahead with our second wedding date in February 2021 and felt it was extra special to be able to have

Imogen there with us. Due to local lockdown at the time, we were only allowed two witnesses and no guests. Imogen hadn't been very well the morning of the wedding so we rang the hospital who said it was best to bring her in that afternoon to get checked. We got married at 1pm and by 4pm we were back on Rainbow ward!

"We walked into daybeds still wearing our wedding clothes (they had said we could both be there as the rest of the daybed patients had gone home for the day) and were greeted with confetti, balloons, banners and cake! The staff had gone all out to ensure we were still able to celebrate being married, despite having to be in hospital! Imogen loved the fuss, and after being checked over by the doctor the decision was made for her to be admitted for fluids and observations. Imogen and I stayed two nights in the "Honeymoon suite" - or just room 9 as its normally known - whilst Mike returned home. It wasn't how we pictured our wedding day, but we are just grateful that Imogen was ok!"

Lorna said, "Imogen has been our light. Despite everything she has had to go through, she is such a happy, mischievous, determined little girl. Watching her thrive and defy her cancer on a daily basis makes us so proud, and gives us the strength we need to keep putting one foot in front of the other."

Imogen is currently attending hospital every four weeks for eye examinations under anaesthetic, alongside laser treatment to monitor her eyes for new tumour growth or potential activity in her current tumours.

Lorna said, "We would like to thank



Imogen had to visit the hospital after her parents got married

the amazing retinoblastoma team in Birmingham, the incredible staff on Rainbow ward at Noah's Ark Children's Hospital in Cardiff, the play specialist who single-handedly kept me sane when I was in with Imogen for chemotherapy and Sarah from CHECT who always has a friendly face, a listening ear, and often a cup of tea. Those things are invaluable when in hospital with Imogen and made such a huge difference to my morale! Finally, we want to thank our family and friends who rallied round and supported us during all of the Covid lockdowns, and in particular all those who got behind the #TeamImmy initiative and donated blood."

Lorna said, "November marked a year since diagnosis. It's really hard to think back to this time last year when we had no idea how close we were to having our whole world turned upside down. It would be really easy to see it as a time to be sad, but we were trying to see it as a celebration. Celebrating all that Imogen has overcome, celebrating how incredibly strong she is, and celebrating the fact that, due to her being diagnosed and subsequent treatment, we are still able to have our beautiful, happy girl here with us."

A huge thank you to Lorna, Mike and Imogen for helping us to spread such important awareness of Rb. If you've been affected by Rb and want more information on any issues raised, please contact our support team. You can read the full story at chect.org.uk/blog/



"We did everything to save our baby's eye"

REAL LIVES

A mum is urging other parents to look out for the tell-tale signs of eye cancer after her daughter was told she will lose her eye to retinoblastoma, a rare cancer that typically affects children under the age of six.

Mum Kara Wedderburn, from Northumberland, noticed that her then one-year-old daughter, Evie, appeared to have an unusual white glow in her eye – a common sign of eye cancer which is usually only seen in certain light. In a photo where she had red eye in one eye, her other eye lacked the red eye – which can also be a sign of retinoblastoma.

Mum Kara said, "I first noticed from a side view in the sunlight that Evie had a white covering on her right eye, at that moment I didn't think much of it because the dog had

recently scratched in between her eyes so I presumed the dog had caught her eye too. The white glow persisted, and I kept noticing it more so than before, I made Evie's dad aware, and he then noticed it from a certain angle too."

"We never imagined it was something as serious as Rb."

The couple decided to take Evie to their local GP – where she was immediately referred to the Royal Victoria Infirmary in Newcastle for further tests.

Kara explained, "The first words we heard were, 'Unfortunately it's not good news – have you heard of retinoblastoma?'. The specialist then explained it was a cancerous tumour – a big one at that – and that Evie may lose her eye, and that she probably had no vision in her right eye at this point. My heart just sank and tears instantly rolled down my cheeks.

"I was around 20 weeks pregnant with my second child, my emotions were all over the place and my world had been ripped apart, life didn't feel like it could get much worse at that point."

◀ **Evie had a white glow in her eye and a squint.**

Kara said, "We had absolutely no idea about retinoblastoma and had never heard of it before Evie's diagnosis. We googled 'white coatings on my child's eye' and it did come up, but we never ever imagined it was something as serious as that".

The family travelled for four hours to Birmingham Women's and Children's Hospital (BWCH), fearing the worst.

Kara explained: "Everything was scary and new, Evie just took it all in her stride, every step she was amazing. We spoke to the consultant who confirmed the diagnosis of retinoblastoma and gave us two options; we could remove the eye, or we could have treatment to try to save the eye. We were told Evie still had a little vision which was enough for us to go ahead and try and save our baby's eye."

After retinoblastoma was confirmed, Evie began her chemotherapy, however, in March 2021 the family were given the devastating news that Evie had developed a new growth beside her optic nerve. They had to act fast to contain the cancer and prevent it from spreading outside of the eye.

"We felt Evie never got a break and we always asked the consultants if we were doing the right thing by continuing treatment. They agreed



we were – Evie still had sight and, from the outside, her eye looked amazing, but the main thing was Evie coped better than anyone so we continued the fight.”

Although after more treatment, Evie was tumour-free – the family were dealt a further blow when a new, aggressive tumour was spotted in her eye. In order to reduce the chance of the cancer spreading outside of the eye, the family were given the news that the best step forward was to remove Evie’s eye.

Kara said, “I felt absolutely distraught, not only has Evie got retinoblastoma, but she’s going to lose an eye because of it too. I just couldn’t stop the tears coming and I instantly thought ‘How could the world be so cruel?’”.

Evie had her eye removed in September 2021 and was given her first prosthetic eye.

Kara said, “Our aim was to get our happy, healthy Evie back. We didn’t expect to be going down this road after our last visit, but that’s retinoblastoma

for you – it’s so cruel.”

“Evie is doing so well after her operation, in fact she is like a different child, so so happy and in no pain whatsoever, which is the main thing. Evie has adjusted amazingly well to her new life with a prosthetic eye and is even making jokes saying she’s cleaned it and put it back in! She is such a star and nothing fazes her. We are immensely proud of our girl.”

“It was so hard for us to watch as we couldn’t do anything but give her pain relief and it wasn’t helping. Now she sleeps through the night and wakes up happy – it’s amazing.”

Kara said, “Evie was one at diagnosis, so just a baby. In a way we were grateful as she was oblivious to it all, it just became Evie’s life and she got excited going to appointments on the train, to play with their toys and to see the play nurses.”

“As Evie is three she doesn’t miss a trick; she understands what’s going



Evie with her mum Kara

on the best way we thought she could. She’s such a special girl and deals with this journey so well. She is a truly extraordinary, amazing and inspiring girl and we are so, so proud of her.”

Kara said, “I wanted to say a special thank you to Birmingham Women’s and Children’s Hospital. Our consultant has been an amazing reassurance for us, we can’t thank him enough for everything! The team are amazing with Evie and we couldn’t have gotten through appointments without them. And the support from Sarah from the CHECT team is amazing.”

“Thank you also to all our family and friends for their continuous support, and especially to my mum Debbie. I couldn’t have got through it without her endless love and support.”

“Our aim was to get our happy, healthy Evie back”

“Evie is a star and nothing fazes her”

A huge thank you to Kara and Evie for helping us to raise awareness of Rb.

Evie’s story was picked up by the national press during Childhood Cancer Awareness Month and was published in the Daily Mail and local press reaching an audience of nearly a million people.

We can’t raise awareness without the help of our CHECT families. If you would like to share your story to help raise awareness of Rb, please contact info@chect.org.uk.

A smiley Evie after she came home from having her eye enucleated





◀ Olivia is an influencer and model

Olivia Deane: How I learned to Love My Eyes

Vogue Portugal model and influencer Olivia Deane, who had retinoblastoma at the age of 12 and is now an advocate of celebrating differences, fronted our #LoveYourEyes campaign to mark World Sight Day. Here Olivia discusses her journey of self-acceptance, and the opportunities it has opened up for her.

My name is Olivia Deane and I am 24 years old from West Sussex.

When I was 12 years old I was diagnosed with retinoblastoma (Rb). I always saw little black floaters, but I can't remember seeing them when being young, I'm unsure when exactly I started to notice the

floaters, however I never complained about them as I thought this was a normal thing that everyone saw. I received chemotherapy and then went into remission for a little while. Unfortunately, it returned much more aggressively, and I had my eye removed at the age of 14.

Retinoblastoma has affected me in so many ways. Having my eye removed at 14 was a scary thing at the time. I felt different and thought so many times 'Why me?'. Every day got easier, but it is something that is part of you.

"Everyone deserves to feel happy, comfortable and included."

When taking out my prosthetic eye I always thought this is me ... my true self. I really started to open up about my experience with Rb and how I feel about living with a prosthetic eye. It was hard to get used to having a prosthetic eye as it's different to having two eyes, I felt uneasy taking pictures as my eyes looked lazy and I just couldn't get used to it. I

felt I was hiding from the world. I really felt it helped speaking about my experience. I plucked up the courage a couple of years ago and took my prosthetic eye out for a picture on my social media to show the world the real me, I felt it was such a weight lifted off my shoulders. I actually felt beautiful in the picture, compared to how I used to feel when I took pictures with my prosthetic eye in.

The picture reached so many people; people who had been through the same and also lots of people with body differences who we've stayed in contact and supported each other over Instagram. It's been so amazing to see and speak to such inspirational people, it's really inspired me to love myself and I should never be ashamed of my beauty spots. I truly believe we are all individually beautiful and it deserves to be seen.

Although I wear my prosthetic eye from day-to-day when travelling, I like to take pictures and videos without it. I feel it defines the real me. I like to have a choice in how and when I feel comfortable. I never usually leave it out for longer than a day.

Since posting pictures regularly, I have stayed in contact with some amazing people with prosthetic eyes. Some who have



◀ Olivia during during chemotherapy

had Rb too, some who have had different cancers, accidents and more. I realised not everyone feels as confident as I do now and how some haven't fully opened up about their story before. I felt so strongly about holding an awareness day so we could all meet and they can tell their stories too. I feel there's never enough awareness and if we can help make a change and build confidence up with everyone who has differences, to help prevent bullying and normalise differences finally would be such an amazing thing to experience and do. I organised a venue, photographers and a videographer to film the whole day and make it into a documentary. My plans are to go to schools, many schools and show the documentary to children/teenagers and explain my journey and allow other people to explain their story on living with a body difference. I want to educate and help children gain more knowledge on disabilities and differences so this can prevent bullying as people will be more understanding and able to approach the subject. Everyone deserves to feel happy, comfortable and included.

The day went successfully, it

was so amazing to meet such powerful, strong, inspirational people! It has helped me so much and we all connected and opened up which was lovely. The documentary is currently being edited; I'm hoping for it to be out in the next few months so watch this space!

Katie Piper – an inspirational presenter who was attacked with acid, causing her to suffer from burns and blindness in one eye – found my Instagram and we have stayed in touch ever since; she has always been my inspiration. She has helped so many people including me. I went on her podcast and spoke openly about my journey with having retinoblastoma. You can find it on Spotify (Extraordinary People: Livi Deane). She also sent such a lovely message to everyone who attended the awareness day, this will be shown in the documentary.

From doing the podcast with Katie Piper I was afterwards messaged by an agency called Zebedee Talent. They have recently signed me and I am now modelling for them; it's

"I really am at my happiest in life right now."

Olivia in Vogue Portugal

all been surreal and just an absolute dream. Ever since I had my eye removed I thought it would hold me back, but I was so wrong. It has helped me achieve things I never thought I would have achieved; I believe Katie Piper when she told me that God will never give you something you can't handle.

Since modelling, I have recently been in Vogue Portugal September 2021 issue and many more exciting shoots. Some I can't mention until it's out.

I really am at my happiest with life now. I want people who have been through the same as me, or similar, to know that things will be ok. Things will work out and life has its paths, some we don't understand but it will always lead us to where we're meant to be. Staying positive and speaking good encouraging words to yourself will always help.

Olivia at her awareness day with Elijah

A huge thank you to Olivia for helping us to raise awareness of celebrating differences.

If you've been affected by retinoblastoma and want more support on body confidence, our support workers Lesley, Sarah and Lena are here to help. You can call them – Lesley 07471199809/ Sarah 07526594762/ Lena 07706919996 or email them at: support@chect.org.uk



Give yourself a lift in 2022!

Do you have a New Year resolution to get more active? Or just to take on a fun, family outdoor activity?

If so, we would love you to raise funds for CHECT at the same time – double the impact!

As well as big events like the London Marathon and the Great North Run, we have over 650

other events you can sign up to on the 'Get Involved' section of our website, and they are UK wide.

From an Inflatable Obstacle Race in Glasgow and the Gateshead Half Marathon, to the BM Ride cycling event on closed Brighton roads, and a skydive in Cornwall - via the London Superhero in the City - we have something for (and near) everyone. You can check out all our events at chect.org.uk/other-ways-to-help/events/.

If you want to go one step further and organise your own event



Enzo and Giuseppe cycled from London to Brighton

(sporting or otherwise), our Fundraising Manager Diane is here to help - email fund-raising@chect.org.uk to chat through ideas, or call her on 020 7377 5578.



How about a Crazy Glasses event?

Perfect for schools, nurseries and the workplace, you can find more details and glasses templates to download at: chect.org.uk/other-ways-to-help/crazyglasses/

Winning together

Continuing their amazing support of CHECT, our wonderful friends at Vision Express began their Joyous Fundraising campaign in October.

Raising funds for CHECT and the Macular Society, colleagues from stores across the UK were invited to use their creativity, employ the best talents of their team or store – and have fun. The aim was for Joyous Fundraising to be flexible and super-easy – and it was wonderful to see the thought involved in supporting our two charities!

From The Great South Run and the Three Peaks Challenge, to

spooky Hallowe'en dressing up, via bake sales and an art auction we are grateful to all stores for getting involved so enthusiastically!

Of course, Head Office joined in too – the Executive Team tackled the fabulous feat of walking, running, swimming, cycling and even rowing, between the most southerly Vision Express store in Helston and the most northerly store in Inverness.

Vision Express have been much-valued supporters of CHECT since 2010 and we love working with all the team, and colleagues across the UK!



Vision Express have been raising funds throughout the UK

Get your hands on some CHECT merchandise!

Our new merchandise page has launched

Whether you are holding a fundraising event, looking for last minute stocking fillers, or just feel like wearing a CHECT T-shirt, head over to the new merchandise page on our website.

Here you will find T-shirts and running vests, pin badges and wristbands – with 100% of all profits coming to our charity. Or if you have an event you are planning for, we have balloons, stickers, collection boxes and leaflets we can send to you to help raise funds and awareness.

Visit chect.org.uk/chect-merchandise/ to find out more. And if you still have some last minute Christmas cards to buy – this is your place!



Could CHECT be your workplace's Charity of the Year?

If your company would like to support us in any way, we'd really love to hear from you. Please email Diane Emery, our Fundraising Manager, at fundraising@chect.org.uk or call 020 7377 5578.

Thank you

We are very grateful to those supporters who have remembered our charity in their will, and also to those who arrange donations in memory of a loved one.

This is a wonderful tribute and we very much appreciate the thoughts of those who support CHECT even at such a difficult time.

Our condolences and grateful thanks are extended to the families and friends of:

**Alan Clifton
Iain MacKinnon Docherty
Anthony Harris
Lindsay Hirst**

What's on...

We are making plans for special CHECT events in 2022 – if you would like to join TeamCHECT at the annual Run-Through Regent's Park, or get involved in a CHECT exercise challenge in February from the comfort of your own home, let us know at fundraising@chect.org.uk and we will email you as and when more details are available!



Children's corner



Jack's Sleepover Antics!

Jack Gwyther, 11, recalls a story which shows how his confidence with his prosthetic eye has grown.

It was a Saturday night when I went round my best friend's 11th birthday party and there were 4 of us. We were all messing about in the living room playing on the Xbox's we had all brought round.



I suddenly whispered into one friend's ear, "Should I take my eye out to scare them?". My friend obviously said yes because we wanted to see their funny reactions. One friend said he had lost his appetite, and I started chasing another - he started laughing, it was all a big joke.

However about 8 years ago it would take my mum, my dad, and the prosthetist to help to take my eye out. I am now 11 years old and have a lot of confidence with my eye, taking it out and putting back in. I find it really funny when I take my eye out and scare my friends. That's one of the positives to having a prosthetic eye!

Max Sets Sail!

Max Macara, 11, tells us about the highlights from his sailing Ellen MacArthur Cancer Trust day trip at Whitemoor Lakes.

As soon as I saw the high ropes, canoes, a huge lake and sailing boats, I knew I would enjoy myself!

Firstly, we headed over to the mini sailing boats where I controlled the sail. It felt as if we going super fast on the boats, especially when we were towed by the life boat. After sailing, I immediately put my hand up to go first on the high ropes, and hopped onto the balance beam. I had to walk up a steep wooden log and then climb up to a high wire. We moved onto 'The Gladiator' - a series of dangling logs, ladders and tyres that you had to climb up in order to reach the wooden platform at the top. I felt proud of myself for doing it in a short time.

Finally, there was 'The Leap of Faith!'. I had never managed to catch a trapeze before on a leap of faith, but I felt hopeful this time. I climbed up the ladder and when I reached the top, my adrenaline was rushing! I jumped as far as I could, and caught the bar! I was so happy, I was shaking from the excitement when I was lowered to the ground.

After a delicious lunch, we had some rowing races on the canoes, which were great fun! As it was such a warm day, we were also lucky enough to be able to enjoy a muddy but relaxing swim in the lake. A little water fight too!

I had an amazing day out with the Ellen MacArthur Trust!



Spaces for these trips are limited, but if you are interested in a future trip, please email: support@chect.org.uk or give your support worker a call.



Ways to help

We need your help! As we all prepare for the festive season, and the beginning of a new year to come, many will no doubt reflect on the past two years, and the difficulties and hardships people have faced.

And we are no different. We know that cancer didn't stop for Covid and that lockdown made an already difficult situation worse for many of our families. Even though we couldn't see you face to face, we continued our support by telephone, video call, email and social media.

Who would have thought that, as we endured the hardships of the first lockdown, CHECT would be facing a potential loss of more than half our income from traditional sponsored challenges

and events organised by our supporters. We are so grateful that our amazing members and friends came to the rescue in different and creative ways, and we thank everyone for their fantastic support during what have been very difficult times for charities.

Sadly, it is not over yet. Although the London Marathon, Great North Run and other events returned this year, raising the funds that all charities need to not only thrive, but survive, is still much more challenging than before the pandemic.

We need your help to offer life-long support to all those affected by retinoblastoma, to raise awareness of this little-known cancer, and to fund research into prevention and treatment.



We receive no government funding and rely on the generosity of individuals, companies and organisations to do what we do. If you can spare a gift this Christmas, please donate what you can to help us to continue to offer support to all families in the UK with a diagnosis of Rb.

Thank you from all of us at CHECT, and from all the families we support, as well as all those who will need our support in the year to come.

Ways to donate

Simply scan the QR code on your smartphone and follow the instructions to donate what you can (you may need to enable QR codes in your camera settings).

Your gift will come straight to CHECT, without having to download an app. Please rest assured that we do not receive your bank details.



*BOPP is regulated by the FCA and licensed by PISP and AISP



Or you can make a donation in the regular way by:



visiting our website: **chect.org.uk/donate**



or by texting **CHECT** to **70470** to donate £3.

Or if you are making a list of New Year resolutions, please consider making a monthly donation to CHECT. Regular gifts are a fantastic way to contribute to the resilience of our charity and provide us with a reliable and dependable source of income - you can sign up at chect.org.uk/donate/regulardonation/

Thank you!