

IMPACT REPORT 2018 - 2022



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INTRODUCTION

As we come to the end of our 2018 - 2022 strategy, it's wonderful to look back at some of the amazing things that we've achieved over the last four years thanks to the incredible support of our members, partners, volunteers, donors and fundraisers.

We don't receive any money from the government and we rely on public support to fund our vital work. Our core aims of support, awareness and research remain and we are constantly looking for new and innovative ways to help us achieve them. We are delighted to be able to share a little of our progress and our plans with you in this report.

As a charity we continued to offer support to 100% of families affected by retinoblastoma (Rb) and clocked over 10,000 hours of support. Our awareness raising meant that the percentage of people that recognised a symptom of eye cancer grew over the four years. Another key achievement is reaching the £1 million mark for funding research. We have also set new records in our annual fundraised income over the past four years!

We are a small charity with a very clear focus on the individuals and families impacted by what is a fast growing and quite devastating cancer. It is this focus that allows us to understand the needs of and continue to make a big difference to this very special group of people.

We hope you will continue to support us on our journey.

Thank you.

**The
CHECT
team!**



WHO WE ARE

Childhood Eye Cancer Trust (CHECT) is the only UK charity dedicated to helping people affected by retinoblastoma (Rb), a rare form of eye cancer. We:

- Provide support and information to families and individuals.
- Fund research into the prevention and treatment of Rb.
- Raise awareness among health professionals and the public.
- Influence policy to improve services for patients.
- Provide lifelong support to families from when their child is diagnosed, throughout treatment and beyond.

Membership to CHECT is free and open to anyone affected by Rb, as well as their friends, family, all supporters of CHECT and health professionals. We've been helping families for more than 35 years.

Retinoblastoma is a rare and fast growing type of eye cancer that affects babies and children, usually under the age of six.

Around 50 children in the UK are diagnosed every year - or one child a week.



Craig Blackwood, Head of Support



Sarah Turley, Support Worker



Lena Copley, Support Worker

SUPPORT

We were founded to provide support and information to people affected by retinoblastoma (Rb) and this remains our core focus.

We have support workers who work alongside the clinical teams in two specialist treatment hospitals – the Royal London Hospital and Birmingham Women’s & Children’s Hospital. This support team provide face to face support at these sites but also provide remote support via phone, email, video call and social media. The team support people holistically and as well as providing emotional and practical support, they also facilitate social events to bring people together to share experiences.

Here are some of our key achievements during 2018-2022:

- 100% of families were offered support following a diagnosis of Rb.
- We delivered 10,000 hours of support.
- We gifted a total of almost £33,000 in CHECT Support Grants to assist with costs associated with an Rb diagnosis.
- We altered our operating process to respond to the COVID19 pandemic, working innovatively to allow people to continue to access support.

100%

**of families
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Pre-pandemic

- We delivered a total of 1,918 face to face support sessions in our hospitals.
- We facilitated 7 Members' Days, with a total of 81 families (329 people) in attendance.
- We awarded 44 children with CHECT Champion Awards to recognise their courage during their or their sibling's cancer treatment.
- We reached over 100 families at 10 "Eye Clubs" - delivered in partnership with clinical colleagues to support children with new artificial eyes.
- We responded to an average of 50 calls/emails per year from concerned non-members requiring support or guidance around symptom worries.
- We formed our Teen Focus Council and held 2 meetings to bring together a group of 13 - 19 year olds with a previous diagnosis of Rb.
- We held 4 Beyond Rb events attended by 50 adults affected by their previous diagnosis of Rb.

During the pandemic

- We delivered a total 1,462 face to face support sessions in our hospitals.
- We increased our remote support provision and delivered over 3,000 support calls and emails from home.
- We responded to 101 calls/emails from concerned non-members requiring support or guidance around symptom worries.
- We held regular online "Storytime" events for children and families to access - with an average of 8 families (11 children) attending each time.
- We held 3 meetings for our Teen Focus Council and commenced work with our funded PhD student to coproduce a robust support tool.
- We celebrated Birmingham Children's Hospital Rb team's 20th anniversary and we continue strong partnership working with clinical teams there and in the Royal London Hospital.
- We appointed a new Head of Support to further expand and develop our support offer and services.

We delivered
10,000
hours
of support

“We would like to thank the team at CHECT for being the best support for us while we’ve been going through the most difficult time of our lives and for always being there at the end of the phone, just to listen and offer advice.”

-Natasha Finney, AJ’s mum



“CHECT have helped our family hugely – not only financially, but mentally, and offering help whenever it was needed.”

-Annabel Byrne, Elijah’s mum

AWARENESS

Retinoblastoma is rare and the symptoms are very subtle, which means that most people aren't aware of it. Sadly this often leads to a delay in children being diagnosed. Raising awareness among both the public and healthcare professionals is vital in helping to drive early diagnosis.

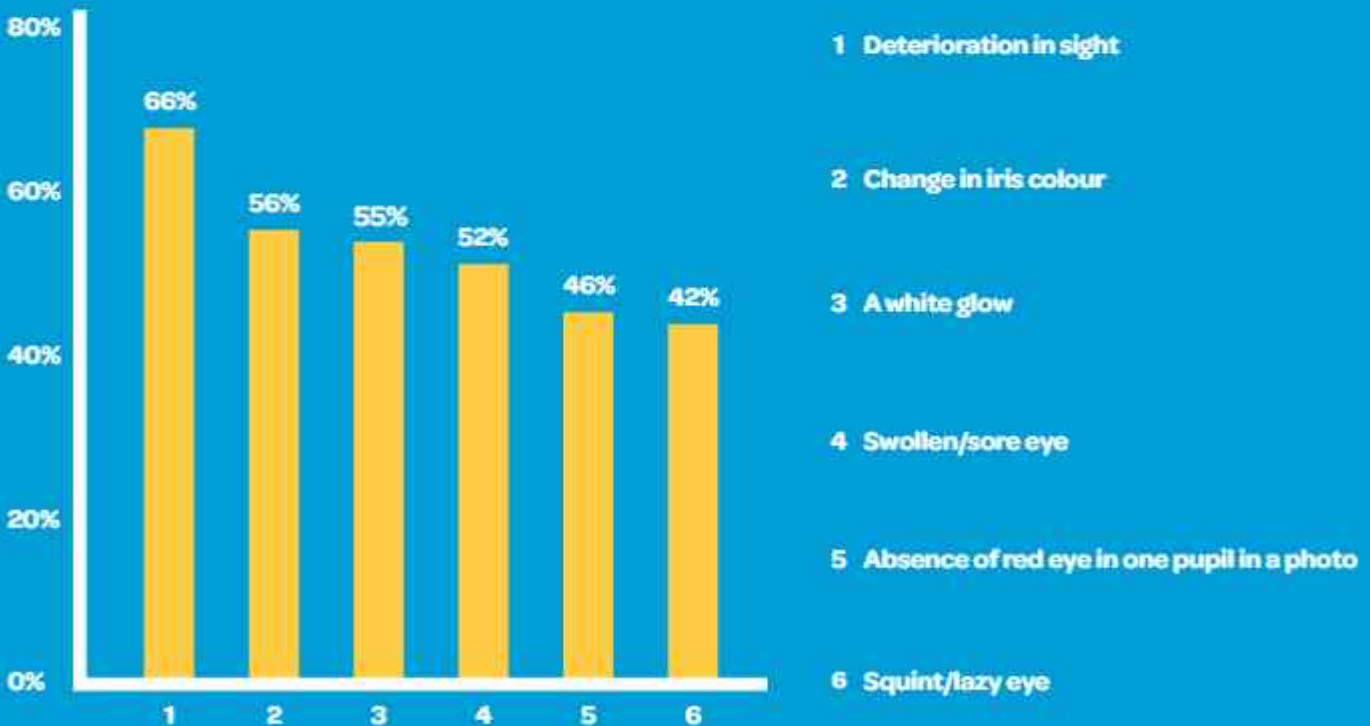
What we've achieved:

We worked with NHS England to launch an awareness campaign, featuring Kitty, which was seen by at least 1.13 million people.

We had major campaigns around key dates in the calendar, including Rare Disease Day, World Retinoblastoma Awareness Week, Childhood Cancer Awareness Month, World Sight Day, National Eye Health Week and Christmas.

We held a Parliamentary event in May 2019 to raise awareness of the main signs and symptoms of retinoblastoma and the need to reduce delays in diagnosis. The event was supported by CHECT trustees and members, and almost 40 MPs attended.

We also worked with the Institute of Health Visiting to update their 'Good Practice Points' factsheet on retinoblastoma, which emphasises main signs and symptoms of Rb and follow-up actions to take.



Percentage of parents that can identify these signs & symptoms of childhood eye cancer.*

*of 1062 parents asked in Jan 2022 by MMR Research Worldwide

The amount of people who felt they knew a symptom of eye cancer increased from 16% in 2020 to 19% in 2021

Adults were more likely to correctly identify symptoms from a list when shown in

2021 vs. 2020



786 media mentions in the UK

56 national magazine and newspaper articles

We had at least 351,411 website hits between 2018-2022.



Mum 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. She was reluctant to turn her head to the right – we later found out this was because she had no sight in her right eye".

Imogen's parents Lorna and Mike booked a doctor's appointment straight away after noticing the symptoms, and luckily their GP urgently referred Imogen. The referral appointment involved an ultrasound, where it was immediately clear that something wasn't right.

Lorna explained, "I was looking at some obvious masses in her eyes on the 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."

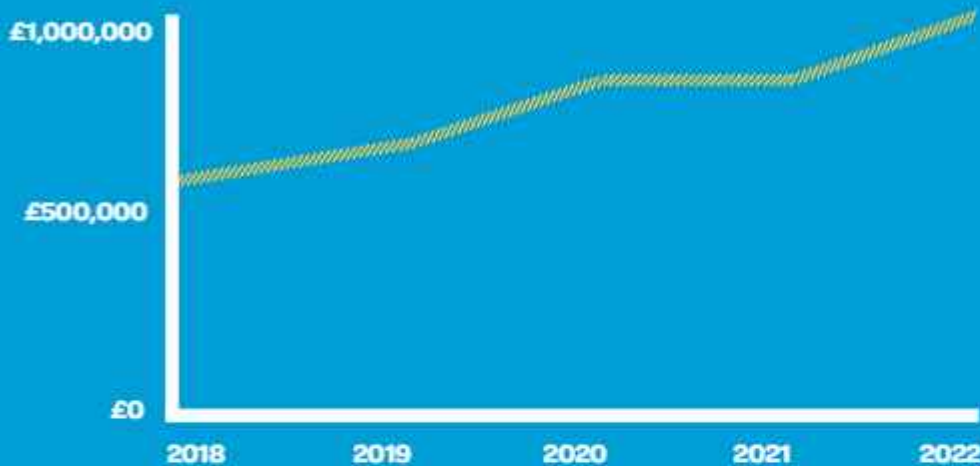
Lorna recalled, "I remember feeling absolutely devastated that our tiny baby could be facing something so

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."

Lorna said, "Mike and I have learnt to lean on each other throughout the last year more than ever before. 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."



RESEARCH



CHECT's all-time investment in research over the £1 million mark.

During the period of the strategy CHECT has averaged an 18% per year spend on research.

Research we have funded from 2018-2022 include:

- Evaluating whether administering PRELP protein to retinoblastoma tissues can inhibit the progression of the cancer, without causing toxicity to unaffected cells.
- Developing a liquid biopsy for retinoblastoma.
- Creating an evidence-based psycho-educational intervention for teenagers and young adults who have had retinoblastoma.
- Comparing blood to aqueous humour (a fluid from the eye) as a liquid biopsy for retinoblastoma; and determining the superiority of the aqueous humour as a source of tumour DNA.
- Assessing the feasibility of retinal organoids as a model system to test the safety and efficacy of chemotherapeutic agents in retinoblastoma.
- Next generation sequencing analysis of retinoblastoma samples to detect those variants associated with good and bad prognosis or with a favourable treatment outcome.



Developing an evidence-based psycho-educational intervention for teenagers and young adults who have had retinoblastoma (Rb).

In 2019 we were delighted to award our first PhD research funding for twenty years to a University of York study looking at the specific challenges that teenagers who have had Rb face as they transition towards young adulthood, in order to develop a specific support resource. There is little guiding evidence about this area, so understanding the psycho-educational needs of teenagers and young adults during this time is therefore essential if we are to offer effective interventions to support them. This PhD studentship aims to develop an evidence-based intervention for teenagers and young adults who have had Rb that offers relevant, accessible and effective psycho-educational support.

The research is being undertaken by Nicola O'Donnell, a trainee health psychologist, who says: "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.) I am passionate about working with teenagers and young adults to hear about their experiences. The Rb community are best placed to shape the resource, so I am really looking forward to working together on the co-production aspect of the PhD. I hope that I can bring my skills and experience and learn from and work alongside CHECT and young people with lived experience to create a meaningful intervention. 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 when living beyond cancer 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 intervention 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 with me. 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 who are interested."

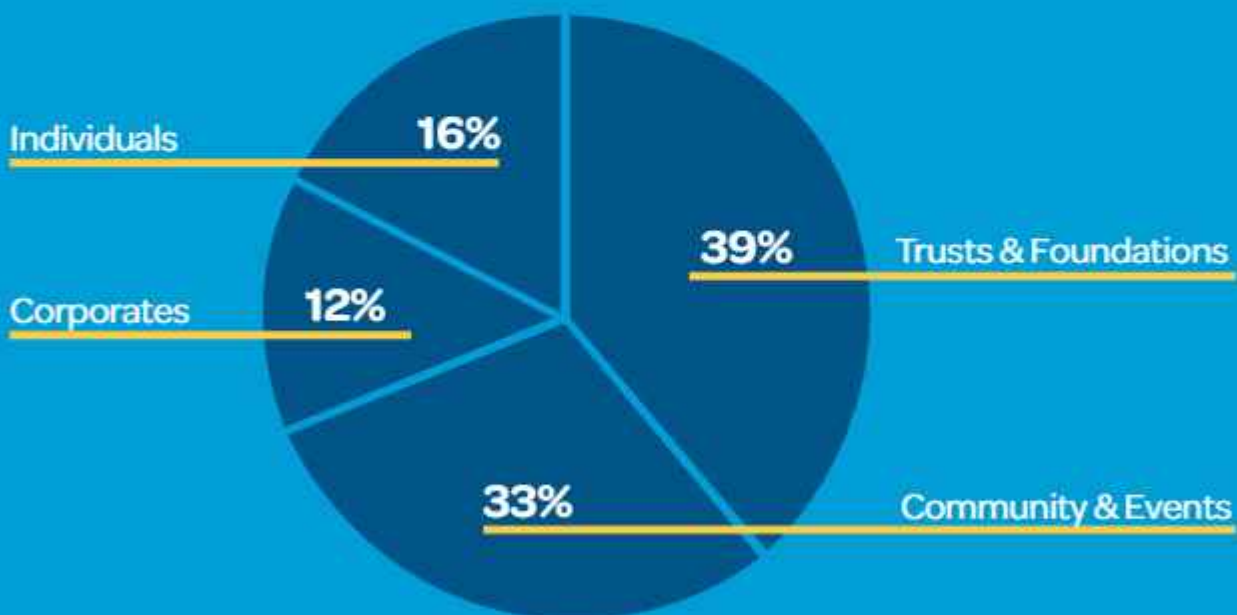


FUNDING

We are truly grateful for the amazing loyalty, commitment and generosity shown by our members and supporters, who make our work possible. From individual gifts to company involvement, this wonderful support continues to exceed our expectations. And we are inspired by those fabulous people who undertake challenges and organise their own events to help us to help those affected by Rb. We would like to express our sincere thanks to all of the charitable trusts and foundations that have supported CHECT over the past four years, and whose kindness has enabled us to continue our vital work. Thank you all – we could not do it without you.

Sources of income 2018 - 2022

For every £1 of income received, 72p was spent on our charitable activities supporting those affected by retinoblastoma.





In June 2020, during lockdown, Noëlle was diagnosed with retinoblastoma (Rb), at the age of 17 months.

Knowing the treatment that Noëlle faced inspired Shaun to devise his own challenge, to raise funds for CHECT. The Great Noëlle Run was Shaun's version of the Great North Run – 13 Half Marathons!

He began straight away and completed the last one in October 2020. As Covid restrictions had eased by then, he was able to begin his last run at the Finish spot of the Great North Run, and was very happy to be able to complete it with his dad and father in law on their bikes.

Shaun raised an incredible £11,844 with this amazing achievement. Now that the Great North Run has returned to its original route, we are thrilled that Shaun is doing the real thing in September 2022, to raise funds for CHECT again!



During lockdown, when in-person events had stopped, 1,500 wonderful people challenged themselves to undertake 2,021 Squats in January to raise funds for CHECT.

We remain so grateful for the dedication of the amazing group, both longstanding supporters of our charity and those new to our cause, who simply wanted to help out.

This virtual event was the largest in CHECT history, and we loved getting to know all our supporters on social media. The whole CHECT team were involved with the project, working from home – and did a few squats themselves, too...

For the past 26 years Roisin Lynch, her friends and family have braved the cold for their Annual Christmas Day Swim for CHECT. We are immensely grateful to Roisin for her dedication, raising around £45,000 for our charity since she started this awesome event!



OUR PARTNERS

We are very grateful to all of the companies, organisations and their staff who have supported us over the last four years in so many ways, from volunteering, to fundraising, to helping us with data entry projects!

We are proud to be in the fifth year of our partnership with Birmingham Optical, a key supplier in the optical industry. Each year the wonderful staff team hold a variety of fundraising activities, and volunteer at our events too. CEO Arran Fewkes leads the way, having run for CHECT in the hottest London Marathon ever in 2018, and tackling the Great North Run in 2022 as a member of TeamCHECT.

We worked with global marketing agency Wunderman Thompson on an exciting new awareness campaign for World Sight Day 2018 – Dot the Uninvisible Friend. The team produced an animated story about a little girl called Alice who is diagnosed with Rb. A ‘blimp’ of Dot visited London, supported by street advertising on digital screens and a press launch at Vision Express in Oxford Street.

The campaign had a fantastic reach across all communications channels, including:

- 4,000 views of the interactive story
- 13 media mentions (national, regional, trade)
- Featured on the homepage of Mumsnet as campaign of the week
- 6,400 Twitter impressions on 11 Oct (compared to 800 average day)
- 216,000 people reached on Facebook during the campaign week

A special shout out goes to those Wunderman Thompson staff who have signed up to regular giving with CHECT as a result of our partnership.

We would also like to thank the teams at PayCheck Ltd, Deltatre, Essilor, Dell Corporation, Sackers, The Shipowners Club, Clearbank, CMC Markets and Hancock & Wood for their amazing support!



Vision Express has been a much valued partner of CHECT since 2010 and has raised more than £660,000 to date, as well as vital awareness of Rb. It was the first optician in the UK to roll out a protocol to ensure a quick and effective referral if Rb is suspected in a child. Together we have developed an e-learning module to ensure that all in-store team members receive professional training on the signs and symptoms of Rb. The aim is to expedite 100% of retinoblastoma cases presenting in Vision Express stores.

Here are some of the highlights of our award-winning partnership over the last four years:

- In September 2018, to celebrate the 30th anniversary of Vision Express, the Ride4Sight Team cycled 300km through the extremely demanding Peak District, starting and finishing at Vision Express Support Centre in Nottingham. The 30 strong team raised over £30,000.
- When Vision Express opens a new or refurbished store, it invites a CHECT Ambassador to be guest of honour at the official ceremony. As well as being a lot of fun for the family, this often results in media coverage after the event, helping to raise awareness of Rb. In the period 2018-2020 (before lockdown) 37 CHECT families attended store events across the country.
- Vision Express stores, like other opticians, closed in accordance with government Covid restrictions but individual Vision Express colleagues and stores continued to show their support for CHECT by joining in with our digital fundraisers the 2.6 Challenge and 2021 Squats.



More than £660,000
raised since 2010



37 families attended
store events





- In 2021, Vision Express announced a new charity partnership, with CHECT and the Macular Society. During 'Joyous Fundraising' month in October, stores took part in Hallowe'en dressing up days, an art auction, bake sales, raffles and tombolas, while individuals raised funds from runs and the Three Peaks Challenge. The Exec Team embarked on their own challenge - walking, running, swimming, cycling and even rowing, between the most southerly Vision Express store in Helston and the most northerly store in Inverness.
- As you may have seen in stores and on social media, the adorable Vision Express mascot Marvin the Mole is raising vital funds for both CHECT and the Macular Society throughout 2022. After joining the Vision Express team in 2021, lovable mascot Marvin the Mole received so much positive feedback from customers and colleagues that Vision Express brought him to life in the form of a soft toy - and 100% of all profits raised from the sale of Marvin will help those affected by Rb and people living with macular disease. We are delighted to be involved with this exciting new initiative. It will help us to raise vital funds and at the same time raise awareness of Rb and the importance of early diagnosis. Marvin encourages us all to book routine eye tests, and in particular, parents to make sure their children have regular checks.

We remain indebted to the wonderful help, support and commitment of all colleagues at Vision Express and we look forward to furthering our partnership and exploring new and exciting projects with them over the coming months and years.

TRUSTS & FOUNDATIONS

We are enormously grateful to all of the wonderful charitable trusts & foundations which have supported CHECT over the past four years.

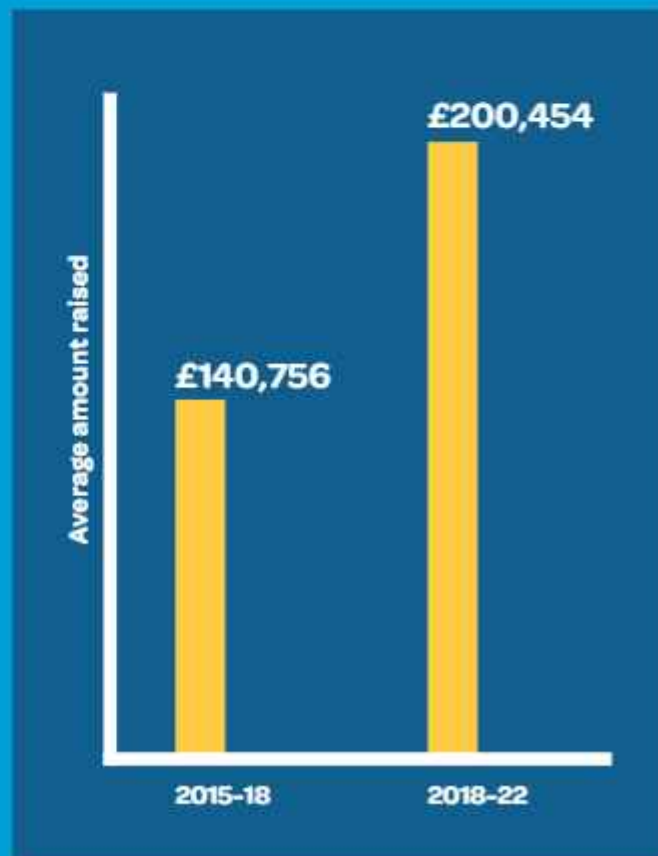
CHECT has been generously supported by the Clive Richards Foundation (formerly the Clive & Sylvia Richards Charity) since 2018. We were delighted to receive a grant of £15,000 per year for two years towards the costs of our work delivering support to families affected by retinoblastoma and driving faster diagnosis through raising awareness of Rb's signs and symptoms. In 2020, in the midst of the Covid-19 pandemic, Mr Richards invited us to apply for a further grant as emergency funding towards our core costs. We were overwhelmed and extremely touched to receive a marvellous grant of £50,000,

which was much needed during this extremely challenging period. Mr Richards also provided the initial inspiration for CHECT's extremely successful digital fundraiser, our Squats campaign held in January 2021. In the coming year the Clive Richards Foundation will be fully funding a ground breaking new research project with an extremely generous grant of £50,000.

Mr Richards has since passed away and is very much missed. We are enormously grateful to Mrs Richards and their Board of Trustees, who continue to generously support CHECT's work.



Mr and Mrs Richards



Comparison of the average amount of money raised per year from Charitable Trusts and Foundations from 2015-18 and 2018-22.

FUTURE PLANS

We are really excited to start delivering our 2022 - 2025 strategy. While our core objectives of support, research and awareness remain, we have a number of new plans to help us achieve and enhance them.

- To remobilise our face to face events schedule and deliver events nationally for members to access.
- To increase our digital support offer, to allow continuity of support and sustained member engagement in between face to face events.
- To survey all members to gather thoughts and experiences, and coproduce support service developments in response.
- Establish specific Teen & Young Adult website in partnership with TFC and drive recruitment and engagement with this group.
- Consolidate a network of late effects services nationally, and advocate for adults affected by the late effects of Rb.
- Develop our digital fundraising strategy to explore innovative ways to engage existing and new supporters.
- Continue our commitment to research as one of the key pillars of CHECT's work.
- Continue to try to build partnerships to create a research-specific funding stream.
- Continue to engage with emerging new technologies such as 3D printing.



THANK YOU



"Thank you to everyone who has supported us over the last four years - whether you donated, volunteered, organised or attended an event, took on a physical challenge, shared your story, liked one of our social media posts, or absolutely anything else, we simply could not do what we do without you."

~The CHECT team







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The Childhood Eye Cancer Trust (formerly known as The Retinoblastoma Society) working on behalf of those affected by retinoblastoma.
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