



Impact Report

2015-2018





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Introduction

As we come to the end of our 2015-2018 strategy, it's wonderful to be able to take a breath and look back at some of the amazing things that we've achieved over the last three years thanks to the incredible support of our members, partners, volunteers and fundraisers.

This strategy covered a special period in our history as 2017 marked our 30th anniversary. To celebrate this event we held our UK Members' Weekend in Buckinghamshire. More than 250 people of all ages came to meet up with old friends, make new ones and enjoy a weekend packed with so many different activities. It was an honour to meet so many of our members, see them having fun and learn more about the things that are important to them.

This is the third three-year strategy that we have published and we continue to use our learning and experience each year to inform our activities for the next. Our core aims of support, awareness and research remain but we are constantly looking for new and innovative ways to help us achieve them. I am delighted to be able to share a little of our progress and our plans with you in this report.

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.

Patrick Tonks, CEO





Who We Are

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

- Provide support and information to families and individuals.
- Fund research into the prevention and treatment of retinoblastoma.
- Raise awareness among health professionals and the public.
- Influence policy to improve services for patients.

We provide lifelong support to families from the moment their child is diagnosed, throughout treatment and beyond.

Membership to CHECT is free and open to anyone affected by retinoblastoma, as well as their friends, family, all supporters of CHECT and health professionals.

We've been helping families for more than 30 years but we don't receive any money from the government and we rely on public support to fund our vital work.



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.



50

└ children are diagnosed with retinoblastoma in the UK each year - or one a week

98%

└ will survive but more than half will lose an eye to stop the cancer spreading



Support

100%

↳ of families offered support following a diagnosis of Rb

7,000

↳ hours of support provided

We were founded to provide support and information to families affected by retinoblastoma (Rb), and this remains a core focus of our work.

We have support workers based at both the Royal London and Birmingham Children's Hospitals – the two specialist centres for Rb in the UK – and available via telephone, email and social media.

Here are some of our key achievements in the last three years:

- We provided £13,400 in grants to help with the costs associated with an Rb diagnosis (eg transport to and from hospital for treatment).
- We held 14 members' days across the UK for families to meet others affected by Rb outside of the hospital environment.
- 56 children were given CHECT Champion Awards to recognise the courage they showed during their, or their sibling's, cancer journey.
- We held five events for teenagers, to help boost their self-esteem and give them the opportunity to make friends with other young members. We created a new online magazine called TeenFocus.
- We launched a new website to provide better support, information and advice about Rb. Within six months, the number of visits had increased by 700%.
- Nine out of 10 newly diagnosed families became members of CHECT.

"He's our very own little superhero – 'Balfour the Brave' – and we couldn't be prouder of him. He doesn't let his artificial eye stop him from doing anything and he's doing great at school, playing lots of sport and swimming. We really couldn't have got through the whole experience without the support of CHECT and will always be incredibly grateful to them."

Claire Baxandall, mum of 'Balfour the Brave', aged 4.





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 achieved:

- 1,003 media mentions, including 59 national magazine and newspaper articles, with information and stories about families affected by Rb.
- Major campaigns around key dates in the calendar, including 150 media mentions in one day on Rare Disease Day in 2016.
- Targeted social media campaigns for healthcare professionals led to 3,600 visits to the professional pages of our website, and over 33,000 video views by GPs, health visitors and opticians.
- 18 articles about Rb in trade media aimed at health professionals.
- We distributed 1,500 leaflets at GP and health visitor events and worked with the Institute of Health Visiting to produce factsheets.

- We attended Optrafair and Primary Health Live trade fairs.
- We had trustee representation at European meetings and a 1,000% increase in international visitors to our website. Our Next Photo Awareness Campaign had over a million views and was shared with organisations in China, USA, Canada and Argentina.

The difference that this has made includes:

- 21% increase in the number of parents aware of Rb.*
- 4% increase in the number of parents aware that white eye is a symptom.*
- 15% increase in the number of parents aware that a squint is a symptom.*
- 36% increase in children being referred within two weeks of their first visit to a healthcare professional, in line with NICE guidelines.**

*Source - annual survey of more than 1,000 parents of children aged under six, carried out by MMR Research on behalf of CHECT.

**Source - qualitative data collected by CHECT called Pathways to Diagnosis, based on discussions with the families of children diagnosed from 2012-2017.

Harley Shevill was 10 months old when she was diagnosed with Rb. Just weeks later she had her right eye removed. Her mum Coral Baxter says: “We noticed a white reflection in Harley’s eyes in certain lighting, but we never thought anything of it. Then she developed a squint so we took her to get checked out but were told there was nothing to worry about. I googled her symptoms and some information about retinoblastoma came up but I thought it couldn’t be anything that serious as she was so healthy and well.”

A few weeks later Coral’s mum was watching the news on television about a little boy from Scotland who had been diagnosed with Rb, and she called Coral and told her to watch it. Coral said: “As soon as I saw it, I made another doctor’s appointment. A week later we were being given the news we had dreaded - Harley had Rb. When she was diagnosed I was totally heartbroken, I didn’t know how we were going to get through it. But in the end it was Harley who got us through it. She was absolutely amazing.”





Research

18

research applications received

£93k

awarded to new research projects

We're committed to engaging in the advancement of knowledge of Rb, its treatment and its impact.

Since 1997, we have funded 17 projects, totalling over £500k, across a range of subjects including clinical, laboratory-based basic science and psychosocial. We aim to ensure that each research project results in publication and presentation.

In 2018, we advertised a new research grant funding round, calling for applications up to the value of £55k.

In particular, we invited applications into psychosocial research after our members told us that this was a priority for them at our 30th Anniversary Members' Weekend.

Research projects we have funded over the last three years include:

- Understanding and overcoming barriers to living with an artificial eye.
- Targeted antibody-drug conjugates for retinoblastoma therapy.
- Supporting the development of a national system to collect and audit data on children diagnosed with retinoblastoma within the national cancer registration service.
- Modelling retinoblastoma using human induced pluripotent stem cells.
- Autonomic reflexes and cardio-respiratory instability during super-selective intra-arterial chemotherapy in management of children with Rb.

CHECT and Fight for Sight co-funded a research project, led by Dr Simon Ramsden and Dr Trevor Cole, to improve the sensitivity of current genetic testing methods that all new families in the UK affected by retinoblastoma now undergo. They said:

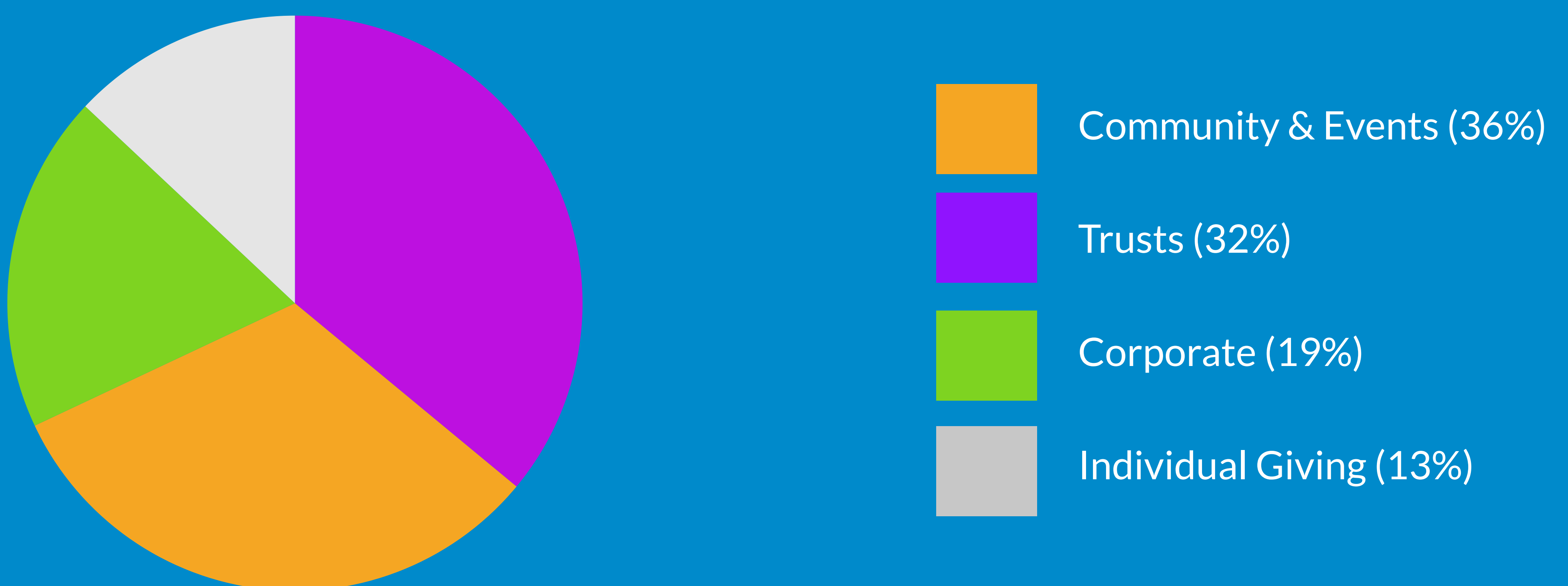
"Thanks to the support of CHECT, we can now identify mutations at much lower levels in the blood than was previously possible. We estimate that we can now identify mosaic mutations in approximately 10% of patients that would have previously tested negative, which means that we can provide accurate risk estimation to more family members than ever before. This, in turn, will enable us to exclude more siblings, previously deemed to be at risk, from costly and distressing surveillance."





Funding

We are truly inspired by the amazing dedication and passion of our supporters, who make our work possible. From individual giving to company support, we would like to express our gratitude to all of our fundraisers who continue to amaze and exceed our expectations. We are extremely grateful to all of the charitable trusts and foundations that have supported CHECT over the past three years, and whose generosity and kindness have enabled us to continue our vital work. Thank you all.



Sources of Income 2015-18

For every £1 of income received, 78p was spent on our charitable activities supporting those affected by retinoblastoma.

Despite undergoing chemotherapy for an incurable brain tumour, mum-of-two Gemma Edgar vowed to cross the finish line of the London Marathon for her son Noah, who has been battling Rb - and that's exactly what she did.

Even though she was having monthly doses of chemotherapy which left her feeling sick and exhausted, Gemma continued to train three to four times a week in preparation for the big day and said that "sheer determination" kept her going.

Gemma said: "I had never felt that there was a charity close enough to my heart to raise all that money for until CHECT, who provided our family with so much invaluable information, advice, care and support. I wanted to raise money for them to ensure that they can continue to help other families who find themselves in a similar situation."

Gemma raised £5,527.53 for CHECT, in addition to the £15,000 that her brother Lee Relf, family and friends have raised in the last two years by carrying out fundraising challenges.



"Noah is my inspiration. Whenever I'm feeling grotty or sorry for myself I think of him and the fact that he was only a baby when he went through cancer treatment, and he never complained."

Gemma Edgar, mum of Noah, aged 3.





Our Partners

We are incredibly grateful to all of the companies and their staff who have supported us over the last three years in so many ways, from volunteering, to fundraising, to providing meeting space to putting up shelves in our office!

Global marketing agency Wunderman selected CHECT as its charity of the year in 2014 and has been working with us ever since. The creative team has produced a number of campaigns for us, including a multi award-winning interactive poster to raise awareness of the symptoms of Rb. A social media campaign and supporting video ensured this poster and its message was seen by over 1.1 million people worldwide.

The staff at Wunderman have also taken part in a number of fundraising events for us, from bake sales and cycle challenges to sponsored leg and back waxing!

In 2017, CHECT was selected as a beneficiary charity of Global's Make Some Noise. This is the official charity of Global, the media group which owns many of the UK's top radio stations, and we were given some amazing opportunities to raise awareness of Rb:

- Radio presenter Gemma Hill from Heart FM West Midlands Breakfast Show kayaked 150 miles from London to Birmingham in five days. The challenge was broadcast live, and the charity and our families featured on the radio throughout the week.
- Teenage member Theo Sergiou was interviewed by Jamie Theakston and Emma Bunton on Heart FM.
- Graham Northfield, whose son was diagnosed with Rb, and CHECT CEO Patrick Tonks featured on Classic FM with John Suchet.



Vision Express have been a partner of CHECT since 2010 and have raised more than £500,000 to date as well as vital awareness of Rb. They were the first optician in the UK to roll out the Opticians' Protocol to ensure a quick and effective referral if Rb is suspected.

Here are some of the highlights of our award-winning partnership:

- We developed an e-learning module together to ensure that all optometrists receive professional training on the signs of Rb. The aim is to expedite 100% of retinoblastoma cases presenting in the company's stores.
- 63 CHECT families attended store events which generated local press activity, helping to raise awareness of Rb.
- In September 2016, more than 35 volunteers from Vision Express took part in Ride4Sight, a 200 mile cycle, raising over £25,000. VIP riders included Olympic cyclist Bryan Steel and Paralympian footballer Darren Harris, both CHECT patrons.
- We worked together on an awareness campaign, #InTheDark, for World Retinoblastoma Awareness Week 2016 featuring Eliza Thomas who was diagnosed with Rb after an eye test at Vision Express. It achieved 26 pieces of media coverage reaching over one million people, the campaign video was viewed over 26,000 times and our collaboration won an award at the UK Social Media Communications Awards 2016.

We remain extremely grateful for the dedication, help and support of all at Vision Express and look forward to growing our work together in this coming period.

63

└ CHECT families have attended store events

£500k

└ Raised since 2010





Future Plans

We are really excited to begin delivering against our 2018-2021 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 allow us to do this, we have ambitious plans to increase our income over the next three years by 10-15%. We plan to:

- Increase the amount of support grants available to our families.
 - Carry out a survey to engage with our members, get their invaluable feedback on how effective our services are, identify any gaps and find new opportunities to improve the support that we offer.
 - Launch a Youth Council to empower and support our young members.
 - Organise at least four members' days a year.
 - Commit around 13% of our income each year to commissioning new research.
 - Develop a digital strategy to find new and engaging ways of reaching parents and health professionals.
- Campaign to raise awareness of a squint as a symptom of Rb, following research highlighting it as the second most common sign after the white reflection.

In addition to our three core aims, we'll continue to liaise with the different organisations involved in a family's journey, to make sure the voice of our members is heard and help deliver the best and most effective experience to all families.



"Retinoblastoma is a life-changing disease but it doesn't need to be a life sentence. My parents always instilled into me that I had to focus on what I had in life instead of what I didn't have which, looking back, is simple but such true advice."

Alison Brightwell, CHECT ambassador and winner of the TES Further Education Teacher of the Year award 2018.





Thank You

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

Patrick Tonks, CEO, CHECT





30

└ years of supporting families affected by Rb

1,600

└ CHECT members





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The Childhood Eye Cancer Trust (formerly known as The Retinoblastoma Society) working on behalf of those affected by retinoblastoma. Registered Charity No. 327493. A company limited by guarantee, registered in England and Wales No. 2143917. Registered office as above.