REGISTERED COMPANY NUMBER: 02143917 (England and Wales) REGISTERED CHARITY NUMBER: 327493

Trustees' Report and
Financial Statements for the Year Ended 31 March 2019
for
Childhood Eye Cancer Trust

Knox Cropper LLP 65 Leadenhall Street London EC3A 2AD

# Contents of the Financial Statements for the Year Ended 31 March 2019

	Page
Reference and Administrative Details	1
Trustees' Report	2 to 17
Report of the Independent Auditors	18 to 19
Statement of Financial Activities	20
Balance Sheet	21
Cash Flow Statement	22
Notes to the Financial Statements	23 to 35
Detailed Statement of Financial Activities	36 to 37

# **Reference and Administrative Details** for the Year Ended 31 March 2019

**TRUSTEES** 

Ian Ellington (Chairman)

Lisa Brown Amanda Moore Elizabeth Coleman Alex Brebbia Andrea Bonzano Lorna Fraser

Ravi Gupta (Treasurer) (resigned 6.10.18)

Matthew Holt Sahar Parvizi Rob Downes

Gemma Boggs (Treasurer) (appointed 6.10.18)

**COMPANY SECRETARY** 

Rose-Marie Sexton

**REGISTERED OFFICE** 

The Royal London Hospital Whitechapel Road

London E1 1BB

REGISTERED COMPANY NUMBER

02143917 (England and Wales)

**REGISTERED CHARITY NUMBER** 

327493

**INDEPENDENT AUDITORS** 

Knox Cropper LLP 65 Leadenhall Street

London EC3A 2AD

**CHIEF EXECUTIVE** 

Patrick Tonks

**BANKERS** 

CAF Bank Ltd PO Box 289 West Malling Kent ME19 4TA

NatWest Mile End Branch Albion Yard

331/335 Whitechapel Road

London E1 1AU

Trustees' Report for the Year Ended 31 March 2019

The trustees (who are also the directors of the charitable company for the purposes of the Companies Act) present their combined directors' report and trustees' report, as required by company law, together with the audited financial statements of Childhood Eye Cancer Trust (the Charity) for the year ended 31 March 2019. The trustees confirm that the trustees' report and financial statements of the Charity comply with the current statutory requirements, the requirements of the Charity's governing document and the provisions of the Statement of Recommend Practice (SORP) "Accounting and Reporting by Charities" applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015).

## **OBJECTIVES AND ACTIVITIES**

# **Objects of the Charity**

The Childhood Eye Cancer Trust is a charity dedicated to helping anyone affected by retinoblastoma (Rb), a type of eye cancer that affects babies and young children, mainly under the age of six. We have been supporting families since 1987.

Around one child a week is diagnosed with Rb in the UK or 50 a year. It accounts for 3% of childhood cancers in the UK and 10% of cancers in babies under one. Around 45% of cases are heritable and this carries with it an increased risk of developing tumours in other parts of the body in later life.

The Charity was originally founded to provide support and information to those affected by Rb. In 1994 we merged with another charity that was funding research projects specifically related to Rb, and in 2004 we changed our name to the Childhood Eye Cancer Trust. As we grew, so did our aims and objectives and we began to run campaigns aimed at raising awareness among health professionals and the public in order to achieve the earliest possible diagnosis for children affected.

## Our aims are to:

- Provide support and information to families and individuals affected by Rb
- Raise funds to support research into issues concerned directly with Rb
- Raise awareness of Rb among health professionals and others
- Influence policy to improve service delivery for those affected by Rb.

# Objectives, Strategies for Achievement and Public Benefit

We are currently approaching the mid-point of our three year strategic plan which covers the period from 2018 to 2021 and our progress against this plan is reviewed annually. Within this strategy period we have continued to successfully deliver on our three core goals of support, research and awareness.

The Trustees are aware of the public benefit guidance published by the Charity Commission. We have considered the objectives of the Charity and have given regard to how these objectives and the associated activities meet the public benefit criteria of advancing health, saving lives and the relief of those in need by reason of ill health.

We are the only UK-wide charity providing support to people affected by Rb and we believe that they benefit from our services in the following ways:

Trustees' Report for the Year Ended 31 March 2019

**Support:** To ensure that everyone affected by Rb in the UK has access to support and information according to their need.

- Our two support and information workers offer support to all families and individuals affected by Rb. This is provided on the wards and in clinics at the two specialist centres for Rb in the UK: Birmingham Children's Hospital and The Royal London Hospital
- Support is provided in other ways including telephone, email and Facebook
- Support for teenagers and young people through a dedicated support worker, specific events and opportunities for information sharing and peer support
- Regional events, meetings and other support opportunities
- A newsletter, blog, information factsheets and leaflets, website and annual members' events
- Grants for those in financial difficulties to help with the costs related to an Rb diagnosis and subsequent treatment.

Research: Proactively engaging in the advancement of knowledge of Rb, its treatment and its impact.

- Supporting and funding clinical, psychosocial and laboratory research relating to Rb
- Working through the Scientific Advisory Committee to identify and support suitable projects from a wide range of sources for funding
- Encouraging applications from the international research community
- Supporting multi-centre and international collaboration and sharing of experience, knowledge and data.

**Awareness - healthcare professionals:** To save lives and minimise the impact of visual impairment by ensuring that healthcare professionals know about Rb and its symptoms, listen to concerned parents and make quick referrals where necessary.

- Targeted activities to healthcare professionals associated with children aged six and under
- Distribution of information and awareness leaflets at relevant healthcare events
- Targeted distribution of diagnostic information, tools and advice on referring
- Education programmes for GPs, health visitors, opticians, optometrists and other healthcare professionals
- Media campaigns and articles for specialist healthcare professional journals and magazines
- Working with healthcare professionals to develop and implement standard referral protocols for those with suspected Rb.

**Awareness - public:** To encourage parents to seek medical advice more quickly by making them aware of Rb and its symptoms.

- Ensuring information for parents about the symptoms of Rb is available in all relevant NHS publications and on all NHS information websites
- Media activity regarding the condition including how and where to seek help
- Developing relationships with organisations able to reach large sections of the public with a view to raising awareness
- Regular and sustained social media activity
- Promoting knowledge of the possible longer-term impact of having had Rb as a child with regard to genetics and other cancers
- Information campaigns targeted towards people affected by Rb as a child
- Specific information and guidance accessible on our website.

**Influencing:** Working with other organisations to bring about improvements in the way in which services are delivered both in the UK and internationally.

- Working with the treatment centres in the UK, the NHS National Commissioning Group, National Artificial Eye Service and other umbrella bodies who provide services to people affected by Rb.

Trustees' Report for the Year Ended 31 March 2019

# **Research Grant Making Policy**

We award grants to groups or individuals who wish to pursue research projects or audits in order to advance the knowledge of Rb and related issues.

Applications go before the Scientific Advisory Committee which is made up of two CHECT Trustees plus experts from the research and Rb field. This committee evaluates the validity and appropriateness of the proposal using an agreed scoring matrix, seeking peer review for large projects and where necessary for other reasons, before making recommendations to the Board for funding.

Grant recipients are required to provide six-monthly progress reports and present a final report to the Board on the conclusion of the project before disseminating the findings and learning through presentations and publication.

#### Use of volunteers

Over 130 volunteers generously gave their time to support us throughout the year in many different ways. They have included: race marshalling, cheering on our runners at events, organising fundraising events, helping with administrative tasks in the office, taking photographs, designing our print materials and providing amazing help and support at our Members' Days. Whether it was one off or ongoing support, we would like to thank each and every one of our volunteers for their invaluable contribution to our work.

We'd also like to thank our dedicated ambassadors for their ongoing commitment to raising awareness of Rb and the work of CHECT.

#### **ACHIEVEMENTS AND PERFORMANCE**

# **SUPPORT**

We were originally created to offer support to the parents of children affected by Rb and this continues to be one of our core priorities. This support has now been extended to anyone affected, including teenagers whose unique needs are very different to those of a very young child or baby, and adults, many of who are living with the late effects of the treatment they received for Rb as a child. Membership of CHECT is open to anyone affected by retinoblastoma as well as their friends, family, supporters of CHECT and health professionals and we do not charge a fee.

In 2018, 100% of families were offered support following a diagnosis of Rb in the UK. This was face-to-face at the two specialist Rb centres - Royal London Hospital and Birmingham Children's Hospital - as well as via email, social media and phone.

A total of 1011 face-to-face sessions were carried out across both hospital sites in 2018. At the Royal London Hospital our support worker carried out 551 face-to-face support sessions and also reached 50 families by attending five Eye Clubs where children are given support to help them with their artificial eye. At Birmingham Children's Hospital our support worker carried out 460 support sessions in clinics.

Most of these families will also receive ongoing support between clinic visits, including contact by telephone, email or social media. We took a further 40 calls and emails from non-members who contacted the charity for support - for example, because they had seen a white glow in their child's eye and were concerned that they might have Rb. Our support workers made a total of six community visits outside of clinic sessions. In total, we provided around 2,500 hours of support.

"I think CHECT does a fabulous job in supporting families. CHECT are the only agency who call me just to ask how I am - not to fill in a form or anything like that - just to find out how we are coping."

"I think that what CHECT provide in terms of support is excellent. The support they have offered has really helped me to become the confident person I am today."

Trustees' Report for the Year Ended 31 March 2019

As ever, Facebook remains an important source of support and information. As well as our main public-facing page, we have a number of specific support groups on Facebook - which are closed to the public - giving members a chance to talk freely and in confidence. They are for parents of children with Rb (318 members) and adults who have had Rb (123 members).

The main reasons for people seeking support from the charity during 2018 were:

- Help and support with emotional issues
- Information about genetics, screening and late effects of Rb
- Financial information and support
- Signposting to other specialist organisations
- Information about holidays and wishes for families affected by cancer.

We gave 36 support grants to families, to help them with the costs associated with an Rb diagnosis and ongoing treatment - for example travel to and from hospital or to members' events for families feeling isolated to meet others affected by Rb.

#### **Events**

In 2018 we held four family members' days across the UK (in Glasgow, York, Colchester and Weybridge) attended by 53 families. These events help to reduce the isolation that some families can feel following a diagnosis and create a local support network for people who may otherwise never meet anyone else affected by Rb outside the hospital environment. In total 217 people attended these events.

Last year saw 31 child CHECT members receive their CHECT Champion Award - given to children who have inspired others with their bravery coping with the impact that cancer has had on them and their families.

"It was clear how much effort went into the day - it is no easy feat to organise 20 odd families of different ages and this was perfect. It was amazing to meet other families - especially those with artificial eyes and the kids had so much fun and were proud to get their awards"

"People got to talk to other families and children going through the same things they are."

# **Teenagers**

We know that teenagers who had Rb as children can face specific challenges around self-esteem, self-confidence and bullying, and we are increasingly looking at ways to support them and ensure that we are meeting their needs.

As part of this focus, 2018 saw the formation of our CHECT Teen Focus Council. CHECT teenagers between the ages of 13 and 19 formed a youth council with the first meeting held in October 2018. The council consists of 8-10 teenagers who meet to represent the views of young people to the CHECT team and also provide extremely valuable help and support to each other. Two meetings were held in this financial year covering topics such as communications, helping those not engaged with CHECT and supporting families with younger children.

# **Beyond Rb**

For some people, the effects of Rb are lifelong and we are constantly looking for ways to ensure that adults who had the condition as children have the support and information that they need.

As well as an active Facebook group, our Beyond Rb group organises 'meet ups' in different parts of the UK. In 2018 we held two Beyond Rb meet-ups (in Newcastle and Dorking) attended by 28 adults.

# Ongoing communication

We produced two editions of our newsletter, InFocus, which was mailed to over 1,300 members and supporters, with further copies available at the Royal London and Birmingham Children's Hospitals.

In addition to InFocus, we also sent a monthly email update to over 1,700 subscribers and have a blog on our website which is regularly updated with content, including news, events, real life stories, research and support articles. Some of this content, along with posts about fundraising activities our members have undertaken, has also been shared on social media, typically attracting strong engagement from our followers.

Trustees' Report for the Year Ended 31 March 2019

## **AWARENESS**

Retinoblastoma is a rare disease which means that most people are not aware of it. Sadly this frequently leads to a delay in a diagnosis being made and, because Rb is a fast growing cancer, quick access to treatment can be vital in order to save a child's eyes, sight and life. Raising awareness of Rb among both healthcare professionals and the public is therefore important in helping to drive early diagnosis and as such remains a key part of our work.

## **Professional Awareness**

As Rb is rare, most healthcare professionals will not encounter a case of it during their career. This means that when they are presented with the symptoms, which are often very subtle, many GPs and health visitors do not recognise it.

# **Pathways to Diagnosis**

Since 2012 we have run our annual Pathways to Diagnosis survey. Data gathered is qualitative, based on discussions we have with families following a diagnosis of Rb. We have now collected 243 Pathways, which gives us a good insight into what happens during this difficult time for families.

In total, 40 children were diagnosed in 2018. Information was collected from 28 children and a further four were diagnosed as a result of genetic screening. It was not possible to collect information for the remaining eight children.

During 2018, referrals were spread across three main healthcare professionals (GP's, Opticians and health visitors), with many more GPs (52% up from 36%) and opticians (58% up from 27%) referring appropriately.

Sadly, this did not impact similarly on the overall referral figures. Just 39% of children were referred urgently (within two weeks) to a specialist centre, down from 57% in 2017. As in 2017, 11% of children waited over six months to be diagnosed at an Rb centre. As far as we can see there was no specific reason for the drop in urgent referrals beyond annual fluctuation. When considering the 2012-18 figures, 2018 is in line with previous years 2015 and 2016. Years with smaller numbers of pathways such as this are more likely to show annual fluctuations.

This year we looked at a new measure: Number of healthcare professionals seen before referral to local ophthalmology department. In 2018, 36% of families saw one healthcare professional, 29% saw two; 29% saw three, and 4% saw four. In every year since Pathways to Diagnosis began, the largest number of families saw just one healthcare professional prior to referral to their local ophthalmology department. Looking at this figure gives us added granularity on families' experiences. Clearly the goal, in addition to a quick referral process, is to reduce the number of health care professionals involved.

54% of families consulted their GP in the first instance, the second lowest figures since Pathways to Diagnosis began. However 29% went to their optician first - the largest number for this previously was 16% in 2016, which underlines the importance of the Opticians Protocol, particularly as 25% of these families were turned away from their opticians without an appointment because of the child's age. 11% went to their health visitor initially, and 4% to A&E.

White eye continues to be the most common symptom reported by parents, but the data has also highlighted the importance of squint as a symptom. Between 2012 and 2018 one third of children diagnosed with Rb had a squint.

In response to families with young children being turned away from their local opticians, during World Retinoblastoma Awareness Week 2018 we relaunched a simplified version of the Opticians Protocol - aimed squarely at front of house staff. Named the Optical Assistants Protocol it highlights how rare it is for parents of young children to seek an opticians appointment, and encourages receptionists to ask why parents want their child's eyes checked. If the parent mentions any of the key symptoms of Rb, the protocol then tells the support staff what action to take.

Trustees' Report for the Year Ended 31 March 2019

Our press release asked optometrists to support Rb Week by taking five minutes to spend with their practice staff going through the protocol. The release was picked up by Optician Magazine and Optometry Today Online. It was also given strong support on Twitter by Birmingham Optical, Essilor, Rawlings Opticians as well as the AOP (Association of Optometrists), Optometry Scotland and Fight for Sight.

During 2018-19 we continued to explore social media as a means for reaching GPs and health visitors. To mark Rare Disease Day 2019 we ran a week-long Facebook campaign targeted at driving GPs to the dedicated GP page on the CHECT website. This resulted in 1,313 unique visits to the page.

In National Eye Health Week we experimented for the first time with creating online quizzes (using Survey Monkey) covering signs and symptoms, incidence and referral. 73 GPs and 181 health visitors took part, with an average score of 70% for GPs and 56% for health visitors.

## **Public Awareness**

It's often mums, dads or other family members who will first spot the signs of Rb - whether that's a white eye seen in a family photo, a squint or another symptom - so public awareness is an important area of our work to help ensure a swift diagnosis. We use traditional and digital media to reach parents and other members of the public and raise awareness of Rb.

#### Media

Previous research carried out by, or on behalf of, CHECT has shown that many people first hear about Rb after reading an article about it, so traditional media coverage continues to play an important part in our communications strategy. During the 2018/19 year we received 583 mentions in the media, including 17 national pieces, reaching a potential audience of over 32.5 million people across online, printed and televised press.

The largest amount of media activity centred on the story of identical twins Aurelia and Indiana in March 2019 for Rare Disease Day. Indiana was diagnosed with Rb after her mum spotted a 'marble-like glow' in her eye. It was covered by 300 media outlets with a reach of 14 million people, including being featured on ITV London news and in the Independent's 'I Newspaper'.

#### Digital

We had 126,380 visits to our website in the 2018/19 year, an increase of 25% on last year. We continue to monitor and adapt the CHECT website to ensure that it's easy to navigate and contains relevant and useful information to visitors.

Our article about 'what to do if you see a white glow in a photograph' remains our most frequently visited page each month and is the most popular landing page.

#### **Social Media**

Our social media presence continues to grow, 6,166 Facebook likes - a 10% increase on the previous year - and 2,940 Twitter followers. Our Tweets reached 392,800 people.

# World Retinoblastoma Awareness Week 2018

To mark Retinoblastoma Awareness Week in May 2018, we shared a press release about a baby girl whose grandmother spotted a white glow in a photograph. This was picked up by the Sun Online, regional press and reached an audience of around a million. Combined with several regional articles centred around CHECT Champions, May 2018 saw a total reach of almost four million people.

#### World Sight Day 2018

Pro-bono agency Wunderman created the campaign of 'Dot the Uninvisible Friend', based on the real-life story of three-year-old Alice who was diagnosed with Rb. The campaign website showed an interactive story of how Alice was living with a tumour (Dot) which was obscuring her vision. Being so young, children aren't able to communicate or realise that something is wrong - therefore it is the parents' role to look for the signs. In this case, Alice's 'Dot' was discovered by her mum taking a flash photo.

Vision Express also took part in the campaign by featuring 'Dot' stickers on the glasses in their Oxford Street store as well as taking part in a photoshoot and displaying the campaign on their in-store digital screens.

Trustees' Report for the Year Ended 31 March 2019

The campaign was advertised in the Metro and on 336 digital screens across London and a large Dot blimp was erected in Spitalfields Market in London. Wunderman estimated that around 1.64 million social media impressions were generated over this time and that brand awareness of CHECT increased by 6% amongst the population and 11% specifically amongst parents. Awareness of the main Rb symptoms were believed to have increased by 11% amongst the general population.

#### **BBC Lifeline**

We were thrilled to be awarded a Lifeline Appeal from the BBC which was broadcast on BBC1 on 24th March and on BBC2 on 27th March. Lifeline is a monthly nine minute film produced by the BBC to highlight the work of a charity and to appeal for donations to support its activities.

Our Appeal gave an emotional insight into the journeys of some of the families in the UK who have been affected by Rb, the work that we do and why supporting this work is incredibly important. We'd like to say a huge thank you to the BBC, to presenter Shane Richie, to the very special families and individuals who took part and to everyone who watched and donated.

As well as the fundraising benefits, the BBC estimate that Lifeline reaches approximately 1 million viewers, further raising awareness of retinoblastoma, its signs and symptoms and the work of the charity.

#### RESEARCH

In July 2018 CHECT awarded £55,000 to Professor Ohnuma at University College London for his 18-month project, **Next generation sequencing analysis of retinoblastoma samples**.

Despite knowing the RB1 mutation, it is difficult to predict the outcome of treatment. This project proposes to study the genetic changes that occur in retinoblastoma, using whole genome sequencing (the process of determining the complete DNA sequence) to detect those variants associated with good and bad prognosis or with a favourable treatment outcome.

This new level of diagnosis could potentially make a significant contribution to the selection of treatment, and avoid the loss of one or both eyes. Also, identification of new cancer modifying genes may provide new targets for treatment. Furthermore, this study aims to establish a new system to diagnose Rb in the clinical setting, which includes detailed examination of patient genome sequencing/analysis.

This year saw the completion of two of our grant funded projects:

# Dr Deanna Gibbs, The Royal London Hospital: Understanding and overcoming barriers to living with an artificial eye.

This study sought to understand the experiences of children and their families following enucleation in order to help develop some clear best practice guidelines regarding the clinical management of this population, as well as promoting innovation in the development of clinical resources to support adaptation to living with an artificial eye. The research team explored the support services and strategies used by children and their families in order to address the physical, mental and emotional barriers encountered.

# Dr Helen Jenkinson in conjunction with Public Health England: Development of a disease-specific register for retinoblastoma.

This project was part-funded by CHECT and represents an exciting opportunity to develop a comprehensive, disease-specific register that will capture data on the diagnosis and management of patients with Rb. Going forward patients and clinicians will be able to access an unprecedented level of information about the individual's Rb journey; enabling them to make informed life choices and ultimately preserve more eyes and sight of future generations. At the time of writing the register is planned to go live in September 2019 as part of the National Cancer Registration and Analysis Service, and it is hoped will provide a template for the development of future disease-specific registers, in particular for rare conditions.

Trustees' Report for the Year Ended 31 March 2019

Two more projects were awarded extensions in order to fully complete their investigations:

# Dr Seigel at the University of Buffalo: Targeted antibody-drug conjugates for retinoblastoma (one-year project)

The overall goal of this project is to improve upon current therapy for Rb by targeting toxic molecules (ADCs) directly to the Rb tumour. The ADCs are designed to kill Rb tumour cells, but spare surrounding normal cells. In turn, this will result in a more efficient eradication of the Rb tumour with fewer side effects for the patient. Whilst it seemed the concept was working in vitro, it was agreed a nine-month no cost extension would be granted in order to now see the in vivo arm of the study.

# Dr Carmel McConville, University of Birmingham: Investigation of the mutational landscape of retinoblastoma

This project was originally joint funded by CHECT and Fight for Sight as part of the Small Grants award scheme, with additional funding from CHECT. In October 2018 CHECT awarded a further £6,500.

The original aim of this project was to use the latest technology, known as 'next-generation sequencing' of retinoblastoma cell lines to identify the genes which are most frequently mutated and to survey how the overall cellular genetic activity is influenced by these mutated genes.

Results obtained from this in vitro work to date have provided strong evidence for a significant role for the BCOR gene in normal retinal development and have indicated that its loss of function is likely to be a key factor driving the formation of tumours. This extension will consolidate these findings in an additional 20 cell lines and confirm their functional relevance in vivo.

CHECT continues to support a further three ongoing projects, a summary of which follows:

## Laboratory / Basic science

Dr Sandy Hung, Centre for Eye Research Australia, Melbourne, Australia: Modelling retinoblastoma using human induced pluripotent stem cells (iPSC).

This team is working on developing a novel cell model for studying Rb, based on the technique of generating pluripotent stem cells from the skin cells of patients with Rb. If successful, this new model could be a valuable tool for researchers in the future. The project is now complete and we await the final report.

#### Clinical

Dr Derek Roebuck, Great Ormond Street Hospital, London: Autonomic reflexes and cardio-respiratory instability during super-selective intra-arterial chemotherapy in the management of children with retinoblastoma.

Following some initial delays, five patients have now been recruited (with a further 18 expected by December 2020), to this important project to investigate changes in the cardiovascular system during intra-arterial chemotherapy.

Dr Zerrin Onadim, Barts Health NHS Trust, Eloise Patterson Project: Study of records held at the Royal London Hospital and Childhood Cancer Research Group on retinoblastoma patients.

This project was funded by CHECT via a donation from the Greendale Foundation, inspired by Eloise Patterson. Following delays gaining relevant permissions to access all the data required, the team are poised to begin the analysis phase.

Trustees' Report for the Year Ended 31 March 2019

## **FUNDRAISING**

## **Fundraising Policy**

CHECT does not use fundraising services, consultants or external professional fundraisers to undertake its fundraising activities. Additionally, no data is shared with or sold to any external agencies. The charity does not purchase external lists of potential individual donors or undertake Direct Mail appeals to such lists. The charity issues a biannual newsletter and a monthly e-newsletter / blog (both of which can be easily unsubscribed from) that share information about the charitable work and fundraising activities undertaken.

The charity occasionally invites individuals to attend events but does not excerpt undue pressure to attend or to donate. It does not approach or pressure vulnerable people to support its work. A complaints policy is in place and is accessible on the charity's web site (www.chect.org.uk). The charity adheres to the Fundraising Code of Practice issued by the Fundraising Regulator.

Any fundraising events carried out on behalf of the charity that we are aware of are supported and monitored by the Fundraising Manager. Any marketing materials and approaches are checked that they comply with the Fundraising Code of Practice and details of income and expenditure are recorded by the Fundraising Manager. Income is acknowledged and grateful thanks are sent, typically with a letter and certificate.

# **Fundraising Activities**

## **Community Activities and Events**

We are always overwhelmed by the passion and dedication of our supporters, who go to such lengths to raise vital awareness and funds for us. Here are just some of the many highlights of the year:

- Dean Ascheri held his ninth annual Golf Day in June, raising £3,544. Dean and Kellie's son Luca was diagnosed with Rb in 2004 and the family have supported CHECT ever since
- The family and friends of Amber Branch, who was diagnosed in March 2018, have been fantastic fundraisers and awareness raisers for CHECT. Among many others two of her cousins held fundraising events one raised £1,300 from a 40 mile cycle and another raised £2,521 from a triathlon
- A group of mums were so inspired when they heard a member of our Teen Council speak at his school that eight of them climbed Ben Nevis for CHECT in September, raising £4,590
- Bristol Reservoirs Fly Fishers Association, who have supported us for some years, kindly sent a donation of £1,000. Volunteers prepare and sell fish that has been caught and is unwanted, and they periodically forward the funds raised
- Long standing supporter Mick Crowley held his sixth annual Tedfest (evening in celebration of all things Father Ted) in Clapham on 2 March. This year his employer also donated £1,000, bringing the event's fundraising total to £2,635. Mick had Rb as a child and over the years has raised just under £20,000 for CHECT
- Ed Fielder, whose son Matthew was diagnosed just before his third birthday in April 2018, enlisted the support of friends and family to raise funds for CHECT: Ed undertook a Dry June; two of his friends did a sponsored head shave; the nursery Matthew attends joined in with one employee undertaking a Pretty Mudder; while another friend joined the Prudential RideLondon. Together they raised over £5,000
- Rhys and Hayleigh Dyke, continued their annual fundraising with a White Collar Boxing Match in July, raising £3,128.

As always, our amazing supporters pushed themselves to the limit in aid of CHECT. Our nine runners in the London Marathon 2019 raised £34,076.36, and RunThrough Regent's Park in July 2018 saw a team of 19 CHECT runners raise a total of £8,217.46 running 5K or 10K on a blisteringly hot day. The Great North Run in September 2018 raised £10,785.73 and 12 cyclists raised £20,675 in the CHECT London to Paris cycle in September 2018.

# **Charity of the Year Partnerships**

A huge thank you to all of the groups and organisations who chose us to be their charity of the year in 2018 or 2019. Trinity United Reformed Church raised a magnificent total of £5,360. We are very grateful to Ethan Burn, who nominated us at Carshalton All Saints School, and led the activities throughout the year, raising a wonderful £1,588.58.

Trustees' Report for the Year Ended 31 March 2019

## **Individual Giving**

We are extremely grateful to all those who support us with a regular gift through a monthly pledge or through Give as you Earn, as well as to those who so generously make a one-off donation to our charity.

## **Corporate Support**

## **Vision Express**

CHECT has been a proud partner of Vision Express since 2010, and the company has played an invaluable role in helping us to raise awareness of Rb, as well as generating significant funds to support our work. Vision Express was also the first optician in the UK to roll out a protocol to ensure a quick and effective referral if Rb is suspected.

We are incredibly grateful to Vision Express staff and customers who raised over £25,000 during the year. In addition, the fourth Ride4Sight challenge celebrated the 30th anniversary year of Vision Express, raising some £32,750 for CHECT. The 30 strong team cycled 300km through the extremely demanding Peak District, starting and finishing at Vision Express Head Office in Ruddington.

When Vision Express opens a new or refurbished store, it has an official ceremony and invites a CHECT ambassador to be guest of honour. 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 2018/19 year, our ambassadors attended 30 store events across the country.

We remain indebted to the wonderful help, support and commitment of all the staff at Vision Express and we look forward to working closely with them over the coming months and years.

#### **Birmingham Optical**

November 2018 saw the end of the second year of our Charity of the Year partnership with Birmingham Optical. Yet again they held an imaginative variety of office events, took part in the Tough Mudder, volunteered at the Barber Show, and Chief Executive Arran Fewkes put in an impressive time at the hottest London Marathon ever. We are now into the third year of our partnership and are looking forward to continuing this valued relationship.

# Sackers and Partners LLP

We are grateful to law firm Sackers and Partners LLP, who generously make their fantastic meeting spaces available to us. As we have no meeting space of our own, this has been an invaluable asset many times over the year.

#### Wunderman

Our thanks to the staff at digital agency Wunderman, many of whom are signed up to regular giving with CHECT. And a special thanks to the 18 strong team, who ran around Alexandra Park in cold December, dressed as Santa, boosting funds already raised from some delicious bake sales.

# Essilor

We are grateful to have been chosen by Essilor as its Charity of the Year, and to have benefitted from the fundraising activities undertaken by the staff team in 2018. We very much look forward to working with the team during 2019 and beyond.

#### **PayCheck**

We were pleased to learn that staff at PayCheck have chosen to partner with Childhood Eye Cancer Trust, to benefit from company donations and staff fundraisers.

Trustees' Report for the Year Ended 31 March 2019

#### **Trusts and Foundations**

#### Income

Income from charitable trusts and foundations in 2018-19 totalled £185,597, the largest sum raised by CHECT in this area of fundraising.

Trusts and foundations fundraising is still relatively new to the charity, and over the past year we have worked hard to continue to strengthen our relationships with existing supporters whilst forging new charitable connections with many other trusts.

# Global's Make Some Noise

We are delighted to have had the wonderful and extremely generous support of Global's 'Make Some Noise'. This is the official charity of the media and entertainment group which owns many of the UK's top radio stations including: Heart, Capital, LBC, Classic FM and Smooth.

The charity pledged £93,000 towards our support work, of which £47,405 was received during 2018/19. The remainder will be received in the coming year. We are delighted to have such a strong relationship with Global's Make Some Noise and to be benefiting from such a generous grant.

## Other grants

Over the past 12 months, we have been fortunate enough to receive a significant grant from the Worshipful Company of Spectacle Makers and generous multi-year funding from the Clive & Sylvia Richards Charity. We are extremely grateful to both organisations for supporting CHECT's work for the first time.

In addition we express our gratitude to the Sobell Foundation, the Barbara Ward Children's Foundation, the February Foundation, the St James's Place Foundation and the Hobson Charity for their much appreciated ongoing support.

We send our most grateful thanks to all of the trusts and foundations that have supported CHECT over the past year.

#### In Memoriam

Trustees and staff would like to thank and offer sincere condolences to families and friends who have given in memory of a loved one during the year, and to those who have kindly remembered us in their will.

We also remember Gemma Edgar who sadly passed away in December. Gemma ran the London Marathon for us in 2018 whilst being treated with chemotherapy for an incurable brain tumour. The Marathon was on her 'bucket list' and we are extremely grateful that she was able to run this in support of her son Noah who was diagnosed with Rb.

Trustees' Report for the Year Ended 31 March 2019

# **FINANCIAL REVIEW**

# Investment policy and objectives

Funds surplus to immediate requirements are to be invested in interest bearing accounts without risk to the capital. Such accounts are to be those offered by institutions covered by the Financial Services Compensation Scheme (FSCS). No more than the amount covered by the FSCS is to be invested in any one institution. In light of very low interest rates in such accounts, the board decided to make one investment of £25,000 in the relatively low risk Smith and Williamson Charity Value and Income Fund.

#### **Reserves Policy**

CHECT maintains its reserves under two categories: (a) unrestricted (general) reserves, which are available for general use in pursuance of the charity's objectives, and (b) restricted reserves, which are for specifically earmarked purposes such as medical research or support to families belonging to a particular area. The unrestricted funds of the Charity as at 31 March 2019 totalled £332,631. The Trustees have determined that the Charity should hold at least six months of running expenses in reserve. This figure represents the amount required to run the charity for six months excluding winding up costs and any special projects. Based on this calculation, the required value of reserves for the year 2019-20 is £249,855. The reserves held as on 31 March 2019 represent 8 months of budgeted expenditure reducing to 6 months at the end of the coming financial year.

The Trustees review the Charity's reserves policy on a regular basis and no less than annually. The reserves position is reported at every board meeting.

## **Financial Performance**

The total incoming resources of the Charity were £529,688, which was an increase of £68,906 on 2017-18's total income of £460,782. It was encouraging to see income growth from community and other events ahead of our expectations thanks to the wonderful efforts of our members and supporters.

Total resources expended during the year increased slightly less than planned at £488,749 (2017-18: £448,452), which included a medical research grant award of £55,000.

Overall the Charity has recorded a surplus for the 2018-19 year of £40,055 compared to a surplus of £12,330 in 2017-18. As at 31 March 2019, this has resulted in net assets increasing from £294,596 (2017-18) to £334,651 in 2018-19. This comprises of restricted funds of £2,020 (2017-18: £1,003) and unrestricted funds of £332,631 (2017-18: £293,593).

## **FUTURE PLANS**

#### 2018-2021 Strategy

We are very excited to continue delivering our 2018-2021 strategy. While our core objectives of support, research and awareness remain the same, we have a number of exciting new plans that will help us to achieve them. We continue our aim to increase our income over the next three years by 10-15% to enable us to fund this.

Our plans include:

# Support

We will increase the value of our support grants to provide a more significant level of financial support to individual families.

We will continue to grow our engagement with teenagers and young people, working together with the Teen Focus Council to achieve this.

We aim to continue to grow our collaboration with the Ellen McArthur Cancer Trust, allowing more children and young people to experience sailing trips that can increase confidence and resilience.

Trustees' Report for the Year Ended 31 March 2019

#### Research

Research continues to be a vital focus for us and our members. We look forward to commissioning more research in the coming financial year and to seeking new funding sources to support this.

We are also looking forward to continue working with the eye research charity Fight for Sight not least as participants in their collaborative grants programme.

## **Awareness**

In 2019, and as part of our digital strategy, we plan to begin to make part of our information available via video, starting with late effects care for adults who have had Rb as a child.

We would also like to introduce more visually engaging video content in our social media posts, thereby increasing engagement across all platforms for all audiences including Instagram, which is still a relatively new channel for CHECT.

#### Influence

In addition to our core focus on support, research and awareness we will continue to liaise with the different organisations involved in a child and family's journey to make sure the voice of our membership is heard and helps influence all, to deliver the best and most effective experience to all families.

#### 2019 Activities

Here are some of the exciting activities we have planned in 2019:

# Revisiting our awareness survey

We have run our awareness survey in 2014, 2016, 2017, 2018 and 2019 with the wonderful pro-bono support of MMR Research Group. Whilst it is helpful to have a continuous set of questions and statistics to compare results, after 5 years, we plan to revaluate our survey and review any changes to the questions we should be asking to even better inform our activities.

# **New Research Projects**

We are planning a call for new research projects during May 2019 and subject to the appropriate quality of applications, we aim to make an award in the autumn. Subject to available funding we hope to make a further research award, possibly a 3 year PhD, towards the end of 2019. We are also looking forward to continue working with the eye research charity Fight for Sight.

**Pedal4Cancer** For the first time, CHECT supporters will be joining this event, in September 2019. Our team will cycle 65 miles / 100 kilometres from the iconic Lee Valley VeloPark, home to the London Olympic cycling events, to Cambridge. The event is not timed and is not a race - it's about having a great time, enjoying the challenge, and raising funds. With a minimum age of 14, it is perfect for our teenage supporters to get involved, too.

#### **Crazy Glasses**

Building on the success of last year, we will again be inviting our supporters, old and new, to hold a Crazy Glasses Day. They are encouraged to hold a Crazy Glasses Day at school, in the workplace, or at home using our dedicated fundraising pack, and share images of their activities on social media using the hashtag #CrazyGlasses.

#### **Corporate Support**

We aim to increase corporate support by specifically approaching companies to adopt CHECT as their Charity of the Year, offering support, fundraising and awareness raising ideas, and an increased portfolio of events to join.

# Members' days

We have four family member's days planned throughout the year and a Beyond Rb event for adults in May in Bristol. We will also have our CHECT Champions Awards ceremonies at some of these events, to recognise the bravery shown by children affected by Rb.

Trustees' Report for the Year Ended 31 March 2019

#### **Teenagers**

We will continue our work with teenagers via the Teenage Focus Council and hope to have a specific event for teenagers during the coming year.

#### Influence and awareness

In World Retinoblastoma Awareness Week 2019 we plan to host a Parliamentary Drop In event for MPs, asking them to pledge their support in raising awareness of retinoblastoma with parents and healthcare professionals in their constituencies.

## STRUCTURE, GOVERNANCE AND MANAGEMENT

## **Governing document**

The Childhood Eye Cancer Trust (CHECT) ('the Charity') is a charitable company limited by guarantee ('the Company'), incorporated on 1 July 1987 and a registered charity.

The Company was established under a Memorandum of Association, which established the objects and powers of the Company and is governed under its Articles of Association. The directors of the Company are also charity trustees for the purposes of charity law and are known as the board of trustees ('the Board'). Under the Company's Articles, the members of the Board are elected to serve for a maximum term of three years. In September 2008, the Articles were amended such that trustees may offer themselves for re-election for one further term (in total 6 years) and thereafter, under special circumstances, a third term at the discretion of the Board. The maximum number of trustees is 15.

## Organisational structure

The Board meets six times a year and at the beginning of each meeting, the trustees are requested to declare any conflicts of interest. No conflicts of interest were declared during this financial year. The Board's performance and trustee's skills are reviewed periodically and where possible new trustees are recruited to meet any needs or gaps identified. The Charity is a signatory to the NCVO's Good Governance Code for the voluntary and community sector.

To assist in the effectiveness and smooth running of the Charity the Board continues to resource two sub-committees to help oversee certain aspects of the Charity's work. Sub-committees are currently set up for: finance and risk (Finance and Risk Committee) and for research (Scientific Advisory Committee).

The day to day management of the Charity is delegated to the CEO, supported by the staff team. At the close of the year, staffing consisted of 9 staff (7.8 full time equivalent): a full time chief executive; two full time fundraisers; two support & information workers - one in London (full time) and one in Birmingham (3 days per week); an information & research manager (3 days per week); a full time office & finance manager, a part time communications manager (3 days per week) and a full time administrative assistant.

The Childhood Eye Cancer Trust is not affiliated with any other charitable organisation and has no related parties except as shown in the notes to the accounts. The Charity is a member of the Association of Medical Research Charities, the National Institute of Health Research and other charities with similar aims to CHECT working within the field of eye health, childhood cancers, genetic disorders and rare diseases.

#### Induction and training of new trustees

The Trust has continued to develop its skills and experience mix with one trustee joining (Gemma Boggs). We continue to seek representation from a GP.

New trustees are provided with information about their role and responsibilities as recommended by the Charity Commission and the National Council for Voluntary Organisations (NCVO). This includes: the trustee role description and person specification relevant to the role, the Charity's confidentiality policy and the eligibility requirements for becoming a trustee. They are also supplied with a copy of the Memorandum and Articles of Association, the strategic development plan and the chief executive's report and minutes from three previous board meetings.

Trustees' Report for the Year Ended 31 March 2019

Trustee roles are advertised on the CHECT web site and on occasion, using external recruitment organisations. Enquiries are also occasionally received from members. A selection panel made up of the CEO, the Chair and another trustee or a member of the charity considers the application and the suitability of the applicant using agreed criteria identified on the person specification and the role description. The prospective trustee is then invited to observe a board meeting prior to appointment and standing for election.

Induction meetings covering the background to current matters take place with the chief executive and key members of the staff team. Training on matters relevant to the role and responsibilities of trustees is encouraged and the Board subscribes to literature pertinent to good governance. All trustees are required to sign: a contract setting out their responsibilities; a confidentiality agreement; the conflict of interest policy; and confirmation of their eligibility to serve as a director. They are also asked to undergo Disclosure and Barring Service (DBS) checks. The majority of trustees have personal experience of retinoblastoma and its impact but individuals with other key skills are also recruited to the Board to ensure an appropriate balance to meet the needs of the Charity.

# Risk management

The trustees regularly assess the risks to the Charity and maintain a comprehensive risk register which includes plans to mitigate or manage the risks identified. In past years, a significant proportion of the Charity's income came from one corporate relationship which was highlighted as a risk and the trustees have worked to mitigate this risk by:

- continued diversification of income streams
- a particular focus to increase trusts and foundations income
- maintenance of close and productive relationships with key corporate partners
- tight cost management
- setting income targets at a slight premium to operational budgets
- awarding additional research grants only when incremental funds allow
- regular income and expenditure reviews.

The risk register is reviewed by the Finance and Risk Committee and then the Board on an annual basis and six-monthly by the chief executive. More frequent reviews are carried out if necessary in response to changes or events. The trustees are satisfied that there are systems and arrangements in place to manage the risks identified as far as possible.

Trustees' Report for the Year Ended 31 March 2019

## STATEMENT OF TRUSTEES RESPONSIBILITIES

The trustees (who are also the directors of Childhood Eye Cancer Trust for the purposes of company law) are responsible for preparing the Trustees' Report and the financial statements in accordance with applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 "The Financial Reporting Standard applicable in the UK and Republic of Ireland".

Company law requires the trustees to prepare financial statements for each financial year which give a true and fair view of the state of affairs of the charitable company and of the incoming resources and application of resources, including the income and expenditure, of the charitable company for that period. In preparing those financial statements, the trustees are required to

- select suitable accounting policies and then apply them consistently;
- observe the methods and principles in the Charity SORP;
- make judgements and estimates that are reasonable and prudent;
- prepare the financial statements on the going concern basis unless it is inappropriate to presume that the charitable company will continue in business.

The trustees are responsible for keeping proper accounting records which disclose with reasonable accuracy at any time the financial position of the charitable company and to enable them to ensure that the financial statements comply with the Companies Act 2006. They are also responsible for safeguarding the assets of the charitable company and hence for taking reasonable steps for the prevention and detection of fraud and other irregularities.

In so far as the trustees are aware:

- there is no relevant audit information of which the charitable company's auditors are unaware; and
- the trustees have taken all steps that they ought to have taken to make themselves aware of any relevant audit information and to establish that the auditors are aware of that information.

# **AUDITORS**

On 31 March 2019, Knox Cropper, the Charity's auditors, transferred its business to Knox Cropper LLP, a limited liability partnership incorporated under the Limited Liability Partnerships Act 2000. The Trustees have consented to treating the appointment of Knox Cropper as extending to Knox Cropper LLP.

The auditors, Knox Cropper LLP, will be proposed for re-appointment at a forthcoming Board Meeting.

This report has been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to small companies.

Approved by order of the board of trustees on 3 August 2019 and signed on its behalf by:

Ian Ellington - Chair of Trustees

#### Opinion

We have audited the financial statements of Childhood Eye Cancer Trust (the 'charitable company') for the year ended 31 March 2019 which comprise the Statement of Financial Activities, the Balance Sheet, the Cash Flow Statement and notes to the financial statements, including a summary of significant accounting policies. The financial reporting framework that has been applied in their preparation is applicable law and United Kingdom Accounting Standards (United Kingdom Generally Accepted Accounting Practice), including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland'.

In our opinion the financial statements:

- give a true and fair view of the state of the charitable company's affairs as at 31 March 2019 and of its incoming resources and application of resources, including its income and expenditure, for the year then ended:
- have been properly prepared in accordance with United Kingdom Generally Accepted Accounting Practice, including Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and the Republic of Ireland'; and
- have been prepared in accordance with the requirements of the Companies Act 2006.

## Basis for opinion

We conducted our audit in accordance with International Standards on Auditing (UK) (ISAs (UK)) and applicable law. Our responsibilities under those standards are further described in the Auditors responsibilities for the audit of the financial statements section of our report. We are independent of the charitable company in accordance with the ethical requirements that are relevant to our audit of the financial statements in the UK, including the FRC's Ethical Standard, and we have fulfilled our other ethical responsibilities in accordance with these requirements. We believe that the audit evidence we have obtained is sufficient and appropriate to provide a basis for our opinion.

## Conclusions relating to going concern

We have nothing to report in respect of the following matters in relation to which the ISAs (UK) require us to report to you where:

- the trustees' use of the going concern basis of accounting in the preparation of the financial statements is not appropriate; or
- the trustees have not disclosed in the financial statements any identified material uncertainties that may cast significant doubt about the charitable company's ability to continue to adopt the going concern basis of accounting for a period of at least twelve months from the date when the financial statements are authorised for issue.

#### Other information

The trustees are responsible for the other information. The other information comprises the information included in the annual report, other than the financial statements and our Report of the Independent Auditors thereon.

Our opinion on the financial statements does not cover the other information and, except to the extent otherwise explicitly stated in our report, we do not express any form of assurance conclusion thereon.

In connection with our audit of the financial statements, our responsibility is to read the other information and, in doing so, consider whether the other information is materially inconsistent with the financial statements or our knowledge obtained in the audit or otherwise appears to be materially misstated. If we identify such material inconsistencies or apparent material misstatements, we are required to determine whether there is a material misstatement in the financial statements or a material misstatement of the other information. If, based on the work we have performed, we conclude that there is a material misstatement of this other information, we are required to report that fact. We have nothing to report in this regard.

# Opinions on other matters prescribed by the Companies Act 2006

In our opinion, based on the work undertaken in the course of the audit:

- the information given in the Trustees' Report for the financial year for which the financial statements are prepared is consistent with the financial statements; and
- the Trustees' Report has been prepared in accordance with applicable legal requirements.

# Matters on which we are required to report by exception

In the light of the knowledge and understanding of the charitable company and its environment obtained in the course of the audit, we have not identified material misstatements in the Trustees' Report.

# Matters on which we are required to report by exception

We have nothing to report in respect of the following matters where the Companies Act 2006 requires us to report to you if, in our opinion:

- adequate accounting records have not been kept or returns adequate for our audit have not been received from branches not visited by us; or
- the financial statements are not in agreement with the accounting records and returns; or
- certain disclosures of trustees' remuneration specified by law are not made; or
- we have not received all the information and explanations we require for our audit; or
- the trustees were not entitled to take advantage of the small companies exemption from the requirement to prepare a Strategic Report or in preparing the Trustees' Report.

#### Responsibilities of trustees

As explained more fully in the Statement of Trustees Responsibilities, the trustees (who are also the directors of the charitable company for the purposes of company law) are responsible for the preparation of the financial statements and for being satisfied that they give a true and fair view, and for such internal control as the trustees determine is necessary to enable the preparation of financial statements that are free from material misstatement, whether due to fraud or error.

In preparing the financial statements, the trustees are responsible for assessing the charitable company's ability to continue as a going concern, disclosing, as applicable, matters related to going concern and using the going concern basis of accounting unless the trustees either intend to liquidate the charitable company or to cease operations, or have no realistic alternative but to do so.

## Our responsibilities for the audit of the financial statements

Our objectives are to obtain reasonable assurance about whether the financial statements as a whole are free from material misstatement, whether due to fraud or error, and to issue a Report of the Independent Auditors that includes our opinion. Reasonable assurance is a high level of assurance, but is not a guarantee that an audit conducted in accordance with ISAs (UK) will always detect a material misstatement when it exists. Misstatements can arise from fraud or error and are considered material if, individually or in the aggregate, they could reasonably be expected to influence the economic decisions of users taken on the basis of these financial statements.

A further description of our responsibilities for the audit of the financial statements is located on the Financial Reporting Council's website at www.frc.org.uk/auditorsresponsibilities. This description forms part of our Report of the Independent Auditors.

# Use of our report

This report is made solely to the charitable company's members, as a body, in accordance with Chapter 3 of Part 16 of the Companies Act 2006. Our audit work has been undertaken so that we might state to the charitable company's members those matters we are required to state to them in an auditors' report and for no other purpose. To the fullest extent permitted by law, we do not accept or assume responsibility to anyone other than the charitable company and the charitable company's members as a body, for our audit work, for this report, or for the opinions we have formed.

Richard Billinghurst FCA (Senior Statutory Auditor) for and on behalf of Knox Cropper LLP

65 Leadenhall Street

London EC3A 2AD

Date: 11/09/2019

# Statement of Financial Activities (Incorporating an Income and Expenditure Account) for the Year Ended 31 March 2019

INCOME AND ENDOWMENTS FROM Donations and legacies	Notes 2	Unrestricted fund £	Restricted funds £	2019 Total funds £ 525,329	2018 Total funds £ 459,029
Other trading activities Investment income	3 4	1,150 3,209	<u>-</u>	1,150 3,209	1,753
Total		431,818	97,870	529,688	460,782
EXPENDITURE ON Raising funds Charitable activities Medical Research and Grant Making Awareness Raising Family Support and Information Influencing Total	5 6	119,340 72,908 127,389 51,314 20,945 391,896	3,000 2,000 91,853 ————————————————————————————————————	119,340 75,908 129,389 143,167 20,945 488,749	114,599 42,179 119,212 149,351 23,111 448,452
Net gains/(losses) on investments		(884)	-	(884)	-
NET INCOME		39,038	1,017	40,055	12,330
RECONCILIATION OF FUNDS					
Total funds brought forward		293,593	1,003	294,596	282,266
TOTAL FUNDS CARRIED FORWARD		332,631	2,020	334,651	294,596

# **CONTINUING OPERATIONS**

All income and expenditure has arisen from continuing activities.

The notes form part of these financial statements

# Balance Sheet At 31 March 2019

FIXED ASSETS	Notes	2019 £	2018 £
Tangible assets Investments	14 15	641 _ 24,116	6,141 
		24,757	6,141
CURRENT ASSETS Debtors	16	14,730	14,371
Cash at bank	10	402,888	317,838
		417,618	332,209
CURRENT LIABILITIES Creditors: Amounts falling of	due within one year 17	(107,724)	(43,754)
NET CURRENT ASSETS		309,894	288,455
TOTAL ASSETS LESS CU LIABILITIES	JRRENT	334,651	294,596
NET ASSETS		<u>334,651</u>	294,596
FUNDS Unrestricted funds Restricted funds	20	332,631 	293,593 
TOTAL FUNDS		334,651	294,596

These financial statements have been prepared in accordance with the special provisions of Part 15 of the Companies Act 2006 relating to charitable small companies.

The financial statements were approved by the Board of Trustees on 3 August 2019 and were signed on its behalf by:

Ian Ellington - Chair of Trustees

# Cash Flow Statement for the Year Ended 31 March 2019

	Notes	2019 £	2018 £
Cash flows from operating activities: Cash generated from operations Finance costs	22	108,075 <u>(365</u> )	(24,677) (418)
Net cash provided by (used in) operating activities		107,710	(25,095)
Cash flows from investing activities: Purchase of fixed asset investments Interest received		(25,000) 	- 1,753
Net cash provided by (used in) investing activities		<u>(22,660</u> )	1,753
			<del></del>
Change in cash and cash equivalents in th reporting period  Cash and cash equivalents at the beginning		85,050	(23,342)
of the reporting period	'9	317,838	341,180
Cash and cash equivalents at the end of the reporting period	ne	402,888	317,838

The notes form part of these financial statements

## 1. ACCOUNTING POLICIES

# Basis of preparing the financial statements

The financial statements of the charitable company, which is a public benefit entity under FRS 102, have been prepared in accordance with the Charities SORP (FRS 102) 'Accounting and Reporting by Charities: Statement of Recommended Practice applicable to charities preparing their accounts in accordance with the Financial Reporting Standard applicable in the UK and Republic of Ireland (FRS 102) (effective 1 January 2015)', Financial Reporting Standard 102 'The Financial Reporting Standard applicable in the UK and Republic of Ireland' and the Companies Act 2006. The financial statements have been prepared under the historical cost convention with the exception of investments which are included at market value, as modified by the revaluation of certain assets.

The presentational currency of the financial statements is Pound Sterling (£).

## **Going Concern**

The trustees consider that there are no material uncertainties about the Charity's ability to continue as a going concern.

# Critical accounting judgements and key sources of estimation uncertainty

The preparation of financial statements in accordance with generally accepted accounting practice requires management to make estimates and judgements that affect the reported amounts of assets and liabilities at the reporting date and the reported amounts of revenues and expenses during the reporting period. The following are the significant management judgements and estimates made in applying the accounting policies of the Charity that have a significant impact on the financial statements:

## Financial instrument classification

The classification of financial instruments, both assets and liabilities, as 'basic' or 'other' requires judgement as to whether all applicable conditions as basic are met. This includes the type of investment or loan and its return. The Charity only has financial assets and liabilities of a kind that qualify as basic financial instruments. These are initially recognised at transaction value and subsequently valued at their settlement value.

# Useful lives of property, plant and equipment (PPE)

Management reviews its estimate of the useful lives of depreciable assets at each reporting date. Depreciation is calculated based on the useful lives of each item.

#### Income

All income is recognised in the Statement of Financial Activities once the charity has entitlement to the funds, it is probable that the income will be received and the amount can be measured reliably.

#### **Expenditure**

Liabilities are recognised as expenditure as soon as there is a legal or constructive obligation committing the charity to that expenditure, it is probable that a transfer of economic benefits will be required in settlement and the amount of the obligation can be measured reliably. Expenditure is accounted for on an accruals basis and has been classified under headings that aggregate all cost related to the category. Where costs cannot be directly attributed to particular headings they have been allocated to activities on a basis consistent with the use of resources.

Grants offered subject to conditions which have not been met at the year end date are noted as a commitment but not accrued as expenditure.

# Raising funds

Raising funds includes all expenditure incurred by the charity to raise funds for its charitable purposes and includes costs of all fundraising activities, events and non-charitable trading.

#### 1. ACCOUNTING POLICIES - continued

## Charitable activities

Costs of charitable activities include all expenditure for providing support and information to families; for raising awareness amongst health professionals and the general public; grants awarded and other expenditure for medical research; and influencing costs to bring about improvements in the way services are delivered to all persons affected by retinoblastoma in the UK and overseas. Influencing activities include, but are not limited to, working with the Department of Health, NHS Commissioning Group - Childhood Cancer and Leukaemia Group, treatment centres in the UK and other charities and umbrella bodies.

## Allocation and apportionment of costs

Costs are allocated dependent on the activity categories of the resources expended. The support costs of overall direction and administration, comprising the salary and overhead costs of the central function are apportioned on an appropriate basis e.g. staff time as set out in the notes.

# Tangible fixed assets

Tangible fixed assets are included in the accounts at cost. The Charity's policy is to capitalise all fixed assets of a value greater than £500.

Depreciation is provided on all tangible fixed assets at rates calculated to write off the cost, less estimated residual value, of each asset evenly over its expected useful life, as follows:

Plant & machinery

25% straight line basis

Equipment, fixture and fittings

25% straight line basis

#### Taxation

The charity is exempt from corporation tax on its charitable activities.

# **Fund accounting**

Unrestricted funds can be used in accordance with the charitable objectives at the discretion of the trustees.

Restricted funds can only be used for particular restricted purposes within the objects of the charity. Restrictions arise when specified by the donor or when funds are raised for particular restricted purposes.

Further explanation of the nature and purpose of each fund is included in the notes to the financial statements.

#### Hire purchase and leasing commitments

Rentals paid under operating leases are charged to the Statement of Financial Activities on a straight line basis over the period of the lease.

# Pension costs and other post-retirement benefits

The Charity contributes to two workplace pension schemes for its employees. Contributions are charged to the Statement of Financial Activities in the period to which they relate.

# Cash and cash equivalents

Cash and Cash Equivalents in the Balance Sheet comprise cash at bank and in hand and short term deposits with an original maturity of three months or less.

## 1. ACCOUNTING POLICIES - continued

#### **Fixed Asset Investments**

The Charity's investments are a form of basic financial instrument and are initially recognised at their transaction value and subsequently measured at their fair value as at the Balance Sheet date using the bid price. The Statement of Financial Activities includes the net gains and losses arising on the revaluations and disposals throughout the year.

Unrealised gains and losses represent the difference between the market value of investments still held at the end of the financial year with their value at the beginning of the year or with their cost if purchased subsequently.

# 2. DONATIONS AND LEGACIES

	Unrestricted Funds £	Restricted Funds £	Total 2019 £	Total 2018 £
Legacies	5,100		5,100	
Donations:				
General donations	37,695	-	37,695	20,749
Standing orders	15,513	-	15,513	17,283
In memoriam	8,208	-	8,208	6,885
GAYE	3,015	-	3,015	2,421
Collecting tins	2,723	-	2,723	754
Community Donations	21,339		21,339	-
Other corporate donations	81,617	7,965	89,582	59,035
Grants from Trusts and Foundations	95,692	89,905	185,597	165,380
	265,802	97,870	363,672	272,507
Marathons, runs and other sponsorship:				
London Marathon	34,076	-	34,076	29,177
Great North Run	10,786	-	10,786	5,875
Other running events and walks	8,255	-	8,255	26,724
Other events	102,883	_	102,833	116,552
	156,000	<u>-</u>	156,000	178,328
General events:				
In House Events	557	-	557	7,899
Other events				295
	557	-	557	8,194
Total income from donations and	407 470	07.070	505.000	450.000
legacies	427,459	97,870	525,329	459,029

The Trustees would like to thank all the members and supporters who have contributed their time and effort to raising money for the Trust.

# Notes to the Financial Statements - continued for the Year Ended 31 March 2019

3.	OTHER TRADING ACTIVITIES		
	Christmas cards	2019 £ <u>1,150</u>	2018 £
4.	INVESTMENT INCOME		
	Dividend income Bank Interest	2019 £ 869 2,340 3,209	2018 £ 1,753 1,753
5.	RAISING FUNDS		
	Raising donations and legacies		
	Staff costs Fundraising costs Support costs	2019 £ 84,411 12,365 22,564 119,340	2018 £ 71,991 22,575 20,033 114,599

As a result of a review of the allocation of staff costs in the current and preceding year, staff costs allocated to raising funds in the preceding year have increased by £71,991 with a corresponding decrease in support costs allocated to raising funds.

# 6. CHARITABLE ACTIVITIES

	Direct costs (See note 7)	Grant funding of activities (See note 8)	Support costs (See note 9)	Totals
	£	£	£	£
Medical Research and Grant Making	373	59,041	16,494	75,908
Awareness Raising	47,119	-	82,270	129,389
Family Support and Information	74,774	6,170	62,223	143,167
Influencing			20,945	20,945
	122,266	<u>65,211</u>	181,932	369,409

Notes to the Financial Statements - continued for the Year Ended 31 March 2019

# 7. DIRECT COSTS OF CHARITABLE ACTIVITIES

	2019	2018
	£	£
Staff costs	100,844	102,555
Newsletter costs	4,342	3,893
Awareness Campaign	2,445	2,610
Other Direct Costs	13,892	30,860
Leaflets and printing	743	
	<u> 122,266</u>	139,918

As a result of a review of grants payable in the current and preceding year, family support grants in the preceding year of £4,073 have been reallocated from other direct costs to grants payable for Family Support and Information in note 8.

## 8. GRANTS PAYABLE

	2019 £	2018 £
Medical Research and Grant Making Family Support and Information	59,041 	22,300 5,330
	<u>65,211</u>	27,630

In the current year, the Trust awarded two grants for medical research of £55,000 and £6,500. Both of these grants are included within accruals as they have not yet been spent. A joint project with Fight for Sight was completed during the year and £2,314 of unspent funds was written back.

During the previous year, the Trust awarded a grant of £25,000 for medical research. Also, a project relating to a previous grant awarded came to an end and £2,700 of unspent funds was written back.

# 9. SUPPORT COSTS

	Governance		
	Other	costs	Totals
	£	£	£
Raising donations and legacies	21,756	808	22,564
Medical Research and Grant Making	16,369	125	16,494
Awareness Raising	81,648	622	82,270
Family Support and Information	61,361	862	62,223
Influencing	20,787	158	20,945
	201,921	2,575	204,496

Support costs are allocated to activities on the basis of staff time.

Support costs, included in the above, are as follows:

# 9. SUPPORT COSTS - continued

Premises rent Premises costs Insurance Repairs & Maintenance Communications and stationery Meetings, seminars and staff training Travel and subsistence Recruitment Accountancy fees Depreciation of tangible fixed assets Bank charges Auditors' remuneration Wages Social security Pensions		Raising donations and legacies £ 7,658 345 214 2,225 3,058 1,186 1,194 1,113 2,921 1,727 115 808	Medical Research and Grant Making £ 1,181 53 33 4471 183 184 172 450 266 18 125 11,571 1,124 320	Awareness Raising £ 5,890 265 165 1,711 2,352 912 919 856 2,246 1,328 88 622 57,716 5,605 1,595
Premises rent Premises costs Insurance Repairs & Maintenance Communications and stationery Meetings, seminars and staff training Travel and subsistence Recruitment Accountancy fees Depreciation of tangible fixed assets Bank charges Auditors' remuneration Wages Social security Pensions	Family Support and Information £ 8,165 368 229 2,372 3,260 1,265 1,274 1,187 3,113 1,841 122 862 33,933 3,295 937	Influencing £ 1,500 67 42 436 599 232 233 218 572 338 22 158 14,695 1,427 406 20,945	2019  Total activities £ 24,394 1,098 683 7,087 9,740 3,778 3,804 3,546 9,302 5,500 365 2,575 117,915 11,451 3,258	2018  Total activities £ 24,467 1,255 665 7,444 8,025 3,488 2,791 981 8,953 5,886 418 2,500 105,976 10,493 2,996  186,338

# Notes to the Financial Statements - continued for the Year Ended 31 March 2019

# 10. NET INCOME/(EXPENDITURE)

Net income/(expenditure) is stated after charging/(crediting):

	2019	2018
	£	£
Auditors' remuneration	2,575	2,500
Depreciation - owned assets	5,500	5,886
Other operating leases	24,394	24,467
Auditors' remuneration - non audit services	3,090	3,000

## 11. TRUSTEES' REMUNERATION AND BENEFITS

There were no trustees' remuneration or other benefits for the year ended 31 March 2019 nor for the year ended 31 March 2018.

#### Trustees' expenses

During the period travel expenses, amounting to £1,822 (2018: £651) were reimbursed to 6 of the Trustees (2018: 4 Trustees).

#### 12. STAFF COSTS

Wages and salaries Social security costs Other pension costs	2019 £ 285,381 26,089 6,409 317,879	2018 £ 264,011 24,384 5,616 294,011
The average monthly number of employees during the year was as follows:		
Average Number of Employees	2019 9	2018 
The number of employees whose employee benefits (excluding employer £60,000 was:	pension costs)	exceeded
£60,000 was. £60,001 - £70,000	2019 1	2018 1

The key management personnel of the Charity are those persons having authority and responsibility for planning, directing and controlling the activities of the Charity, directly or indirectly, including any trustee of the Charity. In addition to the trustees, key management personnel includes the Chief Executive. Total employee benefits, including employer pension contributions and employer social security costs for key management personnel in the period amounted to £77,944 (2018: £75,727).

#### **Pension costs**

Amounts are paid in to two defined contribution stakeholder pension schemes. The pension cost charge represents contributions payable by the Charity.

#### Volunteers

During the year just over 130 volunteers contributed a total of 982 hours in carrying out a variety of administrative and support tasks. If the work carried out by these volunteers had been undertaken by employees paid at the minimum wage, the cost to the Charity would have been approximately £7,500. The Trustees would like to recognise the vital contribution made by the volunteers to the smooth running of the Charity and thank them for their hard work.

# 13. COMPARATIVES FOR THE STATEMENT OF FINANCIAL ACTIVITIES

INCOME AND ENDOWMENTS FROM	Unrestricted fund £	Restricted funds £	Total funds £
Donations and legacies	361,734	97,295	459,029
Investment income	1,753	_	1,753
Total	363,487	97,295	460,782
EXPENDITURE ON			
Raising funds Charitable activities	114,599	-	114,599
Medical Research and Grant Making	16,709	25,470	42,179
Awareness Raising	116,712	2,500	119,212
Family Support and Information	79,376	69,975	149,351
Influencing	23,111		23,111
Total	350,507	97,945	448,452
		***	
NET INCOME	12,980	(650)	12,330
RECONCILIATION OF FUNDS			
Total funds brought forward	280,613	1,653	282,266
	-		
TOTAL FUNDS CARRIED FORWARD	293,593	1,003	294,596

14.	TANGIBLE FIXED ASSETS	Computer equipment £
	COST At 1 April 2018 Disposals	31,117 (2,907)
	At 31 March 2019	28,210
	DEPRECIATION At 1 April 2018 Charge for year Eliminated on disposal At 31 March 2019	24,976 5,500 (2,907) 27,569
	NET BOOK VALUE At 31 March 2019 At 31 March 2018	6,141
15.	FIXED ASSET INVESTMENTS	
		Listed investments £
	MARKET VALUE Additions Revaluations	25,000 (884)
	At 31 March 2019	24,116
	NET BOOK VALUE At 31 March 2019	24,116
	At 31 March 2018	

There were no investment assets outside the UK.

During the year, the Charity invested £25,000 in the Smith and Williamson Charity Value & Income Fund.

# Notes to the Financial Statements - continued for the Year Ended 31 March 2019

16.	DEBTORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		
	Trade debtors Other debtors Prepayments and accrued income	2019 £ 2,072 2,792 9,866	2018 £ 2,539 2,792 9,040
		14,730	14,371
17.	CREDITORS: AMOUNTS FALLING DUE WITHIN ONE YEAR		
	Trade creditors Pension creditor Deferred income Accruals	2019 £ 13,915 1,098 22,705 70,006	2018 £ 10,563 1,856 14,601 16,734
		107,724	43,754

Included within Accruals is £61,500 for research grants awarded (2018: £8,443).

Deferred income relates to donations received in respect of future events, all of which is released in the following financial year.

# 18. LEASING AGREEMENTS

Minimum lease payments under non-cancellable operating leases fall due as follows:

	2019	2018
	£	£
Within one year	<u>11,804</u>	11,242

In March 2018, a two year lease was signed for office space and this lease includes a 6 month notice period for either party to end the agreement.

19.	ANALYSIS OF NET ASSETS BETWEEN	FUNDS			
	Fixed assets Investments Current assets Current liabilities	Unrestricted fund £ 641 24,116 415,598 (107,724)	Restricted funds £ - 2,020	2019 Total funds £ 641 24,116 417,618 (107,724)	2018 Total funds £ 6,141 - 332,209 (43,754)
		332,631		334,651	294,596
20.	MOVEMENT IN FUNDS				
			At 1.4.18 £	Net movement in funds £	At 31.3.19 £
	Unrestricted funds General fund		293,593	39,038	332,631
	Restricted funds Family Support Kent Travel		603 400 1,003	1,217 (200) 1,017	1,820 200 2,020
	TOTAL FUNDS		294,596	40,055	334,651
Net movement in funds, included in the above are as follows:					
		Incoming resources £	Resources expended £	Gains and losses £	Movement in funds
	Unrestricted funds General fund	431,818	(391,896)	(884)	39,038
	Restricted funds Medical Research Awareness Family Support Kent Travel	3,000 2,000 92,870 ————————————————————————————————————	(3,000) (2,000) (91,653) (200) (96,853)	- - - -	1,217 (200) 1,017
	TOTAL FUNDS	529,688	<u>(488,749</u> )	(884)	40,055

**TOTAL FUNDS** 

# 20. MOVEMENT IN FUNDS - continued

Purposes of Restricted Funds  Medical Research  Available for research into various projects that promote the objects of the Charity.  Support  To provide support and information to families and individuals affected by retinoblastoma.  Kent Travel  A fund to provide eligible families living in Kent with one-off travel grants for financial assistance with travel to UK clinics.  Awareness  To raise awareness of retinoblastoma amongst health professionals and others.				
Comparatives for move	ment in funds			
			Net	
		At 1.4.17 £	movement in funds	At 31.3.18 £
Unrestricted Funds General fund		280,613	12,980	293,593
Restricted Funds				
Medical Research Family Support		450 803	(450) (200)	603
Kent Travel		400	(200)	400
		1,653	(650)	1,003
			(030)	
TOTAL FUNDS		282,266	12,330	294,596
Comparative net movement	ent in funds, included in the above	e are as follows:		
		Incoming	Resources	Movement in
		resources £	expended £	funds £
Unrestricted funds		L	L	L
General fund		363,487	(350,507)	12,980
Restricted funds				
Medical Research Awareness		25,020 2,500	(25,470) (2,500)	(450)
Family Support		69,775	(2,300) (69,975)	(200)
		97,295	(97,945)	(650)

460,782

(448,452)

12,330

Notes to the Financial Statements - continued for the Year Ended 31 March 2019

# 21. RELATED PARTY DISCLOSURES

There were no related party transactions for the year ended 31 March 2019.

# 22. RECONCILIATION OF NET INCOME TO NET CASH FLOW FROM OPERATING ACTIVITIES

	2019	2018
	£	£
Net income for the reporting period (as per the statement of		
financial activities)	40,055	12,330
Adjustments for:		
Depreciation charges	5,500	5,886
Losses on investments	884	-
Interest received	(2,340)	(1,753)
Finance costs	365	418
(Increase)/decrease in debtors	(359)	6,502
Increase/(decrease) in creditors	63,970	(48,060)
N. Const. and M. Harris and M. Const. and M.	400.075	(04.677)
Net cash provided by (used in) operating activities	<u> 108,075</u>	<u>(24,677</u> )

# **Detailed Statement of Financial Activities** for the Year Ended 31 March 2019

	2019 £	2018 £
INCOME AND ENDOWMENTS	_	_
Donations and legacies Donations Marathons, runs and other sponsorship General events Legacies Grants	178,073 156,002 557 5,100 185,597	107,127 178,623 7,899 165,380 459,029
Other trading activities		
Christmas cards	1,150	-
Investment income Dividend income Bank Interest	869 	1,753
	3,209	1,753
Total incoming resources	529,688	460,782
EXPENDITURE		
Raising donations and legacies Wages Social security Pensions Fundraising costs	75,050 7,288 2,073 12,365 96,776	63,862 6,323 1,806 22,575 94,566
Charitable activities Wages Social security Pensions Newsletter costs Awareness Campaign Other Direct Costs Leaflets and printing Grants awarded to institutions Travel bursaries awarded	92,416 7,350 1,078 4,342 2,445 13,892 743 59,041 6,170	94,173 7,568 814 3,893 2,610 30,860 - 22,300 5,330

This page does not form part of the statutory financial statements

# **Detailed Statement of Financial Activities** for the Year Ended 31 March 2019

	2019	2018
Support costs	£	£
Other		
Wages	117,915	105,976
Social security	11,451	10,493
Pensions	3,258	2,996
Premises rent	24,394	24,467
Premises costs	1,098	1,255
Insurance	683	665
Repairs & Maintenance	7,087	7,444
Communications and stationery	9,740	8,025
Meetings, seminars and staff training	3,778	3,488
Travel and subsistence	3,804	2,791
Recruitment	3,546	981
Accountancy fees	9,170	8,453
Bad Debt	-	500
Sundries	132	-
Depreciation of tangible fixed assets	5,500	5,886
Bank charges	365	418
	201,921	183,838
Governance costs		
Auditors' remuneration	2,575	2,500
Total resources expended	488,749	448,452
Net income before gains and losses	40,939	12,330
Realised recognised gains and losses		
Realised gains/(losses) on fixed asset investments	(884)	-
Net income	40,055	12,330

This page does not form part of the statutory financial statements

