Thank you to all our members, sponsors, supporters, patrons, partners, the Rb teams and the commissioning teams for their ongoing support and help in achieving our aims.

Tweet us @CHECTUK or find us on Facebook

To help us make a difference
text EYES25 followed by £2/£5/£10 to 70070 (e.g. EYES25 £10)
We make every penny count.

Childhood Eye Cancer Trust, Royal London Hospital, Whitechapel Road, London E1 1BB.
Telephone **0207 377 5578**, email **info@chect.org.uk** or visit **www.chect.org.uk**

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.

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DesignBridge QWERTY

Childhood Eye Cancer Trust
We can see a future

Fighting Retinoblastoma
Childhood Eye Cancer Trust

The Childhood Eye Cancer Trust (CHECT) is a UK-wide charity working to support all children, individuals and families affected by retinoblastoma.

Together with your help we can fight this devastating disease.

Who we are

The Childhood Eye Cancer Trust (CHECT) is dedicated to providing support to people affected by retinoblastoma (Rb). Some of our trustees and staff have experienced Rb first hand and know what a bewildering and frightening time it can be for the whole family when a child is diagnosed.

We work closely with the retinoblastoma teams at the Royal London Hospital and Birmingham Children's Hospital. These are the two UK centres where Rb is diagnosed and treated.

Rb is rare and little known about within the wider public so we aim to provide accurate, up to date information and one-to-one support from the point of diagnosis and beyond, aiming to minimise the negative impact of the condition on the whole family.

Early diagnosis is vital to ensure the best chances of preserving a child's vision, and their life. We believe everyone should know that children can get cancer in their eyes and what the signs are, so we work hard to raise awareness of Rb. We target health professionals with information about this rare cancer, which can help them to make an early referral.

The Childhood Eye Cancer Trust also raises funds to support and fund clinical and scientific research projects specifically related to retinoblastoma.

So what is Retinoblastoma?

Let us take a look at some of the facts...

Retinoblastoma (Rb) is a fast-growing eye cancer which develops in the cells of the retina of babies and young children, usually under the age of six. Rb has one of the best cure rates of all childhood cancers and there are a number of treatments available if detected early enough. In the UK about 98% of children survive Rb. Around 70% of children with Rb in one eye (unilateral) will need to have their eye removed to save their life, and children with both eyes affected may have a visual impairment for life. Retinoblastoma is rare, with around 50 cases diagnosed in the UK each year. In about 45% of cases, the condition is heritable and a person who has had this form of Rb has a 50% chance of passing it on to their children.

We have three main areas of work

Support:

We provide comprehensive support on the ward, at the two specialist treatment centres in London and Birmingham, by phone, through meetings, email, Facebook and Twitter to help guide families through the shock, stress and practical challenges following diagnosis, treatment and beyond.

We also enable members to access support from others who have had similar experience. This includes helping members meet others affected by Rb in their region, away from a stressful hospital environment.

Our printed and online resources provide reliable information and practical guidance pre-diagnosis, through treatment and then at key life stages; e.g. starting school, university or work, planning a family etc.

Research:

Our projects have contributed to some ground-breaking new discoveries about genetics and Rb.

In our drive to create a greater understanding of retinoblastoma, improve treatment outcomes and support those affected by Rb, we proactively fund research projects which seek to address these core aims.

CHECT's research grants are available to individuals, in partnership with universities, hospitals and training centres or other recognised institutions, for one, two or three-year projects and sometimes jointly funded.

Raising awareness:

We campaign tirelessly to increase awareness of the condition, targeting public health literature, local and national media and healthcare professionals. We believe an early diagnosis can make a significant difference to the outcome for the child and the more people who know about it, the better.

We work hard to provide members with a chance to share experiences at fun events away from a medical environment. This can help reduce feelings of isolation often associated with rare diseases.

Meet little Essa

She loves her new friend Elli the Elephant, who offered Essa great comfort after her surgery to remove her eye. Thanks to the German Eye Cancer Foundation we were able to distribute this friendly companion. We want to continue to help little girls like Essa adapt after treatment.

Why join us?

1. You'll have access to support throughout treatment and beyond, from our team of experienced support workers on and off the ward.
2. If eligible you can apply for a small grant from our support fund, which is there to help in times of financial difficulty.
3. You and your family will have the opportunity to meet other individuals and families affected by Rb at regional and national CHECT events.
4. We can provide a tailored linking service where you may share experiences with another member who has been through a similar experience.
5. You can join discussions on any aspect of Rb with other families and individuals on our private Facebook page.
6. We can help you through key life stages – starting nursery and school, further education, work and starting a family. We have a dedicated young people's support worker to help your child through any difficult issues.
7. We can provide information and support for others around you, including your child's school, siblings and grandparents or information for your GP.
8. Our regular newsletter and e-news will keep you informed on research developments, news and service updates, as well as our members' stories.
9. You may benefit from holidays, offers and subsidies which arise from time to time from our supporters and sponsors.
10. You will be able to help us raise awareness of Rb, through distributing CHECT leaflets, sharing your story with the media or acting as an ambassador for CHECT at functions around the UK.

A little bit about being a member...

CHECT does not charge for membership, which is open to everyone aged 16 and over, including extended family, general supporters and professionals. However, a donation is always very welcome.

It's easy to become a member

Just complete the form at the back or email **info@chect.org.uk** for more information. Or just give us a call on **0207 377 5578**. We'd love to hear from you.

What can you do for us?

Here are a few ideas for how you can help:

Join us

Become a member and be part of the backbone of CHECT, from sharing experiences, to passionate campaigning and tireless fundraising. By becoming a member you are already helping others by giving CHECT a stronger voice in the fight against retinoblastoma. Don't forget to invite your friends and family to become members too.

Fundraise

This makes a big difference as CHECT receives no Government funding and relies primarily on the generous efforts of our member fundraisers. We welcome one-off donations and also regular giving through our Friends of CHECT scheme. To find out more about donating and fundraising ideas email **info@chect.org.uk**

Become a Friend

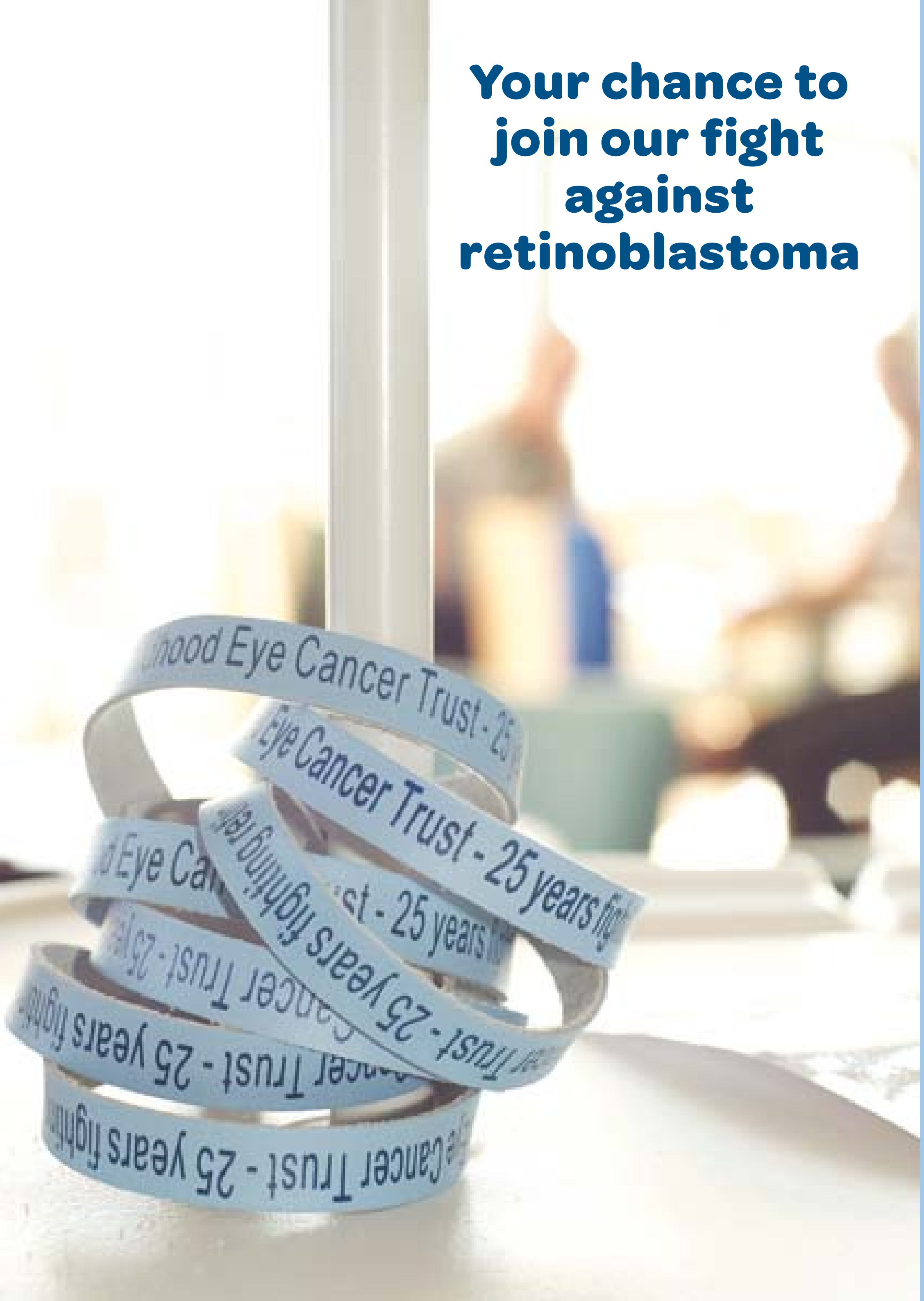
Friends of CHECT help provide the trust with stability through regular giving, enabling us to plan future campaigns and projects with confidence.

Volunteering

Your support is vital as we are a small team and always need extra help. We welcome new skills and expertise to the team and you can help with awareness raising events, regional support networks, database and admin work or assisting at events.

> "We joined CHECT as soon as our daughter was diagnosed and have found it invaluable ever since. As the disease is so rare they were able to provide us with answers at the different stages in our daughter's treatment. It's good to know there is always someone to talk to who understands what we are going through."
>
> **Julia Ferguson,** Member

Your chance to join our fight against retinoblastoma



Yes, I'd like to help CHECT by becoming a member please...

Title: (Mr/Mrs/Ms/Dr) ☐ **First name:** ☐ **Surname:** ☐

Address: ☐

Town/City: ☐ **County/Region:** ☐ **Postcode:** ☐

Country: ☐ **Phone:** ☐ **Mobile:** ☐

Email: ☐

Please let us know how you heard about us: (Please tick)

☐ I am a parent of a child with Rb
☐ I am an adult who had Rb
☐ I am a friend/relative of someone affected
☐ I do not have a personal connection

How we keep in touch

Our newsletter is free to all members, please select the format you would like to receive: (Please tick)

By post: ☐ Print ☐ Braille **or** **By email:** ☐ PDF ☐ Plain text

Please send me more information on: (Please tick)

☐ Fundraising/donating ☐ Volunteering ☐ Raising awareness

Signed: ☐

Date: ☐

Fighting
Retinoblastoma
Childhood Eye Cancer Trust

Please return to: Childhood Eye Cancer Trust, The Royal London Hospital, Whitechapel Road, London E1 1BB. Tel: 0207 377 5578.

Data Protection Notice

The information which you provide in this form and any other information obtained or provided during your membership will be processed in accordance with the Data Protection Act 1988.

By being a member of the Childhood Eye Cancer Trust you agree to your personal information (including sensitive data) being made available to a limited number of employees of the Childhood Eye Cancer Trust and selected volunteers engaged for database work, subject always to compliance with the data protection legislation.

The personal data will be used for the purpose of processing your application, dealing with you as a member of the Childhood Eye Cancer Trust and furthering the stated aims of the charity. We may also use the information to contact you in connection with our fundraising activities.

We will not pass your information on to third parties without your consent (unless required to by law), other than to those engaged in the delivery of our services and then only for a specified purpose.

The Childhood Eye Cancer Trust is registered under the Data Protection Act 1998.