

# HERE TO SUPPORT YOU...



The Childhood Eye Cancer Trust (CHECT) is a charity which supports people affected by retinoblastoma (Rb). We were set up by parents, to help others whose children were diagnosed with Rb. We now support anyone affected by Rb, from diagnosis onwards and can be available at any point in their lives, including helping children, teenagers and adults meet other people who had Rb as a young child.

## BECOME A MEMBER

Becoming a member of the Childhood Eye Cancer Trust is free and open to anyone affected by Rb, as well as their friends, family, all supporters of CHECT and health professionals.

To join CHECT, please download a membership form via our website or ask your support worker for one.

## CHECT SUPPORT

### Our support workers

We know the time during diagnosis, treatment and anaesthetic check ups can be very tough for parents. For this reason we have support workers available during Rb clinics in Birmingham Children's Hospital and the Royal London Hospital.

They work alongside the medical professionals at the hospital but CHECT is a charity and we are not part of the NHS.

Our support workers are here to lend a listening ear and to provide emotional

support. They have a wealth of knowledge about other services which may be useful including practical and financial help available, plus details of other agencies and organisations.

You can meet with a support worker at each visit to the Rb clinic and you can contact them by phone, email or via social media.

We appreciate this is a very difficult time for your family, so please don't be afraid to ask for help - that's what we're here for.

The contact details of our two support workers are:

Sarah Turley at Birmingham Children's Hospital on 07526 594 762 or [sarah.turley@chect.org.uk](mailto:sarah.turley@chect.org.uk).

Lena Copley at The Royal London Hospital on 07706 919 996 or [lena.copley@chect.org.uk](mailto:lena.copley@chect.org.uk).



## CHECT website

Our website has information about all aspects of Rb, including treatment, genetics, research and members' stories. There is also a children's area especially for young people to learn more about Rb.

[www.chect.org.uk](http://www.chect.org.uk)

## Facebook

Our Facebook groups offer the opportunity to anyone affected by Rb to connect with and help each other, and also to share experiences.

There is a closed group especially for parents of children who are being, or have been treated in the UK, one for adults who had Rb as a child (called Beyond Rb);

plus a page for friends and family.

You can follow CHECT news and message us through the main Childhood Eye Cancer Trust Facebook page which is open to all.

You can also find us on Twitter and YouTube too.

## Regional members days

Our members live all over the UK and we organise events throughout the year to give people affected by Rb the chance to meet and chat to each other, as well as talk to CHECT staff.

We also hold our CHECT Champions Awards at these events to recognise the courage and bravery shown by all children who have been affected by Rb.

## InFocus

We produce a newsletter called InFocus twice a year which we send out to members with features on research developments, members' social events, and experiences and news from the Rb community.

## Information leaflets

We have written these to complement the medical information you have been given about your child's treatment by the Rb team.

Our information is drawn from personal experiences of this treatment. The way each parent and child copes naturally varies but we hope that this information will give you some idea of what to expect, along with some useful, practical advice.



**Lena Copley**



**Sarah Turley**

[www.chect.org.uk](http://www.chect.org.uk)

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