



# CHECT Research

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The Childhood Eye Cancer Trust (CHECT) is committed to engaging in the advancement of knowledge about retinoblastoma (Rb), its treatment and its impact. We believe that research is a vital part of the fight against Rb.

Since 1997 we have funded over 20 projects totalling almost £700k, across a range of areas - including laboratory-based basic science, clinical, and psychosocial studies. We aim to ensure that each research project results in publication and presentation.

The lived experience of people affected by Rb is at the heart of our research strategy. Our Scientific Advisory Committee includes a number of members with personal experience of Rb.

At our 30th Anniversary Members' Weekend in 2017 we held a workshop to get input on the areas of psychosocial research our members felt were a priority, and in 2019 we surveyed members to get feedback on our current and future research strategy.

Here are just some of the benefits to families affected by Rb, made possible by CHECT-funded research:

- Increased knowledge of the Rb gene and mutations which can cause Rb, creating the possibility of genetic screening for affected families.
- Development of new technologies to improve the sensitivity of current genetic testing methods.
- Creation of the first rare disease registry of its kind in the UK, leading the way for the establishment of similar registries for other rare diseases across the NHS.



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"I was diagnosed with Rb when I was 15 months old. In addition to having one eye removed, I also had radiotherapy on the other eye. While the treatment saved my life, it had a major impact on my vision, to the point at which I became completely blind in my 20s. In 2011 I underwent genetic testing, which revealed that I carried the heritable form of Rb. Due to this knowledge, when my son was born in 2017 he had genetic testing at two weeks old. Three weeks later he was diagnosed and treated straight away with laser treatment. He is a very happy and healthy two year old, and has perfect vision. The difference genetic testing has made within a generation is incredible."

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Darren Harris, CHECT Patron and dad to Devante

£672k

L awarded to Rb  
research projects

23

L research projects  
funded since 1997

### How do we fund CHECT research?

We do not receive any government support and the majority of our funding is through donations. Thank you to all our supporters for their tireless work raising money for CHECT, and to organisations such as Fight for Sight and the Greendale Foundation, without which none of this research would be possible.

