



3 April 2019

Dear Researcher

The Childhood Eye Cancer Trust (CHECT) is the UK's largest charity in the field of retinoblastoma (Rb). In addition to raising awareness of Rb and supporting families affected by this disease, funding research into retinoblastoma is one of the charity's key aims.

We are currently inviting applications to the CHECT research fund for grants at a value between **£30,000 - 50,000**. This can be to fund:

- **Clinical research** into treatments and outcomes for Rb so that treatment is more effective and the negative impact on those affected is reduced
- Laboratory-based **basic science research** to improve the understanding of the molecular mechanisms and genetic basis of Rb
- **Psycho-social research** into the effects of having Rb so that ways to reduce the negative impact on those affected can be developed.

While CHECT continues to invite submissions for research proposals exploring the whole field of retinoblastoma research, following a recent Members' Event to celebrate our 30th anniversary, CHECT's members have identified particular areas of psychosocial research that are important to them and further detail of these areas is given in the Appendix below.

Impact

Studies should aim to show impact through the creation of new knowledge and address at least one of the following:

1. Inform the charity in how it delivers ongoing support to children, families, young people, and adults affected by Rb and its treatment
2. Provide useful information for agencies with statutory responsibilities for visually-impaired children
3. Be independently useful to adults who live with Rb.

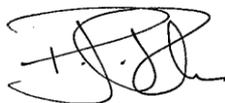
CHECT will consider funding any applications that fall within its [Research Strategy](#), and it is expected that the majority of research funded by CHECT will have the potential to demonstrate benefit to those affected by Rb within the short to medium term, normally considered to be five years from the grant end date. Further details of successful research projects funded by CHECT can be found on our website at www.chect.org.uk. CHECT is a member of the Association of Medical Research Charities.

Applications for funding must be submitted by 20 May 2019 on the attached standard form and sent to petra.maxwell@chect.org.uk. Researchers will be notified of the outcome of their application by October 2019.

Whilst not within this invitation for applications, the Childhood Eye Cancer Trust is hoping to extend a further invitation during 2019 for a PhD studentship, and we will be in touch with regards to this additional grant funding in due course.

If you require any further information regarding this process, please either contact me directly or via Petra Maxwell, the charity's Information & Research Manager.

Yours faithfully,



Patrick Tonks
Chief Executive

Appendix to 2019 Grant Call – Information for Psychosocial researchers

Individuals and families living with retinoblastoma (Rb) have reported to CHECT that there are a variety of psychosocial consequences that emerge through life: from the initial Rb diagnosis, treatment of the disease, learning of its potential for impact later in life, then living with Rb through adolescence into adulthood. These include concerns around vision, self-confidence, fertility, comprehension and second Rb1 gene-related cancers. The charity has identified two themes for this stream of research, listed below, but will also consider other high quality applications in this topic area:

1. The psychological impact of a retinoblastoma diagnosis on the child and/or family e.g.
 - a. The experience of guilt in parents e.g. passing down the Rb gene, or when they feel they 'missed' the diagnosis
 - b. Siblings' experiences of having a sibling with Rb
 - c. Longer term consequences for Rb survivors
2. The psychological impact of retinoblastoma treatment on the child or family e.g.
 - a. The experience of regular examinations under anaesthesia
 - b. Impact of having an artificial eye or disability in relation to radiotherapy treatment; different experiences across the lifespan
 - c. Managing the uncertainty around treatment and outcomes
 - d. Parent's experiences of navigating medical systems and choosing the least bad treatment option



Parent and /or patient involvement is key to this type of research and CHECT would expect to see evidence of working with PPI in the development of an application to this stream.