

Childhood Eye Cancer Trust

Research Strategy – March 2019



1. Objectives

The charity's mission is 'To prevent sight loss and death as a result of having retinoblastoma and to support those affected by it'. In order to fulfill this mission one of its objectives is "to proactively engage in the advancement of the knowledge of retinoblastoma, its treatment and impact on the individual'.

2. Background to CHECT's research

The charity was incorporated and registered in 1987, by parents and interested healthcare professionals, with a view to providing support for families whose children were diagnosed with retinoblastoma (Rb). It was known as the Retinoblastoma Society until 2003 when its name was changed to The Childhood Eye Cancer Trust (CHECT) in order to facilitate a better understanding by the general public and sponsors.

The charity merged with the David Allen Retinoblastoma Appeal in the early 1990s, also a registered charity. This charity was formed by David's parents, in memoriam, with the intention of raising money for research purposes. Upon the merger of the two charities, the funds from the appeal were restricted and used for research projects with a specific focus on retinoblastoma.

Over the years, the charity helped to make significant advances in several areas including: the identification of a genetic mutation that enabled elimination of unnecessary screening; the establishment of a database which has allowed epidemiological studies into the incidence of second primaries in Rb patients; and a study examining the psychosocial impact of enucleation.

The majority of research projects funded by CHECT have supported individuals in partnership with academic institutions for one to three year projects. All studies have led to publication in high-impact professional publications. We have seen direct benefit to both children and adults affected by Rb and many of the findings from our funded research projects have influenced the strategic development of the charity.

3. CHECT's Research Strategy

CHECT aims to fund world-class research into the development, prevention, treatment and consequences of retinoblastoma. The charity will review any applications within these areas. All aspects of research will be considered including, but not exclusively, basic laboratory research investigating disease mechanisms, preclinical experimental studies and clinical research (including, but not limited to, novel treatments, supportive therapies, epidemiology, and psychological impact of retinoblastoma). The charity will also consider participating in the funding of clinical trials.

As part of its strategy CHECT aims to encourage the dissemination of research both nationally and internationally to both professional and lay audiences. The charity is keen to ensure that results are applied to provide clinical benefit.

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The main stream of funding provided by CHECT is an annual round of grants. This funding round will be advertised on the charity's website and disseminated amongst the Rb community. Whilst the focus may change slightly year-on-year the charity will consider funding a range of grants which may include:

- PhD studentships
- Project grants
- Pump-priming projects
- Clinical fellowships

Applications in the annual round are subject to an internal peer review process and may be subjected to an external peer review process (see section 7). Whilst it is envisaged that the annual round will provide the main stream of funding for research by CHECT, the charity may from time-to-time decide to award further grants or consider applications outside the annual grant round. Such instances may occur when the charity receives funding or donations specifically for this purpose. We will also consider co-funding projects in partnership with other recognised funding bodies. In this instance external peer review will be applied.

4. Research Priorities

CHECT will consider funding any applications that fall within its Research Strategy as set out above. The evaluation process of each grant application will consider whether the proposed research fulfills a strategic aim of the charity. 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.

5. Restrictions on research applications

CHECT's grant funding will be allocated to research teams attached to recognised academic or medical institutions.

It is the charity's policy that the use of animals for research purposes is only undertaken when there is no alternative. The Childhood Eye Cancer Trust (CHECT) only funds research which complies with the law and supports the principle of the 3Rs; to refine, reduce and replace the use of animals in research. All research projects which are funded, or partially funded by CHECT must declare from the outset whether animals are to be used at any stage during the research. If animals are used then the numbers must be minimised. All work must be done in accordance with the UK Home Office guidelines (or equivalent) and all laboratories must hold valid certification. If a decision is made after the award of the grant to include animal research then CHECT must be informed as soon as possible.

CHECT is a member of the Association of Medical Research Charities and supports its [statement on the use of animals in research](#).

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6. CHECT's research process and administration

The CHECT trustees determine an annual budget for research grants and are ultimately responsible for the research strategy and grant awarding of the charity. A CHECT Scientific Advisory Committee (SAC) exists to assist the CHECT trustees in these responsibilities. This committee comprises (where possible)

- Up to two CHECT trustees, one of whom has a medical, scientific or research background
- Representatives from each of the disciplines involved in the treatment of retinoblastoma
- A representative from each Rb treatment centre (The Royal London Hospital and Birmingham Children's Hospital)
- A member of the wider research community

The role of the Scientific Advisory Committee is to:

- Consider applications for funding
- Seek peer review where appropriate
- Make recommendations to the CHECT board of trustees for grant funding
- Monitor progress of projects during the term of funding

The full remit and constitution of the SAC are attached (Appendix A)

7. Peer Review

CHECT aims to fund high quality research and all applications will be subjected to internal peer review by the SAC. If the subject of the grant application falls outside the expertise of the CHECT SAC or if the amount requested is greater than £25,000 then the application will be subjected to external peer review. All applicants must suggest at least one external reviewer with their application and may request that certain individuals do not act as reviewers. The SAC may also use external reviewers from the wider Rb community and related fields, including but not limited to oncology and ophthalmology. Prior to sending an application for external review consent will be obtained from the applicant. Any comments from an external reviewer and those from the SAC internal review can be made available to the applicant anonymously if requested. If the SAC feels a project has sufficient merit but requires amendments then the applicant will be invited to re-submit once the reviewers' comments have been considered.

All outcomes regarding funding decisions will be communicated to applicants in a timely fashion with the expected timeline for the decision outcome publicised on the CHECT website.

8. Funding from pharmaceutical companies

CHECT works within the Association of British Pharmaceutical Industry (ABPI) Code of Practice.

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9. CHECT funded research – eligible costs

CHECT supports the view that the mission of charities is to fund medical research, not central overheads.

The Trust funds the full directly incurred costs of all its research awards. However, as a charity, we expect the general running costs (e.g. indirect costs, estate costs, support services) to be provided by government (or government bodies), through funding to universities.

The costs are classified as follows:

- Directly Incurred Costs – actual costs that are explicitly identifiable as arising from the conduct of a project (e.g. staff salaries, equipment, materials, travel)
- Directly Allocated Costs – costs of resources used by a project that are shared by other activities and based on estimates (e.g. principal and co-investigator costs, estates costs)
- Indirect Costs – non-specific costs charged across all projects that are based on estimates (e.g. HR and finance services, library costs)

We will fund the full directly incurred costs of a research project and fund other costs (at our discretion) where it helps us further our charitable mission. We are not willing to fund Directly Allocated or Indirect Costs unless specifically agreed.



Childhood Eye Cancer Trust Remit & Constitution of the Scientific Advisory Committee



Remit

The key roles of the CHECT Scientific Advisory Committee (SAC) are:

1. To advise on research proposals submitted for funding by CHECT. The SAC will provide a written summary outlining the project and the SAC Chair will summarise the cost, benefits, risks and recommendations to the board. This document, and not the project submission form, will be used by the CHECT Board of Trustees to decide whether a project receives funding.
2. To seek external review for project submissions where the research proposal is outside the field of expertise of the SAC members and for all projects exceeding £25,000.
3. To monitor the progress of ongoing CHECT funded research projects and ensure that all projects are completed in accordance with the grant award.
4. To provide six-monthly lay progress reports and an end of project summary to the CHECT Board of Trustees for each funded project.
5. To provide appropriate guidelines to facilitate the proposal, interim and final reporting process of research projects.
6. To set up/ facilitate collaborative meetings on Rb to encourage sharing of ideas and knowledge amongst the Rb research community.
7. To increase the profile of CHECT as a grant maker in the field of retinoblastoma research.
8. To inform the CHECT Board of Trustees and CHECT membership about significant publications and developments in relation to Rb research and provide summaries in appropriate media such as the CHECT website or newsletter.

The CHECT Scientific Advisory Committee does not have the authority to commit to expenditure of CHECT funds without prior agreement from the CHECT Board of Trustees.

Constitution

Membership and expertise

It is preferable that the committee should consist of a representative from each of the disciplines associated with the treatment of retinoblastoma:

- Ophthalmology
- Oncology
- Genetics
- Epidemiology
- Psycho-social

Within these groups there should, where possible, be a balance of representatives from the two Rb treatment centres (The Royal London Hospital and the Birmingham

Childhood Eye Cancer Trust Remit & Constitution of the Scientific Advisory Committee



Children's Hospital). Additionally there should be a member with experience in laboratory research, and up to two members of the CHECT Board of Trustees:

- A lay member
- A member with a medical or scientific background responsible for reporting back to the CHECT Board of Trustees.

The CHECT Chief Executive will be in attendance.

Terms of Office

New members should be recommended and on the agreement of the majority of the committee, be invited to take up office.

The medical/scientific CHECT trustee representative from the SAC should make themselves available for the meeting of the Board of Trustees directly following the SAC meeting, or find a suitable substitute to attend both meetings.

The terms of office will be for three years and only two terms can be served consecutively. A period of one year must elapse before re-election.

The SAC should appoint a Chair and Vice-Chair, of whom one should not be a member of the Board of Trustees.

The SAC will meet twice a year (currently May and November). At least three, or, more than 50% of the committee must be present (whichever figure is higher) to form a quorum. For decisions made out of this cycle, a quorum of three should be adhered to.

A member of the SAC will be responsible for taking the minutes of the SAC meetings.

A sitting member of the SAC may submit an application for funding but must not take part in any part of the grant allocation in that round.

CHECT Research Grant – Conditions of award

1. The Childhood Eye Cancer Trust (CHECT) will usually only make awards to Principal Investigators (PI) in a substantive post. Where the lead investigator for a project does not hold a substantive university or clinical appointment, they must be underwritten by an experienced PI or head of department.
2. All grants are made for a fixed amount in pounds sterling which reflects the grant application and is detailed in the offer letter. Requests for extra funding will only be considered in exceptional circumstances.
3. All grants are made conditional on the project commencing within six months of the date of the offer letter:
 - a. If the project does not commence within six months then CHECT reserves the right to withdraw funding and if any monies have been paid by CHECT at this point, they must be returned within 28 days.
 - b. CHECT will consider extending the start date of the project if a request is made in writing three months after the date of the offer letter.
4. All projects have an agreed duration which must be stated in the application and offer letter. The grant is made conditional on the project completing within this timescale.
 - a. In exceptional circumstances CHECT will consider a no-cost extension of time if a request is made in writing, three months before the agreed date of completion (“a No-Cost Extension”).
 - b. CHECT will require interim reports every three months during any agreed No-Cost Extension period.
 - c. Projects will not be extended for more than 12 months from the expected completion date (as confirmed in writing by CHECT, further to the offer letter).
5. If a project is not completed in timescales as defined above, CHECT will review the situation with the research grant recipient but reserves the right to the return of monies awarded.

CHECT Research Grant – Conditions of award

6. Where an award is made for more than one year, funding will be reviewed on an annual basis.
7. A progress report must be submitted to CHECT Scientific Advisory Committee every six months during the funding period. This must contain sufficient detail to allow assessment of satisfactory progress. In the event that there has been insufficient progress, CHECT reserves the right to withhold future funding and/or recover in full any monies paid to the grant holder.
8. All grant-holders must submit a report at the end of the funding period detailing the work, its results and conclusions. A short lay summary should accompany the report for the benefit of the wider membership of CHECT. The report and summary should be initially submitted in draft, no more than 6 weeks after the end of the funding period (unless an extension has been agreed in writing), to allow the CHECT Scientific Advisory Committee to raise questions/comments, before a final report and summary are presented. The final report should be submitted less than six weeks after receiving questions/comments from the CHECT Scientific Advisory Committee.
9. The Childhood Eye Cancer Trust (name in full) should be acknowledged in any publication or presentation that results in part or in full from this funding: “This research was funded / part-funded by The Childhood Eye Cancer Trust.” A copy should be forwarded to CHECT.
10. Grants are conditional on the draft and final lay summary and report (i) being submitted to CHECT within the timescales set out at 8 above, and (ii) CHECT being acknowledged in accordance with 9 above. Should these conditions not be met, CHECT reserves the right to recover in full any monies paid to the grant holder.
11. Funding for (clinical) projects will be made available at defined project milestones agreed between CHECT and the Principal Investigator; e.g. recruitment of first participant, recruitment of final participant, exit of final participant.
12. When submitting an invoice a clear breakdown of costings should be provided, along with attached receipts and copies of purchases orders. Failure to do this may delay or prevent payment.



CHECT Research Grant – Conditions of award

13. Where equipment is required for a project, this should only be purchased once ethical approval has been obtained.
14. Where items of equipment costing more than £1,000 have been identified in the grant application, monies will not be released until a copy of the supplier's invoice is forwarded to CHECT.
15. All invoices must be received no later than three months after the completion of the award period. Invoices received after this date will not be paid.
16. Annual salary increases will be funded in line with nationally agreed pay awards. Increments resulting from progression to higher scale points can only be funded if accounted for in the original grant application.
17. In the event that CHECT enters into financial difficulties or any type of administration or insolvency proceedings, then the payment of the grant cannot be guaranteed.
18. All invoices and any return of funds should be paid to CHECT in pounds sterling and any international banking costs incurred are borne by the institution.

Signed:

Name:

Position:

On behalf of
(institution):

Date: