

# CHOROIDEREMIA RESEARCH FOUNDATION CANADA, INC.

## RESEARCH PROGRAM GRANT GUIDELINES & CONDITIONS

Note: Unless otherwise specified, all dollar figures in these Grant Guidelines & Conditions and in any associated application or other forms refer to Canadian currency.

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## **A. INTRODUCTION**

The Choroideremia Research Foundation Canada, Inc.(CRFC) was incorporated in 2004 and was designated as a Canadian charitable organization effective January 1, 2005.

### **1. Mission**

The primary goal of the CRFC is to fund medical research leading to a cure or treatment for choroideremia, an inherited, degenerative eye disease which causes blindness.

### **2. Research Grants**

The CRFC's research program is aimed at supporting research projects which will advance scientific and clinical knowledge about choroideremia, potentially contributing to the development of a treatment of and/or eventual cure for the disease. The primary objective of this research funding is to provide support for expenses associated with research projects directed toward a defined objective, conducted by an investigator working alone or in collaboration with others. Grants may be used to employ assistants, to purchase materials, supplies and small equipment, to purchase and maintain animals, and to support travel costs. All expenses funded by the CRFC must relate directly to the work of the research project, and must be expenses which would not be incurred should the research project not be undertaken. The CRFC will not provide funding for ongoing operating or capital expenses of a department or work group, facility renovations, or furniture. Nor will it fund research into the psychological or social aspects of the disease.

Choroideremia is a rare disease, and a specialized area of research. The CRFC's mission is to encourage research which advances the scientific understanding of the disease, and which contributes to progress towards possible treatments or cures, whether such work is undertaken within or outside Canada. Grants are intended to support research by individual investigators or small teams of investigators based at a university or similar research institution. Grants will not be provided to support for-profit organizations.

Grant requests will be considered on an annual basis, or at such other frequency as the CRFC's Board of Directors may deem appropriate. Grant awards will generally cover a period not to exceed one year, and will generally not exceed \$75,000 (in Canadian funds). Recipients of any initial CRFC grant may submit grant renewal requests in subsequent grant processes, but any subsequent funding award will be subject to progress and performance with respect to previous grants (if applicable), to further scientific and budgetary review, and to the availability of sufficient CRFC funds.

## **B. GENERAL PROVISIONS**

### **1. Submission Procedures & Time-lines**

Grant applications must be submitted using CRFC application forms, to the CRFC head office at the following address, by the specified submission date.

Submit all grant applications by mail to:

Choroideremia Research Foundation Canada, Inc.  
16 Candlewood Dr.  
Brantford, ON  
Canada  
N3R 6A1

The grant submission package must include the original and FOUR (4) copies of the application forms and any associated documents on 3-hole punched paper (may be single-sided), plus a copy on CD, in MS Word format.

Timetable:

Grant applications to be submitted by: **Feb. 28, 2009**

The Choroideremia Research Foundation Canada, Inc. reserves the right to decline late or incomplete applications.

### **2. Review Process**

Before being approved for funding, research proposals must undergo a scientific assessment, as well as budgetary review. The CRFC reserves the right to fund any or none of the applications submitted at a particular time.

Scientific review will be undertaken by members of the CRFC's Scientific Advisory Committee (SAC). The SAC will make its recommendations based on the qualifications of the applicant(s) and the scientific merit of the research proposal. Members of this committee may also provide comments on budget estimates. Proposals will be further reviewed and considered by the CRFC's Board of Directors, the approval of which is required before any proposal(s) will be funded.

Members of the Scientific Advisory Committee will not participate in the review of any applications in which they have, or may be perceived to have, a conflict of interest.

For applications considered to require more expertise than is available within the Scientific Advisory Committee, or should one or more of the members of the SAC be unavailable to review applications, the SAC and CRFC will select one or more external reviewers to participate in the review process, taking into account any candidates for such a role (or to be excluded in such a role) suggested by the applicant(s) in the application package.

Applications will be evaluated on the basis of scientific merit, and on their relevance to choroideremia. Research to be funded by the proposed grant must have a direct application to choroideremia, rather than to a more general class of retinal or other diseases.

In general, CRFC prefers to provide adequate support for a more limited number of projects of high scientific merit, rather than providing partial support for a larger number of projects.

### **3. Notification and Acceptance of Awards**

It is anticipated that applications will be reviewed, and award decisions taken within two months of the submission deadline above. All applicants will be notified via direct correspondence from the CRFC shortly after this date of the outcome of the grant evaluation and award process.

Approved awards must be accepted in writing by a date which is no later than two weeks after notification of approval of the application, and work commenced within 60 days of notification. The CRFC may entertain some limited flexibility in the date of commencement of the research project, but must be advised of the anticipated timing at the time of acceptance of the award, and reserves the right to reallocate such funding to other applicants in the event of delays in the project.

The applicant must advise the CRFC of any other funding which may have been approved or is expected to be available to assist in funding the research project, per the following section.

### **4. Other Funding Sources**

Applicants must, at the time of application to the CRFC (if possible, but in any event no later than at the time of acceptance of a CRFC grant), advise CRFC of any other grants currently held or being applied for, or any relevant funding agreements relating to the proposed research work. “Double dipping”, or an overlap in funding for the same work, is not allowed. The CRFC may reduce or terminate funding in the event that funding for work with similar objectives is provided by another organization. While the CRFC allows applicants to submit the same proposal to multiple organizations for the purposes of obtaining funding, if the proposal, or any portion of the research covered by the proposal, is first funded by another organization, then it is the applicant’s responsibility to immediately inform the CRFC of the overlap in funding. Similarly, if alternate funding is obtained after a CRFC grant is awarded, and the grantee chooses the alternative funding, the CRFC must be immediately notified. In the event of an overlap in funding, the CRFC award will

be terminated, or reduced accordingly. The applicant may not transfer CRFC funding to any other project, or expand the scope of, or resources allocated to, a CRFC-approved research proposal, and any funds already advanced by the CRFC and no longer required for their intended purpose must be immediately returned to the CRFC.

The CRFC must be notified of any changes in funding status which may occur during the period of a CRFC research grant.

CRFC grants will not be made to an applicant who already has a CRFC grant unless that grant expires before the new one would begin, regardless of the specific area of research involved.

**Please note that while the CRFC communicates with and, on some projects, may collaborate with, the Choroideremia Research Foundation headquartered in the United States, and with other organizations involved in funding choroideremia research, the CRFC is a separate Canadian charitable corporation. Applications for CRFC funding must be made directly to the CRFC, on CRFC forms, and any projects receiving CRFC funding must fulfill all CRFC requirements.**

## **5. Host Institution/Location of Research**

The host institution identified in the grant application must take full responsibility for the conduct of the research being funded, including integrity in research and associated academic work, full ethical review and oversight, compliance with all applicable animal care and biohazard regulations, and complete financial accounting and control.

If the research funded by the CRFC grant is to be conducted in whole or in part in the facilities of organizations other than the host institution, permission must first be received from the CRFC.

## **6. Payment and Administration of Awards**

Grant funds for successful applications will be deposited with the host institution and administered through an officer of that institution's Finance (or equivalent) department.

Funds may be used only for the purposes of the approved research project.

The first instalment (normally one third of the approved amount) of the grant award will be released shortly after acceptance by the grantee of an approved award. The payment of a second instalment of (normally) one third will be contingent on the receipt of the required mid-year financial report and satisfactory reporting of progress, as discussed below. The final instalment of (normally) one third will be released after the final report for the year, and any required supporting material, has been received, reviewed, and found by the CRFC to be acceptable.

The CRFC operates in Canadian dollars, and all grant awards will be made in Canadian currency. Grant applications and progress/financial reports may be expressed in Canadian dollars or in the local currency of the applicant, but the currency used must be clearly identified, and, if not in Canadian dollars, will, in general, be converted to Canadian dollars for the purposes of review, administration, and cash-flowing by the CRFC. In any financial reporting prepared for the CRFC, budget and actual amounts must be shown in the same currency.

## **7. Grant Amount/Term/Renewals**

Grant awards will generally cover a period not to exceed one year, and will generally not exceed Cdn \$75,000. Recipients of any initial CRFC grant may submit grant renewal requests in subsequent grant processes, but any subsequent funding award will be subject to progress and performance with respect to previous grants (if applicable), to further scientific and budgetary review, and to the availability of sufficient CRFC funds.

## **8. Transfer of Awards (See also discussion under Closing or Suspension of Award)**

Should a research grant recipient be unable to continue the approved research project at the host institution, the CRFC must be notified immediately.

### a) Transfer of grant to another Principal Investigator at the same institution

If the work can be continued via transferring the project to another qualified Principal Investigator at the same institution, and if all other conditions of the grant can continue to be met, the CRFC will consider such a transfer of funding, and continuation of the grant. Such a transfer must be approved by the host institution, and is at the discretion of the CRFC. Should such a transfer not be approved by the host institution, or not be acceptable to the CRFC, the grant will be closed, as described under “Closing of Research/Award”.

### b) Transfer of the grant to another institution

If the Principal Investigator in receipt of a CRFC grant transfers to another institution during the term of the grant, and intends to continue the research for which the grant was approved at the new institution, the CRFC will consider a transfer of the approved grant funding on a case-by-case basis. In order to effect such a transfer, a final accounting by the original host institution would be required, along with the return to the CRFC of any unspent funds. A progress report on the status of the research may also be required, if one has not been recently submitted. I.e. the grant would effectively be closed at the original host institution and, if acceptable to all parties, reopened at the new host institution. Agreement of the new host institution and designation of a new financial officer for the grant would also be required. Any such transfer is at the discretion of the CRFC.

## **9. Closing or Suspension of Research/Award (See also discussion under Transfer of Awards)**

When the work to be funded by an approved CRFC grant is completed, or for any reason cannot be continued, the grant will be closed. Any unspent grant funds (i.e. funds previously advanced by the CRFC for the project but not used for the project) may not be used for any other purpose, and must be returned, with a final report and accounting prepared by the host institution, to the CRFC.

If work on an approved project must be suspended for any reason (e.g. prolonged absence or unavailability of a researcher), the CRFC must be notified as soon as possible. Depending on the circumstances, the grant may, at the CRFC's sole discretion, be suspended (i.e. put on "hold") for a period of time, or closed, in which case unspent funds (as defined above) must be returned, along with a final report and accounting prepared by the host institution.

For the purposes of this section, an absence will be considered by the CRFC to be "prolonged" if it exceeds 30 continuous calendar days.

## **10. Non-Employee/Non-Partner Status**

The granting of an award establishes neither an employer-employee relationship nor a partnership between the CRFC and the recipient of the grant.

## **11. Ethical Requirements, Safety Certificates**

If animals are to be used in the proposed research project, a copy of the IACUC (Institutional Animal Care and Use Committee) approval or comparable institutional approval must be submitted to CRFC before any funds will be released (preferably at the time of application).

If human subjects are to be used for any research project, please submit a copy of the Institutional Review Board (IRB) approval or comparable institutional approval.

By signing and submitting applications to the CRFC, applicants, administrators and their host institutions accept full responsibility for research ethics and its protocols, the use of animal and/or human subjects in the proposed research, confirm that any animal or human experimentation is acceptable to the host institution on ethical grounds, and that the work to be funded by the research grant meets all applicable guidelines and requirements for such experimentation and for the care of laboratory animals, including, without limiting the generality of the foregoing, applicable local, state and national laws, the Association for Research on Vision and Ophthalmology's Statement for the Use of Animals in Ophthalmic and Visual Research, Guidelines published by Canadian Council on Animal Care, and other relevant guidelines.

Where potential biological and/or chemical hazards are involved, the proposed research is not to be

undertaken until it has been accepted by the signing administrator, with appropriate documentation forwarded to CRFC, as meeting requirements regarding biological and chemical hazards as outlined in Health Canada's "Laboratory Biosafety Guidelines" and/or other applicable guidelines.

Applicants considering submitting a research proposal involving human stem cells should first contact the CRFC.

## **12. Intellectual Property Rights**

It is expected that any inventions, discoveries or improvements developed with full or partial support of the CRFC and reported in a scientific publication, be shared upon request with legitimate investigators in a generous and timely fashion in order to advance the research goals of the CRFC.

In the event that any inventions, discoveries or improvements resulting from work funded in whole or in part by CRFC grants may be, or may become, covered by patent applications, patents, or copyrights, the CRFC is deemed to have an interest in any such intellectual property rights reasonably related to the CRFC's contribution to the invention or discovery. The CRFC, inventors, host institution, other funding organizations (if any), and other parties (if any) contributing to the invention or discovery shall together determine the respective interests of the parties in the intellectual property rights or proceeds from the exploitation or application of the intellectual property rights.

The CRFC requires that grantees advise the CRFC, in writing, in a timely fashion of any patent applications or other activity or transactions (e.g. sales, assignments, licensing) relating to intellectual property related to work funded by the CRFC in which the CRFC may have a deemed interest per the above paragraph. The CRFC further reserves the right to publicize the CRFC's involvement in or contribution to the development of any invention or discovery giving rise to any patent or other intellectual property rights, making reference to the grantee's name if applicable, subject to the grantee's right of review and reasonable approval.

## **13. Publications/Acknowledgments/Communications**

It is expected that from time to time results of research funded by the CRFC will be published in recognized scholarly journals. However, the CRFC requests the recipients not to engage in any dissemination of data regarding the findings, including journal manuscript submission, prior to acceptance of the final report by CRFC (see s. 19, Accounting & Reporting below). Where CRFC-funded data are presented, the CRFC shall be informed of journal manuscript submissions and outcomes, and abstract presentations. The CRFC also requests to be acknowledged as the funder of the research (in part or in whole) when related information is disseminated via presentations, press release, formal publications or other forms of communication. A copy of each publication must be forwarded to the CRFC as soon as it is available. The CRFC also requests that investigators notify

the CRFC of citations and other work by themselves or other researchers related to the work funded by a CRFC grant, or of other grant awards obtained as a result of the CRFC funding. Such information is very useful in supporting additional fundraising for choroideremia research.

The title and lay summary contained in the application for CRFC-approved and funded research projects, and/or the summaries, abstracts or other communications associated with any research project funded by the CRFC, may be used by the CRFC and disseminated to the public, without notification to the applicant, in the process of the CRFC informing the public of its activities.

Grant recipients may be asked for their assistance in preparing updates for the CRFC's website or other communication vehicles, and occasionally to make themselves available for media communications.

#### **14. Eligibility**

The principal investigator on any research grant provided by the CRFC must hold an academic appointment in or be formally associated with a recognized university, teaching hospital, or other recognized not-for-profit research institution, which in turn will serve as the host institution.

For-profit organizations are not eligible to receive CRFC grants.

#### **15. Financial Gain/Disclosure of Commercial Interests/Conflict of Interest**

The CRFC will not fund any proposal that has any element of financial gain from the granted funds to any named investigator.

The investigator(s) and others associated with an application for CRFC funding must fully disclose any financial interest they may have in any company or other commercial venture whose business activities are related to the subject matter of the CRFC grant application.

#### **16. Indirect Costs**

CRFC grants may not be used to fund overhead or indirect expenses, including any interest or carrying costs associated with the project.

#### **17. Supporting Publications**

Papers, articles etc. listed in an application must generally have appeared in a peer-reviewed publication. The status of papers submitted but not yet published must be clearly identified.

## **18. Budget Information, Justification & Administration**

A detailed itemized budget for Year One, with appropriate justification sufficient to permit reviewers to assess whether the requested resources are appropriate, under the following categories must be submitted:

1. Personnel, salary and fringe benefits
2. Materials & Supplies
3. Animals
4. Travel
5. Equipment
6. Other Expenditures
7. Financial Contributions from Other Sources (if applicable)

Personnel - Rates of pay and benefit levels shall be in accordance with the salary & benefit scales of the host institution, although the CRFC reserves the right to limit the benefits for which it will provide funding. Names (if known), positions/titles and justification for employing the proposed staff on the research project must be clearly described in the application. The application must indicate whether the proposed staff will be dedicated to the research project, and if not, what proportion of their time will be spent on the project and on what project(s) the remaining proportion of their time will be spent. Grant funds may not be used to fund the principal investigator. Also, CRFC funding may not be used to fund other salaried members of the host institution who are not directly involved in the proposed research, or who would be engaged in work covered by the research proposal even if CRFC funding were not provided. CRFC must be notified immediately of any personnel changes.

Travel - Purpose must be stated in application, and must be directly relevant to the proposed research. Normally must not exceed \$2,500 per year.

Equipment - In most circumstances, CRFC will not fund the purchase or maintenance of capital equipment. Small equipment purchases (generally less than \$1,000) may be considered for CRFC funding as part of a research proposal.

If the research project is projected to extend beyond one grant year (i.e. one 12-month period), a summary budget for each of the above categories for each year of the proposal must also be included.

Re-allocation of funding greater than 15% between approved budget line items (including the Other Expenditures category) requires prior authorization of the CRFC.

The CRFC will not fund any expenditures incurred prior to official notification by CRFC of approval of the award.

## **19. Accounting & Reporting**

Grant recipients must provide interim and final reports to CRFC addressing work accomplished relative to the project plan, and expenditures incurred (and revenues received, if applicable) vs. approved budget. Such reports must consist of an accounting report, a scientific progress report, and a lay summary. Future and current funding is contingent upon satisfactory (to the CRFC) research project progress and financial management of the project.

### When:

Such reports must be submitted within six (6) months of the official start of the grant period (interim report), and within 90 days after the end of the term of the grant (normally one year), or when otherwise requested by the CRFC. In cases of requests for grant renewals (e.g. for a second year), an updated interim report, including a scientific progress report and a financial report showing expenditures to date, and projected to the end of the grant year, must be included with the grant renewal application.

### i) Accounting

The required accounting report consists of a standardized finance report of expenses versus approved budget, broken down by the line items shown under “Budget Information, Justification & Administration” above, relative to the work funded by each CRFC grant, signed by the investigator and the financial officer.

In order to insure proper matching of expenditures vs. budget for the time period in question, please use the accrual method of accounting for expenditures (and revenues, if applicable) included in the approved budget. (The accounting report must also show accrued but unexpended funds.) In order to qualify for CRFC grant funding, all expenses must actually be paid within a reasonable time (normally two months) after the end of the time period represented in the financial report, and must be supportable by actual payment documentation (see below). The CRFC does not fund non-cash expenditures such as depreciation and amortization.

In cases where CRFC funding forms only a portion of the funding for the approved project, total expenses related to the project, and other sources of financing must also be shown.

In situations where the approved grant has not been fully expended by the end of the grant year, authorization to carry forward the unexpended funds must be requested from the CRFC, in writing, prior to the end of the grant year. An expenditure report showing actual vs budget expenditures to date, per the format discussed in this section, as well as an explanation of the circumstances creating the underexpenditure, and an updated projected timetable for the project as it relates to the CRFC grant funding, must accompany such requests. Should the investigator not request approval from the CRFC to utilize unexpended funds, or should such approval not be forthcoming from the CRFC, the

CRFC, at its option, may require the financial officer to return such funds to the CRFC, or may reduce any future funding by a corresponding amount.

Overexpenditures on the total project budget (or on individual line items in excess of 15% without prior CRFC authorization) will not be funded by the CRFC.

Copies of invoices and other documents supporting the expenses charged to the project and, in cases of projects jointly funded by other organizations, funding received from other sources, must be provided to the CRFC if so requested by the CRFC. The CRFC reserves the right to require that such documentation be provided with each financial progress report. Under some circumstances, and at the CRFC's option, such documentation relating to a subset of, or all, expenditures may be requested after the submission of financial progress reports, as part of the process of reviewing such reports. Source documents and other relevant material relating to the project expenditures and financing must also be made available, at the host institution, to CRFC representatives (reasonable notice to be provided), if so requested by the CRFC for audit purposes. Any expenditures not covered by the original approved budget (except those permitted by the above-mentioned 15% line item reallocation rule), or not supported by satisfactory (to the CRFC) invoices or other documentation will not be funded by the CRFC. Any funds previously paid or advanced by the CRFC in respect of such ineligible expenditures must be returned to the CRFC upon request, or, at the CRFC's option, will be deducted from future grant instalments.

#### ii) Scientific Progress Report

The scientific report should discuss progress relative to the objectives of the research, and discuss methods used, results obtained to date, and any publications and presentations associated with the grant. A lay summary (see below) must accompany all interim and final scientific reporting.

As indicated in s. 6 (Payment and Administration of Awards) above, payment of the final instalment of the award will be contingent upon a final scientific report which is acceptable to the CRFC and to its scientific advisers.

### **20. Lay Summaries**

All applications and progress reports must include a lay summary written in language suitable for a general audience at a level no greater than grade 10 (which can be assessed by common word processing programs such as Word and WordPerfect). Such summaries may be made available on the CRFC website and otherwise made public. It is essential to the work of the CRFC, and to the expectations of donors and to other CRFC stakeholders that the CRFC be able to report back to the public, and that such summaries be understandable by lay people. Hence it is a condition of award that recipients of CRFC grants agree to provide such lay summaries, and further agree to revise such summaries, or to accept editorial amendments made by CRFC scientific advisors, if the summaries

are deemed by CRFC as unacceptably difficult to understand.

## **21. Privacy Issues**

Research grant applications and associated material are, subject to exceptions provided for in these Guidelines and Conditions or otherwise required by applicable legislation or regulatory authorities, held in confidence by the CRFC. Information contained in applications is distributed to reviewers and other CRFC personnel and is used to administer the grant program. Lay summaries of funded proposals, with the names of the principal investigators and host institutions may be published on the CRFC website and/or otherwise made available to the CRFC's stakeholders and to the public via media releases, newsletters or other means. The CRFC's financial reports, which are made available to the CRFC's stakeholders and to the public, may identify specific funded research and dollar amounts, along with the names of principal investigators and host institutions. All relevant CRFC records are made available as required to the CRFC's external auditors during the preparation of the annual financial statements.

## **22. Liability**

The Choroideremia Research Foundation Canada, Inc. is not responsible for any claim, judgement, award, damages, settlement, negligence or malpractice arising from the research or investigation related to a CRFC grant award. The investigator's institution must accept responsibility for the conduct of research or investigations related to any such CRFC award, and release the CRFC, its directors, officers, members, employees and volunteers from all claims of liability that may arise from the conduct of research or investigations related to any such award resulting from any act or omission on the part of the institution, its employees, associated researchers, agents or representatives.

## **23. Research Project References**

Applicants must provide the names and contact information of (at least) two funding agencies or organizations for whom research has been conducted and completed previously. Please insure that organizations whose names are submitted are willing and able to provide reference information to the CRFC when requested (e.g. are not prohibited from doing so by internal policies etc.).