

## REGULATIONS GOVERNING THE AWARD OF MEDICAL RESEARCH GRANTS FOR STUDIES AIMED AT TREATMENT OF FRAGILE X SYNDROME

The Fragile X Research Foundation of Canada (FXRFC) offers a grant program designed to encourage research aimed at finding a specific treatment for Fragile X syndrome. Grants up to **\$15,000** per year may be used for the payment of research assistants (technicians and scientists) and are approved for the specific project indicated within the grant application. FXRFC is particularly interested in pre-clinical studies of potential pharmaceutical and genetic treatments and studies aimed at understanding the function of the FMR1 gene.

New applications are considered once a year; **deadline** for applications is **October 1<sup>st</sup>** of each year.

---

### PURPOSE OF GRANTS

The purpose of this grant program is to promote research aimed at finding a specific treatment for Fragile X syndrome. FXRFC's goal is to bring practical treatment into current medical practice as quickly as possible; therefore, preference will be given to research projects that have a clear practical application and the results of which will be shared with other qualified researchers in a timely fashion.

### ELIGIBILITY FOR GRANTS

Institutions receiving grants must be exempt from federal income taxes. Preference is given to institutions within Canada.

Individuals nominated by applicant institutions for the research grant should have training and experience at least equal to the Ph.D. or M.D. level.

### USE OF GRANT FUNDS

1. Grants are approved for the specific project indicated within the grant application. The Primary Applicant will be the responsible designee for the distribution of funds upon written invoice submitted to the Foundation.
2. **No grant funds shall be used for the remuneration of the applicant.**
3. Grant funds may be used for the payment of research assistants (technicians and scientists) provided full disclosure of remunerations planned are expressed within the original application.
4. The amount of a grant is based on the applicant's estimate of the research expenditure under various items as set out in the application. It is recognized that the applicant is the best judge of how the funds may serve the advancement of the project. Minor variations to the distribution of the funds among items set forth in the application are permitted.
5. If any significant alteration is contemplated in the proposed objectives or aims of the project, the financial requirements or the proposed expenditures, the applicant shall notify the FXRFC immediately and may not proceed further with the project until the written approval of the FXRFC authorizing such alterations has been obtained.
6. FXRFC reserves the right to cover any item if explicitly authorized by FXRFC's Board of Directors. Title to any equipment purchased on a grant rests with the FXRFC but may be transferred to the institution of the grantee on termination of the grant if permission is given by the FXRFC.

## TERM

Grants are awarded for the period of one year and may be renewed for a second year, based on satisfactory progress. A financial report and progress report are required at the end of each year.

## AMENDMENT OF POLICIES

The Fragile X Research Foundation of Canada reserves the right to modify its policies governing grants at any time. The grantee agrees to abide by any changes or to terminate the grant at the time when such changes become effective. Failure to abide by the policies governing grants shall be considered sufficient grounds for cancellation of a grant or refusal to consider any pending application by the grantee.

## PROHIBITION OF DISCRIMINATION

No person shall be excluded from participation in or denied the benefits of any program or activity receiving financial assistance from FXRFC because of race, ethnic origin, religion, sex, or sexual orientation.

## HUMAN AND ANIMAL SUBJECTS

Human subjects studied in the course of research conducted under a grant are under no circumstances a responsibility of FXRFC. Human subjects in a program supported by FXRFC shall be volunteers in any survey, study or procedure. Research involving human subjects must have Institutional Review Board approval.

If animals are used in the proposed study, written certification must be provided to FXRFC indicating that the research is to be conducted in accordance with the guiding principles for the care of laboratory animals set out by the Canadian Council for Animal Care unless prior written approval of the Foundation to deviate from them has been obtained.

## OBLIGATIONS OF THE GRANTEE

In accepting a grant, the applying institution undertakes that at its conclusion it will:

1. Submit promptly to FXRFC a complete final report on the work pursued. On awards of more than one year duration, a yearly report will be expected.
2. Supply an accounting of funds received from FXRFC and expenditures made in such detail and in such manner as may meet Revenue Canada procedures. On awards of more than one-year duration, a yearly report will be expected.
3. Recognize the support of FXRFC in any published article resulting from the work pursued with a credit line reading "Supported in part by a grant from the Fragile X Research Foundation of Canada".
4. Recognize the support of FXRFC in any presentation of research at professional meetings and conferences.

## PUBLICATION AND DISSEMINATION OF RESULTS

FXRFC's purpose in providing grants is to speed up progress towards treatment for Fragile X. Therefore, in accepting an award, the Principle Investigator undertakes to publish the results of the work pursued in the primary literature, in a timely fashion. Once published, the reagents, methods, materials, and products of the work must be made available to other qualified researchers. FXRFC reserves the right to share in any proceeds from an invention or discovery developed under this grant, including licensing fees and patent rights.

## PUBLICITY ON WORK UNDER GRANT

The grantee institution and Principle Investigator will cooperate fully with FXRFC in announcement through the news media of grants awarded and in materials prepared to publicize work under the grant. FXRFC will publish periodic descriptions and updates on funded projects in its quarterly members' newsletter.

## APPLICATION PROCESS

Potential applicants are encouraged to submit a brief letter of inquiry describing the proposed project before writing a full application.

Please provide the following information with your application:

- Description of the proposed project using the following headings: Background, Objectives, Approach, Methodological detail, Significance, Originality, Key References (6-12 pages recommended).
- Curriculum Vitae for the Principal Investigator.
- Financial accounting of how the funds will be spent, with dollar distribution into major component items.
- A full accounting of any other current and submitted sources of support for this project and other lab research.
- Requested start date of the project. The earliest possible start date is 3 months after receipt of the application; applicants will be notified of awards within 2 months.

Send 1 complete copy of the application by email to [research@fragilexcanada.ca](mailto:research@fragilexcanada.ca) as an attached file in Acrobat PDF format. Alternately, this electronic copy may be sent on a CD.

Also please send 2 copies of the application to:

**Carlo Paribello MSM, MD, President**  
**Fragile X Research Foundation of Canada**  
167 Queen Street West  
Brampton, Ontario  
Canada L6Y 1M5

Applications must be postmarked by the deadline date.

For further information contact Dr. Carlo Paribello at the FXRFC.

Phone (905) 453-9366; Fax: (905) 453-0095.

## RENEWALS

FXRFC grants are awarded for a single year and are generally renewable, based on good progress being made the first year. We require a renewal application be submitted by one of the FXRFC's regular deadline of **October 1<sup>st</sup>**. The renewal application should consist of a detailed progress report for the first year and work plan for the second year, as well as a financial report of how first-year funds were spent.