

CHOROIDEREMIA RESEARCH FOUNDATION CANADA, INC.

MEMBERSHIP FAQ (Frequently Asked Questions)

Some questions and answers about membership in the Choroideremia Research Foundation Canada, Inc. (CRFC).

1) What is the CRFC?

The CRFC is a not-for-profit, Canadian charitable organization incorporated under the Canada Corporations Act, and designated as a charitable organization by the Canada Revenue Agency, one of the agencies responsible for regulating Canadian charities.

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

2) What does it mean to be a Canadian charitable corporation?

As a Canadian charitable corporation, the CRFC essentially represents a public trust. The CRFC owes a fiduciary duty (a duty acting as a trustee for funds entrusted to it) to its donors and the public to use funds provided by the donors to carry out its mission.

3) What does it mean to be a member of the CRFC? As a member, how can I help?

Members of a Canadian charitable corporation such as the CRFC serve in two capacities:

a) The membership group of the CRFC represents the foundation level of the corporation, analogous to the shareholder level in a for-profit corporation¹. As such, it represents the accountability group for the public trust. In this governance role, members effectively oversee the operation of the charity and are concerned foremost with the proper functioning of the public trust (i.e. that the charity properly carries out its mission). The membership elects the board of directors, and the directors in turn answer to the membership.

As part of this accountability process, the CRFC updates its members (at least annually) on the activities of the corporation, including financial operations, research funded etc. Members participate in annual general meetings, and other general meetings if required (see #5 below). Their responsibilities include electing a president

¹ A Canadian charity such as the CRFC is incorporated without share capital, and, unlike a for-profit corporation, has no owners.

and directors, and voting on other matters such as the appointment of auditors and approval of by-law amendments.

b) Because the CRFC undertakes its mission mostly through volunteers, members also provide the skills, expertise, time and effort to run the day-to-day operations of the organization. Members may participate according to their interests and any particular areas of expertise and experience they may have. Potential areas of participation include fundraising, research grant administration, communications, financial administration, and general corporate administration.

4) How does the CRFC carry out its work?

The CRFC carries out its day-to-day operations through a board of directors (quasi-trustees of charitable property) which is elected annually by the CRFC membership, and through volunteers who work with the directors. The officer positions of the corporation are comprised of a President, Vice-President, Secretary and Treasurer.

5) What time commitment is involved in being a member?

With respect to the governance role of members, general meetings are normally held once per year, and members may participate in person, by conference call, or by proxy. A meeting agenda, annual report, financial statements, and other relevant material, as well as instructions on the options for participating (e.g. conference call or proxy) are sent to members in advance of the meeting.

The amount of time involved in assisting with the ongoing operation of the organization depends on the nature of the assistance the member may wish to volunteer.

6) What do members get out of membership?

Members will hopefully obtain a sense of satisfaction in contributing their time and efforts, small or large, to helping make progress against the disease of choroideremia.

7) Is the CRFC an association of those afflicted with choroideremia or whose lives are somehow affected by choroideremia?

People who volunteer as members will have an interest in advancing the choroideremia research project, and that interest, in turn, may be motivated by either personal experience with the disease or connections to family or friends who are impacted by it. However, being directly affected by the disease is not a specific criterion for membership. As indicated above, the members of the CRFC are individuals who are interested in, and capable of, fulfilling the required governance functions, and who may be able to provide some time and expertise to help the CRFC carry out its mission, regardless of whether or not they are directly impacted by the disease. As a Canadian

charity created to fund medical research into choroideremia, the CRFC does not function as an association of those affected by the disease.

8) If I am looking for an opportunity to have general discussions about choroideremia and/or exchange information with others living with choroideremia, where can I go?

There is a free Yahoo mailing list (at <http://groups.yahoo.com/group/choroideremia/>) which is open to all and has subscribers from various parts of the world. One does not need to be a CRFC member to subscribe, and in fact, membership in the CRFC serves a different function (helping to oversee and operate a charitable corporation) than does reading or participating in the Yahoo list. Although some CRFC members may subscribe to this mailing list, the CRFC does not operate the list, and is not formally associated with it.

9) How does one become a member of the CRFC?

People interested in becoming CRFC members may complete an application for membership (available by contacting the CRFC—see #15 below) and send it, along with payment of the membership fee (see below) to the CRFC head office. Applications must be approved by the CRFC board of directors before becoming effective.

10) What are the costs of membership?

A CRFC membership fee is \$25 per year.

11) How can membership fees be paid?

Membership fees may be paid by sending a cheque to CRFC head office (see below) or online via credit card (or Paypal account) at the CRFC's website at www.choroideremia.ca by clicking on the "Donate Now" button. Payments through the website are usually assumed to be donations, rather than membership payments, so if this method is used, please include a comment or send an email (which can be done through the website) advising the CRFC that the payment is to be treated as a membership fee.

In the case of new membership applications, the payment must be accompanied by a membership application form (see #9 above).

12) Is a charitable tax receipt issued for membership fees?

Yes. Since no benefit of material financial value is provided by the CRFC to members in exchange for membership fees, the Canada Revenue Agency permits charitable tax receipts to be issued for such fee payments.

13) What is the membership period?

A membership applies to a calendar year. New members who join after July 1 of a specific year are considered to be members through to Dec. 31 of the following year. I.e. their first membership fee covers the remainder of the current year, and the entire following year.

14) How do I know when my membership renewal is coming due?

The CRFC Secretary will contact members to advise them of membership expiry.

15) Where can I obtain further information?

General information about the CRFC is available at www.choroideremia.ca. Further information about membership, or about any other aspect of the CRFC can be obtained by contacting the CRFC at

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