

Choroideremia Research Foundation Canada Inc.

Privacy Policy

1. Introduction

During the time of formation and following, the Foundation has accumulated considerable personal information, both qualitative and quantitative, about our current, former and prospective donors.

“Personal information” refers to home addresses and other home-related contact information, opinions and beliefs, birthdates and other identifying data.

The CRFC presently has no paid staff. Where the term "staff" is used in this policy, it includes reference to any paid staff the CRFC may, in future, engage, and any volunteers who conduct, or who assist in the conducting, of CRFC operations. The term "donor(s)" includes members of the CRFC, unless otherwise noted.

2. Policy Intent and Goals

Collecting personal information about our donors is essential to the CRFC's ability to provide customized stewardship, to update donors on our accomplishments and challenges, and to advise our donors that their contributions are being used for their intended purposes.

In response to the introduction of the *Personal Information Protection and Electronic Documents Act* in 2004, as a registered charity the Foundation has put this policy in place to ensure that donor information is adequately protected.

3. Policy

This policy is intended to fulfill the following principles:

- a) **Accountability:** the CRFC is responsible for maintaining and protecting the personal information in its possession.
- b) **Identifying Purposes:** the purposes for which personal information is collected shall be identified before, or at the time, the personal information is collected.
- c) **Consent:** the individual's consent will be obtained for the collection, use or disclosure of personal information, except where the law provides an exemption. Consent may be expressly obtained (for example, in a signed consent, email, or completed donor pledge form) or implied.

When the CRFC receives personal information from donors that enables us to provide a service, such as processing a donation, consent to allow the CRFC to deal with that personal information in a reasonable manner would be implied. When consent is given verbally (for example, by telephone), the CRFC will confirm the verbal consent with subsequent correspondence.

d) Accuracy: the CRFC will keep personal information as accurate, complete and up-to-date as may be necessary to fulfill the purposes for which it is to be used.

e) Limiting Collection: the personal information the CRFC collects shall be limited only to that which is necessary for the purposes identified.

f) Limiting use, disclosure and retention: Personal information shall only be used or disclosed for the purposes for which it was collected, unless an individual has otherwise consented or when it is required or permitted by law. Personal information will be retained only as long as necessary for the fulfillment of those purposes.

g) Safeguards: Physical, electronic and procedural safeguards will be employed to protect CRFC systems and all personal information under our control against unauthorized access and use.

h) Openness: the CRFC will provide information to individuals about our policies and procedures relating to the management of personal information that is under our control.

i) Individual's Access: On written request to our Privacy Officer, donors will be informed of the existence, use and disclosure of their personal information that is in the possession of the CRFC, and may be given access to that personal information as required and permitted by law. Individuals are entitled to challenge the accuracy and completeness of that personal information and request that it be amended. The CRFC will make the requested amendment, if it is deemed to be appropriate.

j) Right to Challenge CRFC Compliance: Individuals will also be able to address a challenge concerning compliance with the above principles to the Privacy Officer.

4. Implementation

a) The CRFC will designate one or more individuals, including a Privacy Officer, to be accountable for compliance with the above principles.

b) Electronic donor records will be stored in dedicated CRFC databases, protected via password control or physical access control as appropriate. Apart from a limited number of individuals specifically responsible for CRFC work, staff does not have access to the CRFC databases.

c) Hard copy donor records will be kept in locked cabinets, or in locked premises, in a

secure place.

- d) Qualitative information will be accurately recorded, in hard copy and/or electronically, in a fact-based and objective manner (i.e. a manner that would be appropriate were an individual to view their own information).
- e) The CRFC will not sell, disclose, barter or trade its donor lists with any organization or individual, including other organizations (Canadian or foreign) engaged in funding research into choroideremia. In some circumstances, we may be required to provide personal information to third parties for legal, audit, or regulatory purposes.
- f) The CRFC will ensure that any third-party contractors it engages will conform to this policy, where applicable.
- g) Individuals or organizations will have the option to decline information updates, and ask to be removed from the CRFC database for the purposes of future mailings and correspondence. (Historical records will be retained for the period(s) of time necessary to meet audit and Canada Revenue Agency and/or other regulatory data retention requirements.)
- h) Training will be provided to or obtained by appropriate staff including the individual designated as Privacy Officer.
- i) This policy will be subject to regular review to ensure its currency related to legislation and regulations.
- j) Donors may ask for further information with respect to CRFC privacy policy or initiate a challenge to compliance by directing their enquiry in writing to the Privacy Officer, Choroideremia Research Foundation Canada Inc , 16 Candlewood Drive, Brantford, Ontario, N3R 6A1 CANADA.
- k) The CRFC will place prominent notice of this privacy policy on its website; hard copies are available by calling (519) 758-0847 or by fax to (519) 758-0448.