

PRIVACY POLICY

1. OUR COMMITMENT

Cystic Fibrosis Canada (“CF Canada”) is committed to protecting the privacy of the personal information of its stakeholders. We value the trust of those we deal with, and of the public, and recognize that maintaining this trust requires that we be transparent and accountable in how we treat the information that you choose to share with us.

During the course of our various projects and activities, we may gather and use personal information. Anyone from whom we collect such information should expect that it will be carefully protected and that any use of, or other dealing with this information, is subject to consent. Our privacy practices are designed to achieve this.

2. DEFINING PERSONAL INFORMATION

“Personal information”¹ includes any factual or subjective information, recorded or not, about an identifiable individual. This includes information in any form such as:

- age, name, ID numbers, income, ethnic origin, or blood type;
- opinions, evaluations, comments, social status, or disciplinary actions; and
- employee files, credit records, loan records, medical records, existence of a dispute between a consumer and a merchant, intentions (for example, to acquire goods or services, or change jobs).

In the course of our organizational activities, this may include such information as financial information related to processing donations or information about an individual having cystic fibrosis.

Exception:

- Business contact information and certain publicly available information, such as names, addresses, and telephone numbers as published in telephone directories, are not considered personal information. Where an individual uses his or her home contact information as business contact information as well, we consider that the contact information provided is business contact information, and is not therefore subject to protection as personal information.

3. PRIVACY PRACTICES

Personal information gathered by our organization is kept in confidence. Our personnel are authorized to access personal information based only on their need to deal with the information for the reason(s) for which it was obtained. Safeguards are in place to ensure that the information is not disclosed or shared more widely than is necessary to achieve the purpose for which it was gathered. We also take measures to ensure that the integrity of this information is maintained and to prevent its being lost or destroyed.

¹ Personal Information Protection & Electronic Documents Act (PIPEDA), SC, 2000 c5.

We collect, use and disclose personal information only for the purposes that a reasonable person would consider appropriate in light of the circumstances. Unless disclosure is compelled by law, we offer individuals the opportunity to opt not to have their information shared for purposes beyond those for which it was explicitly collected.

4. WHAT PERSONAL INFORMATION DO WE COLLECT ABOUT YOU?

We may collect, use, store and disclose different kinds of personal information which we have grouped together as follows:

- **Identity Personal information** includes first name, last name, company you work for
- **Contact Personal information** includes address, email and telephone numbers
- **Financial Personal information** includes bank account and credit card details
- **Transaction Personal information** includes details about payments
- **Technical Personal information** includes internet protocol (IP) address, your login personal information, time zone setting and location
- **Profile Personal information** includes your username and password, donations made by you, your interests, preferences, and feedback
- **Usage Personal information** includes information about how you use our website
- **Marketing and Communications Personal information** includes your preferences in receiving marketing from us and our third parties and your communication preferences

5. HOW IS YOUR PERSONAL INFORMATION COLLECTED?

We use different methods to collect personal information including through:

- 1) **Direct interactions.** You may give us your contact, transaction and financial personal information by filling in forms or by corresponding with us by post, phone, email or otherwise. This includes personal information you provide when you:
 - a) Make a donation and receive a tax receipt, if applicable;
 - b) Subscribe to our publications or to contact us or provide feedback;
 - c) Request marketing to be sent to you; or
 - d) Give us feedback or contact us.
- 2) **Automated technologies or interactions.** As you interact with our website, we will automatically collect technical personal information about your equipment, browsing actions and patterns. We collect this personal information by using cookies, server logs and other similar technologies. We may also receive technical personal information about you if you visit other websites employing our cookies.
- 3) **Third parties or publicly available sources.** We will receive personal information about you from various third parties as set out below:
 - a) Technical personal information from:
 - i) Analytics providers such as Google Analytics;
 - ii) Digital marketing service platforms such as MailChimp;
 - iii) Advertising networks such as Google Adwords and Facebook.
 - b) Contact, financial and transaction personal information from payment processing providers.

6. WHEN, WHERE AND WHY DO WE COLLECT/PROCESS PERSONAL INFORMATION?

We have set out below, a description of the ways we may use your personal information, and which of the legal bases we rely on to do so. We have also identified what our legitimate interests are where appropriate.

Table: Purposes for which we will use your personal information

Purpose/Activity	Type of personal information	Who do we share your personal information with for these purposes
To make a donation, including one-time and monthly monetary donations, and donations of securities and mutual funds and receive a charitable tax receipt, if applicable.	(a) Identity (b) Contact (c) Financial (d) Transaction	(a) We share your Financial personal information only with our third party payment processor, depending upon the type of donation. (b) If you make a donation through a page created by a Team or Individual to fundraise for charity, we share your name and email with the page owner so they can thank you for your contribution; we only share your name, donation amount and/or message to the fundraiser publicly on the page if you provide us explicit consent to do so. (c) If you chose to send an eCard to announce a donation made in memory or honour of someone, we share your name and email with the recipient so they can thank you for the gift.
To subscribe to our publications; to contact us or provide us feedback; to participate in a survey.	(a) Identity (b) Contact (c) Profile	(a) We do not share your personal information for this purpose.
To improve the performance of our marketing programs, and to deliver relevant content and advertisements to serve you better and grow charitable giving in Canada.	(a) Identity (b) Contact (c) Profile (d) Usage (e) Marketing / Communications (f) Technical	We may share your personal information with third party analytics and digital marketing service providers to assist us with these activities such as Facebook.

7. MARKETING

We strive to provide you with choices regarding certain personal information uses, particularly around marketing.

We may use your contact, technical, usage and profile personal information to form a view on what we think you may want or what may be of interest to you. This is how we decide which services may be relevant for you.

Where *Canada's Anti-spam Legislation (CASL)* applies to CF Canada communications with donors or volunteers, CF Canada is committed to complying with CASL and, in particular, the provisions setting out the requirements for sending commercial electronic messages.

You will receive marketing communications from us or any third party if you have requested information from us or made a donation to us and you have not opted out of receiving that marketing.

You can ask us to stop sending you marketing messages at any time by following the opt-out procedure on any marketing message sent to you or by contacting us at any time. Where you opt out of receiving these marketing messages, we may continue to use your personal information in order to provide you with the services you have requested from us.

8. CANADIAN CYSTIC FIBROSIS REGISTRY

CF Canada acts as the custodian for personal health information that is stored in the Canadian Cystic Fibrosis Registry. The Registry is managed by CF Canada using data provided by CF clinics across Canada. The management of data for the Registry is governed by the Canadian Cystic Fibrosis Registry Data Governance Policies in accordance with applicable legislation.

9. CHANGE OF PURPOSE

If CF Canada wishes to use personal information for a new purpose, we will seek consent describing this new purpose and document that consent has been given.

Please note that we may process your personal information without your knowledge or consent, in compliance with the above rules, where this is required or permitted by law.

10. HOW LONG WILL WE RETAIN YOUR PERSONAL INFORMATION?

We will retain your personal information for as long as reasonably appropriate to fulfill the purposes we collected it for, including for the purposes of satisfying any legal, regulatory, tax, accounting or reporting requirements. We may retain your personal information for a longer period in the event of a complaint or if we reasonably believe there is a prospect of litigation in respect to our relationship with you. In some circumstances you can ask us to delete your personal information.

11. PIPEDA - PRIVACY PRINCIPLES

CF Canada's policies and guidelines concerning the collection, use and disclosure of information follow the 10 privacy principles set out in the federal *Personal Information Protection and Electronics Documents Act (PIPEDA)* and/or provincial/territorial legislation.

1. **Accountability for Personal Information** - CF Canada has designated individuals to be responsible for ensuring compliance with its Privacy Policy and PIPEDA principles.
2. **Identifying Purposes of the Information** - CF Canada will clearly identify the purposes for which it is collecting personal information.
3. **Consent for the Collection, Use or Disclosure of Information** - CF Canada will ensure consent for the collection, use and disclosure of personal information in whatever form.

4. **Limiting Collection of Personal Information** - CF Canada limits its collection of personal information only to that which is necessary for the identified purposes. We also have a responsibility to collect information in a fair and lawful way.
5. **Limiting Use, Disclosure and Retention** - CF Canada will ensure that the personal information collected will be used or disclosed only for the purposes for which it was collected. If another use or disclosure is planned, we will ensure consent to this new use or disclosure.
6. **Accuracy of Personal Information** - The personal information collected will be as accurate, complete and as up-to-date as necessary for its use.
7. **Safeguards for Personal Information** - CF Canada personnel at all levels will put in place security safeguards appropriate to the sensitivity of the information.
8. **Openness About the Management of Personal Information** - CF Canada will make readily available to individuals specific information about its Privacy Policy and its practices relating to the management of personal information.
9. **Individual Access to Personal Information** - If an individual requests access to his or her personal information, CF Canada will inform him/her of the existence, use, and disclosure of his or her personal information unless it would threaten the safety, health or mental health of an individual other than who made the request, cause immediate or grave harm, safety or mental health to the individual making the request, disclosure would reveal personal information of another person, or disclosure would reveal the identity of the individual who provided personal information about another individual, and that individual has not consented to the disclosure of his or her identity. If the individual is given access to the requested information, they will be able to challenge the accuracy and completeness of the information and have it amended as appropriate. CF Canada must inform the requester of the action taken with respect to the correction request. If CF Canada chooses not to make the correction, it should, where possible, annotate the personal information record with the correction that was requested but not made, and inform the requester of this decision.
10. **Challenging Compliance** - An individual will be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for CF Canada's compliance.

12. PERSONAL INFORMATION BREACH NOTIFICATION

Any privacy breach of personal information under the care of CF Canada must immediately be reported to CF Canada's Privacy Officer. The Privacy Officer will investigate the nature of the breach and will take appropriate action as required.

In the case of a personal information privacy breach where there is a loss or unauthorized access or disclosure of personal information, and there exists a real risk of significant harm to the individual(s), the individual(s) whose private information is breached will be notified promptly by the organization's Privacy Officer. In considering risk of significant harm to the individual(s) the sensitivity of the breached information and the probability that the information will be misused will be considered.

Based on the jurisdiction in which the affected individual(s) resides, the applicable regulatory authority may also need to be notified. The notice will include a description of the breach, the type of personal information involved, the date of the breach, assessment of the risk to the individual(s), an estimate of the number of individuals to whom there is a real risk, steps taken to reduce the risk, steps take to notify the individual(s), name and contact information of CF Canada's Privacy Officer.

Notice, to the individual(s) whose personal information is breached, must be given directly to the individual if possible, and must include a description of the breach, the type of personal information involved, the date of the breach, steps taken by Cystic Fibrosis Canada to reduce the risk of harm and the contact information of CF Canada's Privacy Officer should the individual(s) have questions.

The notification to the individual(s) must be in person, by telephone, mail, email or other form of communication that is reasonable. Indirect notification must be given if direct notification would cause harm to the individual(s), cause undue hardship to CF Canada, or if CF Canada does not have the individual(s) contact information. Indirect notification must be given by public communication or other similar measure.

If CF Canada notifies the individual(s) involved in a breach, it will also notify other organizations of the breach if such a notification may be able to reduce the risk of harm or mitigate it.

CF Canada will keep a record of any breaches and provide the information to the applicable regulatory authorities upon request. Records will be kept for a 24 month period following any breach.

13. WHEN THIS POLICY DOES NOT APPLY

- a. **Links to other websites** - CF Canada's website may include links to third-party websites, plug-ins, and applications. Clicking on those links or enabling those connections may allow third parties to collect or share personal information about you. We do not control these third-party websites and are not responsible for their privacy practices. When you leave our website, we encourage you to read the Privacy Policy of every website you visit if you have concerns about how your personal information is being used.
- b. **Information in a public forum** - Any information that you reveal in a public forum (e.g. social media) accessible through our site is not subject to our Privacy Policy, and will be seen by third parties not related to Cystic Fibrosis Canada and may be used by them to contact you or for unauthorized purposes.

14. UPDATING OF PRIVACY POLICY

We regularly review our privacy practices for our various activities. CF Canada reserves the right to modify or supplement this Privacy Policy at any time. If any changes are made to this Privacy Policy, a copy of the Privacy Policy as amended will be posted on our website as soon as practicable following that update.

Please check www.cysticfibrosis.ca or contact CF Canada at 1-800-378-2233 for information on our most up-to-date practices.

15. CONTACT INFORMATION

Questions, concerns or complaints relating to the CF Canada's Privacy Policy on the treatment of personal information should be e-mailed to privacy@cysticfibrosis.ca with Attention Privacy Officer in the subject line.

Further information on privacy and your rights in regard to your personal information may be found on the website of the Privacy Commissioner of Canada at www.privcom.gc.ca.

You have the right to make a complaint at any time to the relevant supervisory authority for personal information protection issues. You can contact the Office of the Privacy Commissioner of Canada (“OPC”), see: <https://www.priv.gc.ca/en/contact-the-opc/> (if you are concerned about CF Canada’s potentially commercial use of your personal information) or your applicable regulatory authority. We would, however, appreciate the chance to deal with your concerns before you approach the supervisory authority, so we encourage you to contact us in the first instance.

16. SHORT VERSION FOR USE ON WEBSITES AND/OR NEWSLETTERS

PRIVACY POLICY

Cystic Fibrosis Canada (“CF Canada”) is committed to protecting the privacy and the confidentiality of personal information collected by CF Canada, from CF Canada employees, members, donors, volunteers, and other stakeholders. In order to comply with privacy legislation, we have developed a *Privacy Policy*. Any personally identifiable information which is not publicly available about our employees, members, donors, volunteers and other stakeholders is considered personal information, and will be treated in accordance with this *Privacy Policy*.

Our Privacy Policy respects the ten foundational principles that form the basis of Canada’s Personal Information Protection and Electronic Documents Act (PIPEDA).

Details of our *Privacy Policy* are available by sending an e-mail to privacy@cysticfibrosis.ca with “Attention Privacy Officer” in the subject line, or by contacting CF Canada at 1-800-378-2233.

Approved by the Board of Directors – June 11, 2020