

Janeway Foundation Personal Information Practices



Introduction

This guide has been developed to help people understand how the Janeway Children's Hospital Foundation (the "Foundation") manages personal information. Personal information includes names, email addresses, mailing addresses, telephone numbers, payment information, and patient experience stories (which can include information on their diagnosis and treatment).

What personal information does the Foundation have? Tell me more about why the Foundation has it, where it comes from, what the Foundation does with it, and how long the Foundation keeps it?

Contacts

To understand the Foundation's personal information practices, it helps to first understand what is meant by a "contact". Like most charities, the Foundation maintains a list of people referred to as "contacts". Each contact has some sort of relationship with the Foundation. For example, a person may have become a contact because they gave a donation, subscribed to the Foundation's newsletter, participated in a Foundation lottery, or purchased something from the Foundation.

The Foundation maintains certain basic information about all contacts, such as name and email address. The Foundation uses this basic information to communicate with its contacts. For example, the Foundation might send an email to encourage donations as part of a new campaign. Or the Foundation might send a newsletter to keep contacts up to date on provincial pediatric care initiatives. Contacts can control what communications the Foundation sends them (with some exceptions). As well, contacts can be removed from the contact list upon request.

Depending on the relationship between the contact and the Foundation, the Foundation may have other information about the contact which it uses in other ways. For example, the Foundation keeps a record of each donor's gifts – this record is used to recognize the donor over their lifetime. The types of personal information associated with different types of contacts is discussed in more detail below.

The Foundation generally does not share information about its contacts unless it is legally required to do so by the Canada Revenue Agency. However, the Foundation provides the names and addresses of contacts to printing companies to prepare printed materials for mailing. These printing companies are required to protect this information and keep it confidential. The Foundation does not rent, trade, or sell information about its contacts.

Most personal information about contacts is never discarded – it is used to support the ongoing relationship with the contact. And, because the Foundation is a registered charity, the Foundation is legally required to maintain certain donor records. However, credit card information is not stored once it is processed. As well, some paper records related to donations are destroyed after several years once they are archived in electronic form (the Foundation is legally required to keep paper records for a specific period before they are destroyed).

Donor Contacts

Nearly everyone who gives a donation to the Foundation becomes a contact.

Examples of donor personal information include names, addresses, credit card numbers, and donation amounts. This information is collected when donors give to the Foundation. The Foundation uses this information to evaluate fundraising campaigns, to understand donor giving histories, to encourage future donations, and to recognize donors over their lifetime.

The Foundation collects donor personal information from donors, either through direct contact with a donor, through a fundraising service (e.g. CanadaHelps), or through the Foundation’s community partners. In the case of community partners, the Foundation encourages these partners to arrange for donations to be made directly to the Foundation; however, traditional “sponsor sheets” are sometimes used to record information about donations.

Purchase-Related Contacts

In addition to donors, anyone who purchases something as part of a Foundation fundraiser (e.g. lottery tickets) may become a contact.

Examples of personal information about purchase-related contacts includes names, mailing addresses, email addresses, and items purchased. This information is collected at the time the purchase is made.

In some cases, the purchases are made through a third-party with whom the Foundation has partnered. For example, the Foundation has partnered with another organization to administer the Foundation’s lottery sales – this other organization has specialized software that meets the requirements for holding a lottery in Newfoundland and Labrador. In these cases, the information about purchase-related contacts is forwarded to the Foundation by the Foundation’s partners.

Newsletter Contacts

Any contact that has provided their email to the Foundation will receive the Foundation’s newsletter unless they unsubscribe (that is, they tell the Foundation that they do not wish to receive the newsletter).

Anyone can sign up to receive the Foundation’s newsletter, which will also make them a contact. Subscribers must provide their name and email address.

Patient and Family Experience Contacts

Patients and their families sometimes share stories about a patient's diagnosis and treatment, or the support received by the patient and their family. These stories, along with photos and videos, help the Foundation explain how important it is to support pediatric care in the province. When a family shares their story, the parents and/or legal guardians of the patient may also become contacts.

For the most part, the Foundation collects these stories directly from patients and families; however, additional details about a patient's diagnosis and treatment are sometimes collected from medical staff. These stories are shared in many ways – the Foundation website, social media, print materials (e.g. brochures), presentations, videos, and television. The Foundation only collects and shares these stories, including information from medical staff, with the consent of parents and/or legal guardians.

Patient/family stories are not deleted unless a request is made by the patient/family. The Foundation periodically receives requests from the patients and families for information from their stories many years later. As well, some patient/family stories span more than one generation.

Other Personal Information

The Foundation has other personal information that is not associated with its list of contacts. This other personal information is discussed below.

Janeway Staff Information

Examples of personal information the Foundation collects about Janeway staff includes names, contact information (e.g. telephone number, mailing address, email address), photos, and medical specialties.

One of the ways that the Foundation collects and shares information about Janeway staff is as part of patient/family stories. As mentioned, Janeway medical staff sometimes provide details about a patient's diagnosis and treatment (with the consent of parents and/or legal guardians). As well, Janeway medical staff can help explain the importance of specialized equipment, pediatric research, staff education, and pediatric programs. Janeway staff information that is part of patient/family stories is kept as long as the patient/family story is kept.

The Foundation also collects personal information about Janeway medical staff as part of submissions to the Foundation's educational grant programs. Although submissions are evaluated by Eastern Health, copies of submissions (and information from the submissions) often come to the Foundation as part of the administration of the program. The Foundation shares stories about grant recipients in much the same way it shares patient/family stories to explain how important it is to support pediatric care in the province.

At present, Janeway staff information collected by the Foundation as part of these educational grant programs is only deleted upon request.

Foundation Volunteer Records

Exactly what personal information the Foundation collects (or creates) about a volunteer depends on the work that they will do. This personal information can include names, contact information (e.g.

telephone number, mailing address, email address), photos, credentials, references, vaccination records, schedules, and training-related records. This personal information is used to make sure that it is appropriate and safe for a volunteer to perform certain tasks, to work in certain locations, and/or to work with certain people. This personal information is also used to schedule volunteers.

The Foundation typically does not share personal information about volunteers. However, the Foundation is required to share certain information about its Board of Directors (who serve as volunteers) with the Canada Revenue Agency.

At present, records about Foundation volunteers are only deleted upon request.

Foundation Employee Records

Examples of personal information about Foundation employees include names, contact information (e.g. telephone number, mailing address, email address), photos, credentials, medical conditions, vaccination information, payroll information, and performance coaching information. Like volunteer records, this information is used to make sure that it is appropriate and safe for an employee to perform certain tasks, to work in certain locations, and/or to work with certain people. As well, employee information is needed for payroll and performance coaching.

For the most part, employee personal information is collected directly from employees; however, some information, such as peer performance reviews, are collected from other people. The Foundation only shares employee records as needed or as legally required. For example, the Foundation shares payroll information with its payroll processors and the Canada Revenue Agency.

At present, records about Foundation volunteers (and applicants) are only deleted upon request. That being said, many employee records must be kept for the duration of employment and several years after. As well, some information about the employee relationship, such as who worked with the Foundation and when, is never deleted.

Foundation Employee Recruitment Records

Exactly what personal information the Foundation collects (or creates) about job applicants depends upon what they provide to the Foundation and how far they advance in a job competition. This personal information can include names, contact information (e.g. telephone number, mailing address, email address), credentials, references, and medical conditions. This information is used to make sure that it is appropriate and safe for a prospective employee to perform certain tasks, to work in certain locations, and/or to work with certain people.

The Foundation only shares personal information about job applicants with those involved in the recruitment and hiring process.

At present, records about job applicants are only deleted upon request.

Event Participation Records

One of the ways that the Foundation encourages people to support its efforts is through events. Many events are run by Foundation partners, while some are run by the Foundation or as part of a team effort between the Foundation and its partners. Depending on the event, the Foundation may collect some personal information about event participants, such as name, contact information (e.g. telephone number, mailing address, email address), and photos/video. This information is used to run the event (e.g. notify participants of cancellations, thank people for participating), to report on the success of an event, and to promote future events. The Foundation ensures that it has the permission of participants to use and share photos/videos of their participation in an event.

At present, event participation records are only deleted upon request.

Activities which do not Require the Foundation to Handle Personal Information

Certain Foundation activities that involve personal information do not require the Foundation to handle this personal information. These activities are discussed below.

Website Traffic and Internet Advertising Analysis

The Foundation uses an analytics service to better understand how people engage with the Foundation's website and internet advertising. For example, this service tells the Foundation what percentage of website visitors come from each country/province, the types of pages that directed visitors to the website (e.g. search engine, charity website, social media), and what percentage of people who viewed an advertisement clicked on it.

To analyze website traffic, the analytics service collects partially-identifiable information about each visitor (e.g. Internet Protocol (IP) address) along with other information related to their website visit. Similar methods are used to analyze engagement with Foundation advertisements. This partially-identifiable information is not shared with the Foundation. The Foundation only knows general information about people who visit the website or view advertisements, such as the examples provided above.

Where does the Foundation store this personal information and how is it protected?

This personal information is stored in several places and is protected by many industry-standard safeguards, including confidentiality agreements, firewalls, encryption, and multi-factor authentication. For security reasons, the Foundation is only able to provide general comments about how and where personal information is stored and how it is protected – providing too much detail could make this information vulnerable to an attack.

Much of the Foundation's computing infrastructure is provided by Eastern Health. Some of the Eastern Health computing infrastructure used by the Foundation is owned and operated by Eastern Health, while other infrastructure is provided to Eastern Health (and in turn, the Foundation) "as a service". For example, the Foundation uses Eastern Health email infrastructure which includes some "as a service"

components. Eastern Health maintains an information security management system that uses many industry-standard safeguards. Eastern Health is not allowed to access the Foundation's information without the Foundation's permission.

Some of the Foundation's computing infrastructure is provided by other parties. For example, most donor records are kept in the Foundation's donor management system, which is a cloud-based solution provided "as a service" by a vendor that provides technology to charities. These other providers also protect their systems (and the information in it) using many industry-standard safeguards, such as firewalls, encryption, and multi-factor authentication. The Foundation uses contracts to ensure these protections. Also, like Eastern Health, these other service providers are not allowed to access the Foundation's information without the Foundation's permission.

The Foundation maintains some records on paper. These records are secured using physical controls, such as locked cabinets and locked offices. If service providers are hired to store documents, the Foundation uses contracts to ensure these protections.

What if I want to stop receiving certain communications from the Foundation?

If you no longer want to receive certain communications from the Foundation, you may ask the Foundation to change your communication preferences. However, as a registered charity, the Foundation must comply with legal requirements, so the Foundation may still need to contact you.

You can change your communication preferences by clicking the "Unsubscribe" or "Change My Preferences" link next time you receive an email from the Foundation. You can also change your communication preferences by contacting the Foundation at janewayfoundation@easternhealth.ca or (709) 777-4640.

What if I want to know exactly what information the Foundation has about me?

The Foundation is happy to tell you what personal information it has about you; though some exceptions might apply. The Foundation is also happy to correct any of your personal information that is incorrect and to tell you who has accessed your personal information (to the best of the Foundation's ability).

To access or correct your personal information, please contact the Foundation's President & CEO at janeway.foundation@easternhealth.ca or (709) 777-4640.

What if I have questions, concerns, complaints (or compliments) about the Foundation's personal information practices?

If you have questions, concerns, complaints (or compliments) about the Foundation's personal information practices, please contact the Foundation's President & CEO at janeWAY.foundation@easternhealth.ca or (709) 777-4640.

You may also contact the Privacy Commissioner of Canada to discuss a concern or to make a complaint. You can contact the Commissioner at:

Office of the Privacy Commissioner of Canada, 30 Victoria Street, Gatineau, Quebec K1A 1H3
1-800-282-1376
www.priv.gc.ca