Ataxia Charlevoix-Saguenay
Foundation
Research that heals

Privacy Policy

Adopted and entered into effect: October 2023

Last updated: March 2024

Contents

Privacy protection is important to the *Ataxia Charlevoix-Saguenay Foundation* (the “Foundation”). When carrying out its activities or with respect to its donors, website visitors, participants and partners, the Foundation ensures that confidentiality of personal information is always respected and ensures the respect of the applicable laws in this matter.

1. What We Collect

We collect personal information through email correspondence, forms, and website cookies. This information is collected during the following activities.

1.1. Patient Registry

We collect personal information to maintain a registry of patients affected by Autosomal Recessive Spastic Ataxia of Charlevoix-Saguenay (hereafter "ARSACS").

The registry allows the Foundation to:

- have an idea of the market size and potential for recruitment in clinical trials (which are crucial factors in our discussions with pharmaceutical companies regarding potential for the development of drugs and therapeutic medication);
- inform the people listed in the registry by email of opportunities to participate in research projects, clinical trials and of other important developments concerning ARSACS;
- to facilitate communication with researchers.

We aggregate and de-identify personal information in the registry and use the resulting statistics in awareness campaigns aimed at the public and at corporations, notably regarding the market that may exist for, among others, treatments and diagnoses relevant to ARSACS or for clinical trials.

We collect this information from you directly, or from the person authorized to provide them in your name (e.g. a parent or a tutor), when you enter this information into the form for this purpose on our website.

The mandatory information fields for each patient in the registry include:

- patient contact information (i.e. first and last names, postal and email address);
- patient gender and date of birth;
- in the case of a patient under 18 years of age, the name of the parent or the person who is otherwise authorized to consent on their behalf, the address of the parent or of person who is otherwise authorized, the email address of the parent or of the person who is otherwise authorized, the type of relation with the ARSACS patient.

The optional information fields include:

- patient phone number;
- name of attending physician;
- the phone number of the parent or person who is otherwise authorized.

1.2. Correspondence

When you write to the Foundation, it is possible that you may send us personal information.

1.3. Fundraising

When people make donations to the Foundation, we collect their name, address, phone number and credit card and/or banking information. We collect this information for the purpose of processing any payment associated with their donation. The information is also required to allow the Foundation to issue official tax receipts and to communicate with the donor to transmit the official tax receipt.

1.4. Scientific Activities

We may collect personal information during the scientific activities that the Foundation coordinates in relation to ARSACS (for example, scientific symposia and research projects that we receive from academic researchers). However, we do not collect any medical or scientific information from a person affected with ARSACS.

1.5. Website

We collect information regarding visitors to our website www.arsacs.com. We collect your IP address and the list of web pages that you visited.

2. Who has access to your information

2.1. Within the Foundation

Patient Registry. Within the Foundation, personal information in the patient registry is accessible only to the patient registry manager. This person will normally contact those who are registered roughly annually to ensure that the information is up to date.

Correspondence. When you write to the Foundation, your personal information is accessible only to members of our communications team.

Fundraising. Access to information related to fundraising activities of the Foundation is restricted to our communications team and to the person responsible to issue official tax receipts.

2.2. Externally

Patient Registry. Information in the registry is stored in a coded database located in Montreal. Coded backup copies of this information are maintained in a storage service in the United States provided by Dropbox Inc.

Correspondence. Correspondence is primarily sent to the Foundation via its website. Third parties who provide maintenance, technical development and hosting services may have access to the Foundation's correspondence to ensure the proper functioning of the relevant service.

For purposes of maintenance, hosting and technical development of the patient registry and the website, we allow some third parties to access the non coded content of the registry. This access is limited to what is necessary for this purpose. These third-party providers are corporations who provide hosting and other IT support.

Disclosure to police or other third parties. At the time that this policy was drafted, we have never received orders nor requests to disclose information including personal information from government authorities (e.g. a police service) nor a court, nor other third parties. If we receive such an order or request in the future, we will comply with them to the extent that we consider that we are legally required to do so.

3. How Long We Retain Your Information

Patient Registry. We retain the information in our patient registry until the relevant person withdraws their consent, until the purpose of the activity is realized, or we cease the activity.

Correspondence. We retain correspondence for a period of 6 years.

Fundraising and donations. We retain personal information related to fundraising and donations for a period of 6 years.

Academic symposia and research projects. We retain personal information for a period of 6 years.

Website. We retain personal information related to visitors to our website for a reasonable period.

Destruction of information. After the expiry of the retention periods set out above, we see to the destruction of the relevant personal information within a reasonable delay.

4. How to Access Your Information or Exercise another Right

You have the right to send to the Foundation:

- a request to access your personal information;
- a request to correct your personal information;
- a notice that you are withdrawing your consent to our use or disclosure of your personal information;
- a request to cease disclosing your personal information; or
- a complaint related to our protection of your personal information.

Please address all communication to our privacy officer
mailto:ataxia@arsacs.com
You may also send such communication by postal mail to the following address:

Privacy Officer
Ataxia Charlevoix-Saguenay Foundation
1000 Sherbrooke street West, room 2100
Montréal (Québec) H3A 3G4