

**LOEYS-DIETZ SYNDROME FOUNDATION CANADA/
FONDATION DU SYNDROME LOEYS-DIETZ CANADA**

PRIVACY POLICY

This Privacy Policy is effective as of February 9, 2022.

**IT IS AVAILABLE ON OUR WEBSITE AT
<http://www.loeysdietzcanada.org>**

**CETTE POLITIQUE DE CONFIDENTIALITÉ EST
DISPONIBLE EN LANGUE FRANÇAISE SUR
NOTRE SITE WEB À
<http://www.loeysdietzcanada.org>**

**This policy may be updated from time to time
and we strongly suggest that you frequently
refer to this policy by accessing the website.**

Loeys-Dietz Syndrome Foundation
Canada/Fondation du syndrome Loeys-Dietz
Canada, herein referred to as “**LDSFC**” or “**we**” or
“**our**” or “**us**”) wishes to give effect to the various
obligations concerning the protection of your
Privacy and Personal Information (as defined
below).

We are committed to collecting, using and
disclosing your Personal Information responsibly.
We will also try to be as open and transparent as
possible about the way we handle your Personal
Information. This Privacy Policy explains how we
collect, use, disclose and protect your Personal
Information, including Personal Health Information
when you use our services (the “**Services**”) in
accordance with the *Personal Health Information
Protection Act* (“**PHIPA**”), and the *Personal
Information Protection and Electronic Documents
Act* (“**PIPEDA**”) as applicable and the *Quebec Act
Respecting the Protection of Personal Information
in the Private Sector, the Quebec Civil Code and
other applicable laws* (“**Legislation**”).

1. DEFINITIONS

In this document, the following terms have the
following meaning unless the context requires
otherwise.

Collection means the act of gathering, acquiring,
receiving or obtaining Personal Information from
any source, includes third party sources, by any
means.

Consent means your authorization to act in
accordance with the mission or act which you wish
us to perform or the treatment of your Personal
Information. Consent may be given orally, in writing
or by clicking on an applicable box on our website
or ticking the box on the Consent form, which may
also be found on our website. **Consent is implied
in the event that after receipt of this Privacy
Policy, you continue to require our services.**

Disclosure means making Personal Information
available, or releasing it, to others outside of our
organization such as health care professionals and
your family or caregivers.

Privacy Impact Assessment (PIA) means an
assessment of the privacy-related factors of our
information system or electronic service delivery
involving the collection, use, communication,
keeping or destruction of Personal Information.

Personal Information means information about a
specific identifiable individual, regardless of form,
including, for example, name, date of birth, address
and Personal Health Information.

Personal Health Information means identifying
information about an individual in oral or written
form, which includes but is not limited to information:
relating to the physical or mental health of the
individual, including information that consists of the
health history of the individual’s family, and relating
to the providing of health care to the individual,
including the identification of a person as a provider
of health care to the individual.

Purpose means the Purpose or Purposes for which
the Personal Information is collected about you and
defined more clearly in Article 3 below.

2. ACCOUNTABILITY

LDSFC is responsible for information that it collects, or that is under its control. LDSFC will oversee compliance with the Legislation, as applicable, such as being responsible for the day-to-day collection and processing of Personal Information, responding to inquiries about information practices and responding to requests for access to or correction of Personal Information in its custody or under control.

We employ personnel who may be considered health information custodians (“**Health Information Custodians**”) as defined by the Legislation. Our Health Information Custodians may also collect, use or disclose Personal Health Information when you use our Services. LDSFC will oversee the compliance of our Health Information Custodians with the Legislation.

LDSFC and our Health Information Custodians are responsible for Personal Information in their possession or custody, including Personal Information that has been transferred to a third party for processing. We will use contractual or other means to provide a comparable level of protection while the information is being accessed and/or processed by that third party. To provide you with the Services, LDSFC and our Health Information Custodians will use service providers to perform services on LDSFC’s or our Health Information Custodians’ behalf such as storing and processing Personal Information. LDSFC and our Health Information Custodians will use reasonable efforts to ensure that third party service providers maintain protections on Personal Information in compliance with Legislation, as applicable. We will conduct PIAs in order to assure that Personal Information will receive adequate protection and amend our practices accordingly in the event any shortcomings are discovered.

LDSFC and our Health Information Custodians will implement policies and practices to give effect to the principles, including:

- Establishing procedures to receive and respond to complaints and inquiries;

- Establishing procedures to receive and respond to access and correction requests regarding health records; and
- Reviewing this Privacy Policy and other procedures regarding the protection of Personal Information on a regular basis, performing and reviewing the PIAs on a regular basis, providing a framework for the keeping and destruction of Personal Information and defining the roles and responsibilities of our personnel with respect to Personal Information.

3. PURPOSES

We collect Personal Information when we provide you with our Services. Principally, we collect the following Personal Information from you:

- Name and contact information (including address, telephone and email address);
- Date of birth;
- Other pertinent Personal Health Information;

The Purposes for which we collect your Personal Information and to provide you with information concerning Loeys-Dietz syndrome. **Note that we do not provide health or medical services nor are we responsible for the medical services or other referred services provided by third parties.** These referrals are provided as a service to you but such entities are not under our control.

We use your Personal Information to provide you with our services, to identify and contact you when you request our services, to allow us to contact you and communicate with you for the Purposes, to communicate with healthcare providers including our Health Information Custodians, physicians, nurses, therapists, physiotherapists, pharmacists and any other organizations if you provide your Consent for same. Nevertheless, in the event that you provide Personal Information to us for the purposes, your consent is implied for us to disclose to such professional as well as to authorized members of your family and/or caregivers. We will also use your Personal Information in order to respond to your requests to modify or correct your Personal Information, to plan, administer and

manage our internal operations, to fulfill any other purposes permitted or required by the Legislation or to meet any other legal or regulatory requirements.

If we wish to use your Personal Information for a purpose not described above, we will obtain your consent before changing the purpose with respect to your Personal Information subject to acceptance which may be provided in the Legislation.

We may use systems which automatically process your Personal Information for certain tasks and decisions in order to expedite processing of Personal Information for the Purposes.

We will seek your informed consent for the use and disclosure of your Personal Information and its subsequent use or disclosure of that Personal Information in a manner not stipulated herein.

4. LIMITING USE, DISCLOSURE AND RETENTION OF PERSONAL HEALTH INFORMATION

Personal Information shall not be used or disclosed for purposes other than those for which the information is collected, except with your express consent, or as permitted or required by law.

We use and disclose your Personal Information to service providers that help with LDSFC's operations, such as providing accounting and financial, audit, legal, consulting, practice management and organizing and storing LDSFC's or our Health Information Custodians' practice data. We require such service providers to only use your Personal Information for the Purposes described in this Privacy Policy.

We have protocols in place for the retention of Personal Information. We retain Personal Information for as long as necessary to fulfill the Purposes for which that Personal Information was collected and as permitted or required by applicable law. In destroying Personal Information. We have developed procedures to ensure secure destruction or anonymization in accordance with legal requirements.

5: ACCURACY OF PERSONAL INFORMATION

We endeavour to maintain that your Personal Information is as accurate, complete, and as up-to-date as necessary for the Purposes that it is to be used. Information shall be sufficiently accurate, complete and up-to-date to minimize the possibility that inappropriate information is used to make a decision about you. If you believe that our records of your Personal Information are or become inaccurate or incomplete, you may request in writing that we correct the record as described below.

6. SAFEGUARDS FOR PERSONAL HEALTH INFORMATION

We take reasonable measures to safeguard your Personal Information from unauthorized access, disclosure, use or tampering. Organizational, technological and physical safeguards are in place to protect your Personal Information against loss or theft, as well as unauthorized access, disclosure, copying, use or modification. Your Personal Information is protected by us, whether it is recorded on paper or electronically. We securely maintain and destroy Personal Information to prevent unauthorized access to the information even during disposal and destruction.

We take reasonable steps to verify your identity before granting you access to your account regarding our Services, however, you are solely responsible for maintaining the secrecy of your username, password and any other account information. We also take reasonable steps to ensure that our employees and Health Information Custodians are aware of the importance of maintaining the confidentiality of Personal Information and that unauthorized persons do not gain access to Personal Information that we have disposed of or destroyed.

Personal Information that we or our Health Information Custodians collect may be processed and stored on servers located in **Canada, the United States or elsewhere**. If Personal Information is processed and/or stored outside of Canada, it will be subject to the laws of the jurisdiction where it is processed and/or stored (as the case may be). As a result, Personal Information may be subject to access requests from

governments, courts, or law enforcement in those jurisdictions according to the laws in those jurisdictions. For example, information may be shared in response to valid demands or requests from government authorities, courts and law enforcement officials in those countries. Subject to applicable laws in such other jurisdictions, we use reasonable efforts to ensure that appropriate protections are in place to maintain protections on Personal Information that are reasonably equivalent to those that apply in Canada.

We will take measures to assess whether the Personal Information will receive an adequate protection in compliance with generally accepted data protection principals that are reasonably equivalent to those that apply in Canada and we will take measures to mitigate the risks identified in any PIA.

7. OPENNESS ABOUT PRIVACY

We will maintain internal practices relating to the management of Personal Health Information. This Privacy Policy provides you with a general description of our information practices, our contact information so that you may ask us questions regarding the use of your Personal Information, how you may access or correct your Personal Information held by us and an explanation as to how LDSFC and our Health Information Custodians collect, use and disclose your Personal Information.

8. ACCESS, CORRECTION AND DESTRUCTION OF PERSONAL INFORMATION

We will comply with the Legislation, as applicable, as they define your access and correction to records.

You are free to request correction of your Personal Information where you believe there is an error or omission. With respect to Personal Health Information collected by our Health Information Custodians, you are entitled to require that a statement of disagreement be attached to your information reflecting any correction that you requested but not made by our Health Information Custodians. You are also entitled to require that any person to whom the Personal Health Information has been disclosed within the year before your

request be notified of the correction or statement of disagreement.

You must send a written request to access or correct your Personal Information. Your written request must contain sufficient detail to enable LDSFC or our Health Information Custodians to identify and locate the record. To access your Personal Information please contact us at the address found below. LDSFC will contact you if your request is deficient or it needs to clarify the information you are requesting. LDSFC will also need to verify your identity before processing requests for your Personal Information.

Once the Purposes for which Personal Information was collected have been achieved, we will, at your request, destroy the Personal Information. In the event that we intend to use this Information for a serious and legitimate purpose in accordance with the legislation, we may anonymize the Information. You may request that we no longer disseminate your Personal Information and de-index any hyperlink attached to your name that provides access to the Information if the dissemination contravenes the law or the order of a court.

9. CHALLENGING COMPLIANCE

You can challenge LDSFC's or our Health Information Custodians' compliance with the principles with LDSFC's Contact Person who is accountable for LDSFC's compliance. The name and contact information of the Contact Person is available on request. We have in place procedures to receive and respond to your complaints or inquiries. To file a written complaint please contact us at the address found below. LDSFC will investigate each and every written complaint made to LDSFC. If a complaint is found to be justified, LDSFC will take appropriate measures, including, if necessary, amending any of LDSFC's policies and practices.

10. CONSENT OF MINORS

The consent of a minor under fourteen (14) years of age is given by the person having parental authority. The consent of a minor fourteen (14) years of age or over is given by the minor and by the person having parental authority.

11. CONTACT INFORMATION

If you have any questions, comments or concerns about this Privacy Policy, please contact us at **[insert email and name of contact person.]**

Please check back from time to time to ensure that you are aware of any updates or changes in this Privacy Policy. We will indicate on this page, the date this Privacy Policy was last revised. Your continued access or use of our services serves as acceptance of the Privacy Policy as revised.

12. CHANGES TO THIS PRIVACY POLICY

We reserve the right to change or replace this Privacy Policy at our sole discretion at any time.

Last revision date: the 9th day of February 2022.