

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

PRIVACY POLICY

This Privacy Policy is effective as of November 21, 2023.

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 same 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, your family or caregivers, and, where applicable, insurance companies and insurance policy holders where a transfer of insurance policies to LDSFC is contemplated.

Personal Information means information about a specific identifiable individual, regardless of form, including, for example, name, date of birth, address and Personal Health Information, as well as information with respect to potential donations of insurance policies which include names and addresses of the donor and the policy holder and insurance company, date of birth of the donor, medical information and death certificate of the donor.

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.

Policy means one or more insurance policies which a person or persons wish to donate or transfer to LDSFC.

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.

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 the procedures for the destruction of or anonymization of Personal Information;
- Establishing procedures to receive and respond to access and correction requests regarding health records;
- 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; and
- Reviewing and updating from time to time our policies with respect to the use of artificial intelligence (AI) and other tools for collection, retention, destruction and/or anonymization of Personal Information.

3. PURPOSES

We collect Personal Information when we provide 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 are as follows:

- a) To be able to provide our Services to you 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 to whom we may refer you.** These referrals are provided as a service to you, but such entities are not under our control;
- b) Where you wish to donate a Policy or Policies, we require this information in order to decide whether we will accept the donation and to provide us and all necessary persons with information with

respect to the prospective donation of Policies; and

- c) In order for us to better be able to improve our policies with respect to acceptance of donations of Policies, we will use the Personal Information to track the longevity of the Insureds under the Insurance Policy(ies); therefore, we will retain this Personal Information until such time as you pass away, whether or not we accept the donation of the Policies. Once you pass away and, subject to the legislative and tax requirements referred to elsewhere in this Policy, your Personal Information will be either destroyed or anonymized.

We use your Personal Information to provide 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 professionals 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 as well as to complete our study and preparation of documentation for the donation of the Policy(ies).

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 including electronic data processing systems, artificial intelligence (AI) and other 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. PORTABILITY

At your request we will confirm the existence of the Personal Information and communicate it to you and allow you to obtain a copy of it in the form of a written and intelligible transcript. Unless there are serious practical difficulties the Information will, at your request, be communicated to you in a structured commonly used technological format and will be communicated at your request to any person or body authorized by law to collect such Information.

If you are handicapped, reasonable accommodation will be provided upon request to enable you to exercise the rights of access provided for herein. We may charge you a reasonable amount for the transcription, reproduction or transmission of Personal Information, however, we will advise you of the cost prior to performing such service.

Note that no person of less than fourteen (14) years of age may demand to be informed of the existence of Information of a medical or social nature except through his attorney in the context of judicial proceedings nor may such Information be provided in the event that an opinion of a healthcare professional consultation will result in serious harm to your health.

If we refuse to grant any requests hereunder, we shall give you the reasons therefore.

We may communicate Personal Information about you in the event of your decease to your spouse or a close relative if the Information would help the applicant in the grieving process and if you have not recorded in writing your refusal to grant such right of access.

10. 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.

11. 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.

12. CONTACT INFORMATION

If you have any questions, comments or concerns about this Privacy Policy, please contact us at Joseph Galli, email:

info@loeysdietzcanada.org

13. CHANGES TO THIS PRIVACY POLICY

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

14. LANGUAGE OF THIS PRIVACY POLICY

This Privacy Policy exists on our website at the address indicated above in the French language. Cette politique de confidentialité existe sur le site web décrit ci-haut en langue française.

15. WEBSITE PRIVACY POLICY

This Privacy Policy governs the manner in which loeysdietzcanada.org collects, uses, maintains and discloses information collected from users (each, a "User") of the loeysdietzcanada.org website ("Site"). This privacy policy applies to the Site and all products and services offered by loeysdietzcanada.org.

LDSFC is subject to federal and provincial laws regarding the protection of personal information, namely the Personal Information Protection and Electronic Documents Act and the Act Respecting the Protection of Personal Information in the Private Sector. LDSFC takes privacy issues very seriously and adopts whatever measures are necessary to ensure the confidentiality of information that relates to you personally. By "personal information", we mean any information about you that you provide voluntarily and that is used to identify you. We do not process sensitive information that is not provided by the User via the Site or associated web services.

Personal information obtained through loeysdietzcanada.org is strictly confidential. The only employees with access to such personal information are those authorized to process inquiries or requests that concern the information provided. Except where required to provide a

service you signed up for or to give effect to a court order, personal information will never be made public, sold, or disclosed to third parties without your consent.

Personal Identification Information: We may collect personal identification information from Users in a variety of ways, including, but not limited to, when Users visit our site, register on the site, place an order, subscribe to the newsletter, respond to a survey, fill out a form, and in connection with other activities, services, features or resources we make available on our Site. Users may be asked for, as appropriate, name, email address, mailing address, phone number. Users may, however, visit our Site anonymously. We will collect personal identification information from Users only if they voluntarily submit such information to us. Users can always refuse to supply personally identification information, except that it may prevent them from engaging in certain Site related activities.

Non-Personal Identification Information: We may collect non-personal identification information about Users whenever they interact with our Site. Non-personal identification information may include the browser name, the type of computer and technical information about Users means of connection to our Site, such as the operating system and the Internet service providers utilized and other similar information.

Web Browser Cookies: Our Site may use “cookies” to enhance User experience. User’s web browser places cookies on their hard drive for record-keeping purposes and sometimes to track information about them. User may choose to set their web browser to refuse cookies, or to alert you when cookies are being sent. If they do so, note that some parts of the Site may not function properly.

How We Use Collected Information: loeysdietzcanada.org may collect and use Users personal information for the following purposes:

- To improve customer service: Information you provide helps us respond to your customer service requests and support needs more efficiently.
- To personalize user experience: We may use information in the aggregate to understand how our Users as a group use the services and resources provided on our Site.
- To improve our Site: We may use

feedback you provide to improve our products and services.

- To process payments: We may use the information Users provide about themselves when placing an order only to provide service to that order. We do not share this information with outside parties except to the extent necessary to provide the service.
- To run a promotion, contest, survey or other Site feature: To send Users information they agreed to receive about topics we think will be of interest to them.
- To send periodic emails: We may use the email address to send Users information and respond to their inquiries, questions, and/or other requests. If User decides to opt-in to our mailing list, they will receive emails that may include Foundation news, updates, related product or service information, etc. If at any time the User would like to unsubscribe from receiving future emails, we include detailed unsubscribe instructions at the bottom of each email.
- How we protect your information: We adopt appropriate data collection, storage and processing practices and security measures to protect against unauthorized access, alteration, disclosure or destruction of your personal information, username, password, transaction information and data stored on our Site.
- Sharing your personal information: We do not sell, trade, or rent Users personal identification information to others. We may share generic aggregated demographic information not linked to any personal identification information regarding visitors and users with our business partners, trusted affiliates and advertisers for the purposes outlined above.
- We may use third party service providers to help us operate our Foundation and the Site or administer activities on our behalf, such as sending out newsletters or surveys. We may share your information with these third parties for those limited purposes provided that you have given us your permission.
- Third party websites: Users may find advertising or other content on our Site that link to the sites and services of our partners, suppliers, advertisers, sponsors,

licensors and other third parties. We do not control the content or links that appear on these sites and are not responsible for the practices employed by websites linked to or from our Site. In addition, these sites or services, including their content and links, may be constantly changing. These sites and services may have their own privacy policies and customer service policies. Browsing and interaction on any other website, including websites which have a link to our Site, is subject to that website's own terms and policies.

Changes to this privacy policy:

loeydietzcanada.org has the discretion to update this privacy policy at any time. When we do, we will revise the updated date at the bottom of this page.

We encourage Users to frequently check this page for any changes to stay informed about how we are helping to protect the personal information we collect. You acknowledge and agree that it is your responsibility to review this privacy policy periodically and become aware of modifications. LDSFC will not provide email alerts or notifications when this Privacy Policy has been updated.

Your acceptance of these terms: By using this Site, you signify your acceptance of this policy and terms of service. If you do not agree to this policy, please do not use our Site. Your continued use of the Site following the posting of changes to this policy will be deemed your acceptance of those changes.

Last revision date: the 21st day of November 2023.