

PROVISIONS AND TEXT FOR OBTAINING CONSENT WITH RESPECT TO TREATMENT OF PERSONAL INFORMATION

You have requested LOEYS-DIETZ SYNDROME FOUNDATION CANADA/FONDATION DU SYNDROME LOEYS-DIETZ CANADA (“LDSFC”) assists you in providing information and referral services with respect to your diagnosis. You acknowledge that you are aware that LDSFC is not a health or social service provider, but attempts to assist persons with Loeys-Dietz syndrome and other Heritable Aortic Disorders (HAD) in finding appropriate information and assistance with their syndrome.

This call is made in order for you to consent to how we collect and deal with your Personal Information.

If you would prefer this conversation to take place in the French language, please advise and we will arrange for this consent to be done in that language.

Le présent appel a pour but d’obtenir votre consentement de la façon que nous récupérons et transigeons avec votre information personnelle. Si vous désirez que cette conversation ait lieu en langue française, veuillez nous aviser et il nous fera plaisir de la faire en langue française.

Prior to your communicating any Personal Information to us we require that you take knowledge of our Privacy Policy which is available at :

<https://www.>

Your communicating Personal Information to us is deemed to be confirmation that you have read, understood, and consent to the Privacy Policy.

We are dedicated to maintaining privacy of your Personal Information in accordance with applicable Canadian and Provincial privacy legislation and regulations. Our personnel will also comply with such laws and regulations. When you interact with us, we will be collecting information necessary to advise you with respect to obtaining further information and health services from their parties related to your syndrome. We will collect, store and transmit this Personal Information to third-parties who may be helpful to you such as third-party service providers, clinics, information providers and other similar agencies.

We will maintain reasonable security safeguards to protect your Personal Information. Your records may be processed or stored by us and third-party service provider hereinabove on servers located outside of Canada in jurisdictions such as the United States of America.

In addition, certain governments, courts or law enforcement agencies or regulatory agencies of different jurisdictions may be able to obtain your Personal Information in accordance with their respective laws.

If you are under the age fourteen (14), we require that the consent be granted by your parent or someone having parental authority. If you are a minor (under the age of eighteen (18) in Quebec), over the age of fourteen (14), we require your consent as well as that of your parent or other person having parental authority.

You have the right to access and correct your Personal Information, to withdraw your consent to our collection use and disclosure of your Personal Information in accordance with applicable laws and to require that the Personal Information be transferred to other agencies at your request, or in some cases, that the information be destroyed.

You are entitled to request that we cease disseminating your Personal Information and de-index any hyperlink attached to your name that provides access to the Personal Information if the dissemination would contravene the law or a court order.

Should you wish to exercise any of your rights or dispute our privacy practices you may contact our privacy officer at the following email address:

lindsay.parsons@loeysdietzcanada.org

If you consent to allow LDSFC to collect, use and disclosure your Personal Information as set forth hereinabove and in our Privacy Policy, please press 1 or say, "I consent" or tick the box below and forward to us at the above email address. If not, please hang up and do not provide any Personal Information to us.

I consent to the above stipulations.

I, parent or legal guardian of the minor who has signed above, consent to the above stipulations.
