

Privacy Policy

Background

The federal Personal Information Protection and Electronic Documents Act (PIPEDA) became law on January 1, 2004, and therefore, all organizations are regulated with respect to personal information collected from its constituents. At Muscular Dystrophy Canada, this includes persons with neuromuscular disorders and their families, donors, volunteers and employees. Where a province enacts legislation similar to the federal Act, the provincial statute will apply within the province, in primacy over the federal statute. The following policy is compliant with the British Columbia legislation Personal Information Protection Act (PIPA), effective, January 1, 2004.

Our Commitment

Muscular Dystrophy Canada is committed to protecting the privacy and safeguarding the personal information of all our stakeholders. Muscular Dystrophy Canada endeavours to adhere to all legislative requirements with respect to privacy.

We understand that personal information must be protected and therefore, Muscular Dystrophy Canada will:

- Provide the highest level of confidentiality around the collection, use and disclosure of your personal information;
- Collect only information and use that information with your knowledge and solely for the purpose you are seeking;
- Ask your permission before disclosing any personal information;
- Recognize your right of access to your personal information;

Be available to respond to your questions and concerns about the way we handle the privacy of your personal information.

Our Ten Privacy Principles

1. Accountability

Every employee and volunteer of Muscular Dystrophy Canada is responsible for maintaining and protecting personal information under his/her control. Muscular Dystrophy Canada has designated Melanie Towell as Muscular Dystrophy Canada's Privacy Officer, and is directly responsible for employee information. Other specific queries can be directed to one of the following staff members in regards to their area of management:

- [Berta](#) Mascarenhas, National Director, Marketing & Communications

- [Marla Spiegel](#), National Director, Research, Education and Advocacy
- [Melanie Towell](#), COO, Finance and Administration

2. Identifying Purposes

The purposes for which personal information is collected shall be identified at or before the time the information is collected, i.e. at the time of registration

3. Consent

The knowledge and consent of the individual are required for the collection, use or disclosure of personal information.

4. Limiting Collection

The collection of personal information shall be limited to that which is necessary for the purposes identified by the organization. Information shall be collected by fair and lawful means.

5. Limiting Use, Disclosure and Retention

Personal information shall not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information shall be retained only as long as necessary for the fulfillment of those purposes.

6. Accuracy

Personal information shall be as accurate, complete and up-to-date as is necessary for the purposes for which it is to be used.

7. Safeguards

Personal information shall be protected by security safeguards appropriate to the sensitivity of the information.

8. Openness

Muscular Dystrophy Canada shall make readily available to individuals specific information about its policies and practices relating to the management of personal information.

9. Individual Access

Upon request, an individual shall be informed of the existence, use and disclosure of his or her personal information and shall be given access to that information. An individual shall be able to challenge the accuracy and completeness of the information and have it amended as appropriate.

10. Challenging Compliance/Providing Recourse

An individual shall be able to address a challenge concerning compliance with the above principles to the designated individual or individuals accountable for the organization's compliance.

Complaints

An individual may complain to Muscular Dystrophy Canada's Privacy Officer who can be reached by [email](#) or 1.866.MUSCLE.8 ext. 130, or fax: 416.488.7523. If the response is not satisfactory, an individual may complain, in writing, to: Chair of the Board of Directors of Muscular Dystrophy Canada, 2345 Yonge Street, Suite 900, Toronto, Ontario M4P 2E5. If the matter cannot be resolved, an individual may file a complaint with the Privacy Commissioner of Canada (or applicable provincial body) about any alleged breaches of the law.

Approved by the Board of Directors on January 5, 2004.