



PERSONAL INFORMATION PROTECTION (PRIVACY) POLICY

Policy Statement

March of Dimes Canada (MODC) and its subsidiaries are committed to protecting the integrity and privacy of everyone's personal information under our control.

Among other things, MODC has adopted the *Ethical Fundraising & Financial Accountability Code* (Code) developed by the Canadian Centre for Philanthropy. MODC also has adopted practices and procedures, which give effect to the ten privacy principles contained in the federal *Personal Information Protection and Electronic Documents Act* (PIPEDA). MODC staff and volunteers have been trained on these practices and procedures and they have signed confidentiality agreements with MODC. Described below are the policies applicable to the manner in which MODC collects, uses, discloses and disposes of personal information.

Defined Terms

Under PIPEDA, the following terms have the meaning indicated:

"commercial activity" means any particular transaction, act or conduct or any regular course of conduct that is of commercial character, including selling, bartering or leasing of donor, membership or other fundraising lists.

"personal information" means information about an identifiable individual, but does not include the name, title or business address or telephone number of an employee of an organization.

Note: MODC is a not-for-profit organization engaged in charitable activities. From time to time, MODC shares its donor mailing list with other charitable organizations (MODC doesn't share its client lists). This is one of the best ways for MODC to find new supporters and expand our services for adults with disabilities, but it is considered a "commercial activity" according to the above definition.

Principles

MODC is responsible for personal information under its control and shall designate an individual to be accountable for the organization's compliance with the following principles.

Principle 1 – Accountability

- 1.1 The President and Chief Executive Officer of MODC has ultimate accountability for protecting the personal information of clients, staff, volunteers and donors. The President and Chief Executive Officer is supported in this activity by delegating the day-to-day operational privacy responsibilities to another individual. All MODC staff share the responsibility for adhering to MODC privacy policies and procedures.
- 1.2 The Chief Administrative Officer of MODC has been designated as the Chief Privacy Officer and oversees organizational compliance. Responsibility for the day-to-day

collection and processing of personal information has been delegated to others within MODC.

- 1.3 MODC is responsible for personal information in its possession or custody, including information that has been transferred to a third party for processing. MODC will use contractual or other means to provide a comparable level of protection while the information is being processed by the third party.
- 1.4 MODC has policies and practices to give effect to this policy, including:
 - a. Procedures to protect personal privacy;
 - b. Procedures to receive and respond to complaints and inquiries;
 - c. Training and communicating to staff about their obligations and responsibilities;
 - d. Executing third party contracts which may include additional provisions outside the scope of this policy in order to ensure specific contract compliance.

Principle 2 – Identifying Purposes

MODC identifies the purposes for which personal information is collected at or before the time the information is collected. The primary purposes are the delivery of services, fundraising, quality management, research, billing and meeting legal and regulatory requirements.

- 2.1 Identifying the purposes for which personal information is collected at or before the time of collection allows MODC to determine the information needed to be collected to fulfill these purposes.
- 2.2 The identified purposes are specified at or before the time of collection to the individual from whom the personal information is collected. Depending upon the way in which the information is collected, this can be done orally or in writing.
- 2.3 When personal information that has been collected is to be used for a purpose not previously identified, the new purpose shall be identified prior to use. Unless a law requires the new purpose, the consent of the individual is required before information can be used for that purpose.
- 2.4 All fundraising solicitations by or on behalf of MODC will disclose the purpose for which the funds are requested (Code).
- 2.5 Persons collecting personal information should be able to explain to individuals the purposes for which the information is being collected.

Principle 3 – Consent

The knowledge and consent of the individual is required for the collection, use, or disclosure of personal information, except where inappropriate.

In certain circumstances personal information can be collected, used, or disclosed without the knowledge and consent of the individual. For example, legal, medical, or security reasons may make it impossible or impractical to seek consent. When information is being collected for the detection and prevention of fraud or for law enforcement, seeking the consent of the individual might defeat the purpose of collecting the information. Acquiring consent may be impossible or

inappropriate when the individual is cognitively impaired, seriously ill or psychotic and the substitute decision maker is not available. (Additional information regarding this subject can be found in the Health Care Consent Act and the Substitute Decisions Act.)

- 3.1 Consent is required for the collection of personal information and the subsequent use or disclosure of this information. MODC will seek consent for the use or disclosure of the information at the time of collection. In certain circumstances, consent with respect to use or disclosure may be sought after the information has been collected but before use (for example, when MODC wants to use information for a purpose not previously identified).
- 3.2 MODC does not collect, use or disclose personal information without the knowledge and consent of the individual to whom it relates or the person's authorized representative, except where appropriate. MODC will be truthful in obtaining an individual's consent.
- 3.3 The form of the consent sought by MODC may vary, depending upon the circumstances and the type of information. In determining the form of consent to use, MODC shall take into account the sensitivity of the information, as well as disabilities if applicable.
- 3.4 In obtaining consent, the reasonable expectations of the individual are relevant. For example, an individual seeking service/admission should reasonably expect that MODC, in addition to using the individual's name and address for administration purposes, would also contact the individual to advise on the availability or change in the level of service provided. On the other hand, an individual would not reasonably expect that personal information given to an attendant would be given to a company selling accessibility products, unless consent were obtained.
- 3.5 The way in which MODC seeks consent may vary, depending on the circumstances and the type of information collected. MODC will generally seek express consent when the information is likely to be considered sensitive. Implied consent would generally be appropriate when the information is less sensitive. An authorized representative can also give consent.
- 3.6 Consent may be obtained in one of several ways, including:
 - a. On an application form or service agreement for a product or services;
 - b. A check off box on direct mail solicitations which permits an individual to indicate that their personal information is not to be given to other organizations; if the box is not checked, then it is assumed that consent has been given to share the information with other organizations;
 - c. Consent may be given orally when information is collected over the telephone;
 - d. On a charitable receipt when a donation is made,
 - e. At the time a product or service is used.
- 3.7 An individual may withdraw consent at any time, subject to legal or contractual obligations and reasonable notice. MODC will inform individuals of the implications of such withdrawal.

Principle 4 – Limiting Collection

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

- 4.1 MODC collects, fairly and lawfully, only sufficient information necessary to fulfill identified purposes; it has specified the type of information to be collected as part of its handling policies and practices.
- 4.2 Donors and prospective donors are entitled to know, upon request, whether an individual requesting funds (and personal information) on behalf of an organization is a volunteer, an employee or a hired funds-solicitor (Code).

Principle 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 (PIPEDA).

- 5.1 MODC will not sell its donor lists. Any sharing of donor lists is time limited and involves measures which permit us to verify the use of donor names by another organization.
- 5.2 If MODC transfers personal information to a third party for processing, MODC uses contractual or other means to ensure that the third party provides a comparable level of protection while the information is being processed
- 5.3 If MODC uses personal information for a new purpose, it will document this purpose.
- 5.4 MODC has guidelines and procedures with respect to the retention of personal information. These guidelines include minimum and maximum retention periods.
- 5.5 Personal information that is no longer required to fulfill the identified purposes will be destroyed, erased, or made anonymous. MODC has guidelines and procedures to govern the destruction of personal information. Care is exercised in destruction of personal information to prevent unauthorized access.

Principle 6 – Accuracy

Personal information shall be as accurate, complete, and up to date as is necessary to fulfil the identified purposes for which it is to be used (PIPEDA).

- 6.1 The extent to which personal information shall be accurate, complete, and up to date will depend upon the use of the information, taking into account the interests of the individual. Information shall be sufficiently accurate, complete, and up to date to minimize the possibility that inappropriate information may be used to make a decision about the individual.
- 6.2 MODC will not routinely update personal information, unless such a process is necessary to fulfill the purposes for which the information was collected.
- 6.3 Personal information that is used on an ongoing basis, including information that is disclosed to third parties, will generally be accurate and up to date, unless limits to the requirement for accuracy are clearly set out.

Principle 7 – Safeguards

Security safeguards appropriate to the sensitivity of the information will protect personal information (PIPEDA).

- 7.1 MODC utilizes several safeguard measures to protect personal information, regardless of format, against loss, theft, unauthorized access, disclosure, copying, use or modification. The nature of the safeguards will vary depending on the sensitivity of the information that has been collected, the amount, location, distribution, and format of the information, and the method of storage. The more sensitive the information, the higher level of safeguard that is employed.
- 7.3 The methods of protection include the following, depending on the circumstance:
 - a. Physical measures, for example, locked filing cabinets, alarm systems and restricted access to offices;
 - b. Organizational measures, for example, security clearances and limiting access on a 'need to know' basis;
 - c. Technological measures, for example, the use of passwords, firewalls and encryption.
- 7.4 MODC will make employees and volunteers aware of the importance of maintaining the confidentiality of personal information and requires them to sign confidentiality agreements.
- 7.5 Care shall be used in the disposal or destruction of personal information, to prevent unauthorized parties from gaining access to the information. 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.

Principle 8 – Openness and Transparency

MODC shall make readily available to individuals specific information about its policies and practices relating to the management of personal information (PIPEDA).

- 8.1 MODC will be open about its policies and practices with respect to the management of personal information. Information about such policies and practices is available upon request by an individual and includes:
 - a. The name, title and business address of the designated individual (Chief Privacy Officer) who is accountable for MODC policies and practices and to whom complaints or inquiries can be forwarded;
 - b. The means of gaining access to personal information held by MODC;
 - c. A description of the type of personal information held by MODC including a general account of its use;
 - d. A copy of any brochures or other information that explain MODC policies, standards, or codes;

e. A description of the type of information made available to related organizations of MODC.

8.2 MODC may make information on its policies and practices available in a variety of ways. For example, MODC may choose to make brochures available in its place of business, mail information to its customers, provide online access, or establish a toll-free telephone number.

Principle 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 (PIPEDA).

In certain situations, MODC may not be able to provide access to all the personal information it holds about an individual. Exceptions to the open access principle will be limited and specific. The reasons why access may be denied include prohibitive cost, references to other individuals, legal, security, or commercial proprietary reasons, and information that are subject to solicitor-client or legal privilege.

9.1 Upon request, MODC will inform an individual whether or not the organization holds personal information about an individual. MODC will indicate the source of this information in writing. MODC will allow the individual access to this information. However, MODC may choose to make sensitive medical information available through a medical practitioner. In addition, MODC will provide an account of the use that has been made or is being made of this information and an account of the third parties to which it has been disclosed.

9.2 An individual may be required to provide sufficient information to permit MODC to provide an account of the existence, use, and disclosure of personal information. The information provided shall only be used for this purpose.

9.3 In providing an account of third parties to which it has disclosed personal information about an individual, MODC will attempt to be as specific as possible. When it is not possible to provide a list of the organizations to which it has actually disclosed information about an individual, MODC will provide a list of organizations to which it may have disclosed information about the individual.

9.4 When an individual successfully demonstrates the inaccuracy or incompleteness of personal information, MODC will amend the information as required. Depending upon the nature of the information challenged, amendment involves the correction, deletion, or addition of information. Where appropriate, the amended information shall be transmitted to third parties having access to the information in question.

9.5 If a challenge is not resolved to an individual's satisfaction, MODC will make a record of the unresolved challenge and will endeavour to advise any other organizations to which it previously had provided the information about the existence of the challenge.

9.6 When an individual's request for personal information is denied, the individual will be advised in writing of the reasons for the denial.

9.7 Donor information is collected and stored by MODC in a manner consistent with ensuring the privacy of our donors. Access to donor records and information is managed carefully and maintained by senior staff within the Fund Development department.

Principle 10 – Challenging Compliance

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

The individual will be able to address a challenge concerning compliance with the above principles to the Chief Privacy Officer.

10.1 MODC has developed and implemented simple and accessible procedures for receiving and responding to complaints or inquiries relating to the handling of personal information.

10.2 MODC will inform individuals who make inquiries or lodge complaints of the existence of our complaint procedures and will investigate all complaints.

If a complaint is found to be justified, MODC shall take appropriate steps to address the complaint and, if necessary, make adjustments to its practices and procedures.

Contact Us

Please direct any questions about this policy or any other privacy related concerns or complaints to:

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