Privacy notice to stem cell registry participants

Our Commitment to Privacy
Canadian Blood Services is committed to protecting the privacy and security of personal information in our custody. This Notice explains how Canadian Blood Services collects, uses, retains and discloses the personal information it collects from or about individuals who register to participate in the Canadian Blood Services Stem Cell Registry and donors who are matched with a patient for stem cell donation.

What personal information do we collect?
Canadian Blood Services may collect and retain the following personal information when you participate, or attempt to participate, in our Stem Cell Registry:

- Contact information, such as your name, address, email and telephone number;
- Sex, ethnicity and date of birth;
- Responses to social and health questions;
- Details about your blood and stem cell donation history;
- Human leukocyte antigen (HLA) typing results obtained from your buccal swabs. HLA markers are used to match donors with patients in need of a stem cell transplant;
- Information pertaining to your ineligibility to donate, if applicable.

If you are a potential stem cell match for a patient, Canadian Blood Services may also collect the following personal information:

- Confirmatory and verification test results to determine if you are the best match for a patient;
- Blood typing, transmissible disease and other test results;
- Name and contact information for your health care provider for consultation purposes;
- Your provincial health insurance number;
- Donation outcome information, including test results, if you make a stem cell donation;
- Expense and reimbursement information if travel is required to make a stem cell donation.

How do we use your personal information?
Canadian Blood Services collects and retains your personal information so that we may assess your eligibility to participate in our Stem Cell Registry as a potential stem cell donor and to ensure the safety of blood, blood products and stem cells for recipients. Your personal information may also be used to:

- Send you a buccal swab kit;
- Match and assess your compatibility with patients in need of a transplant;
- Contact you if you are a potential match for a patient;
• Provide you with test results or to request further tests, if required;
• Consult with your health care provider;
• Investigate and report potential donation related reactions or infections;
• Make our programs better and more efficient, including offering opportunities to provide feedback;
• Monitor and improve safety for donors and patients;
• Honour you at Canadian Blood Services award ceremonies and to recognize your contributions as a donor;
• Train employees;
• Contact you for fundraising purposes;
• Comply with legal and regulatory requirements;
• Fulfill any other purposes as permitted or required by law.

We may use your personal information to contact you regarding new and existing programs, activities, donor events and promotions; for opportunities to participate in research; or when there is an urgent need for blood donors. You may opt out of this contact by calling our National Contact Centre at 1 888 2 DONATE (1-888-236-6283).

Who do we share your personal information with?

Your personal information may be shared with the following:
• Canadian stem cell collection centres for the purpose of coordinating a donation;
• International stem cell registries for the purpose of matching potential donors to patients. You will be referred to by donor number only when your information is disclosed;
• Public health authorities in the case of positive transmissible disease test results;
• Other Canadian blood operators to ensure the safety of the entire blood system;
• Researchers provided the research has been approved by an independent research ethics board and meets legal and regulatory requirements;
• Auditors from Canadian Blood Services’ accreditation and regulatory bodies;
• Others as permitted or required by law.

If you are identified as a potential match for a patient and our Stem Cell Registry is unable to locate you using the contact information you provided, your name, date of birth and last address and telephone number on file will be disclosed to the Royal Canadian Mounted Police (RCMP) so they can attempt to locate you.

How do we protect your personal information?

Access to your personal information is restricted to Canadian Blood Services staff, volunteers and service providers who need access to this information to perform their jobs. All Canadian Blood Services employees and volunteers sign confidentiality agreements.
Canadian Blood Services may use third party service providers to perform services such as donor recruitment and communication. In some cases, our service providers may process or store data outside of Canada. These service providers are contractually obligated to implement appropriate safeguards to protect personal information and to use the personal information to which they have access for the purposes of providing these services for, or on behalf of, Canadian Blood Services.

**Withdrawing your consent to participate**

You may withdraw your consent to participate in our Stem Cell Registry at any time by submitting your request in writing to Canadian Blood Services’ Privacy & Access to Information Office by email at privacy@blood.ca, by fax to 613.739.2586, or by mail to 1800 Alta Vista Drive, Ottawa, ON K1G 4J5.

All personal information collected up to the date of your withdrawal will remain in the Stem Cell Registry but no further information about you will be collected. Your personal information will no longer be used to match you with a patient in need of a stem cell transplant.

**Accessing or correcting your personal information**

To request access to the personal information Canadian Blood Services retains about you, please visit our Access to Information page at www.blood.ca.

Canadian Blood Services offers an online Change Your Address form for revising your contact information and at any time you may update your contact information or contact preferences by calling 1 888 2 DONATE (1.888.236.6283).

**How to contact us**

For questions relating to stem cell donation, or enquiries about your eligibility to donate, please visit our website at www.blood.ca or contact Canadian Blood Services’ National Contact Centre:

Toll Free: 1 888 2 DONATE (1.888.236.6283)
Email: stemcellregistry@blood.ca

For questions or concerns about this Notice, please contact Canadian Blood Services’ Privacy & Access to Information Office:

Toll Free: 1.877.262.9191
Email: privacy@blood.ca

If you feel your concerns have not been addressed by Canadian Blood Services, you have the right to contact your provincial Information & Privacy Commissioner or Ombudsman.

Canadian Blood Services reserves the right to modify, amend or restate this Notice from time to time without prior notice.