

## **PRIVACY NOTICE TO PATIENTS** **OneMatch Stem Cell and Marrow Network**

### **Our Commitment to Your Privacy**

#### **Our Commitment:**

At Canadian Blood Services we are committed to protecting the privacy and security of all personal information in our possession. We do so by following relevant laws and best practices and encourage you to read our privacy policy on our website at [www.blood.ca/privacy](http://www.blood.ca/privacy).

#### **Purpose:**

Canadian Blood Services manages the OneMatch Stem Cell and Marrow Network which is a national program comprised of the OneMatch Stem Cell and Marrow Network Registry (the "OneMatch Registry") and the National Public Cord Blood Bank.

The purpose of the OneMatch Stem Cell and Marrow Network is to recruit healthy, committed volunteer donors for patients in need of stem cell transplants. The OneMatch Registry maintains an electronic listing of potential volunteer stem cell donors and a listing of donated umbilical cord blood units stored in the National Public Cord Blood Bank.

#### **About this Notice:**

Your health care team has told you that your condition would benefit from donated stem cells and has recommended that you allow the OneMatch Registry to conduct a search to identify a suitable unrelated volunteer stem cell donor or donated umbilical cord blood unit. In order to do so, we must collect certain personal information about you to conduct that search.

The following information will help you understand the role the OneMatch Registry has in conducting a search and in coordinating the provision of donated stem cells, as well as the management of personal information required by the OneMatch Registry: what information will be collected, what the information will be used for, and for what reasons Canadian Blood Services might disclose the information to other organizations.

#### **About OneMatch:**

OneMatch Stem Cell and Marrow Network operates according to international standards established by the *World Marrow Donor Association* (WMDA). The WMDA is the international organization that promotes the ethical, technical, medical and financial aspects of stem cell transplantation. By adhering to these standards, the OneMatch Registry has access to international registries with millions of volunteer adult donors and umbilical cord blood units.

OneMatch Registry staff coordinates searches in Canada and with international registries to identify suitable stem cell donors or umbilical cord blood units for patients in need of a stem cell transplant. Potential adult stem cell donors and mothers wishing to donate umbilical cord blood must meet a variety of eligibility requirements and undergo a health assessment to ensure the donation process will be safe for them and anyone receiving their stem cells.

#### **What is Personal Information?**

Personal information, which includes personal health information, is information that may be used to identify you. It includes such details as name, address, date of birth and health status.



**Collection of Personal Information:**

Canadian Blood Services will collect certain personal information from your transplant centre, such as name, diagnosis, age, compatibility typing and ethnicity. This information is necessary to search for a suitable stem cell donor or umbilical cord blood unit in the OneMatch Registry and international registries. Your personal information is put into an electronic database which forms part of OneMatch Stem Cell and Marrow Network. The servers for the database are located in Ottawa, Ontario. Because your personal information will be held in Ontario, it may be subject to the privacy laws in Ontario, as well as any privacy laws in your own province.

If you receive a stem cell transplant, we may collect certain post-transplant personal information from your transplant centre, indicating how well your body accepted the stem cells. This information is used by OneMatch Stem Cell and Marrow Network to track the success of the transplants we have facilitated. We are required to collect and track this information to maintain accreditation, and it also helps us understand what factors contribute to a successful stem cell match. In the event that you are transplanted with cells from an international donor or umbilical cord blood unit, this information may also be reported to the registry or cord blood bank that provided those cells. If you receive a stem cell transplant from a voluntary adult donor, and unless you indicate otherwise, information about the outcome of your transplant may be provided to the donor but you will not be identified. If you receive a cord blood transplant, your information will not be shared with the donor's family.

**How Do We Use Your Personal Information?**

Your personal information in the OneMatch Registry may be used to:

- Update and maintain your medical status;
- Search for potential stem cell donors or umbilical cord blood units;
- Contact the transplant centre with which your physician is associated - in the event that a match is identified;
- Assess the quality of the match;
- Track the outcome of your transplant;
- Make our services better and more efficient;
- Support our education and training activities;
- Comply with legal and regulatory requirements; and
- Fulfill any other purposes prescribed by law.

**Your Personal Information May be Shared with:**

- International registries to search for potential stem cell donors or umbilical cord blood units, and, if you receive a transplant, to follow up on the effectiveness of the treatment. As these registries are located in other jurisdictions, their data protection laws may differ from the jurisdiction in which you live;
- Bone Marrow Donors Worldwide: a European organization whose main goal is to collect the HLA phenotypes of volunteer stem cell donors and cord blood units and to co-ordinate their world-wide distribution;
- Health care professionals at your transplant centre;
- Where a potential match has been identified, international registries or Canadian collection centres for purposes of
  - assisting in evaluating the suitability of a potential donor and
  - labelling donated stem cells for transplant to you;
- Accreditation and regulatory bodies provided they agree to keep it confidential; and
- Others, as authorized or required by law.



**Withdrawing from OneMatch:**

If you do participate and later decide to withdraw from the OneMatch Registry, you must discuss the decision with your transplant program team. Following this discussion, if you still want to withdraw from the OneMatch Registry, they will contact Canadian Blood Services. **If you withdraw from the OneMatch Registry, your personal information will no longer be used by the OneMatch Registry to search for a suitable stem cell donor or umbilical cord blood unit.** All personal information collected up to the date of your withdrawal of consent will remain in the OneMatch Stem Cell and Marrow Network database, but no further information will be collected or added to your record.

**How to Contact Us:**

You may contact our Privacy and Access to Information Office for more information about our privacy and access practices, or to request access to or correction of your personal information as follows:

**In Writing:**

Canadian Blood Services  
Privacy and Access to Information Office  
1800 Alta Vista Drive  
Ottawa, ON K1G 4J5

**By phone:**

1-613-739-2483  
1-877-262-9191 (toll free)

**By e-mail:**

Privacy Office - [privacy@blood.ca](mailto:privacy@blood.ca)  
Access to Information Office - [ati@blood.ca](mailto:ati@blood.ca)

**Website:** [www.blood.ca](http://www.blood.ca)

If you feel your concerns have not been addressed by Canadian Blood Services you have the right to contact your provincial Privacy Commissioner or Privacy Ombudsman. For their contact information, look on [www.blood.ca](http://www.blood.ca) under Privacy and Access.