

CANADIAN BLOOD SERVICES STEM CELL REGISTRY PRIVACY NOTICE FOR PATIENTS



The Canadian Blood Services Stem Cell Registry (herein known as “The Registry”) is a national program (excluding Québec) dedicated to recruiting healthy, committed volunteer unrelated donors for patients in need of stem cell transplants. The Registry maintains an electronic listing of potential unrelated stem cell donors and a listing of donated umbilical cord blood units stored in the Canadian Blood Services Cord Blood Bank.

Collection, Use and Disclosure of Your Personal Information

The Registry coordinates searches in Canada and other registries and cord blood banks to identify suitable unrelated stem cell donors or donated umbilical cord blood units. In order to do so, we must collect certain personal information from patients to conduct these searches.

Canadian Blood Services will collect personal information from your transplant centre and health care professional, such as name, date of birth, gender, weight, age, diagnosis, current medical status, previous transplant history, compatibility typing and ethnicity. This information is necessary to search for a suitable unrelated stem cell donor or umbilical cord blood unit in The Registry, Héma-Québec’s Stem Cell Donor Registry and international registries. Your personal information is put into an electronic database which forms part of The Registry.

If you receive a stem cell transplant, we may collect certain post-transplant personal information from your transplant centre and health care professional, indicating how well your body accepted the stem cells. This information is used by The Registry to monitor the outcome of the stem cell transplants we have facilitated and it helps us understand what factors contribute to a successful transplant. If you are transplanted with cells from another registry or cord blood bank, this information may be reported to the registry or cord blood bank that provided those cells. If you receive a stem cell transplant from an unrelated 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 Registry will be used to:

- Update and maintain your current medical status
- Search for potential unrelated stem cell donors or umbilical cord blood units
- Contact the transplant centre with which your physician is associated
- Assess the quality of the stem cell match
- Monitor the outcome of your transplant
- Improve our programs
- Support our education and training activities
- Comply with legal and regulatory requirements; and
- Fulfill any other purpose as permitted or required by law

Your Personal Information May be Shared with:

- Héma-Québec and 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 outcome of your transplant.

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As these registries are located in other jurisdictions, their data protection laws may differ from the jurisdiction in which you live

- Other registries or Canadian (excluding Quebec) collection centres for the following purposes where a suitable unrelated donor has been identified:
 - Assisting in evaluating the suitability of a potential donor; and
 - Labelling of the donated stem cells intended for your transplant
- World Marrow Search and Match to search for potential matches
- Accreditation and regulatory bodies; and
- Others, as permitted or required by law

Accessing or Correcting Your Personal Information

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

How to Contact Us:

For questions or concerns about this Notice, including withdrawing your consent to collection, use and disclosure of your personal information, please contact a Canadian Blood Services privacy officer.

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.