

Notice to Obtain Consent from Patients Participating in the Canadian Transplant Registry

Purpose

The Canadian Transplant Registry (the “Registry”) provides a national listing of persons waiting for a heart, lung, liver, pancreas, kidney, small bowel or multi-organ transplant and a national listing of highly sensitized patients waiting for a kidney transplant. If an organ donor becomes available, organ donation organizations will search the Registry to identify a person waiting for an organ transplant.

Definitions

HLA Test Results: Human leukocyte antigen (HLA) typing is used to match persons waiting for an organ transplant and donors. HLA are proteins or markers found on most cells in the body. The immune system uses these markers to recognize which cells belong in one’s body and which do not.

Organ Donation Organization (ODO): Is the organization responsible for coordinating all organ and tissue donations (including organ procurement and allocation, single waiting list management and process improvement) within a particular province or geographic region. In Quebec, the ODO is Transplant Québec for organ donations.

Personal Information: Is information that is used to identify a person or that allows a person to be identified; for example, the person’s name, address, telephone number, date of birth, health care number, and includes personal health information.

Personal Health Information: Includes any Personal Information regarding a person’s medical profile or condition such as medical history, laboratory test results, etc., and includes transmissible diseases, blood group and HLA test results.

Referral Centre: Is a facility that refers patients that may require an organ transplant to a transplant centre.

Transplant Centre: Is the facility in Quebec responsible for registering persons waiting for a transplant with the ODO that will forward the data required to Canadian Blood Services to be listed and is where the organ transplant is expected to occur

Collection of personal information for the Registry

In order for you to participate in the Registry, your personal information will be collected by Transplant Québec and used to create a Registry record for you. This information may be collected by Transplant Québec from you, your hospital, your laboratory records or other medical records. Your personal information will be put into the Registry which is operated by Canadian Blood Services in Ottawa, Ontario. The Registry is a web-based business application that is accessed by authorized persons through a computer system.

Use of personal information for the Registry

Personal information in the Registry may be used:

- to update and maintain your medical status;
- to identify you as a potential match with an organ donor;
- to determine your HLA compatibility with an organ donor;
- by an ODO to manage offers of potentially suitable donor organ(s) received from another ODO;
- to contact you, through Transplant Québec, regarding opportunities to participate in voluntary research;
- to comply with legal and regulatory requirements, if required; and,
- to fulfill any other purposes prescribed by law.



Disclosure of personal information from the Registry

Personal information in the Registry may be disclosed:

- to health care professionals and medical data clerks at transplant centres and referral centres responsible for a person's care;
- to health care professionals and medical data clerks at organ donation organization's within Canada and their associated HLA laboratories when they access the Registry directly or when your personal information is downloaded into the organ donation organization's computer system, (NOTE: Canadian Blood Services will only permit ODO's to download your personal information if they have entered into a Data Sharing Agreement with Canadian Blood Services to keep your personal information confidential);
- to auditors, or others as permitted, or required, by law;
- to medical researchers needing to contact transplantees or persons requiring a transplant about volunteering for participation in research that has been approved by a research ethics board, if they consent; and,
- for any other purpose prescribed by law.

In addition, in accordance with applicable laws in Quebec, Canadian Blood Services may use or disclose personal information from your Registry record, but which does not identify you, to support research, continuous process improvement, long-term analytics and the Registry management policies.

If you receive a transplant, personal information about your surgery and surgical outcome will be entered into the Registry. Your transplant centre will also continue to monitor your health and the function of your organ after your surgery. Personal information, including medical test results from your hospital stay and follow-up visits with your transplant team, may be entered into your Registry record. This personal information may be used to measure the success of the Registry, improve the matching of donors and recipients in the future, and understand any long-term outcomes for people receiving organ transplants.

Commitment to Your Privacy

Canadian Blood Services is committed to protecting the privacy and security of your personal information in the Registry. Canadian Blood Services does so by following relevant laws and best practices.

Canadian Blood Services will grant access to the Registry only to those Canadian Blood Services staff members, health care professionals and authorized persons at organ donation organizations, transplant centres, referral centres and HLA laboratories who require access to the Registry in order to perform their job functions. All individuals who require access to the Registry are required to sign a pledge of confidentiality to keep personal information confidential.

Withdrawing Consent

If you decide that you no longer wish to participate in the Registry, please contact your transplant centre and you will be given a form to sign and return to Transplant Québec who will notify Canadian Blood Services. All of your personal information that has been collected up to the date of your withdrawal of consent will remain in the Registry, but no further personal information about you will be collected, used or disclosed by the Registry. Transplant Québec will use your personal information to contact you for safety reasons, if necessary.

IMPORTANT NOTICE: IF YOU WITHDRAW YOUR CONSENT PRIOR TO RECEIVING A TRANSPLANT, YOUR REGISTRY RECORD WILL NO LONGER BE AVAILABLE TO ORGAN DONATION ORGANIZATIONS ACROSS THE COUNTRY FOR THE PURPOSE OF IDENTIFYING YOU AS A POTENTIAL MATCH FOR A DONOR ORGAN.

How to Contact Canadian Blood Services



Canadian Blood Services
Société canadienne du sang

Canadian Blood Services respects your right to access and request correction of your personal information. You may contact Canadian Blood Services' Privacy & Access Office for more information about its privacy and access practices, or to request access to or correction of your personal information as follows (your request will be forwarded to Transplant Québec for processing):

- **In writing:**
Canadian Blood Services
Privacy & Access 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
Access to Information office – ati@blood.ca

More information regarding Canadian Blood Services' privacy practices can be found on our website at: 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. Look on our website for their contact information.