PUBLIC NOTICE FOR PARTICIPANTS OF THE CANADIAN TRANSPLANT REGISTRY

The Canadian Transplant Registry (the “Registry”) is operated by Canadian Blood Services in Ottawa, Ontario. The Registry provides a national listing of patients waiting for a heart, kidney, lung, liver, pancreas, 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 procurement organizations will search the Registry to identify patients who may be a potential match for transplantation. Organ procurement organizations are responsible for coordinating all organ donations in a particular geographic region.

Commitment to Your Privacy

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

What is Personal Health Information?

Personal health information is information that identifies you and that relates to your health status as a potential transplant recipient, including your health history, laboratory test results and health card number.

Collection of Your Personal Health Information

Canadian Blood Services will collect your personal health information from the Trillium Gift of Life Network, the organ procurement organization responsible for coordinating all organ donations in Ontario. Canadian Blood Services may also collect laboratory test results from the Human Leukocyte Antigen (“HLA”) laboratory(ies) associated with your transplant program. (Note: HLA laboratories perform tests necessary to match potential organ donors with patients in need of an organ transplant);

Uses of Your Personal Health Information

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

- update and maintain your medical status;
- manage organ offers;
- identify you as a potential match with a donor organ;
- contact you in the event that a match is identified; and
- comply with legal and regulatory requirements.

Disclosure of Your Personal Health Information

We may disclose your personal health information to:

- staff at organ procurement organizations within Canada and their associated HLA laboratories when they access the Registry directly or when your personal health information is downloaded into their computer system. Organ procurement organizations must sign an agreement with Canadian Blood Services prior to downloading information to their computer system.
- staff at your transplant program, associated HLA laboratory(ies), and referral centre who need the information to perform their job functions, (Note: Referral Centres are facilities that refer patients requiring an organ transplant to a transplant program to be listed on the Registry); and
- public health authorities, auditors, or others as permitted, or required, by law.
In addition, Canadian Blood Services may in accordance with applicable law disclose information from your Registry record which does not identify you, to support approved research, continuous process improvement, long-term analytics and organ allocation policy.

If you receive a transplant, your post-transplant personal health information may be entered into the Registry. This personal health information may be used to measure the success of the Registry, improve the matching of organ donors and recipients in the future, and understand any long-term outcomes for people receiving organ transplants. **Your Rights**

You have the right to:

(i) Be informed about Canadian Blood Services’ collection, use and disclosure of your personal health information for purposes of operating the Registry;

(ii) Refuse consent to participate in the Registry. If you decide that you do not wish to participate in the Registry please contact your transplant program to discuss your decision. **Important Notice:** If you withhold your consent to have your personal health information entered into the Registry or later withdraw your consent prior to receiving a transplant, your personal health information will not be available for the purpose of identifying you as a potential match for a donor organ. We strongly recommend that you discuss any decision to withhold or withdraw consent with your health care provider(s);

(iii) Contact Canadian Blood Services to request more information about our privacy and access to information practices, request access to or correction of your personal health information, or make a complaint. Our Privacy and Access Office may be reached at:

Canadian Blood Services
Privacy and Access Office
1800 Alta Vista Drive
K1G 4J5
Tel: 613-739-2483. Toll Free 1-877-262-9191(toll free)
Fax: 613-739-2345
Privacy Office: Privacy@blood.ca
Access to Information Office: ati@blood.ca
Web site: www.blood.ca

(iv) Make a complaint to the Information and Privacy Commissioner if you believe that we have contravened our Protection of Personal Information Policy or Freedom of Information Policy, or if you are not satisfied with the handling of your inquiry or complaint. The Ontario Information and Privacy Commissioner may be reached at:

Ontario Information and Privacy Commissioner
2 Bloor Street East, Suite 1400
Toronto, ON
M4W 1A8
Tel: 416-326-3333
Long Distance: 1-800-387-0073 (within Ontario)
Fax: 416-325-9195
info@ipc.on.ca