

CANADIAN BLOOD SERVICES

Notice to Donors Participating in the Living Donor Paired Exchange Registry

Purpose

The purpose of this Living Donor Paired Exchange Registry (the “Registry”) is to identify potentially suitable living kidney donors for people who need a kidney transplant and whose willing donor is not a match. You may be the donor of an incompatible donor-recipient pair or you may be a “non-directed” donor. A non-directed donor is an individual who is not part of an incompatible donor-recipient pair, but has indicated a willingness to donate to any suitable recipient.

Personal Information

Personal information is information that is used to identify you or that allows you to be identified; for example, your name, address, telephone number, date of birth, and health care number and includes personal health information.

Your **personal health information** includes any information regarding your medical profile or condition such as your medical history and laboratory test results, including transmissible diseases and blood group.

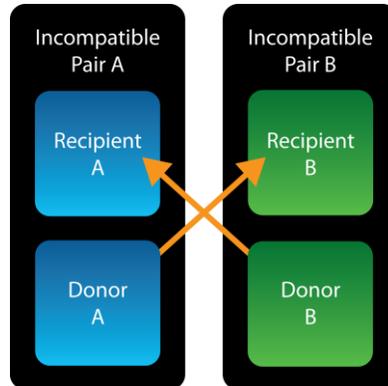
Use of your Personal Information

In order for you to participate in the Registry, staff at your transplant centre will need to collect personal information, which includes personal health information, about you and create a Registry record for you. This personal information may come from you, your hospital, your laboratory records or other medical records. Your personal information will be put into a computer system that is operated by Canadian Blood Services in Ottawa, Ontario. The computer system is part of the Living Donor Paired Exchange Registry.

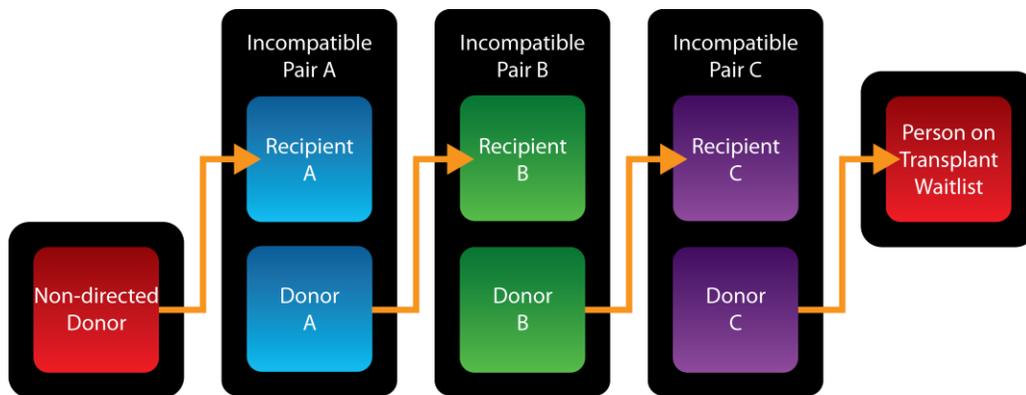
If you are a donor of an incompatible donor-recipient pair, the Registry will use your personal information to try to identify a medically compatible recipient to whom you would be able to donate a kidney. This may be a paired exchange of donors from two incompatible donor-recipient pairs in the Registry (Example A), or you may be part of a domino that begins with a non-directed donor (Example B). In Example B, you may be matched with a recipient in the Registry or you may be an “unmatched donor” at the end of a domino and be matched with a recipient on a transplant waitlist.

If you are a non-directed donor, the Registry will use your personal information to try to identify a medically compatible recipient to whom you would be able to donate a kidney. This donation will begin a domino exchange of donors. Once the Registry identifies a compatible recipient for your kidney, it will then try to match that recipient’s incompatible donor with another recipient in the Registry. If a matching recipient cannot be found, the incompatible willing donor now becomes an “unmatched” donor and will be matched with a recipient on a transplant waitlist.

Example A – Paired Exchange:



Example B - Domino:



We will use your personal information to:

- Try to match you with a potentially suitable recipient for your kidney,
- Contact you in the event that a compatible match is found,
- Contact you regarding opportunities to participate in voluntary research,
- Comply with legal and regulatory requirements, if required,
- Fulfill any other purposes prescribed by law.

Your personal information may be shared with:

- Health care providers at any transplant program involved with your care and with the transplant program of a recipient with whom you have been matched,
- Public health authorities, auditors, or others as permitted, or required, by law,
- Medical researchers needing to contact living donors or potential living donors about volunteering for participation in research that has been approved by a research ethics board,
- For any other purpose prescribed by law.

In addition, in accordance with applicable law in your jurisdiction, we may use or disclose information from your Registry record, but which does not identify you, to support approved research.

If you are matched and your donation proceeds, personal information about your surgery and surgical outcome will be collected and entered into your Registry record. This includes, but is not limited to:

- how many days you were in hospital,
- the type of surgery you had to remove your kidney,
- any surgical complications that may have occurred.

Your transplant program will continue to monitor your health and the function of your kidney after the surgery. Some of that personal information will be entered into your Registry record. This personal information will be used to measure the success of the Living Donor Paired Exchange Registry, improve the matching of donors and recipients in the future, and understand any long term effects on living kidney donors.

Our Commitment to Your Privacy:

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

All Canadian Blood Services staff members sign a pledge to keep your personal information confidential. Canadian Blood Services will grant access to the Registry only to those staff members who require access in order to perform their job functions.

Transplant Physicians, Living Donor Coordinators, Transplant Coordinators, Tissue Typing Laboratory technologists, medical data clerks and other health care professionals who require access to the Registry to perform their job functions will also sign a pledge of confidentiality.

Withdrawing Consent to Continued Collection and Recording of Personal Information in the Registry:

If you decide you no longer wish to have your personal information collected and entered into your Registry record, you must provide Canadian Blood Services with a signed notification of your wishes. To do this, please contact your Living Donor Coordinator and you will be given a form to sign and return to 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 or added to your Registry record. Once you have withdrawn your consent for continued collection and entry of data into the Registry your personal information will no longer be used to match you with a potential recipient. Canadian Blood Services will use your personal information to contact you for safety reasons, if necessary.

Can I Access my Personal Information?

Canadian Blood Services respects your right to access and request correction of your personal information.

You may contact our Privacy & Access Office by telephone at 613-739-2483 or toll free (1-877-262-9191). You may also contact us by e-mail at ati@blood.ca (Access to Information) or privacy@blood.ca (Privacy).

More information regarding Canadian Blood Services' privacy practices, including information on how to access your personal information, can be found on our website at www.blood.ca.

If you have questions or concerns you may also contact your provincial Privacy Commissioner or Privacy Ombudsman.

Consent for Donors to Participate in the Canadian Living Donor Paired Exchange (LDPE) Registry

I, _____
(print Full Name)

consent to have my personal information, which includes my personal health information, entered into the Living Donor Paired Exchange Registry. I agree to the collection, use and disclosure of my personal information for the purposes described in, and in accordance with, the “Notice to Donors Participating in the Living Donor Paired Exchange Registry.”

I understand that by agreeing to have my personal information entered into the Living Donor Paired Exchange Registry I am **not** consenting to any medical procedures. If I am matched and agree to proceed with a kidney donation, my transplant team will discuss the required consent for medical procedures, including surgery, with me.

Donor’s Signature	
Date	

Witness to Donor’s Signature

Witness’ Signature	
Printed Name	
Date	

Preferred Language of Correspondence: English French

I am willing to be contacted about participating in voluntary research: Yes No

Please keep one signed copy for yourself and return 2 signed copies to your Living Donor Coordinator. Your Coordinator will keep one copy on your medical chart and send one copy to Canadian Blood Services.

Consent for Donors to Participate in the Canadian Living Donor Paired Exchange (LDPE) Registry

I, _____
(print Full Name)

consent to have my personal information which includes my personal health information entered into the Living Donor Paired Exchange Registry. I agree to the collection, use and disclosure of my personal information for the purposes described in, and in accordance with, the "Notice to Donors Participating in the Living Donor Paired Exchange Registry."

I understand that by agreeing to have my personal information entered into the Living Donor Paired Exchange Registry I am **not** consenting to any medical procedures. If I am matched and agree to proceed with a kidney donation, my transplant team will discuss the required consent for medical procedures, including surgery, with me.

Donor's Signature	
Date	

Witness to Donor's Signature

Witness' Signature	
Printed Name	
Date	

Preferred Language of Correspondence: English French

I am willing to be contacted about participating in voluntary research: Yes No

Please keep one signed copy for yourself and return 2 signed copies to your Living Donor Coordinator. Your Coordinator will keep one copy on your medical chart and send one copy to Canadian Blood Services.

Consent for Donors to Participate in the Canadian Living Donor Paired Exchange (LDPE) Registry

I, _____
(print Full Name)

consent to have my personal information which includes my personal health information entered into the Living Donor Paired Exchange Registry. I agree to the collection, use and disclosure of my personal information for the purposes described in, and in accordance with, the “Notice to Donors Participating in the Living Donor Paired Exchange Registry.”

I understand that by agreeing to have my personal information entered into the Living Donor Paired Exchange Registry I am **not** consenting to any medical procedures. If I am matched and agree to proceed with a kidney donation, my transplant team will discuss the required consent for medical procedures, including surgery, with me.

Donor’s Signature	
Date	

Witness to Donor’s Signature

Witness’ Signature	
Printed Name	
Date	

Preferred Language of Correspondence: English French

I am willing to be contacted about participating in voluntary research: Yes No

Please keep one signed copy for yourself and return 2 signed copies to your Living Donor Coordinator. Your Coordinator will keep one copy on your medical chart and send one copy to Canadian Blood Services.