CANADIAN TRANSPLANT REGISTRY

Privacy Notice to Potential Recipients Participating in the Kidney Paired Donation Program

Purpose

The purpose of the Kidney Paired Donation Program (“KPD Program”) is to identify potentially suitable living kidney donors for people who need a kidney transplant and whose willing donor is not a match. The KPD Program is supported by the Canadian Transplant Registry, an electronic database operated by Canadian Blood Services.

Definitions

**HLA Test Results:** Human leukocyte antigen (HLA) typing is used to match patients and donors for organ transplants. HLA are proteins or markers found on most cells in your body. Your immune system uses these markers to recognize which cells belong in your body and which do not.

**Personal Information:** 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. Personal Information includes personal health information such as your medical profile or condition, your medical history, laboratory test results, including transmissible diseases and HLA test results, your blood group, etc.

Collection of your Personal Information by the KPD Program

In order for you to participate in the KPD Program, staff at your transplant centre will need to collect Personal Information about you and create a record in the Canadian Transplant Registry. This Personal Information may be collected from you, your hospital, your laboratory records or other medical records. Your Personal Information will be put into the Canadian Transplant Registry in Ottawa, Ontario.

The KPD Program needs to collect your Personal Information to try to identify a medically compatible living kidney donor for you. The KPD Program may identify a match with a donor of an incompatible donor-recipient pair or with a “non-directed” anonymous donor. A Non-directed Anonymous Donor (NDAD) is an individual who is not part of an incompatible donor-recipient pair, but has indicated a willingness to donate to any suitable recipient.

Use and Disclosure of Personal Information in the KPD Program

We will use your Personal Information to:

- identify you as a potential match with a potentially suitable donor;
- contact you in the event a compatible match is found;
- contact you regarding opportunities to participate in voluntary research;
- comply with legal and regulatory requirements, if required; and
- fulfill any other purposes prescribed by law.
In addition, in accordance with applicable law in your jurisdiction, we may use or disclose information from your Canadian Transplant Registry record, but which does not identify you, to support approved research, continuous process improvement, long-term analytics and KPD Program management policies.

Your Personal Information may be shared with:

- health care professionals and authorized persons at any transplant program involved with your care and with the transplant program within Canada of a donor with whom you have been matched;
- public health authorities, auditors, or others as permitted, or required, by law;
- medical researchers needing to contact recipients or potential recipients about volunteering for participation in research that has been approved by a research ethics board, if you consent; and
- for any other purpose prescribed by law.

If you are matched and your transplant proceeds, Personal Information about your surgery and surgical outcome will be entered into your Canadian Transplant Registry record. This includes, but may not be limited to, information from medical tests performed during your hospital stay.

Your transplant program will continue to monitor your health and the function of your kidney after your surgery. Some of your Personal Information, including medical test results from follow-up visits with your transplant team, will be entered into your Canadian Transplant Registry record. This Personal Information will be used to measure the success of the KPD Program, improve the matching of donors and recipients in the future, and understand any long term outcomes of people receiving living kidney donor transplants through the KPD Program.

Our Commitment to Your Privacy

Canadian Blood Services is committed to protecting the privacy and security of your Personal Information in the Canadian Transplant Registry. We do so by following relevant laws and best practices.

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

Withdrawing Consent

If you decide you no longer wish to participate in the Canadian Transplant Registry, you must contact your Transplant Coordinator who will give you a form to sign which will be returned 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 Canadian Transplant Registry, but no further Personal Information about you will be collected, used or disclosed by the Canadian Transplant Registry. If you withdraw your consent your Personal Information will no longer be used to search for a living donor match for you. Canadian Blood Services will use your Personal Information to contact you for safety reasons, if necessary.
How to Contact Canadian Blood Services

Canadian Blood Services respects your right to access and request correction of your Personal Information. You may contact our Privacy & Access to Information Office for more information about our privacy and access to information practices, or to request access to or correction of your Personal Information as follows (your request will be forwarded to your transplant centre for processing):

- In writing:
  Canadian Blood Services
  Privacy & 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 – privacy@blood.ca
  Access to Information – 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.
I, ________________________________

(print Full Name)

consent to have my Personal Information, which includes my Personal Health Information, entered into the Canadian Transplant Registry for purposes of the Kidney Paired Donation Program. I agree to the collection, use, disclosure and retention of my personal information for the purposes described in, and in accordance with, the “Privacy Notice to Potential Recipients Participating in the Kidney Paired Donation Program.”

I understand that by agreeing to have my Personal Information entered into the Canadian Transplant Registry I am not consenting to any medical procedures. If I am matched and agree to proceed with a kidney transplant, my transplant team will discuss the required consent for medical procedures, including surgery, with me.

<table>
<thead>
<tr>
<th>Participant’s Signature</th>
<th>Date</th>
</tr>
</thead>
</table>

<table>
<thead>
<tr>
<th>Parent or Guardian’s Signature, if required</th>
<th>Date</th>
</tr>
</thead>
</table>

Witness to Participant’s or Parent/Guardian’s Signature

<table>
<thead>
<tr>
<th>Witness’ Signature</th>
<th>Printed Name</th>
<th>Date</th>
</tr>
</thead>
</table>

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 two signed copies to your Transplant Coordinator. Your Coordinator will keep one copy on your medical chart and send one copy to Canadian Blood Services.
Consent for Potential Recipients to Participate in the
Canadian Transplant Registry Kidney Paired Donation Program

I, __________________________

(print Full Name)

consent to have my Personal Information, which includes my Personal Health Information, entered into
the Canadian Transplant Registry for purposes of the Kidney Paired Donation Program. I agree to the
collection, use, disclosure and retention of my personal information for the purposes described in, and in
accordance with, the “Privacy Notice to Potential Recipients Participating in the Kidney Paired Donation
Program.”

I understand that by agreeing to have my Personal Information entered into the Canadian Transplant
Registry I am not consenting to any medical procedures. If I am matched and agree to proceed with a
kidney transplant, my transplant team will discuss the required consent for medical procedures, including
surgery, with me.

<table>
<thead>
<tr>
<th>Participant’s Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent or Guardian’s Signature, if required</th>
</tr>
</thead>
<tbody>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

Witness to Participant or Parent/Guardian’s Signature

<table>
<thead>
<tr>
<th>Witness’ Signature</th>
</tr>
</thead>
<tbody>
<tr>
<td>Printed Name</td>
</tr>
<tr>
<td>Date</td>
</tr>
</tbody>
</table>

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 two signed copies to your Transplant Coordinator.
Your Coordinator will keep one copy on your medical chart and send one copy to Canadian Blood
Services.
Consent for Potential Recipients to Participate in the
Canadian Transplant Registry Kidney Paired Donation Program

I, _____________________________________________
(print Full Name)

consent to have my Personal Information, which includes my Personal Health Information, entered into
the Canadian Transplant Registry for purposes of the Kidney Paired Donation Program. I agree to the
collection, use, disclosure and retention of my personal information for the purposes described in, and in
accordance with, the “Privacy Notice to Potential Recipients Participating in the Kidney Paired Donation
Program.”

I understand that by agreeing to have my Personal Information entered into the Canadian Transplant
Registry I am not consenting to any medical procedures. If I am matched and agree to proceed with a
kidney transplant, my transplant team will discuss the required consent for medical procedures, including
surgery, with me.

<table>
<thead>
<tr>
<th>Participant’s Signature</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Parent or Guardian’s Signature, if required</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Witness to Participant or Parent/Guardian’s Signature

<table>
<thead>
<tr>
<th>Witness’ Signature</th>
<th>Printed Name</th>
<th>Date</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

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 two signed copies to your Transplant Coordinator.
Your Coordinator will keep one copy on your medical chart and send one copy to Canadian Blood
Services.