

Living Donor Paired
Exchange Registry

MY KIDNEY DONOR ISN'T A MATCH. WHAT DO WE DO NOW?

Answers for Potential Kidney Recipients



Canadian Blood Services
it's in you to give

YOU HAVE A LOT OF BIG QUESTIONS.

The Living Donor Paired Exchange Registry may be the answer.

At Canadian Blood Services, we are committed to helping Canadians help each other. By building and operating a national Living Donor Paired Exchange Registry, we aim to help more individuals living with Chronic Kidney Disease (CKD).

The Living Donor Paired Exchange Registry works in partnership with Canada's kidney transplant community – giving incompatible living donors another way to help a CKD patient receive a kidney transplant.

Read on to find out how the National Living Donor Paired Exchange Registry works, and how it may be able to help.

WHAT IS LIVING KIDNEY DONATION?

The kidney transplants that most people are familiar with are those using a kidney donated by someone who has died – this is known as deceased donation. It is also possible for a healthy living person to donate a kidney – a living kidney donation. Living kidney donation involves a surgery to remove the kidney from a **living donor**. The kidney is then transplanted into a patient who needs a kidney transplant – the **recipient**. You and your donor are known as a donor-recipient pair.

WHY CAN'T MY DONOR DONATE A KIDNEY TO ME?

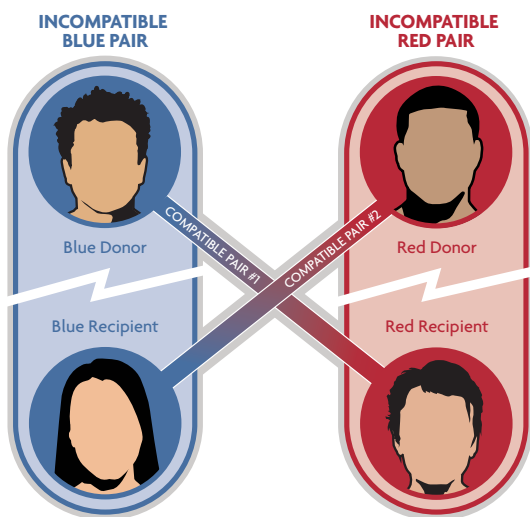
Someone you know is willing to donate a kidney to you, but blood tests show that you are not a match to each other. This means that your blood types are not compatible or you have proteins in your blood (known as antibodies) that will reject his/her kidney. You and your willing donor are known as an **incompatible pair** because it is not medically ideal for you to receive a kidney from him/her.

HOW DOES THE NATIONAL LIVING DONOR PAIRED EXCHANGE (LDPE) REGISTRY WORK?

When an incompatible donor and recipient are interested in a paired exchange, medical tests are done to see if they are healthy enough to participate. If they qualify, their medical information is entered into the LDPE Registry as a pair.

The LDPE Registry is a secure computer database. It contains medical information about incompatible donor-recipient pairs from across Canada. The Registry compares the medical information on all the pairs in the database and identifies pairs that might be able to exchange donors.

Here's how it works:



- *Let's say you and your incompatible donor are the Blue Pair. Red Donor and Red Recipient are another incompatible pair.*
- *Your blood type and cell proteins are a match with Red Donor, and Red Recipient's blood type and cell proteins are a match with your incompatible donor (Blue Donor).*
- *By being in the Registry, the computer can identify these matches. Your doctors can then determine if it is possible to exchange donors. Both you and the other recipient will be closer to possibly receiving a transplant.*

WHAT IS THE ADVANTAGE OF A NATIONAL LDPE REGISTRY?

The National LDPE Registry gives your willing, but incompatible donor another way to try to help you receive a living donor transplant.

The Registry can search a large number of pairs from all over Canada for possible donor exchanges. The chances of finding a compatible donor increase if there are more donors to select from. Without an electronic national registry, only a small number of pairs can be evaluated at one time, making the potential matches more difficult to identify.

WHAT WILL BE REQUIRED OF ME?

To participate in the Registry, you will first need to sign a form consenting to the collection and use of your medical information in the Registry. Your Transplant Coordinator will arrange for you to complete the qualifying medical tests. If you and your incompatible donor are both found to be suitable for surgery, your personal and medical information will be entered into the Registry as a pair.

If a matching pair is found, the matches will need to be approved by the transplant teams. The transplant teams will work with all four participants to arrange the donation and transplant procedures. The surgeries for the donors will happen at about the same time on the same day.

Your incompatible donor's pre- and post-transplant care will be the same as the care provided for other living donors at your local transplant centre.

WHAT ELSE SHOULD I KNOW ABOUT PAIRED EXCHANGE?

Paired exchange is an established practice throughout the world. Living donor-recipient pairs have been matched in Canada, exchanged donors, and had successful kidney transplants.

A kidney from a living donor is usually healthier, may function better, and may last longer than a kidney from a deceased donor. If you receive a kidney through this exchange program, you will still have the benefits of a living donation and it will be a better match for you than your incompatible donor's kidney.

There is a rare possibility that one of the two transplants might not be successful. In approximately 5% of cases, a transplanted kidney does not work; this is usually due to technical problems. You must consider the remote possibility that the kidney donated by your incompatible donor might work well in the other recipient, but that the kidney donated to you may not have the same successful result.

Another consideration is unexpected complications during surgery. There is a rare possibility that once the kidneys have been removed from both donors, you or the other recipient may be unable to receive the transplant at that time. If this happens in your case, the kidney you would have received will be given to the next compatible recipient on the wait list at your transplant centre. When you are medically able to proceed with transplantation, you will be given priority for a deceased donor kidney in your local region.

In rare circumstances, if a recipient becomes seriously ill, he/she may never be able to receive a transplant.

WHAT IS DIFFERENT ABOUT DONATING THROUGH A PAIRED EXCHANGE?

Living Donor Paired Exchange is different in some ways from how donation would have worked if you and your incompatible donor had been a match. Here's how:

- One or more of the matched participants may be required to travel to another transplant centre to accommodate the exchange.
- You will not be receiving a kidney from someone you know, but from another person (e.g. Red Donor) that you may never meet. However, your transplant team will have determined that the matched donor is a good donor for you.

Some people may have different feelings about receiving a kidney from someone they don't know. It is important to discuss your feelings with your transplant team.

The Registry protects your privacy and eliminates the possibility of unwanted relationships. Matched pairs will remain anonymous before and after the transplants. You will likely never meet the other donor-recipient pair.

However, introductions can be arranged after the transplants, but only under the condition that all four participants agree to have their identities revealed. You are under no obligation, nor should you feel pressured, to meet the other recipient and donor.

VOLUNTARY PARTICIPATION AND WITHDRAWAL

The participation of all donors and recipients in this Registry must be completely voluntary. You, and any of the people involved, are free to withdraw at any time before the donor operations take place.

If you change your mind at any time before the donor operations take place, your continuing medical care will not be affected in any way, but the planned paired exchange will not occur.

Your transplant team may decide at any time that it is no longer appropriate for you and/or your incompatible donor to participate in a paired exchange. If this happens, alternative options will be discussed with you.

NOTES

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Canadian Blood Services — dedicated to keeping Canadians healthy.

Canadian Blood Services is a national, not-for-profit charitable organization that provides national leadership for organ and tissue donation and transplantation. In addition, Canadian Blood Services manages the supply of blood and blood products in all provinces and territories outside of Quebec. We also oversee the OneMatch Stem Cell and Marrow Network, Canada's network of stem cell donors.

www.blood.ca/organsandtissues

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