



Indiana University Health

IU Health Transplant

Living Kidney Donation

KIDNEY PAIRED DONATION

Kidney Paired Donation (KPD)

It is important for you to read and understand the information in this *Kidney Paired Donation* education booklet as you consider the option of participation in Kidney Paired Donation (KPD). The IU Health Transplant team is available to assist you throughout the entire donation process, from evaluation through follow-up care. Please feel free to ask any questions you may have at any time.

Participation in KPD

To be entered in a KPD program, a recipient must have a living donor. Both the recipient and donor must undergo an evaluation and be approved as candidates by the IU Health Kidney Transplant committee before they are entered into a KPD program. IU Health participates with multiple KPD programs, and you may be registered with one or more of these programs. Recipients and donors have the right to withdraw from participation in the KPD program at any time, for any reason.

What is KPD?

KPD is an option for patients who need a kidney transplant and have a willing living donor who is incompatible (a poor match). Most recipient and donor pairs are entered into a KPD program because of blood type or Human Leukocyte Antigen (HLA) incompatibility or both. Other pairs may enter if they are seeking a donor better matched in age, size or some medically suggested reason. KPD is an option when one donor (Donor #1) is willing to donate to an individual needing a transplant (Recipient #1) but cannot due to incompatibility. Multiple transplant centers pool their incompatible pairs together and use a computerized matching system to help maximize the number of potential paired exchanges. KPD programs help to identify another incompatible pair (Donor #2 and Recipient #2) with whom they can exchange kidneys to enable a more favorable compatibility and allow a transplant to take place. If Donor #1 is compatible with Recipient #2, and Donor #2 is compatible with Recipient #1, two transplants can be pursued (Diagram 1).

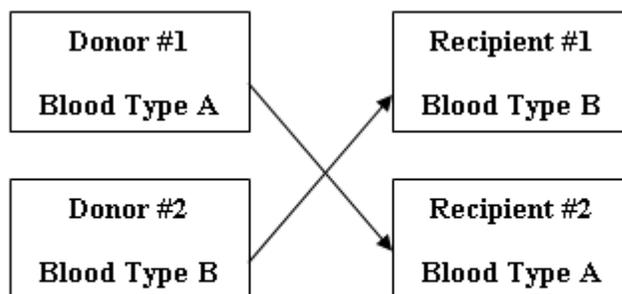


Diagram 1

Additional Types of Pairings

In the beginning of KPD, it was simply two recipient/donor pairs doing an exchange or “swap”, as shown in Diagram 1 above. As KPD has advanced, it has expanded to include other ways to try and benefit as many recipients as possible and to save deceased donor kidneys for those recipients who do not have a potential living donor. Exchanges can be between multiple recipient/donor pairs.

A living donor could possibly help more than one recipient receive a transplant. KPD may also include individuals who wish to donate to any individual who is currently waiting for a kidney transplant. These individuals are called non-directed donors and are not linked to a specific potential recipient. An exchange started by a non-directed donor is called a donor chain (see diagram 2). In a donor chain, the non-directed donor donates to a recipient whose intended donor would then donate to another recipient. The donor at the end of the chain will donate to a candidate on the deceased donor waiting list. Non-directed donors not participating in the KPD also have the option to donate to a recipient waiting for a deceased donor kidney according to Organ Procurement and Transplantation Network (OPTN) policy.

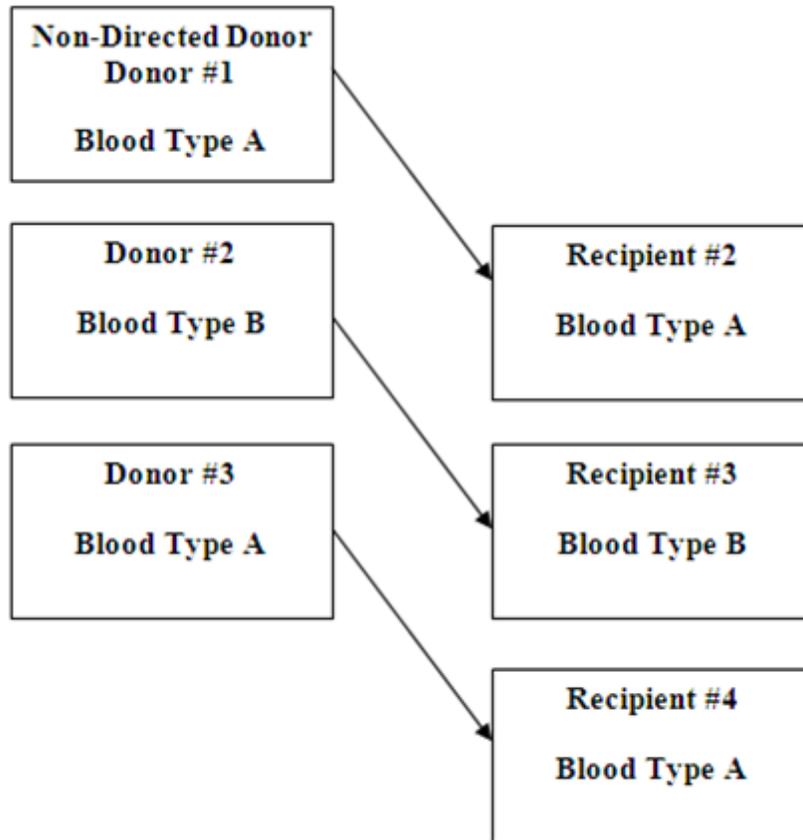


Diagram 2

What will happen if a recipient/donor pair agrees to join a KPD Program?

Once a recipient and donor are approved medically and it is determined that a recipient and potential living donor are eligible to participate in KPD, their medical and personal (including name, social security number, and date of birth) information is entered into the database for each KPD program they are being registered with. This database allows a computerized matching program to identify compatible recipient/donor pairs. KPD donors and recipients do not choose their match. If a potential exchange pair is identified, the match will be reviewed by the transplant surgeon, physicians, and transplant center program staff. If the match is favorable, the potential living donor and the recipient may be asked to provide a blood sample for a crossmatch (mixing of recipient and

donor blood to establish compatibility). The recipient/donor pair will be notified about whether the crossmatch results indicate that the exchange offers a favorable arrangement for all participants and whether the paired exchange will move forward. A KPD donor or recipient may decline an identified match.

A recipient might be matched through the KPD program while the original donor is not matched within that same KPD exchange. To avoid undue delays or failure of the matched exchange, this donor can be a “bridge donor” to initiate a new KPD exchange. Depending on the additional time to establish the new KPD exchange, the bridge donor may need to have another medical evaluation and/or be available to provide blood on multiple occasions for crossmatching.

Once all participants agree to go forward with the exchange, the medical information of both the potential living donor and recipient (as applicable) will be shared with the participating transplant center. Any further evaluation requested by the surgeon or physician to determine the potential living donor’s or recipient’s eligibility will be completed. After the physicians and surgeons accept the medical eligibility of all the participants, the transplants can be scheduled. Efforts are made in two-way and three-way exchanges to schedule the donation surgeries to begin at the same time. Recipient surgeries begin after donor surgeries. In donor chains, surgeries may or may not occur on the same day. Donor and recipient identities are kept confidential. If all involved parties agree, a meeting between matched donors and recipients may be facilitated sometime after transplant.

What information is needed in order to run the match program?

The KPD program utilizes the recipient’s and potential living donor’s date of birth, blood type, genetic tissue type, and any tissue markers (antigens) that need to be avoided in the donor for a compatible match to be made. The program also allows for potential recipients and donors to indicate if and where a potential donor is willing to travel to donate. This information will be used to identify potential recipient/donor pairs. Potential living donor data will be shared with the surgeons, physicians, and transplant team at the potential recipient’s transplant center.

How will medical information be kept confidential?

Prior to locating a possible match, a potential living donor’s or recipient’s information will not be shared with anyone outside of the KPD Program(s) or the participating transplant centers without the participant’s clear permission. Access to the database will be through a secure, password protected system. After a potential match is identified, it is possible that the matched recipient’s health insurance may provide the matched recipient with the name of the actual matched donor on an estimation of benefits form that is sent to the recipient before surgery. This means that recipients may learn of their actual matched donor’s identity. Otherwise, the participants’ medical information will remain confidential to the extent required by law. Potential living donors and recipients should discuss the confidentiality rules at the hospital with their transplant center staff.

What are the risks of participating in the KPD Program?

There is a risk of the loss of confidentiality of medical information if the steps outlined above are not followed. If an exchange pair is identified and the recipient/donor pairs agree to proceed with the surgery, they should understand that, as with any transplant and donor surgery, there are unexpected events that may occur with a paired donation transplant.

- An event may occur in the operating room that makes it necessary to stop a donor procedure. In this case, one recipient would not receive a kidney. If a donor or recipient surgery has begun, this surgery will continue even if another surgery in the match must stop.
- If it is necessary to stop a recipient surgery, a kidney would be available. This kidney would be given to a recipient on the deceased donor waiting list according to OPTN policies.
- The paired donor may have to wait to find a match.
- Potential living donors and recipients may decide to withdraw from participating in the KPD Program at any time, for any reason.
- The paired recipient might not be transplanted even if the recipient's paired donor donates.
- The paired donor might have to wait longer to donate after a match has been identified because of logistical issues.
- The paired recipient might not receive a transplant because of an unexpected issue with the matched donor's kidney found during or after surgery.
- The paired donor's kidney might not be transplanted or the paired donor's matched recipient might not receive a transplant because of unexpected events.
- The matched recipient's insurance might not cover travel costs if the paired donor travels to the matched recipient transplant hospital.
- The paired donor's paired recipient and the paired donor's matched recipient might not have equal outcomes.
- The paired donor's name appearing on the matched recipient's insurance estimation of benefits.
- The paired donor may require additional testing, including multiple blood draws for crossmatching.
- The kidney could be lost in transport.

What if no KPD exchange occurs?

There is no guarantee that a KPD exchange will occur as a result of participating in the KPD Program. If a scheduled KPD exchange fails to be completed, additional matches will be attempted. Failed KPD exchanges will not result in additional priority for the recipient on the deceased donor waiting list. The recipient/donor pair will remain in the KPD database as long as they are medically acceptable and are willing to participate.

What are the risks of participating in a kidney paired donation when the kidney is shipped to the recipient transplant center?

The living donor kidney may need to be shipped via ground and/or air transportation to the recipient transplant center. This form of transportation has the risk of courier delay, flight cancellation, or flight delay which would extend the cold ischemic time of the kidney. Cold ischemic time is the amount of time an organ spends being preserved outside the body after recovery from the donor. Too much cold ischemic time can affect the quality of the organ for transplant. With clear-cut, organized plans, this risk is decreased. There is the risk of problems outside of the transplant center's control such as a plane crash, terrorist activity, and natural disaster. There is risk of damage to the kidney during transport which would be discovered at the time of inspection of the kidney at the recipient's transplant center.

What are the chances a match will be identified through the KPD Program?

It is not known if or when any given recipient/donor pair might be identified as part of a possible matched pair. The more participants in the program, the more likely it is that any given recipient/donor will be part of a pair identified for a possible donor-recipient exchange.

What costs or payments are involved?

There is no cost for registering and there will be no payments or compensation of any kind for participating. Potential donors need to discuss the financial risks of participating in the KPD Program and the resources that may be available with the transplant center. There are national and local resources available, such as the National Living Donor Assistance Center, that may be able to assist those who qualify. Local resources are not the same in all areas and locations. In certain cases, for example, qualifying donors may be reimbursed for limited travel and living expenses. Ask your transplant center about the resources in your area and nationally that may be able to assist living donors.

Contact information

If you have questions, please call IU Health Transplant where the living donor coordinators are available Monday-Friday, 8 am - 4 pm, and can be reached at 800.382.4602 or 317.944.4370. For additional information you may visit the follow websites:

National Kidney Registry (NKR) – www.kidneyregistry.org

Alliance for Paired Donation – www.paireddonation.org

UNOS Kidney Paired Donation – www.unos.org