

# Preparing for your Kidney Transplant

Beth Israel Deaconess Medical Center ■ The Transplant Institute  
**Preparing for a Kidney Transplant**

**Consent Forms (front pocket)**

1. Table of Contents
2. Verification of ABO Type
3. Massachusetts Health Care Proxy Form
4. Patient Responsibility Agreement
5. HLA Requisition
6. Kidney Transplant Evaluation Process Form
7. Kidney Transplant Listing Process Form
8. Multiple Listing Form
9. Kidney Transplant Surgery Consent Form
10. Release of Information Form
11. Transplant Candidate Contact Information

**Additional Information (back pocket)**

1. Kidney Donor Wallet Card
2. Kidney/Pancreas Transplant Orientation
3. Article on “Increased Risk Donors”
4. The Scientific Registry of Transplant Recipients (SRTR)

**I. Education**

1. Multidisciplinary Transplant Team .....	5
2. Surgeon/Physician Coverage Plan .....	11
3. Indications for Kidney Transplant .....	15
4. Clinical Eligibility for Kidney Transplant.....	19
5. Evaluation Process.....	23
6. Consider Living Donation .....	29
Discussing Living Donation with Family and Friends .....	31
Using Social Media .....	34
Kidney Paired Donation – A Transplant Option for Patients with an Incompatible Living Donor.....	36
7. Transplant Listing and Awaiting Your Kidney .....	45
8. Multiple Listing and Waiting Time Transfer .....	51
9. Where Does the Deceased Organ Come From?.....	57
KDPI > 85 Kidneys.....	59

10. Kidney Allocation.....	63
11. The Right Match – You and Your Donor Kidney .....	71
12. The Kidney Transplant Operation .....	77
Possible Complications after Kidney Transplant Surgery .....	82
13. Behavioral Health Services: Emotional and Family Support.....	87

**II. Important Information**

1. Financial Considerations .....	95
2. Information from UNOS: Facts and Figures .....	101
3. A Guide to Clinical Trials at the Transplant Institute.....	119
4. Resource Map for Patients.....	Insert
5. Links to Helpful Web Sites .....	127
6. Glossary .....	133

My signature on this form verifies that I have received this information from my Transplant Coordinator. I have been given the opportunity to ask questions. I understand that the Transplant Evaluation Process is ongoing and that I will continue to receive educational information and will also continue to be given the opportunity to ask more questions with each clinic visit.

Patient Signature: \_\_\_\_\_ Date: \_\_\_\_\_

RN Signature: \_\_\_\_\_ Date: \_\_\_\_\_

# **Multidisciplinary Transplant Team**





## Multidisciplinary Transplant Team

### Transplant Surgeons

Board certified transplant surgeons at BIDMC perform kidney, liver and pancreas transplants. Transplant surgeons have specialized training in the transplant evaluation phase as well as pre- and postoperative care of transplant patients including the management of immunosuppressive (anti-rejection) drugs and drug complications. Transplant surgeons work collaboratively with all members of the transplant team in the selection and care of transplant recipients and donors. Transplant surgeons also perform procedures for patients needing vascular access for hemodialysis or peritoneal dialysis, general surgery in dialysis and transplant patients, and non-transplant hepatobiliary surgery.

### Transplant Nephrologists

The transplant nephrologist works collaboratively with the transplant surgeons in the selection and care of kidney transplant recipients and donors. The transplant nephrologist has specialized training in the management of patients with end-stage renal disease, pre- and postoperative care of transplant patients, and in the use of immunosuppressive therapy including the side effects of the drugs and the complications of their immunosuppression.

### Infectious Disease Physician

An on-site infectious disease clinic provides evaluation and management for patients with any infectious disease challenge, including infection in immunocompromised patients. The infectious disease physician works collaboratively with transplant surgeons, physicians and others at the Transplant Center to manage the complicated medical regimens that are common following transplantation.

### Transplant Psychologist

The transplant psychologist is a behavioral health professional who specializes in transplantation. The transplant psychologist evaluates the behavioral health and psychological needs of patients and families as they confront the challenges of chronic illness, transplantation, and long-term survivorship. The transplant psychologist implements treatment programs to help patients reduce symptoms of depression and anxiety, lose weight, stop smoking, prevent relapse to alcohol and drug abuse, improve quality of life, and more effectively manage stress. Psychological services also are available to help family members cope successfully with demands of caring for patients in need of or recovering from transplantation. The transplant psychologist also coordinates health care of transplant patients with other mental health providers at BIDMC and in the community.

### Nurse Coordinators

In addition to the specialized care provided by the Transplant Institute physicians, nurse coordinators with expertise in transplantation provide coordination of care, education and close personal support throughout the transplant process. They coordinate all aspects of the evaluation process and monitor the status of patients who are pre- and post-kidney transplant. Nurse coordinators also work closely with the nurses on the inpatient Transplant Unit to assure continuous patient/family education and appropriate discharge planning.

### **Transplant Pharmacist**

The transplant pharmacist provides education to new transplant patients about immunosuppression medication, as well as options for new immunosuppressive agents available through clinical trials. The transplant pharmacist is also a resource to the entire Transplant Institute team by providing drug information and education about complex drug interactions.

### **Transplant Social Workers**

The transplant social worker is a licensed mental health professional who does psycho-social assessments as well as offers patients and families assistance and support with the many challenges they face during the transplant process. The social worker is a link to hospital and community based resources that offer practical assistance for each patient's particular set of circumstances.

### **Transplant Nutritionist**

Focused on disease prevention and health promotion, the transplant nutritionist provides patients with the necessary tools and resources, such as individualized meal plans, recipes, educational materials, and nutritional feedings and supplements, to help achieve and maintain a healthy weight. The nutritionist helps patients develop healthy eating plans based on their specific medical needs and requirements.

### **Practice Assistants**

The Practice Assistant greets patients who have an appointment in the Transplant Institute. They make sure that the doctors and the nurse coordinators have the patient's updated medical record, take vital signs at each appointment, and manage the patient clinic flow. The Practice Assistants also assist the Nurse Coordinators with patient test scheduling, lab scheduling, and other medical specialty appointments as needed.

### **Independent Living Donor Advocate**

The Independent Living Donor Advocate ensures that the living donor has received the information that he/she needs to make an informed decision. The Independent Living Donor Advocate is available to the prospective donor throughout the evaluation and post donation.

### **Director of Transplant Services**

In collaboration with the chief of transplantation, the director of transplant services oversees the activities within the Transplant Institute to assure that staffing and financial resources are available to support safe care for all patients and a positive working environment for staff.

### **Transplant Financial Coordinator**

The transplant financial coordinator works with other members of the Transplant Institute team, patients and families to coordinate the financial aspects needed to support the transplant process, from evaluation through postoperative care. The financial coordinator works collaboratively with the insurance companies and BIDMC financial services to obtain authorization for a transplant and to identify out-of-pocket expenses for the patient. The financial coordinator oversees the process of listing patients for transplant with the United Network for Organ Sharing.

### **Transplant Administrative Staff**

The administrative staff in the Transplant Institute has extensive experience working in a patient care setting. They coordinate patient appointments, maintain medical records, schedule surgical procedures and pre-admission testing, answer phone calls, and greet patients and families. While their work is often behind the scenes, it very important to the smooth flow of patient care in the Transplant Institute.

### **Clinical Research Administrator**

The clinical research administrator oversees all activities pertaining to clinical trials within the Transplant Institute and collaborates with physicians to develop and institute innovative transplant research. The clinical research administrator reviews all transplant patients' eligibility for clinical trials, as well as ensures the safe and ethical treatment of research participants. The clinical research administrator maintains compliance with regulatory agencies and manages reporting of clinical research outcomes at the local, state, and national level.

### **Inpatient Transplant Unit Nurse Practitioners**

Nurse practitioners have a master's degree in nursing and are certified by the American Nurses Credentialing Center. They assess, plan and coordinate pre- and post-transplant care. The NP provides direct patient care under the supervision of the transplant surgeons and physicians, and works closely with residents, fellows and the nursing staff.

### **Inpatient Transplant Unit Nurse Manager**

The inpatient Transplant Unit nurse manager provides 24-hour accountability for the unit in terms of developing and sustaining an environment that supports excellence in clinical practice and care of pre- and post-transplant patients. The nurse manager is responsible for ensuring financial viability, integration of services for patients and families, and clinical excellence.



# **Surgeon/Physician Coverage Plan**



## Surgeon/Physician Coverage Plan

The Transplant Program at Beth Israel Deaconess Medical Center (BIDMC) includes kidney (live and deceased donor), liver (live and deceased donor) and pancreas transplantation. Fully credentialed transplant-trained surgeons share coverage for all transplant programs. The surgical transplant team is available 365 days a year, 24 hours a day, 7 days a week and provides coverage only to the BIDMC transplant programs which are all on site at BIDMC. The surgeons are able to be on hospital premises within one hour if necessary. The transplant surgeons have internet access to Donor Net for immediate response to organ offers. The monthly call schedule identifies the surgeon covering each program for organ offers, transplantation, and urgent patient issues as well as the surgeon available for organ procurement. The primary on-call surgeon is identified for each program and the other surgeons provide back-up in the event of multiple transplants. There is always a minimum of two surgeons on call who are available for patient care, transplants and organ procurement. There are four transplant nephrologists who are available at all times to the transplant surgical team and to manage urgent patient issues. The monthly call schedule indicates the coverage schedule for the nephrologists. In addition to the surgeons and physicians, there is a transplant nurse coordinator on call after business hours, on weekends and holidays to assist the patients, surgeons and nephrologists. The main telephone number for the Transplant Institute (617-632-9700) is answered by the transplant staff Monday-Friday 8am-5pm; calls are triaged to the appropriate member of the team during business hours. Between 5pm and 8am on week days and 24 hours on Saturdays, Sundays and holidays the main number to the Transplant Institute is answered by an answering service; calls are directed to the on-call surgeon, nephrologist or nurse coordinator based on a pre-established set of instructions and the monthly call schedule.

Patients are given a copy of this plan when they are listed with UNOS for a transplant. In the event that there is a major change in the program or personnel, patients will be notified in writing.

revised 12/09/19





# **Indications for Kidney Transplant**



## Indications for Kidney Transplant

When your kidneys fail, you need one of two treatments to stay alive: a kidney transplant or dialysis therapy (either peritoneal dialysis or hemodialysis).

Many patients come to the Transplant Institute with the myth that they can live forever on dialysis, but this is simply not the case. While dialysis is a lifesaving treatment, it performs only about 10 percent of the work a functioning kidney does. Dialysis can also cause other serious health problems and complications including, but not limited to:

- Anemia (a shortage of red blood cells, which diminishes oxygen and saps energy and strength)
- Bone disease
- High Blood Pressure
- Heart Disease
- Nerve Damage
- Infection

As a result, the average life expectancy for a patient on dialysis can be decreased.

### Longer Life with a Transplant

Patients who receive a kidney transplant typically live longer than those who stay on dialysis. A living donor kidney functions, on average, 12 to 20 years, and a deceased donor kidney from 8 to 12 years.

Patients who get a kidney transplant before dialysis live an average of 10 to 15 years longer than if they stayed on dialysis. Younger adults benefit the most from a kidney transplant, but even older adults gain an average of four more years after a transplant than if they had stayed on dialysis.

### Research Favors Transplant

Some patients may need to spend time on dialysis as they wait for a good match from a deceased donor kidney or search for a living donor kidney. Spending a long time on dialysis does not ruin your chances of having a kidney transplant, but getting a transplant sooner rather than later is generally the best approach because of the health problems dialysis can cause over time.

Published medical data has shown that the best treatment option is having a transplant before starting dialysis. The benefits of kidney transplant may decrease for patients who have spent a longer time on dialysis.

### Preemptive Transplantation

Preemptive transplantation refers to kidney transplantation before a patient needs to start dialysis therapy. Patients who get a preemptive transplant receive their kidney when their health is generally

good, which can improve new kidney function and enhance overall health and life expectancy.

Almost all transplants before dialysis are from live donors. This is because kidneys from deceased donors are distributed in this region (UNOS Region 1, which includes Massachusetts, Maine, New Hampshire, Rhode Island and parts of Connecticut and Vermont) by a number of considerations, but wait time on the transplant list is one of the most important. You can start gaining wait time on the Kidney Transplant List here in Region 1 when your estimated kidney function is less than or equal to 20% (eGFR < 20). Similarly, if you get listed for transplant after you have started dialysis, you will gain all the wait time back on the Kidney Transplant List from the date of your initiation of dialysis. Go to our website, [bidmc.org/transplant](http://bidmc.org/transplant), for more information about kidney transplantation before starting dialysis.

So having a live donor is the most common and best way to get transplanted before starting dialysis. However, no matter how long someone has been on dialysis, a transplant from a live donor is preferable to a deceased donor for many reasons including improved kidney function.

Preemptive transplant is especially beneficial for patients with type 1 diabetes who may need both a kidney transplant and a subsequent deceased donor pancreas transplant.

### **Better Quality of Life**

Even though kidney transplant is a major surgery with a phased recovery period, it can, in comparison to dialysis, offer you the opportunity for a longer, more satisfying life. Most patients who have been on dialysis and then had a transplant, report having more energy, a less restricted diet, and fewer complications with a transplant than if they had stayed on dialysis. Transplant patients are also more likely to return to work after their transplant than dialysis patients.

### **Here to Help**

Your transplant team is here to help you evaluate your health options early on, and make the treatment choice that is right for you. We can help you understand the risks and benefits of transplant surgery versus dialysis, and the advantages of having a live donor kidney compared to a deceased donor organ. We will carefully and clearly explain your options, offer advice and support, and help you and your loved ones make the best treatment choice.

# **Clinical Eligibility for Kidney Transplant**



## Clinical Eligibility for Kidney Transplant

### How We Select Who Receives a Kidney Transplant

1. The patient needs to have chronic kidney disease (stage 4 or 5). Visit your local National Kidney Foundation (NKF) office or their website (<http://www.kidney.org/kidneyDisease/ckd/index.cfm>) for more information on chronic kidney disease.
2. Kidney transplant has risks and benefits. For any patient, the benefits must outweigh the risks to move ahead with kidney transplant.
3. Each patient must understand the reasons for transplant, the possible benefits and risks, and the possible complications.
4. Each patient must be able to follow medical directions and take medications as prescribed. Each patient must be able to get frequent blood tests and keep scheduled clinic appointments.
5. All patients who want a kidney transplant must meet with a transplant social worker or psychologist. This meeting will identify any social or psychological issues that need to be addressed before transplant.

No one with these conditions should be approved for a kidney transplant:

- Untreated or active cancers
- Advanced heart, vascular or lung disease

Patients with these conditions might not be approved for a kidney transplant:

- Active drug and/or alcohol abuse or dependency
- Inadequate family and/or social support
- Uncontrolled or untreated psychiatric (mental) illness
- Extreme obesity
- Age over 70 with serious medical conditions

*Reference:* American Journal of Transplantation, 2001; Supplement 1: Vol 2: pages 5-95





# Evaluation Process



## The Kidney Transplant Evaluation Process

You have two options to initiate a kidney transplant evaluation.

### OPTION 1: Multidisciplinary Clinic (MDC).

The evaluation for kidney transplantation begins with an initial consult with the MDC team (includes transplant nephrologist, transplant surgeon, social worker, nurse coordinator, pharmacist, nutritionist, financial coordinator). The main goals of the initial consultation are to determine the following:

- when your level of kidney function warrants transplantation
- whether your overall condition is such that you can safely undergo transplantation
- discuss the option of living donor transplant

At the initial consultation, we recommend that you bring with you a member(s) of your family or social support network who will be involved in your care before, during and after transplantation. During this visit, you will attend a 60 minute kidney orientation class and have non-fasting blood work drawn.

The MDC team will take a complete medical history from you, conduct a physical exam, and review all of the outside records, tests and consultations that you have previously had done. It is important to bring with you any records pertaining to your kidney condition and general health. This may include

- reports of vaccines
- blood work
- medication list
- radiology procedures
- Colonoscopies
- mammogram, pap smears and biopsies.

During this visit, the Transplant Nephrologist will try to assess the nature of your kidney disease, the state of your general health and will try to determine if kidney transplantation is an option for you. Alternative therapies may be discussed. The evaluation and listing process will be discussed. Arrangements will be made for a number of tests and consultations to be performed as part of the evaluation.

**OPTION 2:** The evaluation for kidney transplantation begins with an initial consult with the Transplant Nephrologist and Transplant Nurse Coordinator and a separate meeting with the Transplant Social Worker. You will also have routine blood work drawn.

The Social Worker will conduct a full evaluation including an assessment of your personal support system. Kidney transplantation is a major undertaking and one key to a successful transplant is the commitment to your health and wellbeing that you receive from supportive friends and family. If

you have had a history of dependence on alcohol or illicit drugs, you will be expected to comply with the policies of the Transplant Institute with respect to relapse prevention.

You will be evaluated by the Transplant Nutritionist. We may ask you to bring a three-day food record so the nutritionist can review your diet with you. The nutritionist checks this food diary, and your blood work, to be sure you are choosing healthy foods. Also, we want to know that you can successfully follow a special diet. Making the right food choice is an important part of preparing for transplant surgery and for taking care of your new kidney after surgery.

Your nutritionist will also review your overall body mass index (BMI) to help decide if you need to gain or lose weight before surgery. The nutritionist may recommend more physical activity to help you lose weight. Feel free to ask any questions you have about your diet.

You may be scheduled to see the Transplant Pharmacist who will assess for special medication needs.

Once you have completed your evaluation, you will be scheduled to see a Transplant Surgeon who will assess your kidney condition, assess the need for kidney transplantation, discuss the surgery, and post-operative recovery period and discuss possible alternative therapies.

**EITHER OPTION 1 OR 2:** If an evaluation for kidney transplantation is warranted, the following tests will be scheduled for a future date:

1. Chest x-ray (an x-ray of the chest)
2. EKG (an electrical tracing of the heart rhythm)
3. Cardiac Echo (an ultrasound examination of the heart), will need to be done at BIDMC
4. All diabetic patients will see a BIDMC cardiologist (except for Atrius patients)
5. You may need to see your dentist for evaluation
6. A series of other tests will be ordered depending on special circumstances:
  - a. A colonoscopy for all patients over 50 years or those with a family history of colon cancer
  - b. A nuclear medicine stress test for all diabetic patients or those patients with significant risk factors for heart disease
  - c. A mammogram for all female patients older than 40 years according to the American Cancer Society Guidelines
  - d. A pap smear for all female patients according to the American Cancer Society Guidelines.

In addition, the above testing may dictate that you need to see additional specialists.

The evaluation period gives you and your family the opportunity to meet with the Transplant Team and decide if you want to pursue transplantation at Beth Israel Deaconess Medical Center. Please remember that the ultimate decision to undergo surgery belongs to you, and you may withdraw from the program at any time.

## **Activation on the Transplant List**

The Transplant Institute's multidisciplinary team meets weekly and reviews patient evaluation data to determine if:

- Transplant is the best treatment option for you
- Another treatment option may be a better choice for you at this time
- More information/tests are needed to decide what type of treatment is in your best interest

Most people we evaluate for a transplant are suitable candidates. We will notify you in writing when you are activated on the United Network for Organ Sharing (UNOS) waiting list. You will also be notified if the committee determines that transplant is not the best treatment option for you. You always have the choice to be evaluated at another center.

If you are placed on the waiting list, we schedule an appointment to see you in the transplant clinic every six months to a year while you wait for a kidney transplant. During this time, we may request that you repeat some of the tests to determine eligibility for transplant. We will assess whether you have any possible live donors and work with you and your loved ones to ensure that your questions are answered.

## **Identify a Health Care Proxy**

You should select a health care proxy if you have not already done so.

In Massachusetts, you can legally name a person to help you make decisions about your health care if your doctor determines you are unable to express your own wishes. The person is called a health care proxy (or a health care agent).

Please ask your transplant team if you need a copy of the Massachusetts Health Care Proxy form.



# **Consider Living Donation**





## Consider Living Donation

### Living Kidney Donation

The Transplant Team at the Transplant Institute at Beth Israel Deaconess Medical Center encourages living donor transplantation for several reasons. Kidneys from living donors have a better long-term survival rate than kidneys from deceased donors and function, on average, 12 to 20 years. Living kidney donation can often help the recipient avoid having to start dialysis by having a “preemptive transplant.” Preemptive transplantation refers to kidney transplantation before a patient needs to start dialysis therapy. Preemptive transplant happens when a recipient’s health is generally good, which can improve long-term kidney transplant function and enhance overall health and life expectancy.

A living donor transplant is scheduled and planned for, so the surgery takes place at a convenient time for both the living donor and recipient. The waiting time for the recipient is less than that of a deceased donor transplant. In addition, the donor and recipient operations take place at the same time, which means that the kidney is outside of the body for a short period of time. Kidneys from living donors usually start working immediately in the operating room whereas deceased donor kidneys that have been out of the body for a longer period of time may take more time to fully function.

### Who Can Be A Living Donor?

Live kidney donors can be immediate or extended family members, friends, coworkers, strangers or even non-directed donors. A non-directed donor (sometimes called altruistic or good Samaritan donor) is a donor who does not know the recipient and donates anonymously. Donors who are incompatible with their recipients can still undergo evaluation and potentially donate via kidney exchange. Donors and recipients with incompatible blood types can be entered into United Network of Organ Sharing (UNOS) Kidney Paired Donation (KPD) program.

There are some general criteria for a person to be considered as a living kidney donor:

- A living kidney donor must be willing to donate and the decision to donate must be completely voluntary.
- Donors must be over 21 years old, with rare exceptions made for those between 18 and 21.
- Donors must have normal kidney function based on their age.
- All donors must be fully informed of the risks of living kidney donation and give written informed consent.
- A living kidney donor must be in excellent physical and mental health. More information about health history criteria can be found on the living kidney donor site at [www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor).

### Online Living Donor Intake Form

People interested in being considered as a living kidney donor can learn more about donation and

start the process by completing the online intake form at [www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor). *This is the best way for a potential donor to make initial contact with the donor team.* After they do this, the living donor nurse coordinator will contact potential donors to discuss next steps in the evaluation.

## **People Want to Help**

Believe it or not, patients are the primary barriers to doing more living donor kidney transplants. Most patients who need a donated organ do not want to burden family and friends, or put loved ones at risk. Many are reluctant to ask, even though there are people within their social network who are very willing to consider donating a kidney. Our behavioral health team can help patients and families explore their own feelings and concerns about living donation. Together we can develop a plan to talk to your family and friends about this option.

Our expertise in this area is especially helpful in supporting minority patients who need organ transplants and would benefit greatly from living donors. The Transplant Institute has started novel programs to reduce racial disparity in organ transplantation. For instance, to make it as convenient as possible for patients and their loved ones, our transplant health educators will make “house calls” to provide information about living donation and kidney transplantation.

## **For More Information**

These web sites offer additional information about living donor kidney transplantation.

### **American Association of Kidney Patients**

[www.aakp.org](http://www.aakp.org)

### **American Society of Transplantation Live Donor Toolkits**

[www.livedonortoolkit.com](http://www.livedonortoolkit.com)

### **American Transplant Association**

[www.americantransplant.org](http://www.americantransplant.org)

### **Beth Israel Deaconess Medical Center Transplant Website**

[www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor)

### **National Minority Organ and Tissue Transplant Education Program**

[www.nationalmottep.org](http://www.nationalmottep.org)

### **National Kidney Foundation**

[www.livingdonors.org](http://www.livingdonors.org)

### **United Network for Organ Sharing (UNOS)**

[www.unos.org](http://www.unos.org) [www.transplantliving.org](http://www.transplantliving.org)

### **Donate Life – US Department of Health and Human Services**

[www.organdonor.gov](http://www.organdonor.gov)

## Discussing Living Donation with Family and Friends

Living donor kidney transplantation is the preferred treatment option for most patients because it offers the best chance for a high quality kidney in the shortest possible waiting time.

We advise all of our kidney transplant patients to talk to family members, friends, co-workers, and others about their need for kidney transplantation, and the benefits of getting a kidney from a living donor. We know that it can be very difficult to ask someone to consider donating a kidney.

Our transplant staff can help you think through this difficult process and provide you with a strategy for talking to others about donation.

There are lots of reasons why you might be hesitant to ask others about kidney donation. Some concerns and questions that patients have include:

- Why should I rely on others to help me with my illness when I have managed things independently all of my life?
- I don't want to burden others. Wouldn't donation affect family life, work, or leisure activities?
- What if donating a kidney causes health problems?
- What if those who volunteered to donate a kidney weren't really serious?
- What if the donated kidney doesn't work?
- How will my relationship with the donor change after surgery?
- How could I possibly thank someone enough for donating a kidney to me?

These are important questions and they deserve careful consideration. We will work with you to be sure that you have a complete and accurate understanding of how living donors are evaluated and selected. This might ease some of your concern. Research shows that almost all donors are happy they decided to donate and say they would make the same decision over again. Many people say that donating a kidney to someone they love is an important highlight in their life.


### How Do You Ask?

So how can you ask someone to consider donating a kidney to you? Again, our team will work with you to develop a strategy that meets your needs. But in general, you might consider the following approaches that some of our patients have found useful:

- Bring family members and friends together for a single meeting at your home. At this meeting, tell everyone about your kidney disease, why the doctors feel that a kidney transplant is your best option, and why your doctors are recommending a living donor kidney transplant. The advantage of this approach is that you can talk to everyone at the same time. You may like this idea, but find the group format too difficult or intimidating. Ask family members, friends, or others one at a time – individually – to consider donating a kidney. For instance, you might say:

*“I have kidney disease and my doctors have told me that I need a kidney transplant to live longer and to improve my quality of life. The doctors said that a kidney from a living person is better than one from someone who has died. I know that this is a very difficult thing to ask, but would you consider donating a kidney to me? I don’t need an answer right now, but it would be great if you would consider it. No matter what you decide, it’s important for you to know that our relationship won’t change at all.”*

- Fill out the living donor “wallet card” with your information and give them to people when you share your story. These cards are in the front of binder.
- Give them a brochure that we will provide to you. The brochure has a lot of information about being a living donor, how the evaluation is done, and what past living donors have said about the experience
- Write an email or letter and send it to all family members and friends. Again, you can describe your kidney disease and need for a transplant, while also mentioning that you would benefit from a living kidney donor. Our social worker or psychologist can help you with this letter, if it is something you want to try.
- Find an “ambassador” who is willing to talk to others for you. This “ambassador” can be a family member, friend, pastor or other important person in your life. Talk to your Transplant Social Worker or Coordinator for tools your “Ambassador” can use to help you in your search for a living donor.

Beth Israel Lahey Health   
Beth Israel Deaconess Medical Center

**For more information or  
to start the donor evaluation process:**

**[bidmc.org/kidneydonor](http://bidmc.org/kidneydonor)  
617-632-9700**

**Recipient Information**

Name: \_\_\_\_\_

Blood Type: \_\_\_\_\_

Phone: \_\_\_\_\_

Email: \_\_\_\_\_

### Let Us Evaluate Donor Eligibility

One thing that we emphasize to our patients is that you should not decide who is medically eligible to be a living donor – that is our job. Sometimes patients will not talk to a family member because they believe they would not be eligible to donate. Sometimes our patients are right, and sometimes they are not. For example, one of our patients did not ask his sister to be a donor because he thought she was too old (60 yrs old). But when we told him that there was no upper age limit to be a living donor, he asked his sister and she agreed to be evaluated. He now has one of his sister’s kidney and they are both very happy about it! Remember, we carefully evaluate the potential donor’s health history and risk for certain types of health problems in the future. We have a team of professionals – separate from yours – who evaluates each potential living donor and we consider their health above all else during the evaluation.

## Next Steps

What happens after you have tried one (or more) of the strategies mentioned? Ask those who have expressed an interest to access the online donor evaluation on our website, [bidmc.org/kidneydonor](http://bidmc.org/kidneydonor). After they submit their information a member of the donor team will review it and reach out to discuss next steps. If they are eligible to be evaluated further and they are still interested in donating, we will schedule an evaluation. We do a thorough evaluation to be sure the donor really wants to donate, is in good health and completely understands the donation process.

## Careful Consideration Takes Time

You may be thinking, “It’s been a month since I talked to family members or friends, and I haven’t heard back from anyone?” This is common. Being evaluated as a possible living donor is a decision that should be made after careful consideration – and after talking with loved ones about it. After a few weeks or so, we recommend that you ask the people you spoke to whether they have considered being a living donor. If they say, “No, I haven’t really considered it yet,” or “I just can’t do it,” thank them for their thoughtful consideration and then move on to others. It is very important to remember that there are many reasons why someone might not want to be a living donor. It does not mean that they do not care for you or do not love you. Reassure them that you do not think of them any differently and that your relationship is still very important to you. They will feel thankful that you did not pressure them to donate.

## Careful Evaluation Takes Time

Living donors are carefully evaluated by a multidisciplinary team at the BIDMC Transplant Institute. The purpose of the evaluation is to ensure that potential donors are suitable from a medical, surgical, and psychosocial standpoint.

The donor evaluation is a multi-phase process and can take some time. If you have questions about where your potential donor is in their evaluation, it is best to ask your donor directly. Your potential donor’s evaluation is completely separate from your own care and is confidential, so your recipient coordinator or social worker are not involved in the potential donor’s care and cannot share information about the evaluation with you.

# Using Social Media to Look for a Living Kidney Donor

Some people who are waiting for a kidney transplant decide to use social media sites such as Facebook, Twitter, Instagram and others to post about their kidney disease and to look for a living kidney donor. Using social media lets you share your story quickly and simply, and lets you reach a large number of people who might consider live kidney donation for you.

Please think about the pros and cons of using social media to find a living donor **before** posting online. We ask that you consider the information in this handout to help you decide if it is right for you.



## Should I Use Social Media to Find a Donor?

### Benefits of Using Social Media

- Lets many people know about your kidney disease and need for a transplant.
- Widens your search for a living donor; you may reach many people, including some you don't know.
- Speeds up your search; you can message friends and followers quickly.
- Social media may be more comfortable for you than a face to face conversation.
- Your posting may lead to a wider support network in general.

### Drawbacks of Using Social Media

- Once you post personal information online, it is out of your control. Posts can be shared or your information can be copied and pasted to other sites or pages.
- You may be disappointed if you do not get the response you are hoping for.
- You may be victimized by exposing personal information to people who may want to take advantage of you and your situation.
- You may be disappointed if possible donors don't go through with the full donor evaluation, which can be very hard on you and your loved ones.
- Large numbers of possible donors may contact the donor coordinators, and it takes time to review each donor – this may delay the evaluation of any one potential donor.

### If You Decide to Use Social Media

If you've considered the potential benefits and drawbacks of using social media to help you in your search and decided that it is right for you, **please talk to your transplant coordinator and/or transplant social worker BEFORE posting.** They can look over your post and help make sure you're including accurate information. Letting them know ahead of time about your plan to post can also help the live donor team prepare for the possibility of a larger number of inquiries and hopefully make the process more efficient for everyone.

### When Should I Post Something?

Please check with your transplant team about appropriate time to reach out to potential living donors.

## What Should I Include?

Deciding what information to include about yourself, your health, transplant and living donation can be hard!

We have developed some general recommendations to consider including when using social media to find a living donor:

- Share your story of kidney disease and how it has impacted you and/or your loved ones.
- Provide some basic information about transplant (i.e. how long the average wait is, benefits of live donor transplant).
- Provide some basic information about how to become living kidney donor – you can review the basic criteria at [www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor)
- Include a statement that the donor evaluation team is a separate team from your own and it is a confidential process.
- Please remember to include link to the BIDMC Information for Living Kidney Donors webpage: [www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor) and share that the best way to start the process is to complete the online intake form on this page.
- Actively maintain your page with posts and updates to let people know how you are doing and keep them engaged.
- Create a group page if you don't want to use your personal page for any reason.

## Is There Anything I Should Avoid Posting?

You are in control of how much or how little you share in your initial post and it's important to be thoughtful about what you put out there. If someone plans to post on social media on your behalf, please review with them what is and is not ok with you to post.

Some things to consider avoiding when using social media include:

- Personal phone numbers, addresses and emails
- Any health information that you might feel is sensitive and don't want shared with a wide network of people
- Remember that it is illegal to give money or any other item of value in exchange for a donated organ

## Example Post

You can modify it to include your personal experience:

*"Hi there! This is a difficult post to write but I want you all to know what is going on with me. You might already know that I have kidney disease. Well, I just found out that my best treatment option is kidney transplant. This was hard to hear but I am determined to get through this. One of the things the doctor talked about was living kidney donation as an option to get a transplant sooner and avoid dialysis. The wait for a deceased donor transplant can be five years or more with over 90,000 people on the list! The doctor also told us that kidneys from living donors can last longer and function better than kidneys from a deceased donor.*

*I know it's a lot to ask but would anyone be interested in learning more about being a living donor? If you are in good health, you might be able to donate to me. Living donors get a careful and thorough evaluation with a separate team of doctors, nurses and other healthcare professionals to ensure that living donation is as safe as possible for them. If your blood type doesn't match mine, we could be entered into a kidney swap (for more information, see <https://unos.org/donation/kidney-paired-donation/>)*

*Please send me a private message if you would like to talk more or would be interested in helping by considering donation or spreading the word about my need for a kidney transplant. You can also visit the Transplant Institute at BIDMC's webpage to learn more about living donation <http://www.bidmc.org/kidneydonor> or to confidentially complete the online intake form to be considered for living kidney donation. Thank you!"*

**KEEP IN MIND** that while social media can be an effective way to get the word out to people about your illness and search for a living donor, it is not the only tool you have. Think about your social networks and how you're comfortable reaching out to people.

Additional ways to reach people could include:

- Send an email or even a "snail mail"
- Share information through word of mouth at social gatherings
- Host an informational gathering of close friends/family at your home or another place you're comfortable
- Through your place of worship with a prayer request or posting in a bulletin/newsletter
- Ask someone to be a "donor champion" – someone who can help spread the message for you

Beth Israel Lahey Health   
 Beth Israel Deaconess Medical Center  
 Transplant Institute  
 110 Francis Street, 7th Floor, Boston, MA 02215

P: 617-632-9700  
 F: 617-632-9804

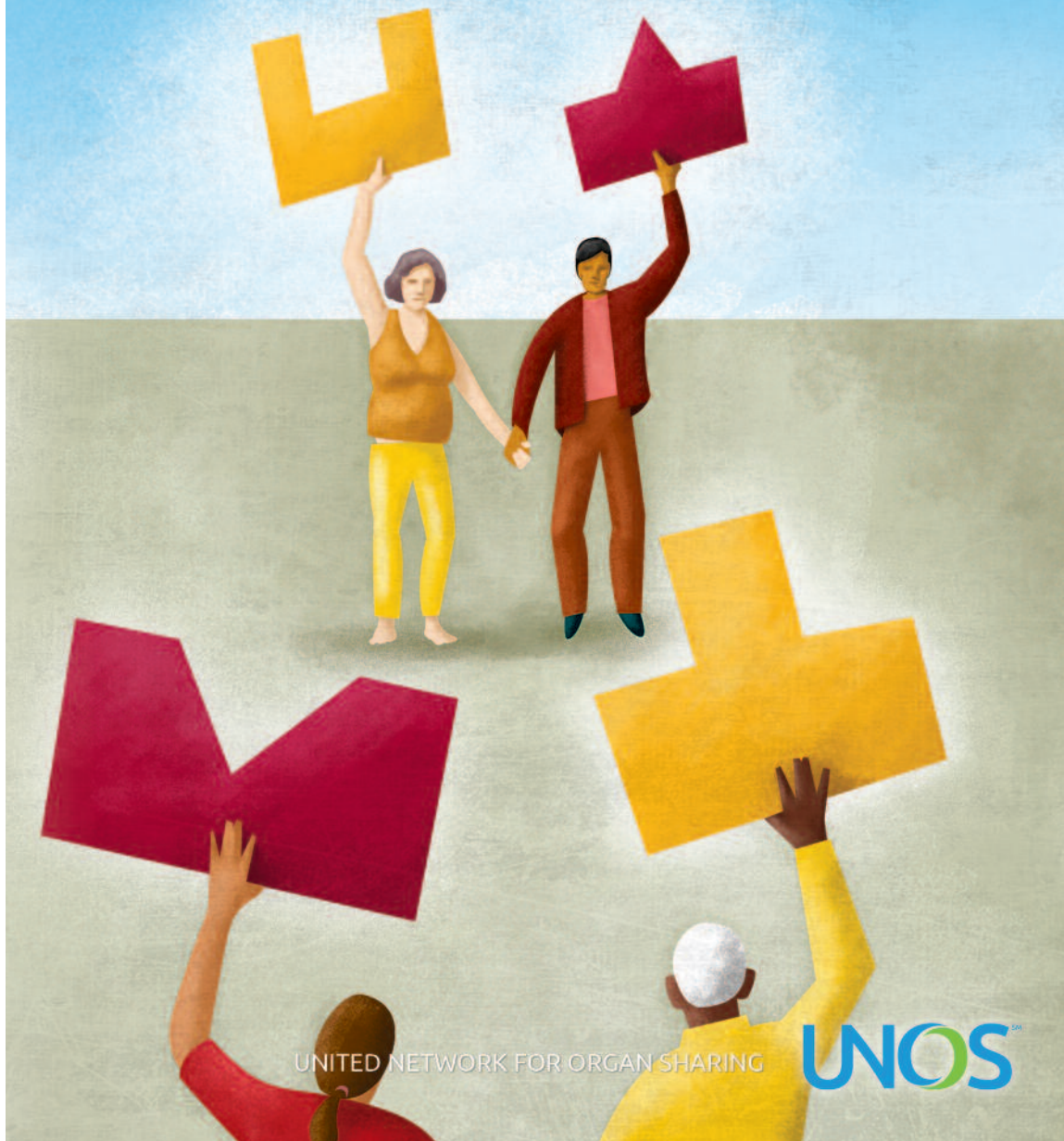
[bidmc.org/transplant](http://bidmc.org/transplant)  
[bidmc.org/kidneydonor](http://bidmc.org/kidneydonor)



TALKING ABOUT TRANSPLANTATION

# *I have a living donor who doesn't match, what can I do?*

## *OPTN Kidney Paired Donation Pilot Program*



*“Being part of a KPD transplant allowed me to help my husband live a normal life. I was also able to help another family live a normal life.”*  
—Paired Exchange Donor

## **UNITED NETWORK FOR ORGAN SHARING**

United Network for Organ Sharing (UNOS) is a private non-profit 501(c)(3) organization that operates the Organ Procurement and Transplantation Network (OPTN) under contract with the federal government. For more information about UNOS, living donation, and organ transplantation, please call 1-888-894-6361 or visit [www.transplantliving.org](http://www.transplantliving.org).

UNOS gratefully acknowledges the following sponsors for their generous support of the Kidney Paired Donation Pilot Program:

### PREMIER LEVEL

**UNITED HEALTH FOUNDATION**

### PLATINUM LEVEL

**NOVARTIS**

### GOLD LEVEL

**PFIZER**

**AMGEN FOUNDATION**

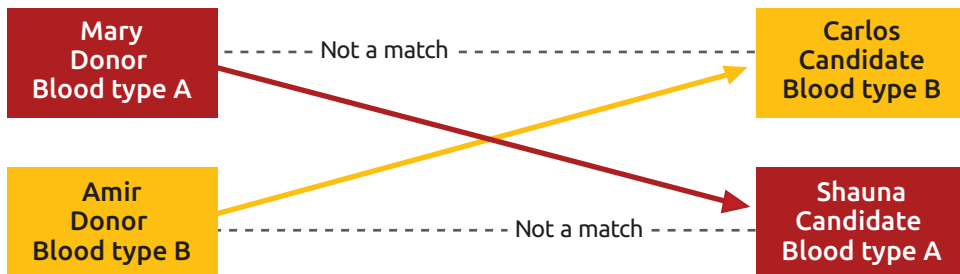
### SILVER LEVEL

**GENENTECH**

Many thanks to New England Organ Bank for sharing the information and illustrations in this brochure.

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## What is the OPTN Kidney Paired Donation Pilot Program (KPDPP)?

The KPDPP matches donors and candidates with other pairs who do not match. Your transplant team enters your medical information into a national database, managed by the Organ Procurement and Transplantation Network (OPTN). We match pairs twice a week, then we work with hospitals to plan the transplants.

## Who can join?

### *Transplant Candidates*

If you need a kidney transplant, are receiving care at a U.S. transplant hospital, and are on the national organ transplant waiting list, you can join. You do not have to be on dialysis. You must have a living donor who is willing to donate a kidney, but the donor does not have to be your same blood type.

### *Donors*

You must be at least 18 years old. You must be willing to take part in a KPD transplant. All donors must complete medical and psychological testing before they can donate.

People who wish to donate a kidney to someone they don't know are called non-directed, altruistic or Good Samaritan donors. These donors enter the KPDPP alone, not as part of a pair. They may allow several transplants to happen.

## What are the benefits of joining the KPDPP?

### *Candidates*

- You could receive a living donor transplant.
- You may spend less time on dialysis.
- You may receive a transplant before starting dialysis.
- You may not have to wait as long for a transplant.

### *Donors*

- Your loved one may receive a living donor kidney transplant.
- Your donation can help other patients and their families.

As with any surgery, kidney donation and transplant involve risks. Discuss these risks with your transplant team.

## Is there a fee to join the OPTN KPDPP?

No, there is no cost to you to join. Discuss the costs of donation and transplant with your transplant team.

### What happens when a match is found?

The transplant team will contact transplant candidates and donors. Tests are arranged to confirm a good match.

### Where would the transplant take place?

#### **Candidates**

The transplant will take place at the hospital where you currently receive care. You can choose to travel to your matched donor's hospital, if they are unable to travel and their kidney cannot be shipped.

#### **Donors**

There are two options.

- 1) You can have your surgery at the hospital who entered you into the KPDPP. Your kidney will be shipped to your matched candidate.
- 2) You could travel to your matched candidate's hospital for surgery.

### What will happen to my status on the deceased donor waiting list?

#### **Candidates**

If you join the OPTN KPDPP, you will remain on the list and you will continue to receive deceased donor kidney offers. Participation does not affect your wait-time or status on the deceased donor list.

### Can donors and recipients meet?

Yes, after surgery, donors and recipients can meet or connect with each other. Both the donor and the recipient must agree. Your transplant team can explain the rules.

### How do I get started?

Contact your transplant team to ask about the KPDPP.

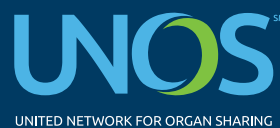
Learn more about living donation and transplantation:

- United Network for Organ Sharing: [www.unos.org](http://www.unos.org)
- UNOS Patient Services Line: 888.894.6361
- Organ Procurement and Transplantation Network: <http://optn.transplant.hrsa.gov>
- National Living Donor Assistance Center (NLDAC): [www.livingdonorassistance.org](http://www.livingdonorassistance.org); 888.870.5002
- National Kidney Foundation: [www.kidney.org](http://www.kidney.org)
- Organ donation: [www.organdonor.gov](http://www.organdonor.gov)

*Our mission is to advance organ availability and transplantation  
by uniting and supporting its communities for the benefit of patients  
through education, technology and policy development.*



[www.unos.org/social](http://www.unos.org/social)



700 North 4th Street, Richmond, VA 23219

[www.unos.org](http://www.unos.org)

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# **Transplant Listing and Awaiting Your Kidney**





## Transplant Listing

If you and the transplant team decide that transplantation is the best treatment for you, you will be listed with the United Network for Organ Sharing (UNOS). UNOS administers and maintains the computerized national organ transplant waiting list. You will join a list of people waiting for a kidney donation from a deceased donor.

The New England Donor Services (NEDS) is the local (regional) organ procurement organization (OPO) for Beth Israel Deaconess Medical Center and the rest of New England, and coordinates sharing organs through UNOS. Staff at NEDS will enter your medical information into a computer and will notify our transplant team when an organ becomes available based on your waiting time on the list, blood type and size match.

The wait for a deceased kidney is longer than the wait for a living donor kidney, and there is no guarantee when a deceased kidney will become available. It could be months or years. The average waiting time for a deceased donor kidney in New England is about 3-7 years.

For more about wait time, and other statistics, visit The Scientific Registry of Transplant Recipients. The SRTR publishes center-specific reports with a wide range of useful information about transplant programs operating in the United States. The information includes many features of the BIDMC transplant program, such as the number of transplants performed in recent years, waiting time and waitlist outcomes, and the post-transplant experience of our patients. The statistics allow comparisons to national averages, as well as to the experience for similar patients at other centers in the country. The waitlist report is based on BIDMC data for patients transplanted within the last five years.

### UNOS Policy

UNOS requires that transplant programs provide a telephone number so that patients can contact UNOS if they have grievances or concerns about multiple listings or any aspect of their transplant care. We are pleased to provide this number, which is in keeping with Beth Israel Deaconess Medical Center's focus on transparency, and our commitment to providing high quality care to the patients and families we are privileged to serve. You can reach UNOS toll free at 888-894-6361 or directly on the web at [www.unos.org/contact.asp](http://www.unos.org/contact.asp).

### Waiting for a Kidney to Become Available

There is no way to know how long you will have to wait before a deceased donor kidney becomes available for you. It could be between 3-7 years, and depends on many factors. Your physician can give you some information based on your blood type, degree of sensitization and other factors.

After you complete the evaluation, and you are accepted and listed for an organ, waiting may be difficult. It helps to remember that once you get the phone call about a possible match, things will move very quickly.

You may also be waiting for a living donor to come forward. Again, this can be a difficult time and we are here to help and support you.

While you wait for the organ, keep your body and mind healthy:

- See your doctor regularly
- Take your medications as directed
- Exercise to the best of your ability
- Follow your prescribed diet

While you are waiting for an organ to become available, you will visit the Transplant Institute every six months to a year, or sometimes more often, so we can monitor your physical and emotional well-being. As always, we encourage you to invite a loved one to these appointments.

Please update your transplant team about any of the following changes:

- health (hospitalization, infection, blood transfusion)
- social support
- travel (especially outside the country)
- demographics (address, phone number)
- medical insurance coverage or financial situation

Some of your testing will need to be updated annually such as stress and echocardiogram; cancer screening tests will be updated as per the American Cancer Society guidelines. Your nurse coordinator will tell you when it's time to update them. Keep a record of any hospitalization, infection or blood transfusion and inform your nurse coordinator immediately.

### **Multiple Calls and False Alarms**

Unfortunately there is the chance that our team may call you to the hospital, only to find there is a problem with the donor organ. Or you may come to the hospital with a medical problem – one that you did not know about – that could jeopardize your health or the success of the transplant. In these cases, it may not be possible to do the operation, which can be disappointing for you and your family.

### **Double-check Phone Numbers**

Make sure we can contact you day and night, no matter where you are. We only have 60 minutes to accept or decline an organ for you, so it is critical that we know how to reach you at all times. Check to be certain that we have the right phone numbers for a family member or friend – someone who will always know where you are. We will contact this person if we can't reach you directly.

# Are You Transplant Ready?

## PRE-TRANSPLANT PERIODIC TESTING

- Lab tests, drug/alcohol screens (if indicated)
- Echocardiogram
- Cardiac testing (if indicated)
- Imaging (CT SCAN, MRI)
- F/u with social work
- Mammogram/pap smear (females)
- PSA/prostate exams (males)
- Endoscopy screening (if indicated)
- Colonoscopy screening (per guidelines)

## WAITING FOR THE CALL

- Is your:
- Phone number and contact list up to date?
  - Phone on and charged?
  - Bag packed?
  - Ride arranged?
  - Child care/pet care in place?
  - Money set aside for rides/medications/co-pays?

## WHAT TO EXPECT WHEN YOU ARE CALLED IN

- You will receive call from transplant coordinator with offer details
- Tell us if you have had any recent illnesses, vaccines, or blood transfusions
- You will be admitted to Farr 10 or Pre-op holding area
- Nothing to eat/drink
- Bring insurance card/medication list
- You may be sent home if there are concerns with the donor organ or your health

## WHAT TO EXPECT AFTER TRANSPLANT

- A mandatory teaching session with coordinator & family prior to discharge
- Weekly f/u appointments for at least the first 6-8 weeks
- Labs twice weekly (minimum)
- You will need help with rides, medications, care at home - family may need to take time off from work/school
- You may need rehab admission, visiting nurse

Has your insurance changed? Ask to speak to our financial coordinators today: **617-632-9700**

**NOTIFY US** of any new medications, health issues, hospitalizations, blood transfusions, changes in your insurance, or changes in phone numbers

Do you know how much your post-transplant medications will cost? Call your insurance company today to see if you have the best plan for you!

Need More Resources?  
[www.bidmc.org/transplant](http://www.bidmc.org/transplant)  
[www.bidmc.wellist.com](http://www.bidmc.wellist.com)  
[www.kidney.org](http://www.kidney.org)  
[www.liverfoundation.org](http://www.liverfoundation.org)

**QUESTIONS?** Contact the Transplant Institute at **617-632-9700**

**Transplant Institute**  
 Lowry Medical Office Building  
 110 Francis Street, 7th Floor, Boston, MA 02215  
 P: 617-632-9700 | F: 617-632-9804 | [bidmc.org/transplant](http://bidmc.org/transplant)

 Beth Israel Lahey Health  
 Beth Israel Deaconess Medical Center

## Preparing for Your Hospital Stay

- Please bring your most recent medication list and your preferred toiletry items.
- One contact person should be designated by you to communicate with the transplant team. This person can update the remainder of your loved ones on your progress.
- The number for the inpatient transplant unit (FARR 10) is 617-632-8731. Please limit multiple phone calls to the unit.
- Please check with your team on FARR 10 for current visitation guidelines before inviting loved ones to visit.
- There are no live plants or flowers allowed on the inpatient transplant unit.
- Children under 12 are not allowed to visit.
- Visitors are not allowed in the post anesthesia care unit (PACU).
- Please ask your social worker for the current list of lodging information near BIDMC.
- Patients and family members are welcome to eat at any of the medical center's cafeterias or coffee shops. Several independent restaurants are also located within walking distance of the medical center.

**QUESTIONS?** Contact the Transplant Institute at **617-632-9700**

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P: 617-632-9700 | F: 617-632-9804 | [bidmc.org/transplant](http://bidmc.org/transplant)



Beth Israel Lahey Health  
Beth Israel Deaconess Medical Center

# **Multiple Listing and Waiting Time Transfer**



## Multiple Listing and Waiting Time Transfer

### *Questions and Answers for Transplant Candidates and Families*

#### **What are the OPTN and UNOS?**

The Organ Procurement and Transplantation Network (OPTN) links all of the professionals involved in the nation's organ donation and transplantation system. The OPTN also strives to make more organs available and increase patient access for transplants. The United Network for Organ Sharing (UNOS) is a non-profit organization that operates the OPTN under a contract from the federal government.

The OPTN and UNOS continuously review new advances and research and use this information to improve organ transplant policies to best serve patients needing transplants. All transplant programs and organ procurement organizations are members of the OPTN and agree to follow its policies.

#### **How am I Listed for a Transplant?**

If you have a condition leading to organ failure, your doctor may recommend you for an organ transplant. To become a transplant candidate, you must be evaluated and accepted by a transplant hospital. It is up to each center to decide whether or not it will accept someone as a transplant candidate.

#### **How am I Considered for Organs from Deceased Donors?**

You are considered for available organs based on a combination of medical facts entered into a computerized matching program. These factors include blood and tissue type, medical urgency, body size, distance between the donor and transplant hospital and time spent waiting for a transplant.

The distance between the donor and transplant hospital is important because the less time the organ must be preserved outside the donor's body, the better the chance that it will function when transplanted. There are three levels considered:

- **Local.** This is usually the area served by the local organ procurement organization (OPO) where the donation occurs. There are 58 OPOs nationwide. These areas are often statewide but can be smaller (such as a large city or part of a state) or larger (a multi-state area). Your Transplant Institute can tell you what your local area is.
- **Region or zone.** If there are no suitable local matches, organs are offered to patients at Transplant Institutes in a wider area. Kidneys, livers, pancreases and intestinal organs are first offered within one of 11 regions of the United States. Heart and lung offers are considered for candidates within 500 miles of the donor site, then 1,000 miles, then 1,500 miles.
- **Nationwide.** If there are no matches in the local area or region, organs will be offered to anyone in the United States who is a potential match.



## **What is Multiple Listing?**

Multiple listing involves registering at two or more Transplant Institutes in different regions. Since candidates at centers local to the donor hospital are usually considered ahead of those who are more distant, multiple listing may increase your chances of receiving a local organ offer.

## **Could Multiple Listing Shorten My Waiting Time for a Transplant?**

Some studies suggest multiple listing can shorten the average waiting times of kidney transplant candidates by several months. This does not guarantee that every multiple-listed patient will have a shorter waiting time.

Many factors affect how long you might wait for a transplant. Of course, not enough organs are donated each year to meet everyone's needs. Everyone in the transplant community shares the goal of increasing organ donation to save and enhance more lives.

Other waiting time factors include how urgent the patient is and how closely the donor and candidate match on body size and blood type. Some kidney and pancreas candidates have a "highly sensitized" immune system because of earlier transplants, pregnancy or multiple blood transfusions. Highly sensitized patients will only be good matches for a limited number of organ offers, so they often wait longer than non-sensitized candidates.

## **Are there any Restrictions?**

OPTN policy allows multiple listing. It will still be up to the individual center to decide whether to accept you as a candidate. You probably would not benefit from listing at multiple centers in the same local allocation area (which is usually the OPO). This is because waiting time priority is first calculated among candidates at all hospitals within the local donation area, not for each hospital individually.

Some transplant programs may not accept multiple-listed patients. Others may set their own requirements for multiple-listed candidates. If you are considering multiple listing, you should ask the transplant team how they handle such requests.

## **What is involved in Multiple Listing?**

As with any transplant listing, you must be considered and accepted by a Transplant Institute. This involves completing an evaluation and agreeing to meet any conditions set by the program (for example, ability to come to the hospital within a certain time if you are called for an organ offer).

You might check with your insurance provider to see if they will reimburse the cost of additional evaluations. You should also consider other costs associated with listing that insurance may not cover. For example, you may need to pay for travel and lodging if the center is further from your home. You should also find out whether your post-transplant medical care will be provided at the center or can be transferred to a facility closer to your home. In addition, you would need to maintain current lab results and contact information for each transplant program where you list. Each person will need current information should they receive an organ offer for you. Through the OPTN database your center can know if you are multiple-listed but may not know the other hospital(s) where you are listed.

### **If I List at More than One Center, How is My Waiting Time Considered?**

As soon as a center accepts you as a transplant candidate, your “waiting time” begins. Depending on the organ you need, waiting time may be a factor in matching you for an organ offer. Waiting time is a more important factor for certain organ types such as kidney and pancreas. It is less of a factor with heart, liver, and intestinal organs. For these organs more priority is given for factors such as medical urgency.

The longest amount of time you have waited at any center is called your primary waiting time. If you list at multiple centers, your waiting time at each center will start from the date that center listed you. OPTN policy allows you to transfer your primary waiting time to another center where you are listed or switch time waited at different programs. For example, if you have waited 9 months at Center A and 6 months at Center B, you could switch your time to have 6 months at Center A and 9 months at Center B.

You are not allowed to add up or split your total waiting time among multiple centers. Again, assume you have waited 9 months at Center A and 6 months at Center B. You could not assume you have 15 total months of waiting time and assign 5 months to Center A and 10 months to Center B.

Any request to transfer or switch waiting time must be approved by the Transplant Institute(s) involved. Most transplant programs require a written request to swap or transfer waiting time, which will then be considered by the transplant team.

### **If I Do Not Multiple-list but Transfer my Care to Another Hospital, What Happens?**

If you want to end your listing at one program and transfer to another, your primary waiting time can be transferred as long as you coordinate with both programs. The new transplant program will probably ask you to request in writing to transfer the waiting time.

Sometimes a transplant program may inactivate for a period of time (for example, to replace a key member of the transplant team who leaves) or close its operations. If this happens, the OPTN requires that the program contact you and provide for your continuing care. If the inactivation is short-term you may choose to remain listed until the program becomes active again, but you will not receive organ offers during that time. If the program closes, the staff will work with you to arrange care at another center without loss of your primary waiting time.

### **Where can I get Additional Information?**

You should first contact the staff of the transplant program where you are listed or want to be listed. They will have the most specific information about how they handle requests for multiple listing and/or waiting time transfer. They will also make any needed arrangements with UNOS.

UNOS maintains a web site, Transplant Living, which contains extensive information for transplant candidates and recipients as well as their family members. The address is [www.transplantliving.org](http://www.transplantliving.org). You may also wish to visit the OPTN web site at [www.optn.org](http://www.optn.org).

UNOS also maintains a toll-free phone information line for transplant candidates, recipients and family members. The number for Patient Services is 1-888-894-6361.



# **Where Does the Deceased Donor Organ Come From?**



## Where Does the Deceased Donor Organ Come From?

If our Transplant Institute staff determines that you are a transplant candidate, we add your medical profile to the national patient list for organ transplant that is maintained by the United Network for Organ Sharing (UNOS) in Richmond, Virginia. You will join a list of people waiting for a kidney donation from a deceased donor.

The majority of deceased donor organs for BIDMC transplant patients come from donors in New England. The transplant is coordinated by the New England Donor Services (NEDS), which operates according to policies set by the United Network for Organ Sharing (UNOS), as supervised by the federal government. When a donor is identified, NEDS sends UNOS information about the donor, including blood type, vital statistics such as blood pressure and weight, donor age and cause of death, information about blood tests, blood test results and social history.

Deceased donors and their kidneys are tested carefully. First, doctors look at the condition that has led to the donor's death or imminent death. Some deceased donors have other medical conditions or diseases. Family members are asked about the behaviors and practices of the donor. Deceased donors are tested for infections including syphilis, hepatitis B and C, HIV, AIDS, and other viruses. Donors are also screened for cancer. Some otherwise good donors may have infections caused by bacteria such as pneumonia or urinary tract infections. This may mean that the transplant recipient will be treated for these infections at the time of transplant.

### Donors at Increased Risk of Infectious Diseases

As mentioned above, all donors are tested for infectious diseases including HIV/AIDS, hepatitis B, hepatitis C, cytomegalovirus, Epstein-Barr virus, and syphilis. Donors with positive testing for HIV are not currently used in our program. Donors with hepatitis C may be used in recipients with hepatitis C infection after discussion with the recipient. Use of a hepatitis C organ often reduces the time a patient spends waiting for a kidney transplant. Donors with a history of hepatitis B infection who do not currently have active infection may also be used. Recipients of these organs will require an additional medication to prevent reactivation of hepatitis B after transplant.

Some donors are considered to have an increased risk of transmitting infections even if all of their testing is negative. The Public Health Service established guidelines in 1994 and revised them in 2013 to identify potential donors who have an increased risk of infection. The most common reasons for donors in our region to be in this category include people who have used intravenous drugs, people who have had sex in exchange for money or drugs, people who have been incarcerated for more than 72 hours, men who have sex with men, people diagnosed with sexually transmitted infections, or anyone who has had sex with someone in the above categories. There are several less common reasons why a donor may be considered at an increased risk of infection.

Donors identified to be at increased risk of disease transmission have the same testing as all other donors. These tests will not necessarily detect a very recent transmission of infection. This means that even with negative testing from the rapid result tests, there is a small risk of transmitting an infection like HIV, hepatitis B, or hepatitis C. Donors in our region are tested using antibody tests that look for the donor's immune system's response to infection as well as tests that look for presence of the actual virus in the donor's blood. Antibody tests may require several weeks to months to become positive in infected donors. Detection of virus in a donor's blood may take several days to weeks. This period during which an infection could be transmitted but before tests

can reveal an infection is called the “window period.” The window period differs between the type of test and among different infections.

The risk of transmission of infections through organs from donors at increased risk of infectious diseases has been studied in the US and elsewhere. When using our most sensitive tests, the highest risk of disease transmission is from donors with recent injection drug use. If we were to perform 1000 kidney transplants from donors in this group, we would expect 3 or 4 patients to develop an infection. Another way to state this risk is that 996 out of a 1000 transplants from donors like this would NOT result in a new infection.

When we offer kidneys in this category, recipients always have the option to accept or refuse the organ. This will not change or jeopardize your status on the Transplant Waiting List. If the organ is used, we will check your blood for signs of infection at the time of transplant and at 6 weeks, 12 weeks, and 6 months after the transplant. Should an infection be identified, we have excellent treatments for HIV and HBV and have newer medications that can cure HCV in many cases.

Potential recipients may ask why they need to know about this group of donors. Due to the opioid epidemic, in our region, over 1/3 of donors are in this category. This number has been increasing each year. It is very likely that the organ you will be offered will be considered at an increased risk of infectious disease transmission. You will always have the option of refusing an organ but we want you to have an understanding of the real risks of disease transmission as well as the risks of refusing an organ. National studies have shown that patients who refuse kidneys in this category wait an average of one year longer for their transplants, receive kidneys of slightly lower quality, and often end up using an organ in this category anyway. Waiting longer for a kidney means more time on dialysis and the risk that you may not ever get a kidney due to worsening health or new medical problems.

It is important to remember that even donors without any known behaviors that increase their risk for infection may still transmit infections although this risk is lower than those known to be at an increased risk. Donors’ families and friends may not know about particular behaviors that increase the risk of infection or they may choose not to reveal this information to the donor team.

This topic is complicated. Your coordinators and physicians are happy to discuss this issue with you at any time during your evaluation or waiting time for your transplant.

### **Donors after Cardiac Death**

Most deceased donors have sustained a terrible brain injury resulting in a category of death called brain death. Roughly 25% of donors have a significant neurologic injury but do not meet the specific criteria for brain death. The families of such donors often decide to stop medical care and let the patient die naturally. In some circumstances, stopping medical care can be coordinated with recovery of organs for transplant including kidneys, livers, lungs, and pancreas. This category of deceased donor is called “donation after circulatory death” or “donation after cardiac death” or “DCD” for short.

We frequently use kidneys from DCD donors. These kidneys are often of good quality. We know that they are more likely to take longer to recover and start working in recipients. Some recipients may even require dialysis while the kidney is recovering. If a recipient needs dialysis after transplant, we call this “delayed graft function.” It is important to know that even kidneys from traditional

brain-dead donors may suffer from delayed graft function (DGF). We know that kidneys from DCD donors are slightly more likely to develop DGF.

In the long-term, kidneys from DCD donors work just as well as kidneys from donors after brain-death. You will always have the option to refuse an organ for any reason. You will not be penalized for declining an organ offer. National data shows that patients who refuse DCD kidneys wait longer for their transplants and have worse overall outcomes than those who accept DCD kidneys.

### **Donors with Hepatitis C**

At this time, we use kidneys from donors with hepatitis C only in recipients who have hepatitis C. Many of these donors are also considered to be at increased risk of other infections (see above).

Newer medications to treat hepatitis C have resulted in a much higher rate of cure of the infection than even 5 years ago. If you have hepatitis C, your nephrologist or surgeon will discuss this option with you in more detail.

Some centers in the US are now researching the use of hepatitis C kidneys in recipients who do not have hepatitis C. This may be an option for our patients in the future, but we are waiting to see the results of these carefully conducted studies.

### **Risk of Transmission of Cancer from Deceased Donors**

Deceased donors are screened for common forms of cancer, because cancer can be spread to the transplant patient with the new kidney. Donors are also thoroughly examined at the time of organ recovery to identify unknown cancers. Even with this testing and examination, there remains a risk of transmitting cancer with the organ. If this happens, transplant drugs usually have to be stopped and often the kidney is removed or lost to rejection. As with some infections that are carried by the transplanted kidney, getting cancer from your transplant can be fatal. Each year, of the roughly 30,000 transplants performed in the US, transmission of a cancer from the donor to recipient is confirmed or suspected 5-15 times.

## **KDPI > 85 Kidneys**

### **What does KDPI mean?**

Every kidney offered for a transplant will have a KDPI score. This is a percentage score that ranges from 0 to 100%. The score is associated with how long the kidney is likely to function when compared to other kidneys. A KDPI score of 20% means that the kidney is likely to function longer than 80% of other available kidneys. A KDPI score of 60% means that the kidney is likely to function longer than 40% of other available kidneys.

### **What goes into a KDPI Score?**

The KDPI is calculated based on facts about the donor that affect how long the kidney is likely to function. These factors include the donor's: age, height, weight, ethnicity, stroke as cause of death, history of diabetes, exposure to hepatitis C, history of high blood pressure, death from loss of brain or heart function, serum creatinine.



### **What are the Advantages of Accepting an Increased KDPI Kidney (above 85%)?**

Being listed for and receiving a transplant of an increased KDPI donor kidney may help you by:

- A shorter wait time for a kidney transplant
- A shorter time spent on dialysis and less chance of dialysis related complications
- Increased chances of long-term survival when compared to remaining on dialysis and waiting for a “regular” or better KDPI kidney to become available.

### **What are some Disadvantages of Increased KDPI Kidneys?**

Kidneys from donors with an increased KDPI (greater than 85%) can have:

- A higher incidence of delayed graft function which means the kidney may take longer to start working. This may lead to a longer hospital stay, additional biopsies to assess kidney function and potential rejection, and possible temporary dialysis until the kidney “wakes up.”
- A higher chance that the kidney will not last for 10-15 years, but more likely 5-8 years on average.

As with all kidney transplants, there is a small chance (<5%) that an increased KDPI kidney will not function.

### **Important Considerations**

- The increased KDPI donor program is nation-wide not just in New England or at BIDMC.
- Choosing to be placed on the increased KDPI kidney waiting list is entirely voluntary. This waiting list does not replace the regular kidney waiting list already in place, so you may withdraw your consent at any time without penalty or loss of time on the regular kidney waiting list.
- Choosing to be listed on the increased KDPI kidney waiting list does not mean that you will automatically get this type of kidney.
- We will notify you at the time you are offered a kidney if it is an increased KDPI kidney (greater than 85%). You may also change your mind at that time and decline to accept the kidney.

### **For More Information**

The transplant staff will explain the different types of deceased donors to you during your pre-transplant clinic visits. You should consider these types of donors carefully well in advance of being asked to decide about a particular type of donor. Your team would be happy to discuss these issues with you and provide guidance.

# Kidney Allocation



TALKING ABOUT TRANSPLANTATION



*Questions and Answers  
for Transplant Candidates about*

# Kidney Allocation

UNITED NETWORK FOR ORGAN SHARING



## Questions and Answers for Transplant Candidates about the Kidney Allocation System

United Network for Organ Sharing (UNOS) is a non-profit charitable organization that serves as the nation’s transplant system—known as the Organ Procurement and Transplantation Network (OPTN)—under contract with the federal government. As the OPTN, UNOS helps create and define organ sharing policies that make the best use of donated organs. This process involves continuously evaluating new advances and discoveries so policies can be adapted to best serve patients waiting for transplants.

All transplant programs and organ procurement organizations throughout the country are OPTN/UNOS members and are obligated to follow the policies the OPTN creates for allocating organs.

### How are kidneys classified?

Every kidney offered for a transplant has a Kidney Donor Profile Index (KDPI) score. This is a percentage score that ranges from zero to 100 percent. The score is associated with how long the kidney is likely to function when compared to other kidneys. A KDPI score of 20 percent means that the kidney is likely to function longer than 80 percent of other available kidneys. A KDPI score of 60 percent means that the kidney is likely to function longer than 40 percent of other available kidneys.

### What goes into a KDPI score?

The KDPI is calculated based on facts about the donor that affect how long the kidney is likely to function. These factors include:

- *Age*
- *Height*
- *Weight*
- *Ethnicity*
- *Whether the donor died due to loss of heart function or loss of brain function*
- *Stroke as cause of death*
- *History of high blood pressure*
- *History of diabetes*
- *Exposure to the hepatitis C virus*
- *Serum creatinine (a measure of kidney function)*

### How are transplant candidates classified?

Each kidney candidate gets an individual Estimated Post-Transplant Survival (EPTS) score. This is a percentage score that ranges from zero to 100 percent. The score is associated with how long the candidate will need a functioning kidney transplant when compared with other candidates. A person with an EPTS score of 20 percent is likely to need a kidney longer than 80 percent of other candidates. Someone with an EPTS score of 60 percent will likely need a kidney longer than 40 percent of other people. Your transplant team can calculate your EPTS score for you.

#### What goes into an EPTS score?

The EPTS is calculated based on facts about the candidate that affect how long you are likely to need a kidney.

These factors include:

- *Age*
- *Length of time spent on dialysis*
- *Having received a previous transplant (of any organ)*
- *Current diagnosis of diabetes*

### How are KDPI and EPTS scores used in allocating kidneys?

The 20 percent of kidneys that are expected to last the longest—those with a KDPI score of 20 percent or less—are first offered to patients likely to need a transplant the longest – those with an EPTS of 20 percent or less. If a kidney with a KDPI of 20 percent or less is not accepted for any of these patients, it is then offered to any other person who would match, regardless of their EPTS score.

Kidneys with high KDPI scores are expected to function for a shorter amount of time than others. They may be best used to help candidates who are less able to stay on dialysis for a long time.

The 15 percent of donated kidneys likely to function the shortest time (those with a KDPI greater than 85 percent) will be offered first to a wider area of the country than other kidneys. The goal is to encourage use of these kidneys by finding a suitable patient as quickly as possible.

Your transplant team can discuss with you the best options for matching based on your EPTS score and the types of kidneys that would best meet your need.

### **How are children and teenagers matched?**

There are not many pediatric kidney candidates (those who are younger than age 18), but they risk having growth and developmental issues if they must wait a long time for a transplant. For this reason, they receive priority for the 35 percent of kidneys that are likely to function the longest – those with a KDPI score of 35 percent or lower.

### **How does the system help hard-to-match patients?**

Some patients are hard to match with most kidney offers because they have uncommon blood types. Others are likely to have an immune system rejection for most kidneys. The new system boosts their chances of getting a matching offer.

People with blood type B often wait longer for a kidney than people with other blood types, in part because it is harder to find a donor with type B blood.

Donors with blood type A generally can't donate to a person with blood type B. However, some blood type A donors have a "subtype" that allows them to match a type B candidate. The system gives first priority for these donor kidneys for type B patients. Since blood type A donors are more common than blood type B donors, more offers should be available for type B candidates.

In other cases, people have developed immune system responses that make it very hard to find a kidney their body won't reject. This may happen because of having a previous transplant or blood transfusion, or even from pregnancy. People who are "highly sensitized" often wait five or more years before receiving even one kidney offer.

The system gives immune sensitized candidates more priority for kidneys they aren't likely to reject. People who have a slightly higher sensitivity get slightly more priority. People who are very highly sensitized (98 percent or above) will get much more priority. Kidneys that are offered first to highly sensitized candidates, but don't get accepted for them, are then offered to other patients.

Your transplant team can discuss with you whether you are sensitized and, if so, the additional priority you would receive for matching kidneys.

### **How is waiting time calculated?**

A transplant program may evaluate and list you for a transplant even before you start dialysis. If you are listed early, you can be matched for deceased donor kidneys based on medical matching criteria in the kidney allocation policy. You would not receive additional priority for waiting time until you either start dialysis or have kidney failure (a creatinine clearance below 20 ml/minute).

### **What if I'm not listed for a transplant but want to be?**

Talk to your doctor about your current health and your treatment options. If you want to be considered for a kidney transplant, it would be best to get evaluated and listed by a transplant hospital when, or just before, you start dialysis or reach end-stage kidney failure. This will allow you to be considered as early as possible for a kidney offer.

### **For more information**

Start with your doctor or the medical team at your transplant center. They know the most about your specific medical condition and treatment. Don't be afraid to ask questions. It will help you to have a detailed understanding of all your treatment options.

UNOS' Patient Services phone line (888-894-6361) can provide information about the OPTN and UNOS, allocation policy and other resources available to you. Additional information is available online on the following websites:

<http://www.transplantliving.org>      <http://www.unos.org>  
<http://optn.transplant.hrsa.gov>      <http://www.srtr.org>



*Our mission is to advance organ availability and transplantation  
by uniting and supporting its communities for the benefit of patients  
through education, technology and policy development.*



[www.unos.org/social](http://www.unos.org/social)

**UNOS**<sup>SM</sup>

UNITED NETWORK FOR ORGAN SHARING

700 North 4th Street, Richmond, VA 23219

[www.unos.org](http://www.unos.org)

# **The Right Match – You and Your Donor Kidney**



## The Right Match – You and Your Donor Kidney

### Words to Know to Understand the Matching Process

**Antibodies:** Proteins produced as part of an immune response to a specific foreign substance (antigen) in order to eliminate that foreign substance from the body.

Antibodies are proteins that are produced by your body's immune system or administered to you to protect you from viruses, bacteria, or other substances that the body sees as threatening or foreign. For example, vaccines are given to give you protective antibodies – the hepatitis B vaccine will give you antibodies to protect you from the hepatitis B virus if you are ever exposed to this virus.

**Antigens:** Protein or carbohydrate molecules recognized by the body that can stimulate an immune response if considered different from one's self.

Antigens are proteins that can cause your body's immune system to produce antibodies – if the body thinks that the antigen is foreign or different from one's self. The body usually will not produce antibodies against itself or its own antigens. For example, if you are blood type A, you carry the A antigen on your red blood cells, therefore you can get blood from someone with blood type A or blood type O. Blood type A has the A antigen on the red blood cells. Blood type O does not have either the A or the B antigen, therefore you can receive blood from type O. You cannot receive blood from blood type B or AB because your body would see the B antigen as foreign and destroy those B blood cells.

The diagrams below will explain who can get what blood type – this is important in transplant, too, as you can only get an organ from a compatible blood type.

There are two types of kidney donors: 1) deceased donors, who are people that have just died and 2) living donors, who may be a relative, close friend, or a person you have never met that is donating altruistically or through a kidney exchange program. Regardless of the type of donor, blood tests are performed on you and your donor to determine the donor's compatibility with you for transplant.

### Transplant Blood Tests to Determine the Right Match With A Recipient and Donor (living or deceased)

There are three important blood tests to determine whether a Kidney Recipient and Kidney Donor Match.

#### 1. Blood Type Matching also known as ABO Compatibility

Blood typing is the first blood test that will determine if your blood type is an acceptable match with a potential donor's blood type. The following blood types are compatible:

- Recipients with blood type O... can receive a kidney from blood type O only
- Recipients with blood type A... can receive a kidney from blood types A and O
- Recipients with blood type B... can receive a kidney from blood types B and O
- Recipients with blood type AB... can receive a kidney from blood types A, B, AB and O

- Whether you are Rh + or Rh – does not affect matching, for example O+ or O –

		Recipient			
Blood Group		A	B	AB	O
Donor	A	Compatible	Incompatible	Compatible	Incompatible
	B	Incompatible	Compatible	Compatible	Incompatible
	AB	Incompatible	Incompatible	Compatible	Incompatible
	O	Compatible	Compatible	Compatible	Compatible

## 2. Tissue Typing

Tissue Typing is a test where the lab takes tubes of your blood and determines some of your own individual genetic building blocks. Another name for this is HLA typing. HLA stands for human leukocyte antigens – genes on your cells that make you, you!

- Parents, children, and siblings can have some of the same genes as genes are inherited- this is why living donors can sometimes be a good match.
- All kidney recipients and any potential kidney donors (living or deceased) get this tissue typing. We need to make sure that the organ is a potential good ‘genetic’ match.

Tissue Typing also measures your antibodies to HLA or antibodies to someone else’s genetic make-up.

- Antibodies usually are helpful in the body as they help fight off infections but in transplant they can cause a rejection as your body’s antibodies will attack the new kidney as they see it as “foreign invader” if you have antibodies to this new kidney.
- You can develop antibodies from previous transplants, transfusions, pregnancy and even things like surgeries or severe infections.
- These antibody levels are measured periodically while you are on the Transplant List by your Transplant Team. If you have a high level of antibodies, it may be more difficult to find a kidney for you that your body will accept.

## 3. Serum Crossmatch

A serum crossmatch is a test that is done with your blood cells and your potential donor’s blood cells before the kidney transplant.

- If your blood serum has high levels of antibodies against the donor blood serum, the donor cells will be destroyed.
- This is called a positive crossmatch – it indicates that your body would reject that donor’s kidney and the transplant cannot take place.
- Once on the kidney transplant list, you will have to have 2 tubes of your blood sent to our lab at the beginning of every month to be available for cross-matching for any

potential deceased donor from New England Donor Services. Speak to your Nurse Coordinator for more information about this.



# **The Kidney Transplant Operation**





## The Kidney Transplant Operation

There are risks with any surgery, and general anesthesia in particular. With advances in surgical technique, pharmaceutical breakthroughs, and the growing numbers of living donors, transplanted kidneys are lasting longer and functioning better. Transplantation success improves overall patient survival rates and enriches the quality of life. Some of our patients at BIDMC have had their transplanted kidney for more than 30 years.

### Surgical Procedure

Kidney transplant surgery generally takes 2 to 3 hours to complete. The surgeon begins by making a hockey-stick shaped incision 8 to 10 inches long in the lower abdomen, on either the right or left side. If you still have one or both original kidneys, the surgeon does not remove them during this operation. Under certain circumstances (for example, if this is your third kidney transplant), the surgeon may remove a previously transplanted kidney at this time.

Next the surgeon will attach the artery and vein of your new kidney. The artery to the kidney is sewn into the side of the artery that supplies blood to your leg and lower abdomen, and the vein to the kidney is sewn into the side of the vein that drains blood from your leg and lower abdomen. The surgeon will also connect the donor kidney's ureter – the tube that carries urine – to your bladder.

The surgeon may also place a stent (tube) in the ureter to hold it open and protect it until it has healed. There is absolutely no discomfort associated with a stent. A urologist will remove the stent during an office visit four or five weeks after surgery.

The team will close your incision with staples or sutures and cover the area with a gauze dressing. With the operation complete, you will go to the post anesthesia care unit (PACU), and from there, to the Farr 10 transplant unit. The surgeon will let your family members know how you are doing.

### The Post Anesthesia Care Unit (PACU)

Following the operation, you initially go to the post anesthesia care unit (PACU) where doctors and nurses monitor you very closely. (Some patients, who may need more intense observation, go to the surgical intensive care unit (SICU), although this is very unusual.) Here's some of what you can expect when you wake up:

- You may hear unfamiliar sounds, such as machinery to monitor your heartbeat, blood pressure and breathing.
- If you have a breathing tube in place, which is very unlikely, you will not be able to talk.
- Some medications may make you very sensitive to the noises around you.
- You might feel nauseated from the anesthesia. Your nurse will give you medication for relief.
- Medication can also help relieve any pain or discomfort you feel from the surgery.
- Nurses will check the dressing on your incision frequently and change it as needed. It is not unusual for fluids to drain from your incision for some time after your operation.

- Doctors and nurses in the PACU will continuously monitor how well your new organ is functioning by taking blood tests, measuring and testing the fluids your body produces, and using other testing methods such as X-rays when necessary.
- Typically patients are in the PACU for 4 to 12 hours. When you are stable, we will move you to Farr 10, our transplant unit, for the rest of your hospital stay.

## **More Information about Tubes, Drains, and Monitoring Devices**

Many of the tubes, intravenous lines, monitoring devices and drains that the team put in while you were under anesthesia will still be in place after the surgery. Here is a little more information about some of them.

### **The Breathing Tube**

Called an endotracheal or “ET” tube, this tube is in your throat and attached to the respirator to help you breathe during surgery. It is usually removed in the operating room as you are waking up; you usually will not remember it being taken out because of the anesthetic medications. In some cases, however, it might be necessary to leave the tube in to help you breathe as you are waking up. If it is still in place when you wake up, the nurses will give you pain medications and sedation to help keep you comfortable until it is safe to remove the tube.

### **Intravenous Lines (IV)**

The IV lines may remain in place for most of your hospital stay. They allow us to draw blood for tests, administer any medications that you may need during recovery, and provide you with fluids to promote blood circulation. They also help assess heart and lung function.

### **Abdominal Drain**

You may have a drain placed in your abdomen that lies close to the kidney. This allows any fluid that collects around the kidney after the transplant to be removed. The drain is usually removed before you are discharged but occasionally will remain in place longer.

### **The Bladder Catheter**

Also called a Foley catheter, this will be placed in your bladder during surgery to drain your urine, and will be in place when you awaken. Your nurse will remove it a few days after the surgery.

The Foley catheter allows staff to monitor your urine output every hour to determine how well your new kidney is working and how much intravenous fluid you need. It also helps keep the bladder from becoming too full, which promotes healing at the suture site, where the donor ureter is attached to your bladder.

### **The EKG/Telemetry Leads**

When you leave the PACU, a nurse may remove the EKG leads used to monitor your heart.

## Stents

Your surgeon may have placed a stent (tube) in your ureter to hold it open during healing. If so, a urologist will remove the stent during an office visit about 4 to 5 weeks after surgery.

## Your Stay on Farr 10

Although recovery times vary from patient to patient, and complications are unpredictable, you can anticipate being in the post anesthesia care unit (PACU) for 4 to 12 hours. Once you leave the PACU, or the intensive care unit, you will move to Farr 10, our inpatient transplant unit. You will learn how to care for yourself here so you will feel confident and comfortable when you are ready to go home.

## Out of Bed

You will be out of bed and walking with assistance the day of, or the day after, your operation. We will give you fluids to drink 24 to 48 hours after the surgery, and you can begin to eat solid foods when you can tolerate them. You may need dialysis if your new kidney does not produce urine right away. While this can be disappointing, it does not mean the kidney will never work properly. Barring any complications, you could go home from the hospital within 4 to 7 days.

While in the hospital, staff will:

- Order blood tests to be drawn at least once a day
- Take your temperature and blood pressure several times a day
- Weigh you every day
- Check your incision several times a day and change the dressing as needed
- Empty the catheter and drain bags
- Adjust your intravenous lines
- Help you learn about your medications; symptoms to watch for at home; specific diet requirements; and any needed post-op care
- Help you prepare to go home or to another facility in numerous ways such as making sure you can bathe and walk by yourself, take your medications properly, change your dressing, and empty any drains

## More about Your Daily Care

While you are on the transplant unit, you will continue coughing and deep breathing exercises to keep your lungs clear of fluid. Your nurses will also encourage you to get out of bed and walk around your room and down the hall at least three times a day. Walking increases your blood circulation, helps relieve gas pains, and helps maintain your muscle tone.

Some people have trouble sleeping while in the hospital, and some people experience strange dreams that seem very real. Many transplant recipients also report memory problems after the surgery.

These problems are temporary. Talk with your doctor if this persists or troubles you. Your appetite and energy level will not be the same as it was before the surgery. In general these will return to baseline within a few weeks of the transplant.

### **Our Nursing Staff**

Our nurses at BIDMC are the heart and soul of patient care delivery. Nursing's dedication to compassionate care is one of the medical center's guiding strengths. Patients, peers and colleagues recognize our nurses for their valued expertise and proficiency.

Patient satisfaction surveys applaud nurses throughout the medical center, including those who are part of our Transplant Institute, for their exemplary efforts in meeting patient needs.

Transplant Institute nurse coordinators and nurses on staff in PACU and Farr 10 have extensive experience with the post-transplant patient. They are often the best resource for patients and families when there are questions regarding your care.

### **Nurse Practitioners**

There are nurse practitioners on the transplant floor who are part of the transplant team and work directly with the surgical doctors. They help coordinate your care and are an excellent resource for updates on your care while you are in the hospital.

### **Physical Therapy**

A physical therapist will visit you post-transplant, and may have seen you pre-transplant. Our therapists will help you regain your strength and teach you how to move about more comfortably.

### **Case Management Services**

Case managers constantly monitor your progress. They help develop a discharge plan, including decisions about whether you should move to a facility for rehabilitation or arrange for homecare services. They work with you and your family to set up these and any additional services you might need.

### **Social Work**

A social worker will also see you, and perhaps your family, to help with coping strategies, home arrangements, and other issues surrounding your transplant.

### **Learning to Care for Yourself**

You will have many things to remember when you leave the hospital. Taking an active role in your self-care and developing a daily routine while you are in the hospital will help you better care for yourself after you go home.

One of the most important things you will learn on Farr 10, under the guidance of our experienced nurses, doctors and other staff members, is how to take care of yourself safely.

Your role as a member and a partner of the transplant team becomes more important than ever at

this point because your new kidney will need a lot of care, attention, and monitoring to do its job. Having a new kidney is a life-long commitment!

### **Learning about Your Medications**

Your transplant team will decide what medications are right for you. You will have to take immunosuppressive medication to prevent the rejection of the transplanted kidney. You will take these medications for as long as you have a functioning kidney transplant.

In addition to the immunosuppressants, you will also have to take medications to prevent infection, although you will not have to take these medications for long. You may also need medications after your transplant to help control your blood pressure and cholesterol.

The team will adjust your meds in the hospital and will continue to monitor their effectiveness after discharge. We will teach you the names and basic effects of each drug you need to take. Remember, taking your medications is your responsibility. If you are unable to take your medications at home for some reason, you must call the Transplant Institute.

You will be enrolled in our self-medication program which enables you to learn how to take your medications safely before you go home. Our transplant pharmacist will meet with you to review this program.

### **Transplant Medication**

These medications suppress the immune system enough to keep the transplanted kidney healthy. The three main categories of medication include induction immunosuppression, maintenance immunosuppression and rescue therapy for the treatment of rejection:

- Induction immunosuppression is the initial high dose medication, both intravenous and oral, that you take in the first 1 to 2 weeks after your transplant.
- Maintenance immunosuppressants are also started while you are in the hospital. You will continue on these medications in order to prevent your body from rejecting the kidney transplant over time.
- Rescue therapy for the treatment of rejection is typically given as an intravenous medication while in the hospital.

## Possible Complications after Kidney Transplant Surgery

We will be watching closely for signs of any complications so that we can treat them quickly. The most common complications are medication side effects, wound complications and infection. High blood pressure, renal (kidney) dysfunction, rejection and ureter complications can occur as well. Please remember that some of these complications are not common.

### Rejection

Rejection is a signal that your immune system has identified your new kidney as foreign tissue and is trying to get rid of it. Preventing rejection with immune-suppressive medications is the first priority. Only about 10 percent of patients may experience some signs of rejection during the first 6 to 12 weeks after the transplant operation. The most common symptoms of rejection are:

- Change in kidney function (an increase of creatinine)
- Tenderness over the kidney
- Decrease in urine output

If it appears that you are having a rejection episode, you may need a kidney biopsy and kidney ultrasound. If tests verify that your body is rejecting the transplanted kidney, we will increase your amount of anti-rejection medication or prescribe a different combination of anti-rejection medications. These types of rejection episodes are nearly always reversible and rarely lead to loss of the kidney so long as you continue to take your anti-rejection medications.

### Infection

The anti-rejection medications that you take to prevent and treat rejection tell your immune system to accept your new kidney in your body. In doing so, they also can be telling your immune system to accept other things that it ordinarily would fight. In other words, the anti-rejection medications put you at greater risk for developing an infection. The most common infections after a kidney transplant are of the lungs, the surgical incision, and the bladder or urinary tract.

To check for infection, your medical team may take sputum (the substance coughed up from your lungs), blood and urine samples, as well as samples from your catheter, wound and drain sites. Symptoms of infection may include fever, exhaustion, diarrhea or vomiting, redness or drainage around your incision, or a cough and sore throat. The infectious disease team at the medical center consults with the transplant team when necessary.

To help prevent infections, you will take antibacterial, antiviral and antifungal medications after your surgery. If an infection develops after you leave the hospital, we can usually treat it with outpatient antibiotics. However, sometimes people need to be readmitted for treatment with intravenous (IV) medications.

### High Blood Pressure (Hypertension)

If you develop high blood pressure after your operation, your doctor will prescribe medication to regulate it. If you already take blood pressure medication, your doctor may change the dose or type of medication you take.

### **Early Renal (Kidney) Dysfunction (also called DGF or delayed graft function)**

Sometimes deceased donor and even living donor kidneys do not work right away. You can think of the kidney as being “asleep” (called DGF). One of the most common causes is acute tubular necrosis, or ATN, which is an injury to the kidney that can result from the surgical process. ATN can last a few days or up to a few weeks. You may still need dialysis after your operation until your new kidney starts to function. If DGF lasts longer than 1-2 weeks, your doctors may do a biopsy on the kidney, to make sure there is nothing else going on, like a rejection episode, to explain why the kidney is still not working.

### **Ureter Complications**

The new ureter the surgeon connected to your bladder may leak or become blocked after the operation. A sudden decrease in urine output and/or pain can be a sign that this is happening. An ultrasound usually will detect the problem. If the ureter becomes disconnected, leaks or is blocked, you will likely need an operation to fix it.

### **Diabetes**

Even if you have never had diabetes, the anti-rejection medications you take to suppress your immune system may cause diabetes. If you had diabetes before your kidney transplant, controlling your blood sugar may be more difficult.

### **Cancer**

The anti-rejection medications you take may also increase your risk for certain types of cancer – sun-related skin cancer and a rare form of lymph node cancer.





# **Behavioral Health Services: Emotional and Family Support**



## Behavioral Health Services: Emotional and Family Support

The care and challenges related to your illness and having a transplant raises its own set of emotional and coping issues – for you, your loved ones, caregiver(s) and friends.

Our behavioral health team, which includes a transplant psychologist and social workers, has created a special program to address this unique circumstance.

We help you understand the physical, emotional and financial impact of your disease and the effect on your family. Together we develop strategies to handle the many special challenges associated with your illness, transplant surgery and care.

**Here are some topics that might be discussed with the social worker or psychologist:**

- Managing the stress of illness, transplantation, or transplant caregiving
- Improving quality of life before and after transplant
- Evaluation and treatment of depression and anxiety
- Pain management
- Smoking cessation
- Weight loss management
- Alcohol and drug relapse prevention
- Insomnia
- Sexual dysfunction
- Enhancing support system stability
- Concerns about living donation
- Accessing community supports and resources

### Your Social Worker and Psychologist

Every patient we evaluate for transplantation meets with a social worker so we can discuss your individual needs:

- Your history, including your previous experience with illness and taking medications
- Any mental health or substance abuse history
- Your insurance options and financial situation
- Community resources if you need transportation and/or home services.

While the psychologist may not meet every patient at the time of transplant evaluation, you can schedule an appointment with them at any time throughout the transplant process. The Transplant

Psychologist has specialized training to help patients cope with chronic illness, reduce depression and anxiety, stop smoking, lose weight, prevent relapse to substance abuse, and improve their quality of life. These services are available to patients both before and after transplantation.

Your social worker and psychologist can also help facilitate discussion between you and your loved ones about a variety of topics including treatment options such as living donation. They can also help you set personal goals and identify any potential barriers to achieving better health and quality of life.

### **Positive Outlook, Positive Outcome**

Our behavioral health program helps enhance care quality and patient outcomes by supporting transplant recipients and living donors before, during and after transplantation. Studies show that emotional well-being plays an important role in recovery and physical health. We know that factors such as depression and anxiety can impact quality of life as well as survival after transplantation.

### **Managing Stress**

Stress is part of life. But too much stress – for too long – is not good for your emotional or physical health. The following are some ideas for lowering your stress level:

- Maintain a healthy lifestyle – eat healthy foods, exercise and get enough rest. Write down the activities that relax you. When you feel stressed, take a break and do one of these things.
- Build a support system of family and friends who will be there for you in good times and bad. When you feel overwhelmed, talk to someone about it.
- Identify the situations that generate stress for you. Do what you can to gain more control over these situations.
- If you feel stressed on a regular basis, or if stress is difficult to deal with, you may benefit from talking to a mental health professional. Ask your transplant team or primary care physician for a referral.

### **Caregiver Stress**

Caregivers are a very important part of the success of transplantation. A caregiver can be a spouse or partner, adult child, family member, or a close friend. Having a caregiver is important because they:

- Help to monitor your health
- Help you meet basic living needs, like cooking, bathing, and simply getting around the house
- Drive you to and from clinic appointments
- Help keep track of your medications and when to take them

- Communicate with the transplant healthcare team
- Assist with taking care of your children
- Help make healthcare decisions for you

For these reasons, it is important for the caregiver to meet the transplant team and to be an active part of the transplant experience.

We recognize that caregiving can be time consuming and stressful. Many of the strategies described above can be just as useful for caregivers to prevent and better manage stress. We encourage caregivers to talk more with their social worker and/or psychologist about any concerns. We can work with you to help you find the resources you need. For example, many caregivers benefit from joining caregiver support groups and participating in their own mental health treatment.

### **Web Sites to Support Caregivers**

#### **National Center on Caregiving**

[www.caregiver.org](http://www.caregiver.org)

A program of Family Caregiver Alliance, the NCC helps develop high-quality and cost-effective programs and policies for caregivers in every state.

#### **The Well Spouse Association**

[www.wellspouse.org/](http://www.wellspouse.org/)

Well Spouse helps support partners of the chronically ill and/or disabled. There are Well Spouse support groups around the country, including in Massachusetts, offering caregiver information on a variety of practical issues. In support groups and on the web, members share thoughts and feelings in a non-judgmental environment with those facing similar circumstances.

#### **Caregiver Media Group**

[www.caregiver.com/](http://www.caregiver.com/)

The Caregiver Media Group provides support, information and guidance for family and professional caregivers. Caregivers can access topic-specific newsletters, articles from Today's Caregiver magazine, online discussion lists, chat rooms, and an online store.

#### **Empowering Caregivers**

[www.care-givers.com/](http://www.care-givers.com/)

Provides useful resources for caregivers, has a chat room and message board, and has a newsletter.

#### **National Family Caregivers Association**

[www.nfcacares.org/](http://www.nfcacares.org/)

NFCA supports, educates and empowers those who care for chronically ill, disabled or aged loved ones. NFCA addresses the common concerns and needs of all family caregivers, regardless of diagnoses, relationships or life stages.

## **Relationship Stress**

Your disease and transplant impact your loved ones in different ways than they impact you. Your partner or family members probably have concerns about your health, your relationships, your children and your finances. Your social worker and psychologist can help your family through issues that may arise and help you talk with each other about your concerns.

## **Talking to your Children**

If you have children you probably are concerned about how your illness is affecting them. They are concerned about you, too. Here is some advice about what to say to your children:

- Keep children informed about what is happening. Children understand and communicate differently at various developmental stages. Your social worker and psychologist can share insight and suggestions.
- Keep things as routine as possible. If you can, let them continue after-school activities such as sports and time with friends. Reach out to other friends and family who may be able to assist you.
- When things cannot be “routine,” let your children know the plan in advance. For instance, tell them who will take care of them while you are in the hospital.
- Spend time with your children. Doing things together like watching television, reading, or simply talking will help them understand that you are still their parent who loves them and is there for them.
- Include the children in the transplant process. Leaving them out may make them feel unwanted and not needed.
- Be careful not to ask too much of teenagers. They certainly can pick up more of the household responsibilities, but not at the expense of spending time with their friends and participating in the activities they enjoy.
- Recognize that some “bad” behaviors may be the result of a child’s fears about their parent’s illness.

Your social worker and psychologist are available to meet with you and your family to discuss transplant concerns and suggest additional resources.

## **Taking your Medications**

We can offer strategies to help you manage your medications. For instance, we can work with you and your family to create reminder cues at home so you remember to take your medicines at the same time each day. Many patients use pillboxes, calendars, notebooks, alarm clocks, and signs to help remember to take their medications. The transplant social worker, psychologist, pharmacist, or nurse can help you decide which system(s) works best for you.

## Quality of Life

As part of our behavioral health program, we ask every patient to tell us about their quality of life. When you have a chronic medical condition, there is a tendency to define your quality of life in terms of what you can or cannot do physically. However, there is more to quality of life than physical well-being. Relationships with others, spirituality, leisure-time activities, and work, among other things, contribute to your overall contentment and happiness.

While waiting for a transplant or recovering from one, your team will continue to assess and help you address issues that may limit your quality of life.

## Substance Abuse

Alcohol and drug abuse can impact your physical health and compromise your transplant outcomes. That is why patients must meet our substance abuse policy requirements before receiving a transplant. If you have a history of alcohol or drug abuse, you must be abstinent for at least three months and participate in an alcohol or drug treatment program. We may also require that you have random toxicology screens so we can document your success in treatment.

All patients with a history of substance abuse or dependency must commit to a life without alcohol or drugs to be considered for transplantation. During one of your clinic visits, the social worker or psychologist will review our Patient Responsibility Agreement with you.

To help patients with a substance abuse history, we can refer you to programs in your local community. These treatment programs are designed to help prevent relapse once you have quit drinking or using drugs.

For community relapse prevention services to meet the requirements of our transplant program, they must:

1. Be delivered by a qualified professional with training and/or experience in treating patients with a history of substance abuse or dependency, and
2. Treatment must focus on:
  - Enhancing your insight into past abuse/dependence
  - Increasing your understanding of how abuse/dependency impacted your current health status
  - Helping you develop more effective coping and stress management skills
  - Enhancing your support system
  - Identifying high-risk situations and developing an action plan to address them
  - Developing effective drink or drug refusal skills
  - Developing effective strategies for coping with cravings and urges to drink or use drugs
  - Managing negative moods and depression



- Implementing strategies to maximize compliance with the transplant regimen and other lifestyle changes

Your community provider must also be willing to provide us with ongoing information about your progress in meeting these treatment objectives.

### **Smoking Cessation**

It is also important for you to stop smoking. Nicotine is highly addictive and smoking can cause many health problems. As a transplant recipient, smoking might put you at even higher risk for certain health problems after transplant. Therefore, we encourage – and sometimes require – transplant patients to quit smoking.

We offer referral to a community-based program focused on smoking cessation. They use treatment strategies that have been proven to be the most effective way to quit smoking – and to stay quit.

### **Additional Supports and Resources**

Your social worker, psychologist and transplant coordinator will also provide you with additional written educational materials and transplant-related web sites to help you learn more about the transplant process. Please refer to the section, *Links to Helpful Websites*, for a list of these sites. It can also be helpful to meet other transplant recipients. Your transplant coordinator or social worker can introduce you to some of our patients and families.

### **Special Concerns**

Every person who sees a social worker or psychologist has a different set of needs. We are all here to help, with experience and access to resources, to make life easier for you, your family and your loved ones.

### **Spiritual Needs and Support**

Beth Israel Deaconess Medical Center has a Pastoral Care staff on site, including a Rabbi, Catholic priest and Protestant chaplain. There is also a network of spiritual advisors representing other faiths in the community who are available to you for consultation. Additionally, your own religious or spiritual community can be another source of comfort and support.

# Financial Considerations



## Transplant Financial Considerations

In addition to dealing with concerns about your medical condition, you need to know how to cover the costs of your transplant and medications, before and after your surgery. Finances can be a concern for patients and good planning will help to reduce this stress. Your transplant financial coordinator and social worker will help you address many of your financial issues and concerns.

Together we can help you develop a plan to manage the financial impact of your illness, transplant surgery, and long-term recovery. We will ask you to take an active role in this process and may direct you to your current insurance provider and other resources in the community. It is also very important to *let us know immediately* if your insurance changes.

### If You Have Insurance

If you have health insurance, ask your insurance company to explain its policy for transplant healthcare and to send you detailed information about your transplant benefits in writing. Some possible questions include:

- Does BIDMC accept my type of health insurance to have a transplant? (Please note: Some insurance companies will allow you to be evaluated for a transplant at BIDMC but **do not pay** for a transplant at BIDMC.)
- Am I covered for a transplant right now? If there is a waiting period, how long must I wait?
- How much of the pre-transplant, transplant and post-transplant services does my insurance cover, and what specifically is covered?
- Are there out-of-pocket costs that I will be responsible for; if so what are they?
- Is there an annual cap on out-of-pocket costs?
- Are there any insurance company rules I need to follow to protect my benefits, such as pre-certification or using only certain providers?
- Is there a “cap” (or maximum lifetime limit) on the amount of health insurance coverage and/or medication coverage that I have?
- Do I need a second opinion, and if so, who will pay for it?
- If I want a second opinion, will my insurance pay for it?
- Will I be covered for skilled nursing or rehabilitation care before or after my transplant?

If your health plan covers only some of the costs, you may also want to consider enrolling in secondary or supplemental insurance. If you have stopped working because of your illness, they can also help you determine if, and how, you can extend your former coverage.

## If You Do Not Have Insurance

Having a transplant can be very expensive over the long-term. Therefore, having health insurance and prescription drug coverage in place is important. There are several options for patients who do not have any type of health insurance.

Our transplant financial coordinators and social workers can help you explore funding options if you do not have insurance. A few possible options for you to discuss with our financial coordinators and social workers include:

- Do I qualify for **Medicaid**, the health insurance program that covers certain patients without insurance?
- Do I qualify for a plan through the **Affordable Care Act**, the new, national insurance program for uninsured residents?
- Does my spouse/partner have insurance that I might be able to enroll in?
- Can I afford to pay privately for an individual insurance plan?
- Are there any fundraising organizations that can help me?
- Should I start my own fundraising effort and if so, how?

You may wish to visit the National Foundation for Transplants, [www.transplants.org](http://www.transplants.org), or Help Hope Live, [www.helphopelive.org](http://www.helphopelive.org). Both of these organizations help patients and families with fundraising for transplant-related expenses.

## Medicaid

Medicaid is the health coverage program for certain low and medium income residents. Your transplant financial coordinators or social workers can refer you to your local Medicaid office to determine if you are eligible for benefits. Eligibility is based on both household income and level of disability.

For more information, contact the Medicaid office in your home state:

### Massachusetts

<http://www.mass.gov/eohhs/gov/departments/masshealth/>

### Rhode Island

<http://www.dhs.ri.gov/Adults/HealthMedicalServices/tabid/807/Default.aspx>

### New Hampshire

<http://www.dhhs.nh.gov/ombp/medicaid/index.htm>

### Maine

[www.maine.gov/bms/](http://www.maine.gov/bms/)

## Medicare

Some patients may be eligible for Medicare. Federal tax money funds this health insurance program, which is administered by the Centers for Medicare and Medicaid Services. Medicare is open to citizens or permanent residents of the United States who are:

- 65 years or older, or
- disabled, or
- who have permanent end-stage renal disease

Medicare, through the end-stage renal disease program, provides some coverage for kidney transplantation for all patients who have paid a minimum amount into the Social Security system.

If you only qualify for Medicare due to your end-stage renal disease (i.e. you are under 65 years old and are not otherwise disabled), you will cease to be covered by Medicare 36 months after you receive a transplant.

For more information about Medicare-covered services, call the **Centers for Medicare and Medicaid Services**, toll free at 877-267-2323 or visit [www.medicare.gov](http://www.medicare.gov). You can also speak with our transplant financial coordinator.

## Insurance Coverage after a Transplant

After you can return to work, you will want to take a close look at your employer's health insurance options. Your company may have a yearly open-enrollment period, which may mean a change in your health plan. If you must change your health plan, you should ask if transplantation is covered, if there is a lifetime maximum on transplant coverage and medication coverage, and if there is a pre-existing condition waiting period. Be sure to keep your financial coordinator updated on any changes in your insurance to ensure a smooth transition in your transplant care. Our financial coordinator or social worker can help you organize these and other questions.

## A Financial Plan

Developing a financial plan is a critical part of preparing for a transplant. We expect you to work with the social worker and financial coordinator at the Transplant Center, and with the case manager at your insurance company, in an effort to minimize the financial impact of a transplant.

## For More Information

Here is a list of helpful websites and/or phone numbers:

### Employee Benefits Security Administration

[www.dol.gov/ebsa/](http://www.dol.gov/ebsa/)

### HealthWell Foundation

[www.healthwellfoundation.org](http://www.healthwellfoundation.org)

### Industry-sponsored Assistance Programs

[www.needymeds.com](http://www.needymeds.com)

**Massachusetts Division of Insurance**

<http://www.mass.gov/>

**Massachusetts Organ Transplant Fund**

[www.mass.gov/dph/dhcq/transplant/quesots.htm](http://www.mass.gov/dph/dhcq/transplant/quesots.htm)

**Massachusetts Rehabilitation Commission (MRC)**

[www.mass.gov/mrc/](http://www.mass.gov/mrc/)

**National Association of Insurance Commissioners**

[www.naic.org](http://www.naic.org)

**National Foundation for Transplants**

[www.transplants.org](http://www.transplants.org)

**SHINE (Serving the Health Information Needs of Elders)**

[www.800ageinfo.com](http://www.800ageinfo.com)

**Social Security Administration (SSA)**

[www.ssa.gov](http://www.ssa.gov)

**SSI**

[www.ssa.gov/ssi/](http://www.ssa.gov/ssi/)

**SSDI**

[www.ssa.gov/benefits/disability/](http://www.ssa.gov/benefits/disability/)

**Medicare**

[www.medicare.gov](http://www.medicare.gov)

**VA Health Benefits Service Center**

<http://www1.va.gov/health/>

**Center for Consumer Information and Insurance Oversight**

[www.cms.gov/ccio/index.html](http://www.cms.gov/ccio/index.html)

Provides information to help consumers appeal health plan decisions, understand the Consumer Assistance Program, and more easily understand and evaluate their health insurance choices.

**Centers for Medicare and Medicaid Services**

[www.cms.gov](http://www.cms.gov)

877-267-2323

**Employee Benefits Security Administration**

[www.dol.gov/ebsa](http://www.dol.gov/ebsa)

202-219-8776

**Healthcare.gov**

[www.healthcare.gov](http://www.healthcare.gov)

Provides information on insurance options and provides assistance to enable consumers to obtain maximum benefits from recently enacted Federal healthcare legislation.

**HealthWell Foundation**

[www.healthwellfoundation.org](http://www.healthwellfoundation.org)

A non-profit organization to assist people with out-of-pocket health costs such as medications, insurance co-payments and deductibles.

**Help Hope Live**

[www.helphopelive.org](http://www.helphopelive.org) 800-642-8399

Assists patients and families in fundraising for transplant-related expenses.

**Medicaid**

**Massachusetts**

[www.mass.gov/](http://www.mass.gov/)

**Rhode Island**

[www.dhs.state.ri.us/dhs/adults/dmadult.htm](http://www.dhs.state.ri.us/dhs/adults/dmadult.htm)

**New Hampshire**

[www.dhhs.state.nh.us/dhhs/medicaidprogram/default.htm](http://www.dhhs.state.nh.us/dhhs/medicaidprogram/default.htm)

**Maine**

[www.maine.gov/bms/](http://www.maine.gov/bms/)

**Mass. Division of Insurance**

[www.mass.gov/portal/health-safety/insurance/](http://www.mass.gov/portal/health-safety/insurance/)  
617-521-7794 or 617-521-7490 (TTD/TDD)

General insurance information, publications, and consumer rights in Massachusetts.

# **Information from UNOS: Facts and Figures**





TALKING ABOUT TRANSPLANTATION

UNOS  
*Facts and  
Figures*

UNITED NETWORK FOR ORGAN SHARING

UNOS



The United Network for Organ Sharing (UNOS) coordinates the nation's organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants. Based in Richmond, Va., UNOS is a private, nonprofit membership organization.

UNOS members encompass every transplant hospital, tissue matching laboratory and organ procurement organization in the United States, as well as voluntary health and professional societies, ethicists, transplant patients and organ donor advocates.

## UNOS at work

UNOS assists the transplant community and the patients it serves in a number of ways:

- increasing public awareness of the critical need for donated organs and tissues
- maintaining the national organ transplant waiting list
- coordinating the matching and distribution of donated organs
- collecting and reporting data on transplant recipients, donors and outcomes
- serving as a forum to create and define organ sharing policies that maximize the use of donated organs
- establishing transplant physician and surgeon training and experience criteria for UNOS membership
- producing professional education tools
- providing extensive information about organ transplantation to patients, the public and the transplant community

*More than 33,000 men, women and children received life-saving organ transplants last year.*

**Facts and  
Figures**

## Funding

UNOS is a private, nonprofit IRS-designated 501(c)(3) organization. About 10 percent of UNOS' funding is derived directly from its federal contract. The rest of its operating budget comes from computer registration fees paid by members, project grants from foundations and corporations and tax-deductible charitable contributions.





## Use of technology

To work effectively, UNOS must collect and provide highly detailed, instantly accessible information. At the same time, it must maintain a high level of security to protect the confidential medical records of individual patients and donors. As a result, UNOS develops and uses sophisticated technology that emphasizes accessibility and reliability.

UNet<sup>SM</sup> is UNOS' computer-based network for allocating donated organs and managing transplant data. Every organ sharing institution is electronically linked in a secure, real-time environment over the Internet so that donated organs can be placed as quickly as possible. While UNet<sup>SM</sup> utilizes the Internet for common accessibility to UNOS members, it employs highly secure encryption and password access to protect confidential medical data.

## UNOS Web site

The UNOS Web site ([www.unos.org](http://www.unos.org)), launched in March 1995, provides a wealth of transplant data, informational resources and news about UNOS and the process of organ donation and transplantation. The site is used by many people with an interest in transplantation, including the following:

- transplant patients and their families
- donor family members
- medical professionals
- news media
- potential living donors
- students

*More than a half a million organ transplants have been performed in the U.S. since UNOS began keeping records in 1988.*

**Facts  
and  
Figures**

## Utilizing data

About 25 full-time researchers and statisticians continually analyze and report data on transplant recipients, donors, outcomes and trends.

- Transplant professionals use the data to develop policies and practices to improve the likelihood of a successful donation or transplant.
- Public health researchers use the data to identify trends that will shape the future of the field.
- Patients and their families can assess their treatment options.
- The news media and the general public gain a greater understanding of the transplant system's achievements, as well as its ongoing challenge to meet the needs of people awaiting transplants.

## UNOS and the history of transplantation

### Development of organ transplantation

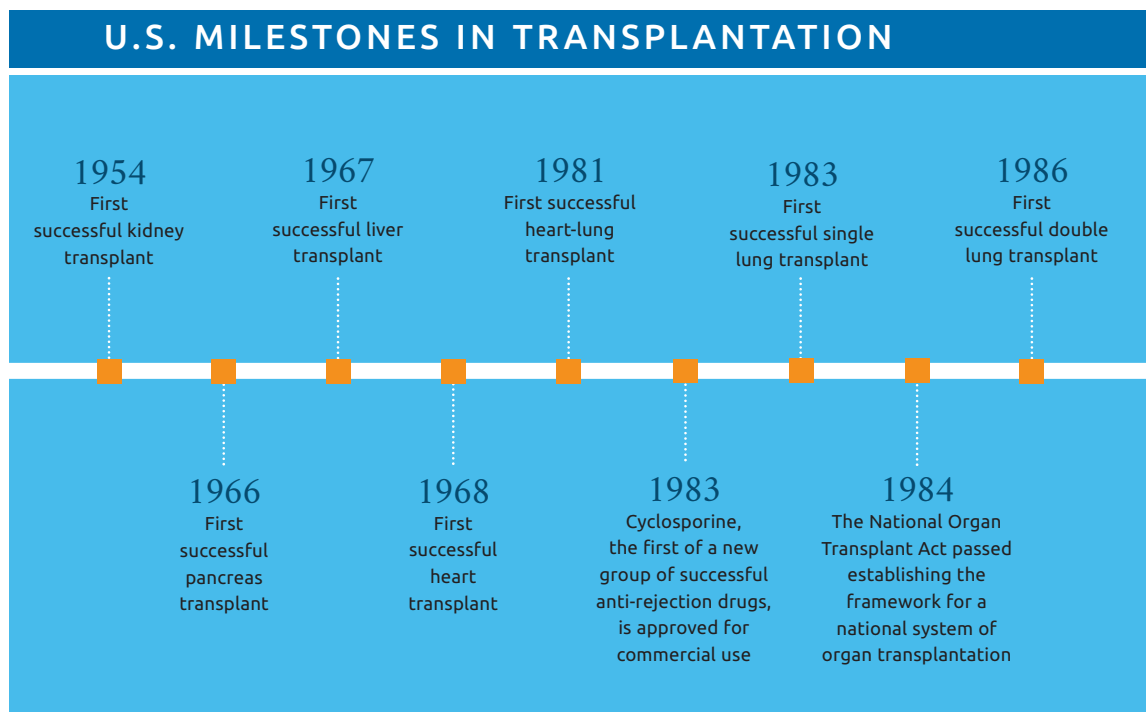
In 1954, the kidney was the first human organ to be transplanted successfully. Liver, heart and pancreas transplants were successfully performed by the late 1960s, while lung and intestinal organ transplant procedures were begun in the 1980s.

Until the early 1980s, the potential of organ rejection limited the number of transplants performed. Medical advances in the prevention and treatment of rejection led to more successful transplants and an increase in demand.

### UNOS' beginnings

UNOS originated in 1977 as an initiative of the South-Eastern Organ Procurement Foundation (SEOPF). SEOPF was the first organization to develop a computerized system to use medical information to match organ donors with transplant candidates.

SEOPF began the Kidney Center in 1982, with staff working around the clock to regionally place available organs. This operation evolved into the UNOS Organ Center.



UNOS was formally incorporated as an independent, non-profit organization in 1984 to meet the growing demand for transplants nationwide.

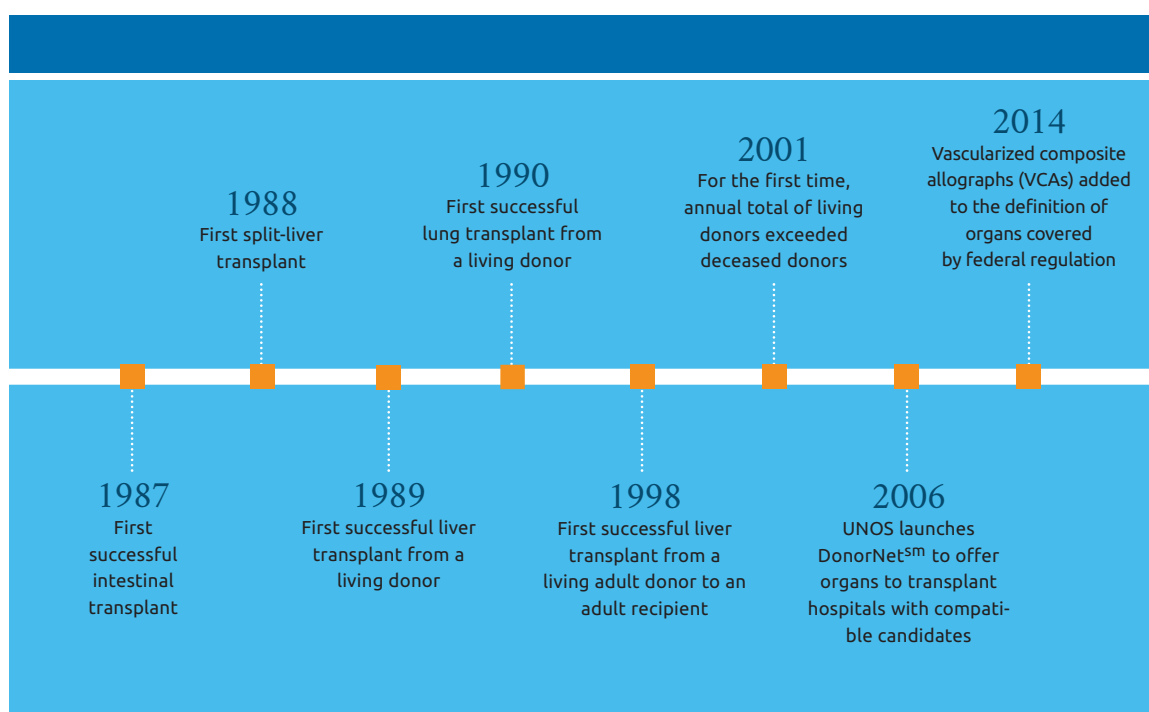
## National Organ Transplant Act

Also in 1984, Congress passed the National Organ Transplant Act, which prohibited the sale of human organs and called for a national Organ Procurement and Transplantation Network (OPTN) to facilitate organ recovery and placement. The act assigned the task of developing equitable organ distribution policies to the OPTN.

## UNOS and the OPTN

UNOS was first awarded the national OPTN contract in 1986 by the U.S. Department of Health and Human Services. It continues as the only organization ever to operate the OPTN.

In this capacity, UNOS has served as the forum by which the entire U.S. transplant community and the public continually improve the nation's transplant system.





## Developing transplant policy

### Board and committees

A 42-member board of directors makes policy decisions. Board members represent the diversity of professions and viewpoints within the field of organ transplantation.

To aid in its deliberations, the board receives input from more than 20 permanent and ad hoc committees. These committees address a variety of specific perspectives and interests, including the following:

- patient and donor family issues
- medical issues specific to the various transplantable organs
- needs and concerns of ethnic minorities and children needing transplants
- technical aspects of organ recovery and matching
- ethical principles
- collection and reporting of scientific data

### OPTN/UNOS committees

Data Advisory Committee

Ethics Committee

Executive Committee

Finance Committee

Histocompatibility Committee

Kidney Transplantation Committee

Liver and Intestinal Organ Transplantation Committee

Living Donor Committee

Membership and Professional Standards Committee

Minority Affairs Committee

Operations and Safety Committee

Organ Procurement Organization Committee

Pancreas Transplantation Committee

Patient Affairs Committee

Pediatric Transplantation Committee

Policy Oversight Committee

Thoracic Organ Transplantation Committee

Transplant Administrators Committee

Transplant Coordinator Committee

Vascularized Composite Allograft Transplantation Committee

**Ad Hoc Committees**

Ad Hoc Disease Transmission Advisory Committee

Ad Hoc International Relations Committee

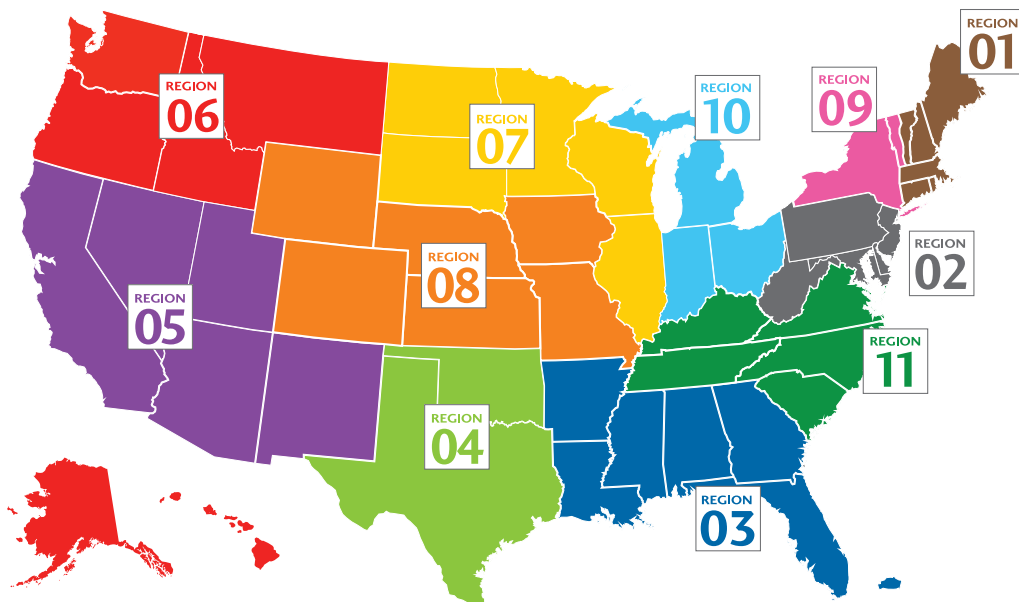
**Regions**

UNOS has established 11 geographic regions for administrative purposes.

Each region is assigned a UNOS staff administrator to assist in coordinating regional activities.

To ensure geographic representation, each region is represented on the board of directors and on each permanent standing committee.

**UNOS REGIONAL MAP**



## Policy development process

UNOS strives to achieve consensus in policy development. The field of organ transplantation depends on the cooperation of many people and organizations, and it is vital to ensure that the perspectives of all interested parties are heard and addressed.

Each committee typically meets two to four times per year. Based on current discussion and data analysis, the committee may draft a new or revised policy to address a particular issue.

UNOS publishes all substantial policy proposals for public comment\* by other committees, the various UNOS regions and interested persons or organizations. The sponsoring committee will consider all comments received before it makes a final recommendation to the board. The board then considers policy proposals in light of the input received.

While the UNOS board approves OPTN policies for voluntary application, these policies are subject to review and approval by the U.S. Department of Health and Human Services before they can become binding under federal regulation. The UNOS board also acts independently on issues that are not within the responsibilities of the OPTN.

## An evolving forum

Continuing advances in the science and practice of organ transplantation require ongoing refinement of policy. To ensure the best possible solutions for patients awaiting transplantation, the policy development process is

- inclusive—encouraging participation by interested persons and organizations;
- responsive—assessing and modifying policies to remain current with the field;
- equitable—helping to ensure that all patients have an equal chance of receiving a suitable organ; and
- evidence based—making decisions based on extensive and valid scientific data and analysis.

View public comment notices at

*[OPTN.transplant.hrsa.gov>Governance>Public Comment](https://optn.transplant.hrsa.gov/Governance/PublicComment)*.

*In a single year, more than 10,000 volunteers within and beyond the transplant community devote thousands of hours to UNOS' life-critical mission.*

**Facts and  
Figures**

## Prioritizing patients for transplantation

Each organ type has its own individual distribution policy, reflecting the unique medical considerations of each type of transplant. However, certain general factors apply to all organ allocation policies:

- Patients who are close biological matches with a particular donor offer (including blood type, body size and/or tissue typing match) are given priority. Closer matching tends to result in better long-term survival after transplantation.
- For heart, liver and intestinal organs, patients whose medical status is most urgent receive priority over those whose medical status is not as urgent.
- When possible, organs are offered first to patients locally, then to a larger region, then nationally. This is done to minimize organ preservation time, which is associated with better transplant survival. However, there are exceptions to this sequence for particularly well-matched organ offers and for the most urgent category of liver patients.
- The policies strive to ensure equivalent access for patients who might be at a disadvantage because of the progression of their disease or their ability to receive suitable organ offers. For example, most policies afford children special priority because of the medical risks they face while awaiting transplant.
- Waiting time is used to break ties between patients who are similar in other respects. Patients who have waited longer at their current medical status receive priority over those who have waited less time.

The UNOS computer system is programmed to consider each of these issues automatically when matching donor organs to patients awaiting a transplant. Therefore, the patients ranked highest will be those who have both the greatest need and greatest likelihood for a successful transplant.

## Matching organs with patients in need

### The organ offer process

When a deceased organ donor is identified, a transplant coordinator from an organ procurement organization enters medical information about the donor into the UNOS computer system.

The system then matches the donor's medical characteristics with the medical information of candidates awaiting a transplant. The computer generates a ranked list of patients for each organ recovered from the donor.

The transplant team of the first person on the match run is offered the organ needed. Often the top-ranked patient may not get the organ for one of several reasons, including the following:

- he or she cannot be located or cannot reach the hospital in time for a transplant
- he or she is temporarily too sick to receive a transplant
- the medical team believes the organ would not benefit the candidate due to the donor's age or medical condition
- medical tests performed after the initial offer show the candidate's immune system would likely reject the organ

If an offer is turned down for one transplant candidate, the organ is offered to the next candidate on the match run. These offers continue until the organ is placed or until no potential recipient can be located in time for a successful transplant.

### Facts and Figures

*Every year the Organ Center assists transplant organizations by offering over 10,000 organs and lining up transportation for more than 2,000 organs.*



## UNOS Organ Center

The UNOS Organ Center places many organs and also helps members with running computer matches, arranging transport for organs, updating patient records and providing information about organ sharing policies.

The Organ Center is staffed 24 hours a day, seven days a week, 365 days a year. If a catastrophe prevents use of the current facilities, operations can be switched in minutes to a fully equipped disaster recovery site.

## Addressing the donor shortage

### Increasing organ availability

Transplantation has saved and enhanced the lives of more than 700,000 people in the United States. It is the leading form of treatment for many forms of end-stage organ failure.

With this success, however, has come increasing demand for donated organs. Today, more than 117,000 people are awaiting transplants nationwide. Sadly, about 20 patients die every day while awaiting an organ.

Living donation (transplanting all or part of an organ from a living person) has dramatically increased the number of transplants performed. In addition, UNOS has enacted a number of policies to encourage more efficient use of available organs, such as “splitting” livers from deceased donors to allow two recipients to be transplanted.

The only long-term solution to the organ shortage, however, is for more people to agree to become organ donors. UNOS works closely with medical professionals to increase their understanding and support of the organ donation process. UNOS also works closely with the U.S. Department of Health and Human Services (HHS) and national organizations such as Donate Life America to foster the public’s knowledge and commitment regarding organ donation.

UNOS staff will gladly address any questions you may have about organ donation and transplantation.

#### **United Network for Organ Sharing**

**700 North 4th Street**

**Richmond, VA 23219**

**[www.unos.org](http://www.unos.org)**

**[askunos@unos.org](mailto:askunos@unos.org)**

**(804) 782-4800**

## How you can help

### Working together. Saving Lives.

UNOS is a non-profit 501(c)(3) organization, certified by the Better Business Bureau's Wise Giving Alliance.

Since 1988, UNOS has facilitated more than a half million organ transplants! Our success is possible thanks to the selfless gifts of organ donors and donor families, and the tireless efforts of our members, volunteers, and staff. Our mission is to save as many lives as possible through organ transplantation by:

- increasing organ donations and increasing transplants
- making the organ transplant system as fair, safe and efficient as possible
- helping transplant candidates and recipients make informed health choices (go to [www.transplantliving.org](http://www.transplantliving.org))
- promoting best practices among transplant professionals
- collecting, analyzing and sharing clinical transplant data to improve care and outcomes
- celebrating organ and tissue donors and inspiring others to be as generous (go to [www.donormemorial.org](http://www.donormemorial.org))

## UNOS begins with YOU!

### Become part of the solution!

- Sign up to be an organ and tissue donor by visiting [www.unos.org](http://www.unos.org).
- Promote organ, eye and tissue donation in your community. Contact your local Organ Procurement Organization or tissue bank and see how you can help.
- Make a charitable contribution to UNOS. For more information go to [www.support.unos.org](http://www.support.unos.org).



*Our mission is to advance organ availability and transplantation  
by uniting and supporting its communities for the benefit of patients  
through education, technology and policy development.*



[www.unos.org/social](http://www.unos.org/social)



700 North 4th Street, Richmond, VA 23219

[WWW.UNOS.ORG](http://WWW.UNOS.ORG)

# **A Guide to Clinical Trials at the Transplant Institute**



## A Guide to Clinical Trials at the Transplant Institute

Clinical trials are also called research studies. Research studies test many types of treatment in patients who are waiting for or who have undergone a transplant. These studies include new medicines such as anti-rejection and anti-infection drugs, new approaches to surgery, new combinations of treatments, and psychological or behavioral health interventions. The Transplant Institute at Beth Israel Deaconess Medical Center is currently involved in a number of clinical trials that are available to patients prior to transplant, at the time of transplant, and after transplant.

The goal of clinical trials at the Transplant Institute is to learn and understand the best ways to:

- Take care of transplant recipients
- Prolong survival of the transplanted organ
- Prolong life expectancy
- Enhance quality of life
- Improve medications currently used for transplant patients
- Improve psychological functioning and behavioral health

### Possible Benefits of Being Part of a Clinical Trial

- If the treatment under study has a positive effect, you may be the first to benefit.
- What doctors learn in studies may help people who need a transplant in the future.

### Possible Risks of Being Part of a Clinical Trial

- New treatments are not always better than standard treatments and, in some cases, may not be as good.
- Treatments in research studies may have known or unknown side effects.

### Safeguards that BIDMC has in Place for Patient Protection

- Research studies undergo multiple levels of review before they are approved to begin treating patients.
- The BIDMC research committees review all research studies.
- The BIDMC Institutional Review Board (IRB) performs a final review. Members of the IRB are health professionals along with people from the community much like you. The IRB protects patient safety by reviewing the trial protocols and making sure that the informed consent document explains the risks, potential benefits and alternatives.
- Throughout the clinical trial, you will see your doctor on a frequent and regular basis.
- You are able to withdraw from the clinical trial at any time.
- The trial is stopped immediately if the patients experience harm.

## **You Might be Eligible for a Clinical Trial**

The Transplant Institute reviews every patient for his or her eligibility to participate in a clinical trial. Your doctor or another person on the research team will let you know if a clinical trial is right for you. Before you agree to participate in a clinical trial we will explain the following:

- Why the clinical trial is being done
- What will happen during the clinical trial
- The plan for the clinical trial including the required visits and tests
- What side effects you may have
- How the clinical trial may affect your daily life

You will be able to ask any questions you might have about the clinical trial. The research team will give you a copy of the informed consent form that explains all the details of the clinical trial. The team will ask you to take a copy of the informed consent form to review and share with people who will be part of your decision. If you decide to take part in the clinical trial, we will ask you to sign the informed consent form in the presence of your physician. If you sign the informed consent form, you can still change your mind and withdraw from the clinical trial at any time without jeopardizing your transplant treatment.

It is important to look at all your treatment options with the help of your family and doctor to decide if a clinical trial is the best approach for you.

## **Questions to Ask Before Taking Part in a Clinical Trial**

About the clinical trial

- Why is this clinical trial being done?
- How will it help me?
- What will happen to my transplant with or without this treatment?
- How do the risks and side effects of the standard treatment compare with the treatment being studied?

During the clinical trial

- What kind of tests and treatments are part of the clinical trial?
- How could the clinical trial change what I do every day?
- Will I have to stay in the hospital during the clinical trial? If so, how often and for how long?
- How long will the clinical trial last?
- Who will have access to my medical record? How am I protected?
- How will I be checked after the clinical trial?

## Costs

- Will my insurance cover being in the clinical trial?
- Will I have extra costs because of the clinical trial?

## **To Learn More About Clinical Trials at the Transplant Institute**

- Call the Transplant Institute at 617-632-9700
- Ask your doctor or nurse to explain your available options
- Visit the NIH Clinical Studies web site. [ClinicalTrials.gov](https://clinicaltrials.gov) provides patients, family members, and members of the public easy and free access to information on clinical studies for a wide range of diseases and conditions.



# Resource Map for Patients





# **Links to Helpful Web Sites**



## Links to Helpful Web Sites

### **BIDMC and Other Links**

Ask your social worker for phone numbers if you do not have access to a computer.

#### **BIDMC Transplant Website**

<http://bidmc.org/transplant>

#### **BIDMC Lodging Program**

<https://www.bidmc.org/centers-and-departments/social-work/lodging-program>

#### **BIDMC Patient Guide**

[www.bidmc.org/patientguide](http://www.bidmc.org/patientguide)

#### **BIDMC Living Donor Website**

[www.bidmc.org/kidneydonor](http://www.bidmc.org/kidneydonor)

#### **BIDMC Maps and Directions**

[www.bidmc.org/directions](http://www.bidmc.org/directions)

#### **BIDMC Lodging List**

[www.bidmc.org/transplantlodging](http://www.bidmc.org/transplantlodging)

### **Organ Banks**

#### **New England Donor Services**

[www.neds.org](http://www.neds.org)

#### **The Organ Procurement and Transplantation Network**

[www.optn.org](http://www.optn.org)

#### **Scientific Registry of Transplant Recipients (SRTR)**

[www.ustransplant.org](http://www.ustransplant.org)

#### **United Network for Organ Sharing (UNOS)**

[www.unos.org](http://www.unos.org)

[www.transplantliving.org](http://www.transplantliving.org)

### **Organizations Including Transplant Recipient and Donor Care Foundations**

#### **American Association of Kidney Patients**

[www.aakp.org](http://www.aakp.org)

#### **American Cancer Society (ACS)**

[www.cancer.org](http://www.cancer.org)

#### **American Diabetes Association**

[www.diabetes.org](http://www.diabetes.org)

#### **AT-RISC Alliance (skin cancer awareness and education in transplant patients)**

[www.at-risc.org](http://www.at-risc.org)

#### **Donate Life – US Department of Health and Human Services**

[www.organdonor.gov](http://www.organdonor.gov)

#### **Healthy Transplant**

[www.healthytransplant.com](http://www.healthytransplant.com)

#### **Kidney School**

[www.kidneyschool.com](http://www.kidneyschool.com)

#### **Kidney Transplant/Dialysis Association**

[users.rcn.com/ktda1/](http://users.rcn.com/ktda1/)

#### **Living Donors Online!**

[www.livingdonorsonline.org](http://www.livingdonorsonline.org)

#### **National Council on Minority Education in Transplantation**

[www.transweb.org/comet](http://www.transweb.org/comet)

#### **National Institute of Diabetes & Digestive & Kidney Diseases/NIH**

[www.niddk.nih.gov](http://www.niddk.nih.gov)

#### **National Foundation for Transplants**

[www.transplants.org](http://www.transplants.org)

#### **National Kidney Foundation**

[www.kidney.org](http://www.kidney.org)

#### **National Pancreas Foundation**

[www.pancreasfoundation.org](http://www.pancreasfoundation.org)

#### **Transplant Health**

[www.transplanthealth.com](http://www.transplanthealth.com)

Beth Israel Deaconess Medical Center

**Transplant Recipients International  
Organization**

[www.trioweb.org](http://www.trioweb.org)

**TransWeb**

[www.transweb.org](http://www.transweb.org)

**Caregiver Foundations and Organizations**

**The Caregivers Marketplace**

[www.caregiversmarketplace.com](http://www.caregiversmarketplace.com)

**Caregiver Media Group**

[www.caregiver.com](http://www.caregiver.com)

**Empowering Caregivers**

[www.care-givers.com](http://www.care-givers.com)

**National Center on Caregiving**

[www.caregiver.org](http://www.caregiver.org)

**National Family Caregivers Association**

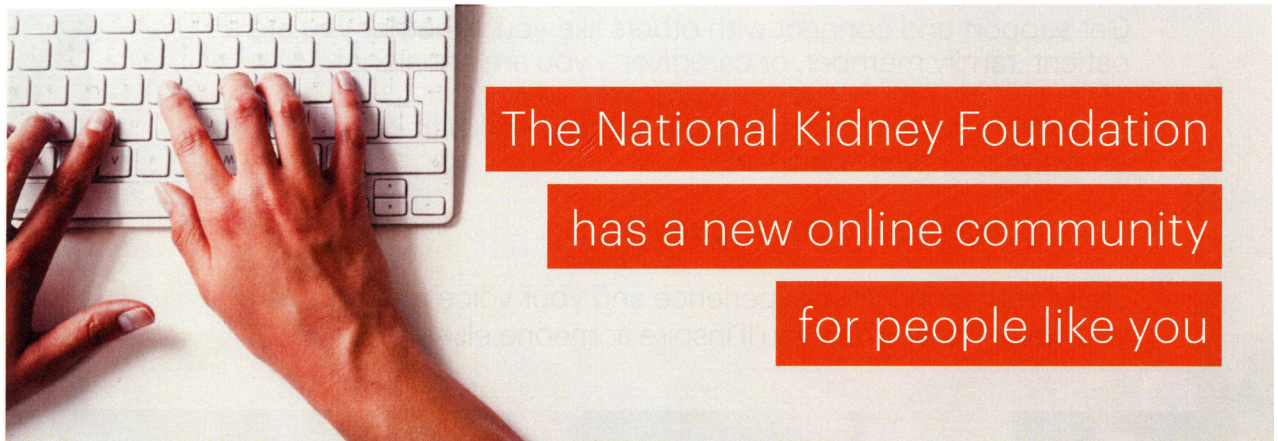
[www.nfcacares.org](http://www.nfcacares.org)

**The Well Spouse Association**

[www.wellspouse.org](http://www.wellspouse.org)



# HealthUnlocked



The community encourages discussions on various aspects of kidney disease and health. Connect with other people dealing with the same issues.



Just like other social networks (think Facebook, Twitter, LinkedIn and Instagram), you can create your own profile page, like other people's posts, ask or reply to a question and follow other people.



The difference with HealthUnlocked is that you can network anonymously and connect with other people who are affected by kidney disease. On the community, you can talk about your health, symptoms, management and much more.

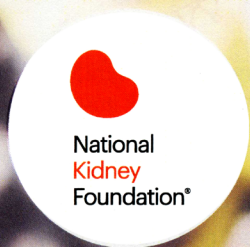
Join our community on HealthUnlocked, the world's largest social network for health

**Dialysis:** [healthunlocked.com/nkf-dialysis](https://healthunlocked.com/nkf-dialysis)

**Early Stage CKD:** [healthunlocked.com/nkf-ckd](https://healthunlocked.com/nkf-ckd)

**Transplant:** [healthunlocked.com/nkf-kidneytransplant](https://healthunlocked.com/nkf-kidneytransplant)

- Get support and connect with others like you. Whether you are a patient, family member, or caregiver – you are not alone!
- Learn from others how they cope and live well with kidney disease, on dialysis, or post-transplant.
- Gain confidence in managing your health.
- Share your story! Your experience and your voice are valuable – you never know when you'll inspire someone else!



**Dialysis:** [healthunlocked.com/nkf-dialysis](http://healthunlocked.com/nkf-dialysis)

**Early Stage CKD:** [healthunlocked.com/nkf-ckd](http://healthunlocked.com/nkf-ckd)

**Transplant:** [healthunlocked.com/nkf-kidneytransplant](http://healthunlocked.com/nkf-kidneytransplant)

# Glossary





## Glossary

This glossary of commonly used organ donation, transplantation and dialysis access terms is courtesy of OrganDonor.gov, with adaptation by the Transplant Institute at Beth Israel Deaconess Medical Center, Boston, Massachusetts.

The official U.S. Government web site for organ and tissue donation and transplantation, [www.organdonor.gov](http://www.organdonor.gov), is maintained by the Health Resources and Services Administration (HRSA), Healthcare Systems Bureau (HSB), Division of Transplantation, an agency of the U.S. Department of Health and Human Services (HRSA).

Portions of the glossary were also adapted from and courtesy of, HRSA's 2004 *Partnering With Your Transplant Team: The Patient's Guide to Transplantation*. Rockville, MD: Health Resources and Services Administration, Special Programs Bureau, Division of Transplantation.

## A

### **ABO (Blood Type) Incompatible**

Refers to a transplant donor and recipient whose blood type does not match. ABO is a blood type classification system. There are four main blood types – A, B, AB and O – determined by the presence of certain proteins on the surface of red blood cells. When blood types do not match, donor tissue and organs can be rejected by the recipient's immune system. In some cases, however, using plasmapheresis and immunosuppressive drugs, it is possible to transplant organs even when donors and recipients have different blood types. See plasmapheresis and immunosuppressive drugs.

### **Allocation**

The system of ensuring that organs and tissues are distributed fairly to patients who are in need.

### **Antibody**

A protein substance made by the body's immune system to attack a foreign substance, for example, a transplanted organ, blood transfusion, bacteria, virus, yeast infection or pregnancy. Because antibodies attack transplanted organs, transplant patients must take powerful drugs. (See anti-rejection medicine.)

### **Antigen**

A foreign substance, such as is on a transplanted organ or tissue, which triggers the body to reject or destroy it.

### **Anti-Rejection Medicine (immunosuppressive drugs)**

Medicines that reduce the body's ability to reject a transplanted organ or tissue.

## **B**

### **Biopsy**

A tiny piece of tissue removed from the body (usually with a needle) and examined under a microscope. This test is performed to diagnose rejection of a transplanted organ.

### **Bladder**

A muscular pouch that stores urine until it is passed from the body.

### **Brain Death**

Occurs when a person's brain activity stops permanently. It is impossible to return to life after brain death.

## **C**

### **Catheter**

A flexible, thin tube placed in the body to drain fluids or hold open vessels.

### **Creatinine**

Found in the urine, this waste product is measured to evaluate kidney function. An abnormally high creatinine level can indicate kidney disease and/or failure.

### **Crossmatching**

A laboratory blood test performed before the transplant to determine if the recipient's immune system will reject the donor organ. A "positive" crossmatch means the recipient's immune system produces antibodies against the donor blood type, and the transplant cannot be done because the antibodies would destroy the donor organ. The donor and the recipient are "incompatible." A "negative" crossmatch means there is no antibody reaction from the recipient's immune system, the donor organ is likely to be accepted by the recipient's immune system, and the transplant can move forward. See "virtual crossmatching."

## **D**

### **Deceased Donor**

A person who has been declared dead and whose organs and/or tissue have been donated to a transplant recipient.

### **Dialysis**

The use of a machine to correct the balance of fluids and chemicals in the body and to remove wastes from the body when kidneys are failing. See hemodialysis and peritoneal dialysis.

## **Donation**

In relation to organ and tissue transplantation and blood transfusion, this is the act of giving organ(s), tissue or blood, without compensation, to someone else.

### **Donation After Brain Death**

Most of the organs used in transplants come from people who have suffered brain death as the result of an accident, heart attack or stroke. Brain death is total cessation of brain function, including brain stem function. There is no blood flow or oxygen to the brain; the brain no longer functions in any manner and will never function again. Although the brain has stopped functioning, the heart, supported by drugs, may continue to beat and pump blood while a ventilator sustains breathing. These organs are generally in better condition for transplantation.

### **Donation After Cardiac Death (DCD)**

Some patients who have sustained traumatic brain injury cannot be declared dead based on the definition of brain death. In these cases, the patient is declared dead upon cardiac death, which is the cessation of cardiac and respiratory function when the patient is withdrawn from life support. Donation after cardiac death occurs only after the patient or family has decided to withdraw life-sustaining therapies for reasons entirely apart from any potential for organ donation. When fatal cardiac arrest occurs outside the hospital, organ donation is not always possible because continuous blood circulation is necessary to keep organs healthy.

## **E**

### **End-stage Renal Disease (ESRD)**

A very serious and life-threatening failure of the kidneys to remove waste (ultimately urine) from the body. This condition can be caused by many diseases such as diabetes, high blood pressure and glomerulonephritis, and is treatable with dialysis, where the waste is removed by a machine. However, the preferred treatment of ESRD is kidney transplantation. Transplantation offers patients “freedom” from dialysis, so they can lead a more normal lifestyle, and lengthens their lives.

### **Extended Criteria Donor (ECD)**

An ECD organ comes from a deceased donor who has additional risk factors, compared to other deceased donors.

## **G**

### **Glomerular Filtration Rate (GFR)**

A measurement of kidney function used to determine the severity of kidney disease.

## **Graft**

A transplanted organ or tissue. A graft can also refer to prosthetic material used to connect blood vessels together for many reasons including dialysis access, to bypass a blockage, or to repair damaged vessels.

### **Graft Survival Rate**

The percentage of patients who have functioning transplanted organs (grafts) at a certain point in time. The data are usually measured in one-, three- and five-year time periods.

## **H**

### **Hemodialysis**

A form of renal replacement therapy (dialysis) where a person's blood is removed continuously and filtered through a machine that removes excess fluid and toxins. The filtered blood is then returned to the person. The procedure usually takes about 3 to 4 hours per session, and is usually done about three times per week.

### **High Blood Pressure (Hypertension)**

High blood pressure occurs when the force of the blood pushing against the walls of the blood vessels is higher than normal because the blood vessels have either become less able to stretch or have gotten smaller. High blood pressure causes the heart to pump harder to move blood through the body. High blood pressure can cause kidney failure and heart disease if not treated.

### **Histocompatibility (HLA System)**

The examination of human leukocyte antigens (HLA) in a patient, often referred to as "tissue typing" or "genetic matching." Tissue typing is routinely performed for all donors and recipients in kidney, pancreas and liver transplantation to help match the donor with the most suitable recipients to help decrease the likelihood of rejection of the transplanted organ.

### **Human Leukocyte Antigens (HLA)**

Molecules found on cells in the body that characterize each person as unique. These antigens are inherited from parents. In donor-recipient matching, HLA determines whether or not someone will accept an organ from a donor.

## **I**

### **Immunosuppressive Drugs**

Chemical agents that cause the human body not to produce antibodies that normally fight off foreign material in the body. The production of these antibodies needs to be suppressed in order to permit the acceptance of a donor organ by the recipient's body.

## **K**

### **Kidneys**

A pair of organs that maintain proper water and electrolyte balance, regulate acid-base concentration, and filter the blood of metabolic waste, which is excreted as urine. Kidneys can be donated and transplanted.

## **L**

### **Laparoscopic Nephrectomy**

An operation to remove a kidney using smaller incisions and instruments. Performed under general anesthesia, this minimally invasive approach offers many benefits compared to traditional open surgery. With smaller incisions, patients experience less pain, recover more quickly, return sooner to their normal activities, and have less visible scarring.

### **Living Donor**

A person (unrelated or related to the transplant recipient) who donates an organ while still alive. There are significant advantages to living donation: patients do not have to spend time on the organ waiting list and may never need to undergo dialysis. Living donor organs are often a better tissue match, and typically function longer – and work better – than deceased donor organs.

## **N**

### **National Organ Transplant Act (NOTA)**

Passed by Congress in 1984, NOTA initiated the development of a national system for organ sharing and a scientific registry to collect and report transplant data. It also outlawed the sale of human organs.

### **New England Donor Services (NEDS)**

NEDS is the local (regional) organ procurement organization (OPO) for Beth Israel Deaconess Medical Center and the rest of New England, and coordinates sharing organs through UNOS. Staff at NEDS will enter a patient's medical information into a computer and will notify the transplant team when an organ becomes available based on the patient's waiting time on the list, blood type and size match.

### **Noncompliance**

Failure to follow the instructions of the medical team, such as not taking medicines properly or not attending clinic appointments. Noncompliance can lead to the failure of a transplanted organ.

## O

### Organ

A part of the body, made up of various tissues, which perform a particular function. Transplantable organs are: heart, intestines, liver, lungs, kidneys, and pancreas.

### Organ Preservation

Methods used to maintain the viability of organs between removal from the donor and transplantation into the recipient. These methods include preservation solutions, pumps and cold storage. Preservation times can vary from 2 to 48 hours depending on the type of organ being preserved.

### Organ Procurement Organizations (OPO)

The OPO staff (transplant coordinators) coordinate activities relating to organ donation in states and regional areas throughout the U.S. Their activities include: evaluating potential donors, discussing donation with family members, arranging for the donation process (removal and transport of donated organs,) and educating the public about the need for donors.

## P

### Pancreas

Long, irregularly shaped gland, which lies behind the stomach. Special glands in the pancreas secrete insulin. Pancreas transplants give patients with diabetes a chance to become independent of insulin injections. In addition to insulin, the pancreas secretes digestive enzymes (into the small intestine) that aid in the digestion of proteins, carbohydrates and fats.

### Panel Reactive Antibody (PRA)

This is a blood test used to assess how a potential organ recipient will react to a donor organ. A patient with a PRA of 80 percent will likely reject 80 percent of donor kidneys. Patients with a high PRA have priority on the waiting list. The more antibodies in the recipient's blood, the more likely the recipient will react against the donor organ. For example, patients who have received multiple blood transfusions are likely to have more antibodies in their blood and a higher PRA.

### Peritoneal Dialysis

A form of renal replacement therapy (dialysis) where a special fluid is flushed into the abdomen via a surgically placed tube. The fluid is allowed to sit (dwell) in the abdomen for a period of time. During this time, extra fluid and toxins from the body migrate into the abdominal fluid and are removed by emptying the fluid using the surgically placed tube.

**Preemptive Transplantation**

Kidney transplantation before a patient needs to go on dialysis. Patients who get a kidney transplant before dialysis usually do better overall than patients who are on dialysis who get a transplant. They live longer and the transplant itself lasts longer. In addition, most measures of quality of life (such as not feeling fatigued, returning to work) are better with a transplant compared to being on dialysis.

**Primary Graft Non-Function**

When the transplanted organ (kidney, liver or pancreas, for example) fails to work properly and stops functioning.

**Pulmonary Hypertension**

Abnormally high blood pressure that occurs inside the pulmonary artery.

**R****Recipient**

A person who has received a transplant.

**Rejection (Acute and Chronic)**

The body's way of protecting itself against a foreign invader such as infectious germs. The body sees the transplanted organ or tissue as a foreign invader and attempts to destroy it. This can be acute and happen very quickly or chronic, which would be the slow failure of an organ to function. Anti-rejection (immunosuppressive) drugs help prevent rejection.

**Renal**

Having to do with, or referring to, the kidneys.

**S****Scientific Registry of Transplant Recipients (SRTR)**

In 1987, Congress passed the National Organ Transplant Act that mandated the establishment of the Organ Procurement and Transplantation Network and SRTR. The purpose of the SRTR is to provide ongoing research to evaluate information about donors, transplant candidates and recipients, as well as patient and graft survival rates. The SRTR contains historical data from October 1, 1987 to the present. The registry tracks all transplant patients from the time of transplant through hospital discharge, and then annually for up to 3 years or until graft failure or death. URREA, University Renal Research and Education Association, operates the SRTR under contract with the Federal Government.



### **Sensitized**

Having antibodies in the blood, which means a potential recipient will react against a greater number of potential organ offers. Sensitization is measured by panel reactive antibody (PRA). A highly sensitized patient is more likely to react against an organ and, therefore, has a smaller pool of potential organs that he/she may receive.

### **Sleep Apnea**

A disorder marked by shallow breathing, or brief pauses in breathing, while sleeping, resulting in daytime drowsiness.

### **Standard Criteria Donors (SCD)**

A standard criteria donor organ comes from a deceased donor who is declared brain dead.

### **Survival Rates**

Survival rates indicate what percentage of patients are still living or grafts (organs) still functioning after a certain period of time.

## **T**

### **Tissue Typing**

A blood test that helps evaluate how closely the tissues of the potential donor match those of the recipient.

### **Transplantation**

The transfer of cells (e.g., stem cells), tissue or organs from one person to another, or from one area of the body to another.

## **U**

### **United Network for Organ Sharing (UNOS)**

A nationwide umbrella for the transplant community; a non-profit organization that administers and maintains the Nation's organ transplant waiting list under contract with the Health Resources and Services Administration of the U.S. Department of Health and Human Services. Located in Richmond, Virginia, UNOS also brings together medical professionals, transplant recipients and donor families to develop organ transplantation policy.

### **Ureter**

A muscular tube that carries urine from the kidneys to the bladder. Each kidney has one ureter.

## V

### Virtual Crossmatching

A computer-screening program to help match patients with the most suitable donors. Unlike crossmatching, which tests blood in a laboratory, virtual crossmatching is solely computer based. By evaluating a patient's known HLA antibodies, the computer can identify unacceptable or incompatible donor HLA antigens. Transplant professionals use this information to select recipients for donor organs that are likely to have a "negative" crossmatch (that is, no antibody reaction, for the best chance that a donor organ will be accepted by a recipient's immune system). A final "real" crossmatch is still always done before a transplant is performed.

## W

### Waiting List (sometimes called a "wait list")

A national list that exists for all patients who are waiting for a transplant. It lists the total number of patients and the numbers of patients waiting for specific organs. It is used to locate the best recipient for a particular donated organ.