



Transplant Alliance

Pre-Kidney Transplant Education Guide

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WVU Medicine Transplant Alliance Contact Numbers

Transplant Office

WVU Medicine J.W. Ruby Memorial Hospital
1 Medical Center Drive
Box 8301
Morgantown, WV 26506

Phone: 304-974-3004
Toll free: 1-844-988-7267 (WVTRANS)
Fax: 304-598-4899
WVUMedicine.org/Transplant

Transplant Office Hours

Monday through Friday
8 am to 4 pm
Closed on weekends and holidays

For urgent calls, after hours, weekends, and holidays, please call the Transplant Office main number, and ask to be put in contact with the Transplant Coordinator on-call.

For routine questions, please contact the office during normal business hours or send a message through MyChart that will be addressed the next business day.

WELCOME

Thank you for your interest in kidney transplant at the WVU Medicine Transplant Alliance. The goals of a successful transplant are to help recipients feel better, live longer, become more active, and to enjoy a better quality of life. We hope this information will help guide you as you consider transplantation as a treatment option.

The main benefits of a kidney transplant are:

- // Longer life
- // Increased feeling of well-being
- // Fewer restrictions on diet and activities
- // Increased energy level
- // Return to work or school

Transplantation is a complicated process that includes much more than just the surgery. Evaluation, waiting for transplant, and recovery following surgery are all part of a long journey for the transplant candidate and family. Even after full recovery, some lifestyle changes are necessary for continued health.

Please review the information we have provided you in this Pre-Kidney Transplant Education Guide. Read it thoroughly, and share it with interested family and friends. We encourage you to bring this guide with you to each visit. If you have any questions prior to your evaluation visit, either write them down, or feel free to call the Transplant Office at 304-974-3004.

Within this guide are several forms you will need to **complete prior** to coming in for your evaluation. Also included in this guide is information about MyWVUChart. We encourage you to utilize this tool throughout your transplant journey

Your evaluation day is: ____/____/____

Please remember to bring this book and the completed forms (caregiver contact information form and medication/allergy form) found in the pocket of the guide and any questions with you to your evaluation appointment.

We look forward to meeting you!

The Kidney Transplant Team

Who is on the Transplant team?

TRANSPLANT TEAM- A group of professionals at the transplant center who work to make a transplant successful. Each person on the team is an expert in a different area of transplantation.

Member	Role
You	<ul style="list-style-type: none"> // Learn about transplant as a treatment for kidney failure // Decide if you want a transplant // Participate in the evaluation process // Discuss needs and concerns with team // Complete all required testing // Continue to communicate with team // Care for yourself before and after transplant
Family/Support Team	<ul style="list-style-type: none"> // Learn about transplant, and ask questions // Accompany candidate to appointments // Support candidate decisions
Transplant Surgeon	<ul style="list-style-type: none"> // Surgical evaluation, including medical history, physical exam, and ordering tests // Educate you on the transplant surgery // Perform the operation // Care for you after transplant
Transplant Nephrologist	<ul style="list-style-type: none"> // Medical evaluation, including history and physical // Educate you on transplant process // Care for you after transplant
Transplant Coordinator Your point of contact at WVU Medicine Transplant Alliance	<ul style="list-style-type: none"> // Provide education about the transplant process // Be your advocate throughout the transplant process, and answer questions you may have // Organize information about your case for the Transplant Selection Committee // Register you on the transplant waitlist // Monitor routine testing while on the waitlist // Maintain communication between you, your doctors, your dialysis unit, and the Transplant Team // Coordinate your admission for kidney transplant // Coordinate post-transplant care

<p>Transplant Social Worker</p>	<ul style="list-style-type: none"> /// Evaluate your ability to cope with the stress of transplantation and your ability to follow a rigorous treatment plan /// Help you and your family with emotional concerns before and after transplantation /// Help you plan for the day-to-day and long-term needs, such as how and where to get your medicines
<p>Transplant Dietitian</p>	<ul style="list-style-type: none"> /// Assess your nutritional status and dietary knowledge /// Provide education and recommendations for your diet /// Help you develop, begin, and maintain any dietary changes
<p>Transplant Pharmacist</p>	<ul style="list-style-type: none"> /// Evaluate your current medication list, and identify any possible drug-drug interactions /// Teach you about your medications /// Assess compliance with your medication regimen /// Review any over-the-counter medications or supplements
<p>Transplant Financial Coordinator</p>	<ul style="list-style-type: none"> /// Review your insurance coverage and benefits information /// Help you understand your insurance policy /// Discuss potential options for coverage during the transplant process /// Needs to know of any changes to your insurance coverage immediately
<p>Administrative Staff</p>	<ul style="list-style-type: none"> /// Schedule your evaluation and follow-up appointments /// Answer Transplant Clinic telephone, takes a detailed message, and connects you with the appropriate Transplant Team member
<p>Support Personnel</p>	<ul style="list-style-type: none"> /// Collect and maintain data on each patient for research purposes and federal regulations
<p>Other Referrals</p>	<ul style="list-style-type: none"> /// Each patient is assessed to determine if other specialists are needed

Your Transplant Journey

As you go through this journey, the Transplant Team will be with you each step of the way. The following pages serve as a basic overview of what to expect throughout your journey, from evaluation for transplant candidacy to being listed on the waitlist for transplantation.

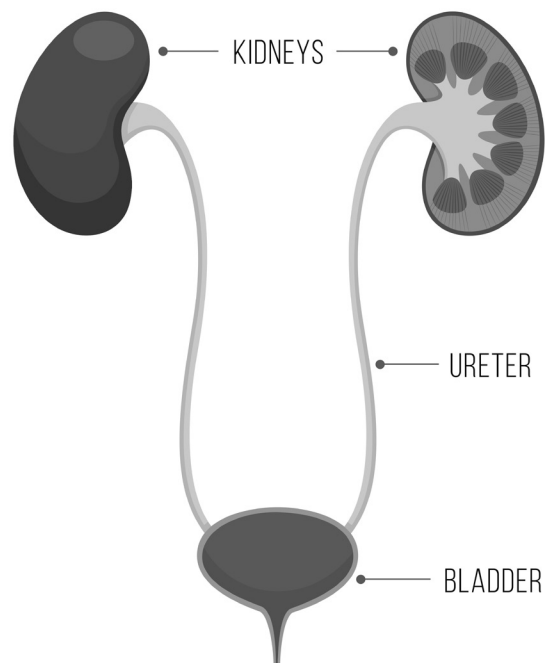
WHERE ARE YOUR KIDNEYS, AND WHY DO YOU NEED THEM?

Your kidneys are located in the back of your abdomen on the left and right side of your spine. The kidneys receive blood flow from the aorta, the big artery from your heart that sends blood to your entire body.

After filtering blood, the kidneys return it to veins that take blood back to your heart. The filtered material, called urine, is emptied into small tubes called ureters that drain into your bladder. This process helps balance the amount of fluid, salt, and electrolytes in your blood and also gets rid of some waste.

Your kidneys' job:

- // Regulate certain electrolytes, such as sodium and chloride
- // Regulate fluid levels in your body
- // Regulate potassium, which is vital to your heart activity
- // Help manage the production of red blood cells
- // Help make vitamin D, which is important for bone health
- // Help regulate blood pressure



WHAT IS CREATININE, AND WHY IS IT IMPORTANT?

Creatinine is a waste product made by your muscles. The amount of muscle you have can affect your creatinine levels to some degree. This is one of the waste products your kidneys filter out of your blood. By measuring the levels of creatinine in your blood and urine, we are able to see how well your kidneys are working. Too much creatinine in your blood (serum creatinine) or too little in your urine (creatinine clearance) may be a sign that your kidneys are not working well. Another test you may hear of is your blood urea nitrogen or BUN (said B-U-N). BUN measures how your kidneys filter urea, another waste product. BUN can also rise with dehydration.

WHAT HAPPENS WHEN YOUR KIDNEYS STOP WORKING?

When your kidneys lose the ability to filter, fluid, waste, and minerals build up in your bloodstream. As materials build up, they can reach toxic levels and cause swelling, difficulty breathing, and even death. This condition is called kidney failure.

Kidney failure can be caused by a number of conditions, such as:

- // Hypertension
- // Diabetes
- // Glomerulonephritis
- // Cystic disorders
- // Urinary tract abnormalities
- // Obstructive disorders
- // Autoimmune disorders
- // Cancers
- // Congenital disorders
- // Drug toxicity
- // Infection

The severity of kidney failure depends on how well your kidneys are able to do their job. The less your kidneys are able to filter your blood, the worse your symptoms may be. Symptoms of kidney failure include:

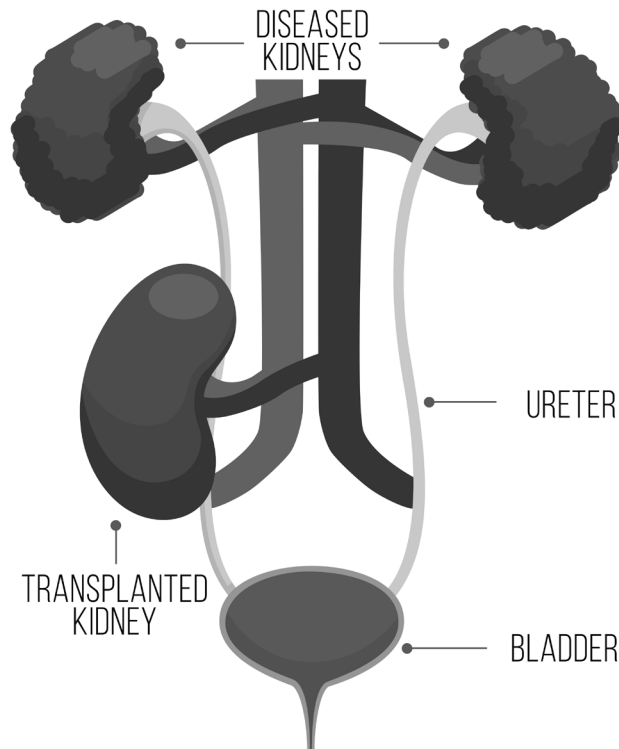
- // Swelling
- // Shortness of breath
- // Decreased urine output
- // Fatigue, tiredness
- // High blood pressure
- // Nausea and vomiting
- // Weight loss or fluid weight gain

Lifestyle changes and medications may slow kidney failure or aid in symptomatic relief at times. When these methods fail, patients who have kidney failure need dialysis or a transplant to stay alive. Kidney transplant is often the best treatment option.

All patients on chronic dialysis or with worsening kidney function should be evaluated to see if they are a candidate for a kidney transplant.

WHAT IS A KIDNEY TRANSPLANT?

A kidney transplant is an operation during which a working kidney from a donor is placed into a person whose kidneys do not work. Usually, your old kidneys are left in place. Typically, your old kidneys do not cause problems. Removal of the old kidneys can be a big operation, so it is avoided unless necessary.



Steps of kidney transplant surgery

- // You are put to sleep (general anesthesia).
- // A Foley catheter (tube) is placed in your bladder to drain urine (even if you do not make urine now) and to measure how much urine you make.
- // A central line (large IV) is placed in your neck.
- // Your surgeon makes an incision, usually starting below your belly button and curving up towards your hipbone. The surgeon will choose your left or right side based on your anatomy and surgical history. Your new kidney is placed in your lower abdomen, and your old kidneys are left in place.
- // The blood vessels of your new kidney are attached to the blood vessels that go to and from your leg.
- // A stent (a small, soft plastic tube) is placed into the donor kidney's ureter, the tube that drains urine from the kidney to the bladder, and the ureter is attached to your bladder. A urologist will remove this approximately 3-4 weeks after transplant.
- // The incision is stitched or stapled closed, and then you are woken up and taken to the recovery room.

TYPES OF KIDNEY TRANSPLANT

There are two types of kidney transplants: a living donor kidney transplant and a deceased donor kidney transplant. A living donor kidney transplant is a surgery in which a surgeon puts a kidney from a living person into someone whose kidneys no longer work. You only receive a living donor kidney if you know someone who will donate to you. A living donor kidney is the best option: they tend to work better and last longer.

Living Donation

You only need one working kidney to live normally; therefore, a living person can donate one of his or her two kidneys. The donor could be a family member, a friend, a coworker, or a generous stranger. If your donor is not compatible, a “swap” or exchange can be arranged. If you do not have a living donor, then you will be placed on a waiting list to get a kidney from a donor who has died and is an organ donor.

Benefits include:

- // Less time spent on dialysis with fewer complications
- // Scheduled surgery at most opportune time for patient and donor
- // Better long-term survival rate

Who Can be a Living Donor?

A living donor can be any adult (over the age of 18) who is healthy and does not have kidney disease. They can but do not need to be a relative. Most people do not know that living kidney donation is a safe option. It will be important that you spread the word about organ donation and living donation to increase your chances of finding a donor.

The living kidney donor will undergo an evaluation similar to yours but by the Living Donor Transplant Team. Care must be taken to ensure that it is safe for the potential living donor to donate. There is no guarantee that a person will be able to donate a kidney as there may be health, emotional, or social issues that keep him or her from donating.

Remember: if you have a potential living donor being evaluated for donation, the Transplant Office cannot share ANY information with you about them, or to them about you, to comply with the federal privacy laws.

Please refer to the United Network for Organ Sharing (UNOS) booklets for more information on Living Donor Transplant and the Organ Procurement and Transplantation Network (OPTN). We are happy to answer any of your questions about living donation.

Deceased Donation

A deceased donor kidney transplant is when a kidney from someone who has recently died is removed, with consent of the family, and placed in someone whose kidneys have failed and no longer work.

GETTING READY FOR TRANSPLANT: EVALUATION PROCESS, LISTING, AND WAITING

Getting a transplant can be a long process. There are many steps involved to be sure you are safe to have a transplant and will benefit from kidney transplant. We call this the pre-transplant process. The pre-transplant process involves the following steps:

- // Referral and evaluation
- // Patient Selection Committee review
 - Approved for transplant listing
 - Declined (not a transplant candidate)
 - Deferred for transplant listing (further evaluation is needed)
- // Waiting for an organ and finding a living donor

The Transplant Team will guide you through the formal evaluation process to determine if you are suited for kidney transplant. The goal is to determine if your likelihood of benefiting and having success after transplant is greater than your risk for complications or death from transplant.

EVALUATION

Goals of the evaluation process:

- // Educate you and your family about the kidney transplant process
- // Decide if you want to pursue kidney transplant
- // Establish your baseline medical condition
- // Identify any health conditions that need treatment or investigation before transplant surgery
- // Determine if a kidney transplant is your best treatment option
- // Assess your readiness for and your commitment to the transplant process
- // Determine if you would not benefit from kidney transplantation or if the risks would be too great

The evaluation process involves numerous tests and assessments to determine if you meet criteria for kidney transplantation. This requires assessing your physical health, your mental readiness, and other factors that would influence the success of transplant.

A list of possible diagnostic tests required for the evaluation process can be found on page 13-14 of this manual. The Transplant Team will determine what testing you will need. Depending on your medical history, you may require many tests on this list or other tests not listed.

Kidney transplant is not a cure; it is a lifelong commitment of caring for your gift of life. Without your commitment, you will most likely become sicker and in worse condition than before transplant.

Lifelong responsibilities after a kidney transplant include:

- ✓ Follow-up appointments: clinic and blood work
 - Initially twice a week
 - Once stable may have telemedicine visits
- ✓ Taking antirejection medications twice a day every day
- ✓ Taking care of all your health needs
- ✓ Kidney biopsies occur at one month, six months, one year, and as needed

Evaluation Process

The evaluation process includes your evaluation day plus any additional tests or doctor's visits that are required.

Before you come to your evaluation appointment, please:

- ✓ Make sure to read all information provided.
- ✓ Complete all forms located in the pocket of this guide. This will help make evaluation day move more quickly.
- ✓ It will be a long day, so plan accordingly and expect the visit to last 4-6 hours.
 - Wear comfortable clothes/shoes.
 - Bring all medications with you (make sure your support person has their medications as well).
 - Bring snacks/lunch or be prepared to buy something from the cafeteria.
 - o You are not required to fast for your evaluation.
- ✓ Bring any medical records/reports from outside of the WVU Medicine system that have not already been provided to the Transplant Office.
- ✓ It is not recommended to bring children or other dependents with you to your appointments.

If you need to cancel your scheduled evaluation appointment, please let the Transplant Office know as early as possible. We will then work to get your appointments rescheduled.

- ✓ Please arrive to the Transplant Alliance Clinic no earlier than 15 minutes prior to your scheduled appointment to allow for registration and paperwork completion.
 - If you are running late, please contact the Transplant Office at 304-974-3004.
- ✓ It is recommend that you bring one of your primary caregivers with you to your evaluation appointment.
- ✓ Once you arrive, you and your support person will be shown to a clinic room where your evaluation will take place. The Team members will rotate into your room providing you with the time and information needed. They will answer any questions you might have.
- ✓ Take notes, ask questions, and write down questions that come later.
 - Questions are important; do not hesitate to ask them.
 - If you did not understand what was said to you during a visit, ask that it be repeated and clarified for you at that time.

- /// We will also be taking a photo of you at your evaluation appointment to reference during your transplant journey and to present you to the Kidney Transplant Selection Committee.

What Happens on Evaluation Day?

On your initial evaluation day, you will meet with members of the Transplant Team, have a physical exam, receive education, and get a list of diagnostic tests that are required to find out if you are suitable for transplant. You may have blood work drawn as well as a chest x-ray and EKG at the outpatient lab in the Physician Office Center (a short walk from the clinic). You may have additional tests performed that day.

Diagnostic Tests – Testing will be specific to what the team deems appropriate for your evaluation. These tests help determine if you meet criteria for a kidney transplant. Your insurance company may need additional results before it can authorize transplant benefits. The Transplant Team needs the other tests. **All of these tests must be completed before you can be added to the waitlist.** If you delay or take a long time to complete testing, some test results may expire and need to be repeated.

Some testing is age and gender based. Some helps to identify if you have cancer. You may not need all of the following tests.

Test	Description
Abdominal-Pelvic Ultrasound	Looks at the organs and other structures in the abdomen and pelvis
Blood Tests	Determines your blood type; measures your sugar level; detects disease or medical conditions; assesses overall organ function; tests for infections
Cardiac Catheterization	Looks at blood vessels of the heart and measures the heart's pumping abilities; requires needle/catheter in your blood vessels
Carotid Artery Ultrasound	Measures the blood vessels that supply blood to your brain to determine if decreased blood flow is present or risk of stroke
Chest X-Ray	Looks for signs of disease in your heart and/or lungs
Colonoscopy	Assesses your colon and rectum for signs of disease, including cancer
CT Angiogram	Measures blood flow to certain parts of your body, including the heart or brain
CT Scan	A special x-ray that shows detailed images of organs and other structures of your body
Doppler peripheral arterial of lower extremities	Special ultrasound technique used to evaluate blood flow through the vessels in your legs
Dobutamine Stress Echocardiogram	Used to evaluate function of the heart at rest and during stress caused by medication instead of exercise
EKG (Electrocardiogram)	Assesses the electrical activity of your heart
Echocardiogram	Records the position and movement of the walls of the heart, including the valves; can be transeophageal, transthoracic, or both

Mammogram (Female only)	Detect the presence of breast cancer
MRI	Provides a picture of organs and other structures of the body in greater detail than a CT scan
PAP Smear (Female only)	Screens for prostate cancer and other abnormalities of the male reproductive system
Pulmonary Function Test	A group of tests used to assess how well your lungs are working
Prostate-specific Antigen (PSA) (Male only)	Blood test that screens for prostate cancer or inflammation of the prostate
24-Hour Urine Test	Tests urine from a 24-hour period of time to measure kidney function
Urology Testing	Determines the health of the urinary system
Renal Biopsy	Further investigates cause of renal failure (usually not needed)
6-minute walk test	Tests to see how far you can walk in 6 minutes and how your body responds to walking

You will complete your initial evaluation appointment on the scheduled day, however, you may be required to have additional appointments and testing before your evaluation process is complete. A Transplant Team member will reach out to you after your evaluation to schedule and coordinate any additional consults or tests.

Patient Selection Committee (PSC)

The PSC consists of transplant physicians, surgeons, social worker, dietitian, financial coordinator, pharmacist, Transplant Coordinator, and other healthcare providers. The committee meets and discusses each candidate and whether they meet the criteria for transplantation. The committee makes a group decision whether transplant is the best treatment option.

All the information collected during the evaluation process will be reviewed at the PSC meeting. The information collected throughout your evaluation will help the committee determine if transplant is an appropriate treatment option for you.

Every transplant center has a different set of selection criteria. You must meet the selection criteria in order to be listed for transplant. This means you may be a candidate at one center and not another. You may request a copy of the WVU Transplant Alliance Selection Criteria from your Transplant Coordinator.

Outcomes of Patient Selection Committee (PSC)

The PSC will meet regularly to discuss candidates who have completed the evaluation testing. Test results and consult findings will be used to determine a plan for each candidate. There are multiple outcome options:

- ✓ **Approved for Listing** – Decision made to place on UNOS and WVU Medicine Transplant Alliance waitlist
- ✓ **Declined for Listing** – Decision made to not place on UNOS or WVU Medicine Transplant Alliance waitlist

/// **Deferred for Listing** – Inability to make determination to place on UNOS or WVU Medicine Transplant Alliance waitlist pending further clinical testing and/or documentation

A Transplant Coordinator will notify you regarding the decision of the committee by telephone and by mail within 10 days. Your referring physician and dialysis unit, if applicable, will also receive a letter detailing the outcome of the Patient Selection Committee's decision.

If you are not a candidate for transplant, you will receive detailed information regarding this decision. If you are accepted for transplant candidacy, the team will need to get insurance authorization for kidney transplantation. Once this authorization is obtained, you will be notified and placed on the UNOS and WVU Medicine Transplant Alliance waitlist.

If you have questions, please contact your Transplant Coordinator at 304-974-3004.

What is UNOS

The Organ Procurement and Transplantation Network (OPTN) is the name of the transplant system in the United States. The OPTN brings together medical professionals, transplant recipients, donor families, and representatives from transplant associations to develop organ transplantation policy. UNOS serves as the OPTN under contract with the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (DHHS). The OPTN regulates how organs are distributed in this country and maintains the official national waitlist of transplant candidates awaiting organ offers.

The United Network for Organ Sharing (UNOS) is a non-profit organization that manages our nation's organ transplant system under contract with the federal government. UNOS uses data and technology to continuously strengthen the system, increase the number of transplants in the United States, and ensure that patients across the nation have equitable access to transplantation through policy, regulation, and education.

The United Network for Organ Sharing provides a toll-free patient services line to help transplant candidates, recipients, living donors, and family members understand organ allocation practices and transplantation facts and data.

Visit their websites at unos.org and <https://optn.transplant.hrsa.gov>.

The Wait List

You will be notified via phone and in writing when you are officially listed for transplant. The transplant waitlist is managed by OPTN, a private, non-profit organization that is responsible for matching organs and ensuring organ allocation policies are followed. Organ allocation is complicated but primarily based on blood type and the amount of time spent on the waitlist.

UNOS uses a computerized database (UNet) that stores your information so that when a donor kidney becomes available, it can be matched with a recipient. Working with UNOS, organ procurement organizations (OPOs) are responsible for the evaluation and procurement of deceased donor organs for organ transplantation. The OPO works with donor hospitals to ensure that organs are allocated to the appropriate recipients based on the national transplant waitlist. OPOs also educate the public to increase awareness of organ donation. In West Virginia, our local OPO is the Center for Organ Recovery and Education (CORE).

While you are waiting...

Waiting for an organ can be stressful. The length of time you wait depends on many factors and can be on average from 3-7 years. There is no way of knowing when an organ offer may occur. Often, organ offers occur in the middle of the night. You must always have a working phone with you, and you must answer it anytime day or night.

The Transplant Team must be able to contact you. If contact information for yourself or your caregiver(s) changes, the Transplant Team needs to be notified immediately. We ask that you and your caregiver(s) be able to travel to WVU Medicine J.W. Ruby Memorial Hospital quickly, as directed, if you receive a call for organ transplant.

While you are waiting, you will need to keep in contact and have regular follow-up appointments with the Transplant Team. Most patients must return to the Transplant Alliance every 6-12 months while on the waiting list. Updates to your testing, blood work, and routine health maintenance will continue while you are waiting. It is important that you keep up with all of these things in order to stay active on the transplant waitlist.

While you wait, it is important to keep yourself as healthy as possible. Staying active during your waiting period is especially important. Set aside time each day to get a little exercise. Take a walk outside, go for a bicycle ride, or engage in an exercise program that has been approved by your primary care physician/nephrologist. Sometimes it is hard to make yourself walk or do physical activity when you do not feel well. Keeping yourself as active as possible before your transplant will have a positive impact on your recovery and regaining your strength post-transplant.

Prior to receiving a kidney transplant, you will need to have a Crossmatch performed to ensure that the kidney has a good chance of success. We ask that you have blood samples sent to the HLA lab at least every month when on dialysis or every other month if not on dialysis. If there is not a current sample (within 30 days while on dialysis or 60 days for those not on dialysis), you will be asked to drive to Morgantown to have a sample drawn which will then be couriered to the HLA Lab. Without the ability to run this test, there is a possibility that you will miss the opportunity to have a kidney transplant.

Please make sure to keep the Kidney Transplant Team aware of any of the following:

- // Hospitalization
- // Traveling
- // New physician consult/testing
- // Moving
- // Visits to the Emergency Department/
Urgent Care
- // Change of insurance

“Dry Run”

Sometimes the kidney transplant surgery is cancelled at the last minute. This is called a “dry run.” This can occur because the organ was not suitable for transplant, or it was not a good organ for you. It can be frustrating when this occurs. However, know that even though you did not receive that particular organ, you will remain on the waiting list and continue to receive other offers. The surgeons only place an organ that is expected to function well.

Kidney transplant candidates also receive many offers that are “back-ups.” A back-up offer means that someone else is on the list before you, but there are reasons to suspect that patient may not get the kidney. For example, the person ahead of you on the waitlist may be sick or may not be compatible with the organ. If this happens, the back-up patient will receive the kidney. Most candidates for kidney transplant will receive multiple back-up offers prior to being transplanted.

TIPS FOR PREPARING FOR YOUR TRANSPLANT SURGERY

Make sure your Transplant Team knows how to reach you at all times. When an organ offer becomes available, the Transplant Team needs to be able to contact you as soon as possible.

- // Have your cell phone on you with the ringer on the loudest setting at all times.
- // Keep your phone charged, and carry your charger with you at all times.
- // Provide the Transplant Team with contact information for close family and friends, in case we are unable to reach you at your main contact numbers.

Have your caregiver team in place. Your caregiver team will consist of your primary and back-up caregiver as well as other family and friends.

- // Choose at least 2 primary and 2 back-up caregivers. Your caregivers should be people you feel comfortable with and who have the time and flexibility to help care for you.
- // Be clear with your caregivers about what you are asking them to do for you and what will be expected of them.
 - See “Caregiver Expectations” section of the guidebook.
- // When developing your caregiver team, consider where they will stay while you are in the hospital for transplant surgery. The Transplant Social Worker has information about local lodging. Before you are discharged, our team will want to meet with your caregiver to do discharge education.

Consider setting up a phone/email tree or blog to keep your loved ones up to date and limit the amount of calls you and your caregiver are receiving while you are trying rest and recover after surgery.

Get your personal affairs in order.

- // Fill out your advanced directives and healthcare power of attorney forms and provide them to the Team to add to your records.
- // Make a plan for how your bills, mail, and emails will be managed while you are unable to do so.

Keep in mind that your call for transplant could come at any time, so you will need to have a plan for childcare and pet care in place.

Have a transportation plan in place. When you get the call for an organ offer, you will need to be able to get to WVU Medicine J.W. Ruby Memorial Hospital as directed by the Transplant Coordinator. This call could come any time day or night, weekends, or holidays.

- // Have gas in the car.
- // Keep some cash available at all times.
- // Have a driver and a back-up driver who are willing to bring you into the hospital at any time.
- // Have the address/directions to the hospital available at all times.
1 Medical Center Drive, Morgantown, WV 26506
- // Have alternative directions to the hospital in case of road closures/traffic.
- // During home football games, additional travel information will be provided.

Pack your bags. When you are called in for transplant, you will need to be ready to go fairly quickly.

You should have your transplant bag packed ahead of time, or at least a checklist to work off of while packing

Things to pack include:

- // Loose/comfortable clothing and pajamas
- // Good supportive shoes (for when you do physical therapy)
- // Hygiene items
- // Your current medication list
- // Insurance information
- // Phone chargers
- // Diabetic supplies
- // Glasses
- // PD Supplies

** Support person should also have their bag with same items as above plus their medications if they will not be returning home nightly.*

Learn as much as you can about transplant and what to expect throughout the process. As you learn what to expect, you may feel more comfortable. Knowledge is power, and empowered patients are more likely to be active participants in their care. We want you to be at the center of your Transplant Care Team.

- // Review this transplant guide completely and often until you are called for transplant.
- // Consider joining a transplant support group either in person or online.

WHAT ARE THE RISKS OF TRANSPLANT?

Although kidney transplant is a proven treatment for kidney failure, it has the same risks as all surgeries do. Surgical complications after kidney transplant include:

Bleeding – Usually occurs within the first 12-24 hours of surgery. Your Transplant Team will monitor you closely for signs of bleeding or other complications after surgery. Sometimes, you may need blood transfusions if the bleeding is substantial. Any blood transfusions put you at a low risk of being exposed to blood-borne infections, such as HIV or Hepatitis C. The risk of contracting these diseases from a blood transfusion is about 1 in 500,000 (or less) in the United States. If bleeding occurs after your surgery, there is also a possibility that you will need to go back to the operating room to stop the bleeding.

Blood-clotting problems – Whenever someone has surgery or is not moving around because he/she is in bed in the hospital, there is a chance for blood clots to form in the legs. These blood clots can break free and travel through your heart to your lungs causing serious problems with breathing (Pulmonary embolism) or even death.

Vascular thrombosis – A serious complication where blood clots form in the arteries or veins of your new kidney. This stops blood from coming into or leaving your kidney which can lead to the loss of the transplanted kidney. If you are prone to blood clots, you may be put on blood thinners to make sure this complication does not occur.

Pain – You will experience pain after surgery. We will try to control your pain with medications. When it is time for you to go home, your pain should be controlled with pain medications you take by mouth.

Nausea and vomiting – Anesthesia and medications, especially pain medications, can cause nausea and/or vomiting. Most medications have side effects.

Infections – Anytime you have surgery, you are at risk to develop infections. After transplant, you will be on medications that put you at an even higher risk for infections for the rest of your life.

Diabetes – Some of the anti-rejection medications along with weight gain and other genetic risk factors put you at risk for developing or worsening Type 2 diabetes after transplant.

Urine leak – A leak could occur in the connection between the new ureter and your bladder. If it does, it may require a procedure in radiology or surgery.

Renal artery stenosis – The main blood vessel giving blood to your new kidney may become scarred as it heals. This may narrow the size of the artery and decrease the amount of blood going to your kidney. If this happens, it may affect your kidney function and cause high blood pressure.

Ureteral stenosis – The connection between the ureter and your bladder is another site that can scar after surgery. If this happens, the transplanted kidney may produce less urine, swell, and increase levels of creatinine in your blood. This complication is also decreased by the use of a stent. Treatment may include a trip to radiology to place a stent or to replace an existing stent or to the operating room for a Nephrostomy tube.

Lymphocele – Your body carries a fluid called lymph alongside your blood vessels in tiny tubes. This fluid is milky in nature and plays a role in your body fighting infections. These tubes carrying lymph are cut during your surgery and may leak, causing a fluid collection. Sometimes, these collections put pressure on your new kidney, causing blockages or kidney damage. If this happens, the lymphocele may need to be drained, either by radiology or surgically.

Delayed graft function – Once your kidney is put in place, it may not filter blood or make urine right away. Many factors can cause delayed graft function including time that the kidney spends on ice, transplant medications, or the quality of the donor. If you are not on dialysis before your transplant, you may be on dialysis after your surgery until your new kidney starts working at its full capacity. You may even start dialysis for the first time, temporarily, after transplant. This may take up to a few weeks. This is very common (up to 40% of transplant recipients).

Primary graft non-function – There are rare cases where you receive a kidney transplant, and the kidney does not start working. If that happens, you are placed back on dialysis, if you were previously on dialysis, and relisted for kidney transplant without losing your previous wait time.

Rejection – Transplant rejection may occur early or later after transplant. It is often treatable but can cause loss of the kidney transplant.

Disease recurrence – Some diseases that damaged your original kidneys can return and damage the new kidney. This can happen quickly or slowly after transplant, depending on the disease. Diseases that may reoccur include diabetes, hypertension, FSGS glomerular nephritis. PCKD does not return.

Skin cancer – Your anti-rejection medications put you at a much higher risk for skin cancer than the general public. You can decrease this risk by wearing sunblock when in the sun and seeing a dermatologist regularly.

Cardiovascular complications – Especially right after surgery, you are at increased risk for problems with your heart and blood vessels, including new arrhythmias, heart attacks, strokes, and blood clots. For this reason, we may require additional heart testing before you are listed for transplant.

Death – The risk of death during or immediately after your transplant is low. Your life expectancy with your transplant is longer than if you were to stay on dialysis.

TRANSPLANT

Once you are called in for transplant, you will be asked to report to WVU Medicine J.W. Ruby Memorial Hospital. Upon arrival, you will be assessed and have blood work drawn, and x-rays may be obtained. Depending on your lab work, you may require dialysis prior to transplant. If you are on peritoneal dialysis, bring your supplies with you to the hospital.

Deceased donor organs are difficult to predict. You may report to the hospital in the middle of the night, on weekends, or even holidays. Once the donor organ arrives to the hospital and the surgical team is ready, you will go to the operating room. The surgeon will assess the kidney in person prior to the transplant.

The length of the surgery will vary from patient to patient. Kidney transplant surgery typically lasts between three-to-five hours. After surgery, you will recover in an Intensive Care Unit (ICU) or step-down unit, usually for 24 hours. Doctors and nurses will monitor your vital signs, urine output, fluid status, laboratory results, overall recovery, and how you are feeling. During recovery, you and your caregiver team will receive education on how to care for your new organ. The average hospital stay is 4-10 days.

After the Transplant

If you live far away from J.W. Ruby Memorial Hospital, you may need to stay close for a time after you are discharged from the hospital. You will have frequent follow-up appointments (2 times per week), lab work, and scheduled kidney biopsies (at 1 month, 6 months, and 1 year). For several weeks following transplant, you will not be able to drive and will also have other physical restrictions (you may not lift more than 10 pounds for 3 months). You will need to have a 24/7 caregiver available during the first few weeks after transplant. This does not have to be one person, but someone will need to be available to help you during this time.

CAREGIVER EXPECTATIONS

During this journey, it is important to develop a team of caregivers that you can rely on to provide support when it is needed. Emotional, physical, mental, and spiritual support will be needed throughout your transplant journey.

The Role of the Caregiver

Your Caregiver Team can have many people, but one person should be identified as your primary caregiver. We recommend that your caregiver team consist of at least four members: two primary caregivers and two additional caregivers that can act as back-up caregivers if needed.

- // We recommend one of your primary caregiver(s) attend your evaluation appointment.
- // We encourage primary caregivers to attend all appointments with you.
- // If a primary caregiver is unable to attend appointments, a back-up caregiver should accompany you.

Caregivers can be family members or friends, neighbors, or other community members. They do not have to have a medical background or perform medical care but should be people who are committed to help you with a variety of activities, such as:

- Support/companionship
 - Making meals and snacks
 - Reminding you of medication times
 - Assisting with transportation to clinic/testing
 - Noticing changes in your behavior or wounds and notifying the transplant office
 - Monitoring your incision and notifying the Transplant Office with any changes
 - Collecting and recording data as directed
- // You should have a caregiver coverage plan to provide 24 hours a day for at least one week after discharge from the hospital (may be longer). Remember that this does not need to be just 1 person.
 - // Caregiver support will continue after the first week of discharge but may not require 24-hour coverage.
 - // Your Caregiver Team will also be needed to provide/arrange transportation while you are unable to drive.

Use the Caregiver Contact Information Form to help gather information and plan for your caregiver team.

CENTER FOR ORGAN RECOVERY AND EDUCATION AND DONATE LIFE

Center for Organ Recovery and Education (CORE)

CORE is an Organ Procurement Organization (OPO) located in Pittsburgh, Pennsylvania. This OPO works with the United Network for Organ Sharing (UNOS) to coordinate all organ donations and allocations. CORE coordinates the surgical recovery of organs, tissues, and corneas for transplantation. It is also responsible for facilitating communication between donor families and recipients. CORE promotes organ donation, education, and research for the purpose of saving and improving lives through transplantation.

Donate Life

As you begin the process of evaluation for transplant, we request all candidates talk with their families and friends regarding organ donation. At the start of your transplant journey, you should consider the following:

- // Are you a registered donor?
 - Even though you are in need of a transplant, there is still the possibility to donate other organs, corneas, and/or tissue.
- // Are your family and friends registered as organ donors?
- // Please take this opportunity to discuss organ donation with family and friends.

There are nearly 106,000 men, women, and children on the waiting list for organ transplants in the United States. In addition, others await cornea and tissue donations to improve their quality of life. You can register to be an organ donor when obtaining or renewing your driver's license or at any time using the following website, or scan the QR code:

www.registerme.org/wvmedicine



Talk with the Transplant Team regarding how you can help raise awareness about organ donation.

Frequently Asked Questions (FAQs) About Kidney Transplant

How do I know if I need a kidney transplant?

End-stage renal disease (ESRD) occurs when the kidneys have lost about 90 percent of their ability to function normally. If you are on dialysis or your GFR is less than 25, you may need a transplant. When your GFR is less than 20, you may begin gaining time on the transplant waitlist (once evaluation complete and approved).

Who pays for the costs of transplant?

Each patient's insurance coverage is different. A financial coordinator at WVU Medicine will work with your insurance company to obtain approval for some or all of:

- Evaluation/testing of the recipient and donor
- Surgery of the recipient and donor
- // The financial coordinator will discuss with you the findings from the insurance company and your responsibility.
- // Questions for you to consider and understand about your insurance coverage:
 - What part of the transplant cost is covered?
 - How does this apply to my deductible?
 - What is the cap on my insurance coverage?
 - What happens if my financial coverage runs out?
 - How will a change in my job status affect my insurance?
 - What would the increase be in my deductible?
 - Do I need to go to a certain facility for these tests to be covered?
 - Are expenses for food, housing, and transportation covered while I wait for my transplant?
 - How much coverage will I receive for post-transplant medications?
 - What is the co-pay amount?
 - If I am on disability, what is my disability? If it is ESRD (kidney failure), you will not be eligible for disability after transplant.

What other expenses should be expected?

- // Possible out-of-pocket expenses:
 - Transportation/fuel (gas)
 - Hotel/lodging
 - Childcare
 - Food
 - Co-pays/deductibles

- Follow-up testing/appointments
- Monthly drug costs will vary and can range from \$0 - \$3,500 per month
 - Medicare Part B coverage at 80%
- Loss of income due to leave of absence from work
 - Household management

Is the evaluation process very difficult?

The transplant evaluation process is very thorough. In addition to kidney testing, tests will be performed to assess the function of all major organ systems. Screening tests for infectious diseases and cancers will be performed. In addition to the physicians on the Transplant Team, you will be assessed by other specialists to try and predict how well you and your family will cope with the expectation of the transplant regimen.

The Patient Selection Committee meets regularly to discuss patient evaluations and make decisions on appropriate treatment. The Committee uses a set of rules, called selection criteria, to guide its decision.

The outcomes can range from approved for listing, needs additional testing (deferred), or declined for transplant.

If approved for listing, when will I be added to the UNOS Waiting List?

Following committee approval, the Financial Coordinator will submit to your insurance company for insurance approval for transplant.

All health maintenance results will need to be completed/submitted to the Transplant Office prior to listing.

Once all results and insurance clearance are received, you will be contacted and added to the UNOS waiting list.

What does deferred for additional testing mean?

The Transplant Coordinator will relay what testing the Committee has requested. Transplant team members will help you to schedule or send a prescription for the needed testing. Once the results come back to the Transplant Office, you will be re-presented to the Patient Selection Committee. You will be notified following that discussion.

Additional testing can be specialized physician consults and/or testing.

If I am declined, what does that mean?

If the Committee declines to list you for transplant, they will provide you a detailed rationale for this decision. Sometimes, this occurs because you are too well for transplant or other issues make you an inappropriate candidate at this time.

Each transplant center has a unique set of rules for listing patients. You can always request that your evaluation records be forwarded to another transplant center for consideration by its program.

How long is the waiting list?

Unfortunately, the waiting times for kidney transplant are long – often around 3-7 years. Each patient on our waiting list returns for outpatient visits to our Transplant Clinic every six to 12 months or as medically indicated.

The allocation of kidneys is primarily based on dialysis or waiting time and blood type.

Finding a living donor can shorten waiting times.

What happens when an organ offer is available?

The Transplant Team will review donor organ offers to determine if suitable for the identified recipient. The Transplant Coordinator will notify you when an organ has been accepted for you, at which time you will be asked questions regarding your health status and be informed of when you need to report to WVU Medicine.

You will be provided a time to arrive to begin pre-op procedures. You can wait in the hospital for 6 to 24 or more hours. Bring at-home medications for you and your support person with you.

How long will transplant surgery last?

On average, surgery can take 3-5 hours once begun. Family may feel time is longer as you may actually be waiting in the pre-op/OR room while being prepped.

How long will I be in the hospital?

This will vary person-to-person, but on average, discharge will occur 4-10 days after the transplant procedure.

Will I have pain after surgery?

The incision can cause pain and/or discomfort when you cough or move. Pain medication will be provided to help control that pain. Pain control is important for deep breathing and coughing to prevent infections in your lungs.

Pain can also be a sign of kidney rejection following the healing of the incision.

Can my family stay with me?

We encourage your family to be present while waiting for the transplant surgery to begin. Following surgery, you may be in the Intensive Care Unit (ICU) to start your recovery. Family will be permitted in for short periods of time according to the ICU guidelines. WVU Medicine has very open visiting hours, at which time family is encouraged to provide emotional support. Pandemic status may cause some restrictions as needed. However, be aware that rest is an important part of recovery.

The Transplant Team will be able to assist with putting in a request with the Rosenbaum Family House and/or provide contact numbers for local hotels with hospital discounts.

Anyone who is ill, should not visit. This includes colds, flu, other infections, or exposure to COVID 19.

What medications will I have to take afterward?

Anti-rejection (immunosuppression) medications are taken lifelong:

- // Multiple medications to prevent rejection
- // Decreased dose of medication over time
- // Medications for other health issues (blood pressure, insulin, etc.)

How does a person's quality of life change if he/she gets a transplant?

Most patients say that having a transplant improves the quality of their lives. They say they feel better and have more energy to spend time with their family, do their hobbies, travel, and go back to work.

What can I find out about my donor? Can I contact the family?

Many transplant recipients want to know more about their donor and may want to express gratitude for the donation of their new organ. A process for contacting your donor's family has been created in order to protect each party's privacy. Respect for the privacy of your donor's family also impacts the ability of medical personnel to provide details about your donor. Following your transplant, the WVU Medicine Transplant Alliance will provide a "Thank You" card, which you can sign, and the Transplant Team will forward to it the Organ Procurement Organization (OPO). Some recipients will receive correspondence back from their donor.

Any correspondence to the donor family should go through the Transplant Office. The team will document the letter in your electronic medical record and then forward to the OPO, which will then make your letter available to your donor's family.

Will I be able to have children?

Yes, but it is important to understand that transplantation may complicate pregnancy, and pregnancy can complicate transplant. We request you discuss your family planning wishes with the Transplant Team prior to getting pregnant. Many anti-rejection medications can cause serious birth defects; women wishing to become pregnant may require changes to their medications prior to pregnancy to avoid these birth defects.

Fertility is not impaired after a transplant. Women may become more fertile.

The methods for contraception available to men and women who have transplant may be limited slightly after transplant.

Can I swim in a public pool?

Do not swim until your incision is healed and stent, catheter, and lines have been removed.

Yes, you may swim in chlorine-treated swimming pools. Ocean swimming may be permitted if water quality is safe.

Do not swim in dirty water or small freshwater lakes/ponds. Transplant patients should be cautious of water quality warnings and not swim if the water is not safe or not tested. If you see green scum around the edges, avoid the water.

Can I eat sushi? Raw meat?

No – unless it's cooked or smoked. Seafood and meat must be cooked.

Can I travel outside of the US?

Yes, to most places, but it is recommended that you do not travel outside the US for the first year after transplant. You should always talk with your Transplant Team regarding your plans to travel outside the country.

// Things to keep in mind:

- Vaccinations you need to travel
- Water and food sanitation
- Proximity to a transplant facility
- Checking with your health insurance regarding requirements

- Expense of vaccines needed
- Ensure you have more than enough medication for your entire trip
- Pack your medications in your carry-on luggage

Will I take on memories or traits from my donor?

No, you will not take on the traits of your donor.

When can I drive? Do I need to wear a seatbelt?

You will not be able to drive for approximately two to four weeks after your kidney transplant. You should speak with your surgeon before driving for the first time after your transplant. The initial doses of the medications we prescribe can cause tremors, weakness, and blurred vision. These side effects, which are often worse in the first few months, as well as pain medications, make handling a car difficult. Therefore, we recommend that you abstain from driving until the Transplant Team clears you to do so.

A transplant patient should always wear a seatbelt when in the car.

When can I return to work?

Depending on your line of work, you can return in six weeks following kidney transplant. Patients who perform very physical jobs require longer times away from work. You may wish to discuss career counseling with the Transplant Team's social worker.

- // How long does it take to fully recover?
- // Generally, it takes three to six months for full recovery from surgery. Keep in mind that age and previous medical problems may cause a longer recovery.

This information is for educational purposes only and not intended to replace the advice of your Transplant Team. Please contact the WVU Medicine Transplant Alliance Office at 304-974-3004.

Your Quick Guide to WVU Medicine

Below is a list of locations you may visit during your transplant journey.

J.W. Ruby Memorial Hospital	
Cafeteria Breakfast 6:00 am to 10:00 am Lunch 11:00 am to 3:30 pm Dinner 4:00 pm to 7:30 pm Grab and Go 9:00 pm to 5:00 am	4 th floor
Discharge Pharmacy	1 st floor (Lobby)
Endoscopy/GI lab	2 nd floor
Gift Shop	1 st floor (Lobby)
Information Desk	1 st floor (Lobby)
Pulmonary Function Test	2 nd floor
Radiology	3 rd floor
Registration	1 st floor
Same Day Surgery	2 nd floor
Starbucks	1 st floor

Heart and Vascular Institute (Southeast Tower)	
Cardiac Catheterization	2 nd floor (2SE)
Heart Failure Clinic	4 th floor (4SE)
Cardiac and Pulmonary Rehabilitation	4 th floor (4SE)

Physician Office Center	
Outpatient Laboratory Monday through Friday 6:30 am to 6:00 pm Saturday 8:00 am to 12:30 pm <i>Closed on football game days</i>	1 st floor
Outpatient Medical Center Pharmacy Monday through Friday 7:30 am to 6:00 pm Saturday 10:00 am to 2:00 pm <i>Closed on holidays and football game days</i>	1 st floor

Valet Parking: In addition to self-parking, valet parking is available at all locations listed above from 7 am to 5 pm Monday through Friday. Valet parking is free, and tipping is not required.

IMPORTANT TELEPHONE NUMBERS

Admission	304-598-4000 ext. 75040
Billing	800-516-5548
Cardiac Catheterization Lab	304-598-4012
Cardiac Rehabilitation	304-598-4648
Echocardiogram Lab	304-598-4395
Rosenbaum Family House	304-598-6094
Transplant Alliance Office	304-974-3004
Transplant Alliance Office Toll-Free Number	1-844-988-7267
WVU Heart and Vascular Institute	304-598-4478
J.W. Ruby Memorial Hospital (Main Number)	304-598-4000
Medical Records	304-598-4110
Outpatient Lab (Physician Office Center)	304-598-4870
Patient Registration (J.W. Ruby Memorial Hospital)	1-800-324-1468
Pulmonary Lab (J.W. Ruby Memorial Hospital)	304-598-4147
Security (J.W. Ruby Memorial Hospital)	304-598-4029

Glossary

Candidate – A person registered on the organ transplant waiting list

Compatible Donor – A person whose blood and tissue type and other medical factors match with the recipient

Deceased Donor – An individual from whom at least one organ is recovered for the purpose of transplantation after the declaration of death

Dialysis – A method of filtering the blood, including removing fluid from blood and balancing chemicals, when the kidneys are unable to do so

Evaluation – The process of gathering information about the potential transplant candidates

Inactive candidate – A candidate who is temporarily unable to receive a transplant at a given time and appears inactive on the transplant waiting list

Informed Consent – A person's voluntary agreement, based upon adequate knowledge and understanding of relevant information, to participate in research or to undergo a diagnostic, therapeutic, or preventive procedure

Kidney Paired Donation (KPD) – When recipients exchange living donors to increase the number of compatible pairs

Living Donor – A living person who donates an organ or part of an organ for transplantation into another person

Living Donor Team – Transplant hospital staff whose job is to evaluate and protect the interest of living donors

Match – When a donor organ is compatible with a recipient for transplant

Organ Offer - When a deceased donor organ becomes available for an active candidate for transplant. The Transplant Team is notified with possible organ offers and assesses if the organ is appropriate for the active candidate. If the organ is appropriate, the active candidate may be brought into the hospital to proceed with transplant.

Organ Procurement and Transplant Network (OPTN) – Links professions involved in donation and transplant systems. They focus on improving systems so that more life-saving organs are available for transplant.

Organ Procurement Organization (OPO)– An organization authorized by the Centers for Medicare and Medicaid Services to procure organs for transplantation

Recipient – A candidate that has received an organ transplant

Transplant Team – A group of professionals at the transplant center who work to make a transplant successful. Each person on the team is an expert in a different area of transplantation.

United Network for Organ Sharing (UNOS) - A group that operates the federal government transplant policies and managed the database (UNet) that stores the information about candidates, donors, and recipients.

Waiting List – A computerized list of candidates that are waiting to be matched with a specific deceased donor organ for transplant. When a donor organ becomes available, the matching system generates a new, more specific list of potential recipients based on specific criteria.

Waiting Time – The amount of time a candidate is on the national wait list. Waiting times can vary depending on many factors.

