

## **Frequently Asked Questions For Waitlisted Patients**

### **Questions About My Follow-up On the Waitlist**

#### **Q: How long will I have to wait for a new kidney?**

- Wait time for a donor organ is dependent upon several factors. These include your blood type, tissue matching, presence of preformed antibodies, and the time from which you began dialysis.
  - Expected patient waiting times will vary depending upon your geographical location within the United States as well as the local Organ Procurement Organization (OPO).
  - The following lists of websites can be used a source for information regarding the organ transplant wait list, waiting times, and organ donation.
    - [www.unos.org](http://www.unos.org)
    - <http://optn.transplant.hrsa.gov>
    - [www.transplantliving.org](http://www.transplantliving.org)
- Average wait times in the D.C., Maryland, and Virginia region are as follows:
  - Blood Group A: 3 years (1095-1190 days)
  - Blood Group B: 5-6 years (1838-2125 days)
  - Blood Group O: 5 years (1778-1891 days)
  - Blood Group AB: 2 years (578-866 days)
- As of December 4, 2014, your wait time will be calculated from the day you started dialysis (not the date you completed your evaluation)
  - For patients listed before they started dialysis, your time will still calculate from your date of listing.

#### **Q: How often should I expect to be in touch with the transplant center?**

- We typically like to see patients once a year while on the waitlist so that we can keep updated on medical issues that might affect getting a transplant
- For patients with more significant medical history, we may see you as frequently as every 6 months
- While we may only be in touch with you every 6-12 months, you should always feel free to contact us at 202-444-3700. Your coordinator while on the waitlist is Arlette Jackson (at our Georgetown offices) or Eloida Gonzalez (at our Washington Hospital Center offices) and they will have all of your most current information.

#### **Q: What sort of events do I need to let the transplant center know about?**

- We would like to hear about any and all significant changes to your medical condition:
  - Any time you have surgery
  - Any time you require an overnight hospital stay
  - Any abnormal screening tests ordered by your primary care provider
  - When in doubt- call us! We would rather hear too much than too little
- We want to know about any change in your contact information:
  - Any time you move or change your phone number
  - Any change in your dialysis center

- Any change in your nephrologist or primary care doctor
- We want to know about any change in your insurance information
  - When you change insurance plans, we need to make sure that you still have coverage for all of the
  - needed post-transplant medications.
- **If you are having elective surgery of any kind, you should let us know before the surgery happens**

**Q: What testing is needed while I am on the waitlist?**

- Monthly blood testing (1 red top tube)
  - We need a sample of blood sent to our lab every month you are on the list. We use this blood to test you against the donor kidneys to make sure you are a match. If we do not have blood from you, we cannot test the kidneys, and you will not be offered a transplant.
    - If you are on dialysis, your dialysis unit should be taking care of this. **Be sure to check with your dialysis center that this is being done.** If you are not yet on dialysis, you should receive the required supplies in the mail so that you can have the blood drawn locally.
- Annual testing for Hepatitis and other viruses
  - We will do this for you at your annual visits to the transplant center
- Annual chest X-ray and electrocardiogram
- Repeat heart testing (a stress test and an echocardiogram) every 2 years
- You must keep current with standard screening tests including (as appropriate) pap-smears, mammograms, colonoscopy, and prostate specific antigen testing
  - PSA tests should be updated yearly (men over 50)
  - Mammograms should be updated every 1-2 years (women over 40)
  - Pap smears should be updated every 2-3 years (all women)
  - Colonoscopies should be updated every 5-10 years (all patients over 50)

**Q: What can I do to make my transplant easier or safer?**

- **You should stop using all tobacco products** (cigarettes, cigars, pipes, dip)
  - The use of tobacco products affects your immune system. It makes you more likely to get an infection, but also makes the immune system more likely to attack the kidney. Some studies have found that people who smoke are **eight times more likely** to lose the kidney than people who do not smoke. You should speak to your doctor about programs and medications that may be appropriate for you to help you quit smoking.
- **If you are diabetic, it is very important to have good control of your blood sugars** prior to your transplant. Immediately following your transplant, you will likely need adjustment to your regimen, and this is easier to accomplish if your sugars were in good control prior to the transplant.
- **Keep your weight well controlled.** Surgical complications increase for patients who are more overweight. We look at the body mass index (BMI) which adjusts for how tall you are (you can calculate your own BMI by using a site like: [http://www.nhlbi.nih.gov/health/educational/lose\\_wt/BMI/bmicalc.htm](http://www.nhlbi.nih.gov/health/educational/lose_wt/BMI/bmicalc.htm)).
  - Patients with a BMI above 40 will not be offered a kidney
  - Patients with a BMI above 35 are still at higher risk for complications
  - Ideally, patients will have a BMI at or below 30 at the time of their transplant

**Q: What should I know about the new way kidneys are given out (the Kidney Allocation System), which went into effect on December 4, 2014?**

- My time on the list now starts from my first day of dialysis
  - Even if you were listed after many years of dialysis, you will gain those years on your waiting time
  - For patients listed before they are on dialysis, their time will start at listing, so there is still a large advantage to being listed before starting dialysis.
- Kidneys expected to last the longest will be given to patients who are expected to live the longest
- Kidney quality will be described by the Kidney Donor Profile Index (KDPI)
- **Expected Post Transplant Survival (EPTS)** will be calculated by your age, your time on dialysis, whether you have diabetes, and whether you have already had a transplant.
  - The top 20% of kidneys (KDPI) will go to the top 20% of recipients (EPTS).
- There will be no further need to ‘transfer’ time between transplant centers. Your time on the list will be the same at all centers at which you are listed (based on when you started dialysis)

**Q: Will Medicare cover my transplant?**

- If you are a U.S. citizen, or a legal permanent resident who has lived in the country for 5 years, you are eligible for Medicare once you are on dialysis.
- If you never applied for Medicare while on dialysis and now receive a transplant, you can still qualify for Medicare coverage.
- Regardless of when you applied for Medicare, if you are not 65 years old or on disability, **your Medicare coverage will end 3 years after you receive your transplant.**
  - If you received a living donor transplant, you should continue your Medicare for the full 3 years allowed- your donor’s medical expenses will no longer be covered once you give up Medicare.
  - Patients on Medicare should consider what insurance options will be available to them once this 3 year deadline arrives.
- If you have Medicare, make sure you have Medicare Part A and B and D (Pharmacy coverage)
  - Part B is the portion of your insurance that covers your physician fees and your anti-rejection medications.
  - Even with full Medicare coverage, Medicare will only pay for 80% of your doctor’s fees and medication costs. Without additional (secondary) coverage, you will be responsible for 20% of these costs post-transplant.
  - **These costs can be hundreds or even thousands of dollars. We strongly advise you to find secondary insurance in addition to Medicare.**

**Q: How can I ensure I have adequate health care coverage post-transplant?**

- Know what your current insurance coverage is and who is paying for it.
  - **Medication costs alone can run \$3,000-6,000 per month after transplant.**
- If any of your insurance premiums are paid by the American Kidney Fund, you should know that the American Kidney Fund will not pay for your premiums post-transplant. **You** will be responsible for these premiums post-transplant.
- The MedStar Georgetown Transplant Institute has financial coordinators who are experts in transplantation and insurance coverage. If you are concerned about your coverage, please call us. Our coordinators will be happy to advise and assist you in getting the best possible coverage for your transplant needs.

- If you are concerned about adequate health care coverage, we encourage you to apply for secondary insurance through your states' Healthcare Exchange Plan.
  - More information about this can be found at [www.healthcare.gov](http://www.healthcare.gov)

**Questions About the Kind of Kidneys That I Might Receive**

**Q: What are my options for transplantation?**

- Patients can receive a kidney either from a living donor (living donor kidney: LDK) or a deceased donor (deceased donor kidney: DDK). An LDK is superior to a DDK in several ways.

|                    | <b>Living Donor Kidneys<br/>(LDK)</b>    | <b>Deceased Donor Kidneys<br/>(DDK)</b> |
|--------------------|--|---|
| Function           | 90%+ Function Immediately                | 70% Function Immediately                |
| Kidney Lifespan    | Average 15-20 years                      | Average 10-12 years                     |
| Immune Suppression | Less                                     | More                                    |
| Time to Transplant | Months                                   | 3-5 years on<br>waitlist                |
| Scheduling         | When Convenient for<br>patient and donor | Whenever organ is<br>available          |

**Q: What is the Kidney Donor Profile Index (KDPI)?**

- KDPI is a way of describing which organs will tend to do better over time.
- Each organ is given a score between 0 and 100. **The lower the number, the better the kidney.**
  - The score is based upon 10 factors measured in the donor
    - Age
    - Height
    - Weight
    - Ethnicity
    - Hypertension
    - Diabetes
    - Cause of Death
    - Kidney Function
    - Hepatitis C status
    - Donor Cardiac Death

- KDPI is used *only* for deceased donors
- KDPI replaces earlier categories such as Expanded Criteria Donors (ECD) and Donor Cardiac Death (DCD).
  - ECD kidneys are roughly equal to kidneys with a KDPI of 85-100. If you had previously considered receiving an ECD kidney, you should consider kidneys with a KDPI of 85-100.
  - **If you previously signed a consent to receive ECD kidneys, you will automatically be listed as willing to accept kidneys with a KDPI of 85-100.** You may, of course, change your decision at any time by calling the transplant institute and speaking with your coordinator. Even if you consent to receive a high KDPI kidney you continue to have the right to refuse any offer made to you.
- Kidneys with a KDPI of 0-20 will *only* go to recipients who are estimated to have the best expected post-transplant survival (EPTS). These recipients will tend to be those who are:
  - Without diabetes
  - Have not had a prior transplant
  - Younger
  - Shorter time on dialysis

#### Q: What is a Centers for Disease Control (CDC) High Risk Organ?

- All donors are screened for potential communicable diseases at the time of organ allocation. This includes screening for Hepatitis B, Hepatitis C, HIV, and syphilis.
- All CDC high risk organs have tested **negative** for HIV, Hepatitis B, and Hepatitis C.
- However, certain higher risk groups may have a negative test after recently catching the virus. These high risk groups are:
  - Men who have sex with other men (MSM)
  - Use of IV, intramuscular, or subcutaneous injection of drugs
  - Sex in exchange for money or drugs
  - Persons who have had sex in the preceding 12 months with a person described above
  - Inmates
  - Persons who cannot be tested for HIV infection
  - Persons whose history, exam, medical records reveal other evidence of HIV infection or high-risk behavior.
- Although the exact risk of transmission is unknown, we can estimate the risks in these groups:
  - For HIV, the risk is between 1 and 5 in 10,000
  - For Hepatitis C, the risk is between 1 and 30 in 10,000[Data from Kucirka et al. (2011) Current Opinion in Organ Transplantation 16:256]

#### Q: What about hepatitis B core positive donors?

- Donors that test positive for the hepatitis B core antibody are patients who have been infected with the hepatitis B virus in the past.
- These donors do not have any evidence of active Hepatitis B infection
- If you have not already been vaccinated against the hepatitis B virus, your chances of being infected with the hepatitis B virus from a hepatitis B core positive donor are between 1 and 3 in 1000.
  - Even more assuring is that even with this low rate of disease transmission, active hepatitis does not usually occur.

- With continued follow up, the rare occurrence of hepatitis B disease transmission from a hepatitis B core positive donor is not likely to adversely affect your health.
- If you receive a transplant from a donor who is hepatitis B core positive, you will receive a medication (lamivudine) after your transplant. In addition, your hepatitis B status will be closely followed with blood tests at several time points after your transplant.
- By accepting offers from hepatitis B core positive donors, your chance of receiving a quality organ with less waiting time is increased.

### **Questions About Living Donor Kidneys**

#### **Q: Who can donate a kidney to me?**

- Donors can be anyone who is healthy enough to donate
  - They do not have to be related to you
  - They do not have to be of the same age, race, or sex as you
- The kidney you receive must be of a compatible blood type
  - Blood group A recipients can receive from Blood Group A or O (75% of all people)
  - Blood group B recipients can receive from Blood Group B or O (50% of all people)
  - Blood group O recipients can receive from Blood Group O (45% of all people)
  - Blood group AB recipients can receive from all blood groups
- You cannot have any antibodies against the kidney you receive.
  - People can make antibodies against a kidney in the following ways:
    - They have received blood transfusions
    - They have been pregnant
    - They have had a prior transplant.
  - If any of these occur, you should let the transplant institute know so that we can re-test your antibody levels.
- **Even if you know you have a donor who is incompatible, they may still help you get a transplant through a paired kidney exchange.**
- **Even if you looked for a potential living donor in the past it's important to always think of new possibilities.**

#### **Q: What is 'Paired Kidney Exchange'?**

- Patients may have a living donor who is not able to donate directly to them because of a different blood group, or because of antibodies in the recipient's blood. These donors can still donate their kidneys via **Paired Kidney Exchange (PKE)**.
- In a PKE, your donor will donate their kidney to another patient on our list (with whom they are compatible) and you will receive a kidney from that person's living donor.
  - Through PKE, you will always receive a living donor kidney
  - The transplants are done virtually simultaneously (within a day of each other) so we will not ask you to offer a donor in the hope of some future transplant
  - Because we must clear both sides of these exchanges, it can take several weeks or months to find an acceptable pair to match you and your donor .

- At the MedStar Georgetown Transplant Institute, we do paired exchanges within our center, but we are also part of the National Kidney Registry (NKR) and the UNOS Kidney Paired Donation Program, which allows us to do paired exchanges with other centers across the country
  - This will improve your chance of finding a matching pair
  - Participation in the NKR or UNOS KPD program does not require either you or your donor to travel to any other center. Your surgery will still be done at MGTI.
- Paired Kidney Exchange offers the best option for patients who are highly sensitized from prior transplants, blood transfusions, or pregnancies to receive a matched organ.
- **Even if you are compatible with your donor, paired kidney exchange may be able to give you a better quality kidney than your original donor. You should ask your coordinator about compatible paired kidney exchange if you are interested in this option.**

**Q: I have a person who is interested in donating, how do I start this process?**

- Potential donors must contact the transplant institute. Our donor liaison is **Alvanetta Cribbs**, who can be reached at **202-444-3714**.
- Donors will first be sent a questionnaire to see if they are healthy enough to donate.
- If they pass the questionnaire, the next step is to do blood tests to see if they are a match
- If both of those steps pass, they will need to come to see us at the transplant institute to complete their evaluation