

# Transplant Waiting List

This section will provide you with information you need to know once you have been listed on the national waiting list for kidney transplant. Even recipients with a living donor will be placed on the UNOS waiting list when they are cleared for transplant.

Listing your name with the United Network of Organ Sharing (UNOS) marks the end of your evaluation process. You and your nephrologist will be notified by the transplant center of the listing. UNOS is responsible for the matching of deceased donors and recipients. All transplant centers participate in UNOS and the federal government oversees its activities. Waiting time on the list may vary from several months to several years. The waiting time is determined by several factors:

## Blood Type

There are four major blood groups. A, B, AB and O. Every effort is made to place organs within the same blood group. Blood group O is the most common blood group and therefore has the greatest number of patients waiting.

## Antibodies

Antibody levels are measured prior to listing. This level is called the PRA. The higher the antibody level, the more difficult it is to match with a kidney. Patients develop antibodies from blood transfusions, pregnancies or previous transplants.

## Donors

The ratio of the number of donors and recipients in a community will impact waiting time.

How long you have been waiting does not determine when you receive an organ. A computer generates a new list of possible recipients each time a donor organ becomes available. Again, the list is based on blood type, antibodies, organ size and time on the waiting list. Each new list that is generated is looking for the best match. Therefore it is important to remember that you do not "move up" the list each time a new donor becomes available.

## Multiple Listing

Some patients choose to be listed at more than one transplant center. This is an accepted practice at all transplant centers and with UNOS. The only restriction is you cannot be listed at two transplant centers that are in the same UNOS procurement area. There will be a primary and secondary center for every person who is listed at multiple centers. You start accruing time at the secondary centers at the time you are listed with them. You can transfer your waiting time from your primary center to a secondary center. Also, if you move and need to transfer to another center all together you may do so without losing your accrued time. For additional information on Multiple Listing, please contact your transplant team or refer to the UNOS handbook. "Questions and Answers for Transplant Candidates and Families about Multiple Listing and Waiting Time Transfer."

# Finding The Right Organ

Whether you are having a living or deceased donor transplant, finding the right organ begins with blood tests. Finding a donor with the right blood type and antibodies is the most important step to finding the right organ.

## Our Immune System- 101

Normally our immune system protects our bodies from foreign invaders such as bacteria and viruses. Our immune system sees the donated kidney as a foreign invader. To make sure that our body finds this foreign invader friendlier, blood tests are done to insure that the donor does not have antigens that will make your body “fight” or reject the donated kidney.

We have trillions of cells in our body and all have a number of proteins floating on their surfaces. Rejection occurs when the immune system recognizes that the cell proteins (antigens) on the transplant organ do not match the body’s own cell-surface antigens.

There are two main sets of antigens that affect the compatibility of transplant organs

- Blood Type (ABO) antigens
- Tissue Type (HLA) antigens

## Blood Type

When a donor organ is being looked at, the transplant team first ensures that the organ is coming from a donor with a matching blood type. RH factor does not matter for transplant. Here is an example of what blood types match:

<b>Recipient</b>	<b>Donor</b>
A	A or O
B	B or O
O	O
AB	A, B, AB, or O

## Tissue Type

Every recipient and donor has tissue typing completed to ensure a good match. HLA (human leukocyte antigens) are genetic markers found on your cells. Three of these antigens are important for transplantation. You inherit a set of 3 from each parent, for a total of 6 antigens.

Parents will match at least 3 of the 6 antigens for their children. Siblings break down a little differently:

25% will be a perfect match - 6 of 6 antigens

50% will match 3 of 6 antigens

25% will not have any antigens match

HLA matching while important to know, is not as crucial as it was years ago. Today's immunosuppressant medications make it possible for someone to receive a zero antigen match kidney and still have a successful transplant.

## Crossmatch

A crossmatch is a blood test that determines if the recipient will accept or reject an organ from a potential donor. If you have a living donor, you may have up to 3 crossmatches before transplant: initial, interim, and final.

A positive crossmatch means that your immune system has antibodies (fighting agents) to the donor's HLA and the transplant cannot occur.

A negative crossmatch means that no pre-formed antibodies are present and the transplant can proceed.

## Antibodies

The amount of antibodies your body has made plays an important roll in how easy it will be to find a “match”. One of the blood tests you will have done is called an PRA (Panel Reactive Antibody). This will tell the percent (number) of antibodies in your body. The higher the number of antibodies after blood transfusions, pregnancies and previous transplants.

**If you are on the UNOS waiting list for a deceased donor organ, you must have your PRA drawn twice monthly. If blood samples are not sent, you may not be eligible for a transplant when an offer is received. Make sure you understand what you need to do to ensure that this blood test gets done.**

Treatment options such as IV Ig/Plasmapheresis and/or Rituximab are available for patients who have a living donor but have a positive crossmatch or incompatible blood types. These same treatment options may help lower your PRA and increase your chances of getting a deceased donor organ. Your transplant team will discuss these with you anytime they are applicable.

# What To Do While You're On The Waiting list

You, your nephrologist and your dialysis unit have received a letter telling you the date you were listed with UNOS. This letter also explains what you will need to do while you are on the waiting list, including:

## Required Monthly Lab Work

This lab work will measure your antibody levels every month. If you are on dialysis, these labs can be drawn in the dialysis unit. If you are not yet on dialysis, these labs can be drawn at the clinic of your choice. Blood kits must be sent in twice a month on the 1st & 3rd Monday or Tuesday. Please refer to your letter for more detailed information.

## Treatment Plan

You will receive a treatment plan with your letter. Please read through this plan, complete it and return it to the transplant social worker as soon as possible. Having a plan in place will help you to be prepared for a kidney offer.

## Phone numbers

You will be asked to provide a list of phone numbers for the team to use when trying to reach you for a kidney offer. Please send this list right away.

## Health Maintenance

Keep current on all of your recommended health maintenance including flu and pneumonia vaccines. It is recommended you get vaccinated for the flu once a year. You should get vaccinated for pneumonia once every 5 years.

## Hang In There

Try not to get discouraged by the long wait. By following these guidelines you will stay active in your healthcare and will be prepared for the day you “get the call.”

# When To Notify The Transplant Institute

There are several situations that may arise while you are on the UNOS waiting list that require communication with the transplant team.

Communication between you and the transplant team is very important. By keeping the program informed of changes, you can help prevent unnecessary travel to Sioux Falls for a kidney offer that may have to be canceled because of your current situation/health condition. Call the Transplant Institute if:

## You Have Surgery

Some types of surgery require that you be placed on "hold" on the UNOS waiting list until you recover. The program needs to know what kind of surgery you had, when you had it, and where it was performed so records can be gathered. A letter will notify you if you have been put on "hold".

## Severe Illness

Anytime you become ill enough to require hospitalization you should contact the transplant program with information on why you were hospitalized, the dates you were in the hospital and where you were hospitalized. It is possible you will need to be on "hold" until your illness is resolved.

## Change in Address or Phone Number

We always need to have current information on how to reach you. You never know when an offer for a kidney will be made.

## Changes in Insurance

Make sure you notify the transplant program whenever you have a change in insurance coverage. This will allow us to make sure your insurance has adequate coverage for kidney transplant.

You will receive a Healthcare Follow-up and Insurance Form to complete on a quarterly basis. Please complete this and return to the program as soon as possible. This is an additional way to communicate important changes to the program.

# What Does "Hold" Mean

Being placed on "hold" while you are on the UNOS waiting list means you have been moved to an **inactive status**. During this time, you are not eligible to receive a kidney offer. You continue to accumulate time during inactivation. There are several situations that require a person to be made inactive on the UNOS waiting list. They include, but are not limited to:

## 1. Health Status

Recent surgery or illness

## 2. Non-Compliance

Compliance with medical care is very crucial after a transplant. There is much research about compliance before a transplant and how it impacts compliance after transplant. The most significant measure of compliance is your dialysis routine. Non-compliance with dialysis is related to bad transplant outcomes and you may need to be placed on "hold" and be asked to participate in a contract.

**Contract:** If there have been compliance problems identified by the transplant team through communication with your physicians and/or dialysis unit, the transplant social worker will write up a contract outlining areas to improve and a time frame for making the improvements.

## 3. Unavailability

If the program is routinely unable to reach you, you may be put on "hold" until a plan can be developed on ways to reach you. Also, there must be a plan in place for quickly getting to Sioux Falls should an offer be available (i.e.: no transportation; extended vacation). Please notify the transplant social worker if you have questions about these situations.

# Annual Re-Evaluations

Once you are on the waiting list, you will come in for a re-evaluation every year. The practice of re-evaluating wait list transplant candidates is recommended by the transplant community. With the ever-increasing number of patients on the national waiting list, the wait time for a deceased donor transplant has increased. The re-evaluation will make sure you are still healthy and able to have a kidney transplant.

To help reduce your waiting time, the transplant team urges all transplant candidates to consider speaking with family and friends about living donation. Living donation will get you off the wait list faster, getting you off or preventing dialysis. This will help you live longer. There is very little risk to a living donor. Living donors do not have to pay for their medical expenses. If you want more information on living donation, call your transplant social worker.

# What Should I Do When I'm Called For Transplant?

Getting a call for transplant can be an exciting and nervous time. Being prepared and having a plan is the best thing you can do.

The following information will help prepare you for your transplant:

- Inform the coordinator if you have had any recent illness/or blood, hospitalization
- Get the name of the transplant coordinator who called you.
- Give the coordinator your cell phone number if you have one. Make sure you bring your cell phone with you, especially if you have more than a 15-minute trip to the hospital.
- Do not eat or drink anything after you get the call.
- If you have diabetes or blood thinners, ask the coordinator what you should do about your medication doses for the day.
- Go to Admissions at the hospital. If you are coming after hours, go through the E.R. entrance.
- Use the following packing guide to prepare for your hospital stay.

# Packing For Surgery

You should bring the following items with you when you come to Avera McKennan for your transplant surgery:

Patient education binder

Bring all medications

Blood pressure cuff

Thermometer

Glucometer if you have diabetes

Most recent income tax return form or social security award letter to verify your income in the event you need help obtaining medications.

Comfortable clothes and extra money for about 2 weeks if you are staying in Sioux Falls after your transplant.

Phone cards for long distance calling

Contact the transplant social worker if you need help obtaining these items.

<Date>

<First Name> <Last Name>

<Address>

<City, St, Zip>

**SAMPLE**  
-THIS IS A REPLICATION OF THE  
QUARTERLY UPDATE YOU WILL  
RECEIVE IN THE MAIL WHEN YOU ARE  
ADDED TO THE UNOS WAIT LIST.

Dear <First Name>:

On a quarterly basis, I am sending letters to all patients who are affiliated with the Avera McKenna Transplant Institute to update their address, phone numbers, medical and financial information.

Please correct any inaccurate information and fill in any empty blanks. If all of the information is accurate, check correct. If you have changed to another insurance company, please send a photo copy of both sides of the card to me. Please return to me in the enclosed stamped self addressed envelope.

Insurance Company: <Ins Company>

Policy Holder: <Policy Holder>

Policy Holder Social Security #: <SS#>

Medicare #: <Medicare #> Part A \_\_\_\_\_ Part B \_\_\_\_\_

Medicare Effective Date (as shown on card): <Eff Date>

Medicaid # and State: <Medicaid #> <ST>

Other: <Other>

If the above is correct check here:

For any questions or concerns, please feel free to contact me at  
605-322-7350 or toll free 1-88-909-1112

Sincerely,

Michele Snyders, MSW

*Transplant Financial Counselor*

# Quarterly Health Care Follow-up for Waiting List Patients

Name \_\_\_\_\_

**Please review the attached phone numbers for accuracy. Please indicate whether you have had any of the following in the past 3 months.**

1. What is your Nephrologist's name? \_\_\_\_\_

2. Hospitalizations (please give dates and reason for admission) \_\_\_\_\_

3. Surgery \_\_\_\_\_

4. Illness \_\_\_\_\_

**SAMPLE**  
-THIS IS A REPLICATION OF THE  
QUARTERLY UPDATE YOU WILL  
RECEIVE IN THE MAIL WHEN YOU ARE  
ADDED TO THE UNOS WAIT LIST.

5. Antibiotic Therapy (is yes, please list reason for taking) \_\_\_\_\_

6. Blood Transfusions (dates and number of units) \_\_\_\_\_

7. Coumadin Therapy (dose and reason for taking) \_\_\_\_\_

Please return these completed forms as soon as possible in the enclosed stamped and self-addressed envelope. If you have any questions or concerns, please call the pre-transplant coordinator at the Avera McKennan Transplant Institute at 605-322-7350 or Toll Free 1-888-909-1112.

## TRANSPLANT PLAN

You have just been added to the UNOS transplant wait list. This means that at any time, you may get a call to come to Sioux Falls for surgery. To help you prepare for the call, we have created a tool called the **Transplant Plan**. This tool will ensure that when you receive the call, you will have everything in place to come to Sioux Falls for surgery. Having a plan in place helps avoid last minute crisis and starts you off on the road to success.

Enclosed is a copy of the plan. Please go over the plan with your family and other important support people who will be helping you at the time of your transplant. Have your support person sign the plan.

Once you have completed the plan, send a copy of the plan to the transplant program for your chart. **Make sure you have a copy for yourself! All patients listed for transplant must have a copy of their plan in their chart.** If you need help completing the plan, contact your dialysis or transplant social worker. They can help you find resources you may be lacking. Your plan will be updated at your yearly re-evaluation appointments.

If you have questions, please call the transplant social worker at:  
888-909-1112.

**BEFORE SURGERY**

1. I have made arrangements with my employer for time off work?  
\_\_\_\_\_ Yes                      \_\_\_\_\_ No                      \_\_\_\_\_ Not Applicable

2. I have children who will need care while I am in the hospital  
and when I first get home.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No

If yes, the person(s) who will help me with this is:

\_\_\_\_\_

3. My plan for getting to the hospital is:

\_\_\_\_\_

a. I have gas money.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No  
b. My car is reliable.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No  
c. I can get there quickly.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No

4. I have a blood pressure cuff.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No  
(Bring this to the hospital)

5. I have a thermometer.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No  
(Bring this to the hospital)

6. I have diabetes.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No

If yes, I have a glucose meter                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No  
(Bring this to the hospital)

7. I have a bathroom scale.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No

8. I will bring all my medicine to the  
hospital when I have surgery.                      \_\_\_\_\_ Yes                      \_\_\_\_\_ No

**DISCHARGE**

- 1. I will need to stay in Sioux Falls after transplant.  
(Be prepared to stay at least 2 weeks.)  
 Yes     No
  
- 2. I have a place to stay in Sioux Falls.  
 Yes     No
  
- 3. I need the Transplant Social Worker to assist me with lodging in Sioux Falls.  
 Yes     No
  
- 4. The person who will stay with me is:  
\_\_\_\_\_
  
- 5. I have someone to help me when I go home.  
 Yes     No
  
- 6. I understand there are frequent outpatient follow-up appointments for the first 3 months after transplant that I must attend after I have been discharged to my home community.  
 Yes     No
  
- 7. The person who will drive me to my follow-up appointments is:  
\_\_\_\_\_

\_\_\_\_\_  
Patient's Signature

\_\_\_\_\_  
Date

\_\_\_\_\_  
Support Person's Signature

\_\_\_\_\_  
Date

## FINANCES

1. My primary insurance is \_\_\_\_\_
2. My secondary insurance is \_\_\_\_\_
3. My Medicare becomes (became) primary on \_\_\_\_\_
4. I have Medicare due to age or disability.  
\_\_\_\_\_ Yes \_\_\_\_\_ No
6. I have insurance that pays most/all of my prescription costs.  
\_\_\_\_\_ Yes \_\_\_\_\_ No  
(If No, please bring your tax return forms with you)

## HEALTH/INSURANCE CHANGES

I understand that I will receive insurance and health care letters on a quarterly basis from the transplant clinic. I agree to complete and return these letters in a timely fashion.  
\_\_\_\_\_ Yes \_\_\_\_\_ No

I will **immediately** notify the transplant program if there are significant changes with my health or insurance.  
\_\_\_\_\_ Yes \_\_\_\_\_ No