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Introduction

Happy Autumn! We send out this newsletter twice a year to keep you up to date on new information pertaining to our Transplant Service. It's also our way to say 'hi' to those of

you on the waiting list. Although some of the information in this greeting may be repetitive, we hope that it will refresh your memory and perhaps spark new questions or areas of interest to investigate.

Our Transplant Team would like to wish all of you much health and happiness until we see you again!

Frequently Asked Questions

The following is a group of questions asked frequently. We felt that they are asked enough that they are worth putting in writing.

Who is UNOS (United Network for Organ Sharing)?

UNOS is the federal agency in charge of regulating all US Transplant Centers. UNOS is responsible for providing guidance and standards for all Centers. Every time there is an organ donor within the United States, UNOS provides a "list" of potential candidates to receive the organ(s) that have been offered for

donation. You can find out more about UNOS by going to their web address at www.UNOS.org

What is an Antibody Level or PRA?

An antibody level is a reading that is a lab test performed at the initial kidney transplant evaluation and then every 6 months following listing. This is a lab test that tells how much antibody is in an individual's blood. Having a low antibody level is desired. Zero percent is the best reading. The highest reading is 100%. The higher the reading, the more difficult it becomes to find a match. For example, if your antibody level is 60%, then approximately 60% of the

organ offers for a kidney will not be acceptable. Thus, the higher the antibody level the longer the waiting list time. If you would like to know your antibody level, please contact your transplant coordinator.

Why do I have to have a blood sample drawn every month? What's the problem with skipping a month?

The reason this is so important is because having your current blood at the hospital is like having you here in person every time we have a potential kidney offer for transplant. If the sample is older than 30

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Yes, I will

www.yeswillwisconsin.org

days, we are no longer able to use the sample to test you for compatibility with a kidney donor. We are able to tell if you **MIGHT** be compatible with a donor and if your name comes up on the list, we would have to do the ‘real-time’ compatibility testing when you get to the hospital. This process takes time and delays the transplant, which is not desirable. If timing is a critical factor, you may even be skipped over and not called in. If you want to be sure that your samples are being received, please call the tissue typing lab at 608-263-8815.

How Much Longer?

Many times those waiting for a kidney transplant wish to know “Where am I on the waiting list? What number am I?”. We wish this had an easy answer, but the simple answer is that there is no particular number given to anyone when they are placed on the list. The kidney offer that is generated by UNOS is based on a formula that takes multiple variables into account; one of the variables is your genetic markers. We are able to quote an average waiting

time, but please be aware that based on your Antibody Level this average time can vary greatly. Every transplant center has different waiting times and if you are listed at other centers, the times quoted below will be different.

What is the average waiting time for a kidney transplant at UW Health?

Blood Type O - 894 days
 Blood Type A - 247 days
 Blood Type B - 604 days
 Blood type AB - 298 days

Can I be on more than one transplant list?

Yes! You may be on multiple transplant lists. Being on multiple lists does not count against you and may actually increase your chances of being called in for a kidney transplant sooner. Check with your insurance company first to find out which transplant centers are recommended for best coverage.

What does ‘transferring waiting time’ mean?

If you are listed at two Transplant centers, you are able to ‘flip-flop’ your waiting time from one center to the other. This concept becomes an advantage if you have a significant amount of waiting time accumulated at one center and the center that you would transfer the time to has a shorter waiting time for your blood group. If you would like more information about this process, please contact your transplant coordinator.



www.uwhealth.org/transplant
 and
our.uwhealth.org

Remember to check our website for updated transplant information.



Staying Active on the Wait List – Updates Needed

Update your transplant coordinator as soon as possible when:

- Your phone number or address changes.
- Your insurance changes.
- You experience any illnesses or open wounds.
- You are admitted to a hospital for any reason.
- You travel out of the area.

Keep these standards in mind:

- Transplant re-evaluation is required every 12-21 mo.
- Blood samples must be sent **every 28 days** to the UW Histocompatibility Lab – coordinate with your dialysis unit or Nephrologist.
- The monthly blood sample **must** include **two** forms of patient ID on the tube (name and birth date).
- Some patients need to repeat a cardiac stress test yearly.
- Men over age 50 need an annual PSA blood test.
- Women over age 40 need an annual mammogram.
- Adult women of all ages need an annual pap smear.
- All patients over age 50 need an updated screening colonoscopy every 5-10 years.



Tips to Prepare You for “The Call”

- Keep your phone on and charged **at all times**. Be ready!
- Depending on your insurance, you may need to pay for a one-month supply of medication. Some of these are quite expensive. Think ahead about how to handle this expense.
- If you live a distance from UW Transplant Center, have a plan in place for transport any time – day or night. In most cases you will need to be on the road within 30 minutes of receiving the call.
- Map out your travel plans to get to UW Hospital. Mapquest (www.mapquest.com) is a free Internet service that can give you directions. Our address is 600 Highland Ave. Madison, WI 53792
- If you must travel by air to our transplant center, please plan ahead. Have flight schedules available and/or charter pilots ready on-call 24/7.
- Charter flights land at a private air terminal where there is no onsite taxi service. Local taxi companies include: Badger Cab (608-256-5566); Green Cab (608-255-1234), Madison Taxi (608-255-8294) and Union Cab (608-242-2000)
- Reminder: UW Hospitals and Clinics is a non-smoking healthcare setting. Smoking is not permitted by patients, visitors or employees anywhere on the hospital and clinics property.

FAX UPDATED MEDICAL RECORDS

Fax reports from updated exams to 608.262.5624

Attn: (My Transplant Coordinator's Name)

Call your transplant coordinator to confirm the receipt of medical records faxed by other medical offices.

What to Pack

- *Driving Directions to UW Hospital (600 Highland Avenue, Madison, WI 53792)*
- *Yellow kidney binder*
- *Loose-fitting clothes (elastic waisted pants or shorts, t-shirts)*
- *Non-skid slippers or shoes with closed toes*
- *Complete medication list & pill bottles*
- *24-hours of dialysis supplies if you are on Peritoneal Dialysis*
- *Personal toiletries*
- *Insurance cards*
- *Phone card and/or cell phone*
- *List of doctors, health care providers & pharmacy, along with phone numbers & addresses*
- *Keep cell phone on during the drive to UW Hospital!*

Meet our Newest Team Members



Dixon B. Kaufman, MD, PhD

Dr. Kaufman is the Chief of the Division of Transplantation and is the Ray D. Owen Professor of Surgery. He received his medical degree from the University of Minnesota, where he also completed his residency and fellowship training, and received his PhD. Dr. Kaufman is board certified in surgery.



Susan M. Jacobson, RN

Sue Jacobson is a registered nurse transplant coordinator who works with kidney and liver transplant patients, primarily prior to transplantation. She graduated from Finley Hospital School of Nursing in Dubuque, Iowa.



Leah Kappelman, RN, BSN, CCTC

Leah Kappelman is a registered nurse transplant coordinator who works with kidney and simultaneous kidney/pancreas recipients following transplantation. Leah received a bachelor of science degree in nursing from the University of Wisconsin-Milwaukee. She is a board certified transplant coordinator.



Jennifer Soppe, RN, BSN

Jennifer Soppe is a registered nurse transplant coordinator who works with kidney transplant patients, primarily following transplantation. She received her bachelor of science degree in nursing from Edgewood College, Madison, WI.



Meet our Newest Team Members (cont)



Amy Elaine Stoll, MSW, CISW

Amy Elaine Stoll is a social worker who works with kidney and liver transplant patients, primarily prior to transplantation. She received her bachelor of arts degree in Psychology and Anthropology from Lawrence University, Appleton, WI and her Master of Social Work from the University of Iowa, Iowa City, IA.

What is My Chart?



UW Health is pleased to offer you the privacy and convenience of UW Health MyChart - secure online access to portions of your UW Health medical records.

UW Health MyChart allows you to:

- Receive test results online
- View and print selected health issues, medications, allergies and immunizations
- Schedule, cancel and view appointments
 - Send secure electronic messages to your health care team

and more

To learn more, go to www.uwhealthmychart.org

If you would like to set up a "MyChart" account, please go to www.uwhealth.org. You will see a red box near the top right. Click on that red box. If you already have an account, enter your ID/password. If you do not have an account, scroll to the bottom of the page and click on the red words "How do I sign up?" You will be given 3 choices. If you choose #3, click on the words "request an account". Fill in the required information. Your ID and password will be mailed to you. Having access to MyChart will allow us to share lab results with you, check on your next appointment, etc.

Do I Have to Get the Flu and H1N1 Vaccines?

The UW Health Transplant Program strongly recommends both the seasonal flu and H1N1 vaccines. Keep in mind that both of these vaccines should be dead viruses in the form of an injection. The nasal form of the vaccines should NOT be used with transplant patients since they contain live viruses. Both vaccines can be given at the same time.

Check with your local doctor about vaccine clinics and availability. The UW Transplant Clinic does not routinely provide these flu vaccines.

- Additional information can be obtained from the U.S. Centers for Disease Control and Prevention (CDC) website: www.cdc.gov

Considering Living Donation

Why should I consider living donation?

- Patients who receive a living donor kidney have better outcomes and higher success rates than patients who receive a deceased donor kidney
- You can avoid long delays waiting on the national list

Does my donor need to be a family member?

- No. If someone is in excellent health and is over 18 years old, with the same blood type as the recipient, they may be considered as a donor.
- If you have a friend or family member interested in donating that does not end up being a direct match for you, you can also explore the National Paired Exchange Program. A paired kidney exchange occurs when two or more incompatible pairs of recipients and donors donate or swap between each other.

What are the risks to my donor?

- Studies have shown that living kidney donors can expect to live a normal life span with no long-term health consequences.
- While risks are minimal, they do exist, and are discussed in detail with donors by the transplant team so that they can make an informed decision.

Who pays for living donation?

- The recipient's insurance pays for the donor's evaluation and surgery
- Donors need to consider the financial impact to them for travel expenses and time off of work. There are some programs that may help offset these costs.
- Of note, buying and selling organs has been illegal in the United States since 1984.

How do I ask my family and friends to consider donation?

- You don't need to directly ask someone to donate – you just need to educate them about your treatment options.
 - Let them know that your doctors have recommended living kidney donation as your best treatment option
 - Let them know that you are making all of your family and friends aware of this, so that if anyone is interested, they can get more information from the transplant center
 - They can call the transplant center and have a confidential conversation with a transplant nurse
 - Donation is voluntary, and they can change their mind at any time
 - Let them know you do not want anyone to feel pressured to donate, and if they choose not to donate, or are unable to do so, you know this doesn't mean they don't care about you

Where can I get more information about living donation?

- www.uwhealth.org/livingdonor
- www.livingdonorassistance.org
- www.livingdonorsonline.org
- www.lkdn.org



600 Highland Avenue
Room F8/152
Madison, WI 53792-1735

TEL: 608.263.1384
FAX: 608.262.5624
We're on the Web!
See us at:

uwhealth.org/transplant

My Transplant Coordinator's Name: _____
My Coordinator's Phone Number: _____

My Social Worker:

Amy Elaine Stoll: 608.261.1281 or
Nancy Arnold: 608.261.1991

My Financial
Counselor: _____
if my last name starts with

A-G: Christy Middleton: 608.263.1503
H-O: Nancy Jo Blum: 608.263.1505
P-Z: Julie Padfield: 608.263.1502

To order Tissue Typing Kits:

608-263-8815 Option#1

United Network for Organ Sharing (UNOS)

The United Network for Organ Sharing (UNOS) provides a toll-free patient services line. This is designed to help transplant patients and their families before and after surgery. The aim is to increase knowledge of organ allocation practices and transplant data.

You may also use this number to discuss a problem you have with your transplant center or the transplant system in general. The toll-free number is 1-888-894-6361.

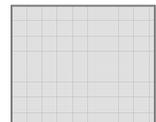


Need Help to Stop Smoking?

Counselors are available by phone 7 am to 11 pm. Callers can also leave a message for call back.

1-800-QUIT-NOW or for Spanish-language **1-877-2NO-FUME**

For a list of smoking cessation support resources by county:
www.medicine.wisc.edu/quitline/programs



PATIENT NAME
STREET ADDRESS
CITY, ST 22134