



# While You Are Waiting



## Introduction

Happy Spring!

We send out this newsletter twice a year to keep you up to date on new information pertaining to our Transplant Service.

It's our way to say "hi" to those of you on the waiting list.

Although some of the information in this newsletter may have been shared with you before, 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!

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## What Happens to My Monthly Blood Sample?

The minute you are listed on the UNOS kidney transplant waiting list, you are available for a deceased donor kidney offer with the same blood type. Although an average wait time might have been provided to you based on your blood type, it is important to remember that some people get kidney offers prior to the average wait time, and some get kidney offers after the average wait time. Because it is unknown when your

offer will occur, we want you to be eligible at all times.

One way to stay eligible for a kidney offer is to send in your monthly blood sample (sometimes referred to as a serum sample). In the ideal world, this blood sample should be received by our lab every 28 days. The reality is that for most patients, their blood sample will be drawn "the first Monday of each month",

or "the second week of the month" depending on the dialysis or physician schedule.

If needed, our program can provide kits for the monthly blood draw. Typically the kits are sent in batches of four. You only need to use one kit every 28 days. Each patient's circumstances are different in terms of where the kits are sent., and if the kit is needed.

(cont pg 2)



**Yes, I will**

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

They can be sent either to you or to the dialysis unit. If you are having your blood drawn at your physician's office, you will have to remember to bring the kit (with the red top blood tube) with you at the time of your blood draw.



After your blood is drawn, the tube should be labeled with your legal first and last name and birth date (If these TWO identifiers are not on the red top tube, our lab will not accept the sample). The tube can then be wrapped up according to the package directions.

The outside cardboard box is pre-stamped and pre-addressed for our lab. The sample is sent via the US mail.

Your coordinator does not check to make sure your blood sample is arriving each month. It is up to you to monitor when it is being drawn and sent. If you are listed

at more than one center, make sure EACH center is getting your blood sample as instructed.

Upon arrival, your blood is stored in the lab's -70 degree freezer, where it stays until there is a potential kidney offer. At the time of an offer, your blood is used to compare you to the deceased donor. This is where the 28 day cycle becomes important.

When there is a kidney offer we use your stored blood sample to do a test called Flow Cross-matching. This is a test to see if there is any reaction between you and the potential donor. In other words, are you a good match with the donor? If there would be a reaction, the test is telling us you may reject this kidney and you are not a good match. A current sample is needed for this testing because your immune system (antibody activity) can change over time.

We need to make sure you do not have a reaction to each donor. If the blood sample is older than 28 days we can not do this testing and you may be passed over for a kidney offer.

The cross match testing is done to determine which group of patients are possible candidates for the donor kidney. Once the testing starts, the process takes between 4-6 hours. Upon completion, a list of possible patients is generated, and from there, a decision is made as to who will be called in for a kidney transplant. If you do not have a current sample at our lab, then this crucial test can not be done.

Now you see how important the monthly blood sample is while you are waiting for your kidney transplant. Should you have any specific questions about the monthly sample, please ask your coordinator.

**To order kits  
for your  
monthly blood  
sample,  
please call  
608-263-8815  
#1.**



## Increased Risk Donors

*(previously referred to as High Risk)*

You may be offered an organ from a deceased donor that is thought to be at increased risk for spreading certain infections according to CDC (Center for Disease Control) guidelines. Donors are considered “increased risk” because of what the CDC deems to be high risk behavior such as

prostitution, intravenous drug use, or homosexuality. We will not accept organs from such donors unless we feel that the good far outweighs the would-be risk. We believe that the risks of getting this type of kidney are very small or we would not suggest you accept it. The transplant

coordinator will inform you at the time that the kidney is offered if it is from an increased risk donor. You can then decide whether to accept this type of kidney. If you choose not to accept the kidney, you will not lose your place on the waiting list.



## NKR 60 Person Chain

The UW Transplant team recently participated in a 60 person transplant chain through NKR, the National Kidney Registry. 30 patients received kidneys from 30 donors.

This was the largest kidney donor chain to date. NKR coordinated surgeries with 17 hospitals in 11 states.

If you have a donor that is not a match with you due to incompatible

blood types or antibodies, ask your transplant coordinator whether this program may be right for you.

For more information on NKR:

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



## Capital City Run/Walk

The Capital City Run/Walk, to be held July 28th, is a unique summer evening 5K road race/walk promoting organ, tissue and eye donation and Wisconsin’s online Donor Registry.

The run happens at twilight.

It begins at the Capital Square, and ends with a private pool party at Goodman Pool.

For more information:

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

&

[www.capitalcity5k.org](http://www.capitalcity5k.org)



Saturday, July 28th,  
2012

## *Living Well . . . with Your Transplant*

**May 17th, 2012  
Summertime and  
the Cooking is  
Easy!  
6:30-8:00 pm**



Community Conference Center, Room #2,  
8700 Watertown Plank Road, Wauwatosa

## *Organ Transplant Support Group*



This free educational support group is designed for anyone who has been touched by organ transplant: recipients, family members/support persons, living donors, donor family members as well as health professionals.

The group meets every other month, on the 2nd Monday of the month, at:

Restoring Hope  
Transplant House  
7457 Terrace Avenue  
Middleton

The next meeting will be held Monday, May 14th from 6:30-8:00pm.

For more information, contact Judi Christie at 608.845.8838 or Annette Jopp at 608.661.5720.

## *Appointments in LaCrosse*



Beginning in April, team members from UWHealth will be traveling to LaCrosse several times a year to see patients being evaluated for kidney or combined kidney/pancreas transplant.

If you live in the LaCrosse area, and would like to have your annual re-evaluations completed locally, please ask your transplant coordinator if this is possible.

This program is not currently able to see patients after transplant.

## Meet our Newest Team Members

### *Susan Meredith, RN, BSN*



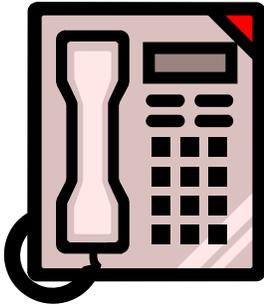
Susan Meredith is a registered nurse transplant coordinator who works with kidney transplant patients prior to transplantation. She received a bachelor of science degree in nursing from the University of Wisconsin-Madison, and has over 20 years experience at UWHC, most recently with the Trauma Life Support Center ICU. She has previously worked with heart, bone marrow, and liver transplant recipients.

### *Joleen Semmann, RN, BSN*



Joleen Semmann 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 the University of Wisconsin-Madison, and has 19 years of experience at UWHC, most recently with the Trauma Life Support Center ICU. She has previously worked with bone marrow and liver transplant recipients.

## Important Phone Numbers



**My Transplant  
Coordinator's Name:**

\_\_\_\_\_

**My Transplant  
Coordinator's Phone #:**

\_\_\_\_\_

**My Social Worker's  
Name:**

\_\_\_\_\_

**My Social Worker's  
Phone #:**

\_\_\_\_\_

**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

## 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 to Quit 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](http://www.medicine.wisc.edu/quitline/programs)

## Staying Active on the List

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 12-18 months
- 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 (legal first & last 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 a screening colonoscopy & follow-up at recommended intervals.



## 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 waist 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 (with charger)
- List of doctors, health care providers & pharmacy, along with phone numbers & addresses
- **Keep cell phone on during the drive to UW Hospital!**



University of Wisconsin Transplant Program  
600 Highland Avenue, F8/152  
Madison, WI 53792-1735

Phone: 608.263.1384  
Fax: 608.262.5624

To:

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WWW.UWHEALTH.ORG/TRANSPLANT  
&  
OUR.UWHEALTH.ORG

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## *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](http://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); Madison Taxi (608-258-7458); 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.