While You Are Waiting

Happy New Year!!!

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!

Introduction

Housing Options in Madison

If you or your family needs help finding a place to stay in Madison while receiving medical care at UW Hospital and Clinics, please contact the UW Hospital and Clinics housing coordinator at (608) 263-0315 from 7:30am to 4pm, or stop by the hospital's main information desk on the second floor between 7:30am and 9pm daily.

Our staff can help you locate affordable accommodations nearby and special rates are available when reservations are made by housing coordinator staff.

Some options that may interest you include the following:

- Restoring Hope Transplant House opened it’s doors in December. Their mission is to provide a warm home away from home for guests undergoing organ and bone marrow transplant, and their loved ones.

- The Ronald McDonald House is a "home away from home" for families whose children are undergoing treatment for serious illness or injury at Madison health care facilities.
Which Vaccines Should I Get?

The UW Health Transplant Program strongly recommends theseasonal flu vaccine. Keep in mind that this vaccine should be a dead virus in the form of an injection. The nasal form of the vaccine should NOT be used with transplant patients since they contain live virus. Check with your local doctor about vaccine clinics and availability. The UW Transplant Clinic does not routinely provide flu vaccines.

You should also ask your doctor about whether you need boosters for pneumococcal(pneumonia), pertussis(whooping cough) as well as shingles vaccines.

If you are planning a living donor kidney transplant, PLEASE check with your coordinator before you get any vaccine. They will talk with you about how this may or may not affect your antibody reaction with your living donor.

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

Blood Transfusions

We ask that you only receive blood or blood products if it is absolutely necessary. If your doctor feels you must receive a transfusion, we ask that the blood be filtered(leukopen) and that you remember to inform your coordinator as soon as possible.

About 2 weeks after any transfusion, a blood sample must be sent to our tissue typing lab for antibody testing. During this two week period, you will need to be on waiting list hold so that we don’t offer you a kidney to which you have developed antibodies.

National Kidney Registry (NKR)

UW Transplant is proud to partner with the NKR, the leader in paired exchange transplantation.

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

Insurance Changes

If your insurance changes, please let your transplant coordinator know as soon as possible! It is very important that we have up-to-date insurance information on file for you so that we can ensure you are accurately billed for our services.
Community Conference Center, Room #2,  
8700 Watertown Plank Road, Wauwatosa

Appointments in LaCrosse

UWHealth travels to La-Crosse several times a year to see patients being evaluated for kidney or combined kidney/pancreas transplant. If you live in the La-Crosse 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.

Monthly Blood Samples

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

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 from 6:30-8:00pm.

For more information, contact
Judi Christie at 608.845.8838
or
Annette Jopp at 608.661.5720
## Important Phone Numbers

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<th>My Social Worker's Name:</th>
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If my last name starts with:

- A-G: Christy Middleton 608.263.1503
- H-O: Terri Persson 608.263.1505
- P-Z: Julie Padfield 608.263.1502

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## 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.

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## 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
- Women over age 21 require a pap smear every 1-3 years, based on medical history
- 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 your cell phone on during the drive to UW Hospital!**
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.
- Need to make housing arrangements? Call the housing desk at (608) 263-0315.
- 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.