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Happy Summer!

We send out this newsletter twice a year to keep you up to date on new information pertaining to our Transplant Services. It's our way to say "hello" 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 for you to investigate.

Our transplant team would like to wish all of you health and happiness until we see you again.

Don't miss the 17th Annual Transplant Picnic

Sunday, August 25th
11:30-3 pm



Vilas Park Shelter
1400 Vilas Park Drive
Madison

Plan to eat at 12:30. Bring your own tableware and a dish to pass.
Lawn games will be provided. **Rain or shine!**

Call Annette (608) 413-0068 or Judy (608) 514-3274 with questions.

Don't miss out! Our website is full of important information about transplant and organ donation. You can also subscribe to *The Ripple Effect*, a quarterly electronic newsletter about organ and tissue donation and transplantation. Visit: uwhealth.org/transplant and uwotd.org



UW Health offers secure online access to your UW Health medical records through MyChart. You can receive test results, view and print selected health issues, medications, allergies and immunizations, schedule, cancel and view appointments, send secure electronic messages to your health care team, receive and pay your current bills, view payment history and more. You can sign up during your next appointment, at any UW Health clinic or online at: uwhealth.org/mychart.

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 visit: uwhealth.org/livingdonor or kidneyregistry.org

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 (leukopoor) and that you remember to inform your coordinator as soon as possible.

About two 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.

Insurance Changes



If your insurance changes, please let your transplant financial 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.

Monthly Blood Samples



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

Appointments in La Crosse



UW Health 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-evaluation completed locally, please ask your transplant coordinator if this is possible. This program is not currently available for post-transplant patients.

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 and health care professionals. The group meets every other month, on the second Monday of the month, at:

Middleton Public Library
7425 Hubbard Avenue
Middleton
6:30-8 pm

For more information, contact:

Judi Christie: (608) 514-3274 or Annette Jopp: (608) 413-0068

Join us at the
Capital City
Legacy of Life Luncheon and Workshops
and
5K Run/Walk
Saturday, July 27, 2013
Madison

Transplant recipients, living donors, individuals waiting for a transplant, donation professionals and family members of deceased donors are invited to be a part of the 2013 Legacy of Life Day.

The day includes: networking, exhibits, workshops, awards luncheon, the run/walk and private pool party.

Form your own team, or join the UW Transplant Tour de Force team or UW OTD Orange Maniacs team for the run/walk.

Learn more and register for any of the day's events at: kidneywi.org



Skip the Wait: Find a Living Donor

You can dramatically shorten the time you wait for a transplant by actively seeking a living donor. This checklist may help you prepare.

† **Educate yourself about your disease**

Before you discuss your disease with anyone, learn about your disease. Be prepared to answer questions such as: “How does your disease impact your life?” “Why can’t you just go on dialysis?” “How will a kidney transplant improve your life?” and “Why can’t you wait for a deceased donor kidney?”

Did you know?
Kidneys from deceased donors last an average of **8-10** years, while kidneys from living donors last an average of **12-20** years!

† **Understand living donation**

The information in your binder and online at uwhealth.org/livingdonor will help you prepare for this conversation. Prepare to answer questions about all aspects of donation such as the donor testing process, surgery, recovery and possible risks.

† **Ask for more help**

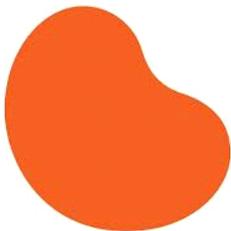
After you’ve studied your binder and our website; let us know if you have more questions. We have additional resources, or may partner you with a living donor recipient or living donor mentor who has faced the same issues. Keep your transplant coordinator’s phone number with you at all times so you can connect interested potential donors directly with him/her.

† **Reflect on your relationships and everyone’s personalities**

Reflect on the situation from the potential donor’s point of view to determine how they would best receive the information. Some issues to consider include: Are you/the potential donor talkative or quiet, private or open, one-on-one communicators or comfortable in a group of people.

† **List places to find potential donors**

Anyone who is willing to donate can, and should, talk to your transplant coordinator about eligibility. Consider all options including relatives, friends and people in your church, school, social clubs and community. Don’t rule-out your children. Consider what you would do if your parent needed a transplant.



† **Draft a living donor request letter and organize information to give to potential donors**

Include our transplant center contact information, noted below. Even if you don't mail the letter and information, be ready to hand it out. Tell them not to answer that day, let them know you will not bring up the topic again and assure them your future relationship is not based on their decision.

† **Consider a group approach to speaking with potential living donors**

A meeting with a Living Donation Outreach Educator can help provide information and start the conversation with your friends and family. This can help you feel confident that accurate information is shared.

† **Consider broader messaging**

You may decide to share your need for a kidney more publicly through a community bulletin, a holiday newsletter or via social media. Our staff has tips and tools to help you navigate these options, which can be labor-intensive and emotionally charged.

† **Role play the living donor request conversation with your ambassador or transplant coordinator**

Role play may help you feel more comfortable with the situation and could help you sort out what you want to say, as well as let you practice answering questions potential donors may have.

† **Ask someone to be your living donor**

Remember to give them time to process the information and to think carefully about their decision.

† **Remember that becoming a living donor is an immense decision.**

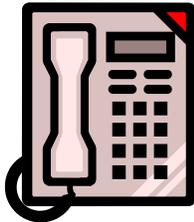
People's willingness to donate (or not) is not an indication of the depth of their feelings for you.



People interested in being evaluated as your living donor should contact your transplant coordinator.

UW Transplant also has an online living donor inquiry form at:
uwhealth.org/livingdonor

Important Numbers



UW Health Transplant Program:	(608) 263-1384
Fax:	(608) 262-5624
Housing Desk:	(608) 263-0315
Monthly blood sample kits:	(608) 263-8815 #1
Financial Counselors (By first letter of your last name)	
A-G Christy Middleton:	(608) 263-1503
H-O Terri Persson:	(608) 263-1505
P-Z Julie Padfield:	(608) 263-1502

UNOS Information



The United Network for Organ Sharing (UNOS) provides a toll-free patient services line, designed to help transplant patients and their families before and after surgery. Their information can increase your 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. Contact UNOS toll-free at **1-888-894-6361**.

Need to Quit Smoking?



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

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

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

UW Hospitals and Clinics is a non-smoking environment. Smoking is not permitted by patients, visitors or employees anywhere on the hospital and clinics property.



Promote Organ Donation

Learn more about the facts of organ, tissue and eye donation and join the volunteer team at UW Organ and Tissue Donation. Visit their website at: uwotd.org.

Staying Active on the List

Your transplant coordinator needs to know this information as soon as possible:

- If your phone number or address changes
- Any changes with your insurance
- If you experience any illnesses or open wounds
- If you are admitted to a hospital for any reason
- If you plan to travel out of the area
- If you receive a blood transfusion

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 this with your dialysis unit or nephrologist
- The monthly blood sample **must** include **two** forms of patient ID on the tube (legal first and 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 and follow-up at recommended intervals



Fax Updated Medical Records

Fax your updated exam reports to the attention of **your transplant coordinator's name**. The fax number is (608) 262-5624

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 and pill bottles
- 24-hours of dialysis supplies if you are on peritoneal dialysis
- Personal toiletries
- Insurance cards
- Phone card and/or cell phone (and charger)
- List of doctors, health care providers and pharmacy, along with their phone numbers and addresses
- **Keep your cell phone on during the drive to UW Hospital**



UW Health Transplant Program
600 Highland Avenue, F8/152
Madison, WI 53792-1735

Phone: 608.263.1384
Fax: 608.262.5624

To:

UWHEALTH.ORG/TRANSPLANT

Tips to Prepare You for “The Call”

- Keep your phone on and charged **at all times**. If you get a new phone number, make sure we have it.
- When we call you in for transplant, caller ID may say “blocked number” or “private number.” Make sure you answer all of your calls!
- Are you ready to leave home at a moment’s notice? Do you need a plan for who will take care of your children, your pets, your plants?
- Depending on your insurance, you may need to pay for a one-month supply of medication. Some of these are quite expensive. Have a plan in place.
- 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. Keep your tank full of gas.
- Map out directions to UW Hospital and Clinics. Use a service like Mapquest (mapquest.com) which is a free Internet service that gives easy to follow directions. Our address is 600 Highland Avenue, 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.
- Think about setting up a phone/email tree or blog (such as carepages.com) or a key contact person so that you are not receiving a lot of phone calls each day when you are in the hospital