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Look At Our New Format

Greetings! Welcome to the University of Wisconsin Hospital & Clinic's Kidney Transplant Newsletter! If you are new to this mailing, we hope you enjoy this information.

This newsletter is one of the ways we stay in touch with patients on the kidney transplant wait list.

Please take time to read and refresh your transplant knowledge.

As time passes, it's easy to forget the "little things" you need to do while on the wait list. Use this letter to brush up on what is new in the field of transplant and within our department.

We hope you like the new

format. Notice the bright headlines and bigger type.

If there are topics you would like to see covered in future issues, please let us know. We try to include information to make your wait time go smoother. Patient feedback is always helpful.

Happy reading!

Preventive Health Care

- Flu shots are encouraged and recommended by our department for most wait list patients. However, please check with your primary care doctor or Nephrologist to make certain you do not have any other medical conditions that would preclude you from receiving this vaccine.
- Have you been vaccinated for Hepatitis B? Is your surface antibody positive? If not, please talk with your primary care doctor or Nephrologist to see if you should undergo the series of 3 injections to protect against this preventable virus.
- Talk with your Registered Dietician (transplant program or dialysis unit) if you are trying to lose weight. Many patients are urged to reach a healthy body weight for transplant surgery. A health weight makes recovery go smoother and lessens your chance for other major health conditions.
- Discuss exercise options with your primary care doctor or Nephrologist to help with weight loss and overall health.
- If you need help to stop smoking or use of chewing tobacco, talk to your primary care doctor or Nephrologist.
- If you receive a blood transfusion, be sure the blood is "filtered" to avoid developing antibodies (sensitizes you for transplant). Call your coordinator if you receive any blood products.

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.



“Consider being a volunteer at the 2010 Transplant Games or competing as part of Team Wisconsin.”

2010 U.S. Transplant Games

Madison, Wisconsin will be the site of the 2010 U.S. Transplant Games sponsored by the National Kidney Foundation. We are very excited and honored to be host to this national event. The games will be July 29 to August 4, 2010.

Athletic competition is open to any man, woman or child who has received a life-saving organ transplant, including kidney, lung, heart, liver, pancreas or bone marrow.

Gold, silver, and bronze medals will be awarded in a dozen sports: Golf, Swimming, 3-on-3 Basketball, 5K Road race, Tennis, Bowling, Volleyball, Badminton, Track & Field, Racquetball, Cycling, and Table tennis.

The Transplant Games aim to:

- Showcase the success of transplant and call attention to the critical need for more organ donors in the U.S.
- Recognize and pay

tribute to the more than 4,000 American families who donate the organs and tissues of their family members each year.

- Offer a form of rehabilitation for chronic disease patients through the use of athletics.
- Establish a commitment to patient wellness, increasing longevity and improving transplant success.

For more information visit: www.transplantgames.org

Staying Active On “The List” – Updates Needed

Annual medical updates are needed to keep wait list “active” status:

- Be sure your transplant coordinator has up-to-date phone numbers for you. Kidneys may become available anytime – day or night. We have **ONE** hour to reach you or the organ must be offered to someone else.
- Call your transplant coordinator with any changes of address, phone numbers or insurance.
- Notify your transplant coordinator of all illnesses or open wounds. In some cases, we cannot offer transplant surgery if you are ill or have an infection due to the chance of increased complications.

- You may request to be placed on “hold” if you plan to travel out-of-area. This means that you will not be called with an organ offer during your travel dates. Upon return, you will go back to “active” status. You will continue to accrue wait time while on hold.
- You may be scheduled for a transplant re-evaluation every 1-2 years. Frequency depends on your health conditions.
- Make sure your dialysis unit or Nephrologist office is sending your blood samples to the UW Histocompatibility Lab monthly. If we don’t have up-to-date samples for cross-matching, you may not be offered a kidney.

Samples **must** have **two** forms of patient ID on the tubes (name and birth date).

- Patients sometimes need to repeat a cardiac stress test yearly. Ask your transplant coordinator if you need an update.
- Men over age 50 should have annual PSA blood tests (prostate cancer screening).
- Women over age 40 need an annual mammogram (breast cancer screening).
- Adult women of all ages need an annual pap smear (cervical cancer screening).
- All patients over age 50 need an up to date colonoscopy (cancer screening).

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 that we received records faxed by other medical offices.

Newest Staff Member – Living Donation Outreach Educator

Those needing a kidney transplant often say they don't know how to ask someone to consider kidney donation. Research shows that sometimes family and friends are interested, but don't immediately offer because they want to learn more or don't know how to get started.

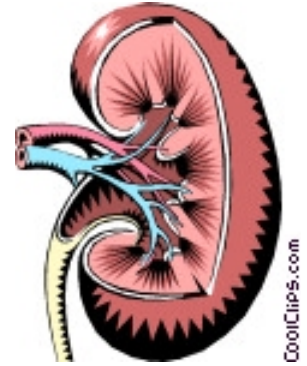
The UW Transplant Program would like to introduce Kelli Willard West to our team. Kelli joined us in June 2008 as our Living Donation Outreach Educator. Her role in the transplant process is to help facilitate communication between kidney patients and potential living kidney donors.

Kelli's position was modeled after a research project at a Florida transplant center. Group meetings were held in patients' homes to educate families about living donor transplant. This intimate, yet informal, educational style helps ease concerns and is designed to start discussion. The group meeting gives those who may want to donate a chance to get information, ask questions, and make informed choices.

Following these types of meetings, potential kidney donors were more willing to proceed with testing to donate a kidney. Our team hopes that many patients will consider the

opportunity to have Kelli come to their home or community for a group/family-style meeting.

Kelli meets with each patient at their kidney transplant evaluation or re-evaluation to assess their individual situation. The evaluation is followed up by phone calls and – if desired – patient home meetings. If you have not had a chance to speak with Kelli to discuss her educational services, please feel free to call.



CoolClips.com

Kelli Willard West, MSSW, APSW
Living Donation Outreach Educator
(608) 261-1993
kwest@uwhealth.org

New Video & Internet Information

UW Transplant Program
 Patient education videos developed by our transplant team can be viewed on the internet. These are great tools to refresh your memory on important transplant topics. There are even "tests" to check your knowledge.

Go to website: www.uwhealth.org/transplant and click on "Patient Education Videos and Quizzes."

DVD copies are also available to patients.

Other Resources
 The American Society of Transplant Surgeons (ASTS) has produced two 30-minute patient education videos:

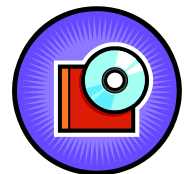
Kidney Transplantation: A Guide for Patients and their Families

Living Kidney Donation: What You Need to Know

English and Spanish versions are available for free online viewing under patient education at the ASTS website: www.astsonline.org

The UW Transplant Program also has copies of the videos available through a "lending library" with postage-paid return envelopes.

Please contact Kelli Willard West at the above phone number if you don't have internet access and would like to borrow a DVD copy.





What to Pack

- *Driving Directions to UW Hospital (600 Highland Avenue, Madison, WI 53792)*
- *Kidney binder*
- *Loose-fitting clothes (elastic waist pants/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*

When You Get “The Call”

Tips for a stress-less surgery & hospitalization:

- 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 pay for 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.
- Map out your travel plans to get to UW Hospital. Mapquest is a free internet service that can give you directions.
- 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.
- Reminder – UW Hospitals & Clinics is a non-smoking healthcare setting. Smoking is not permitted by patients, visitors or employees anywhere on the hospital and clinics property.

Be Informed – High Risk Donor Consent

You may be offered an organ from a deceased donor that is thought to be “high risk” for spreading certain infections. This is a Centers for Disease Control (CDC) guideline. Donors are noted as “high risk” if they were known to engage in certain high risk behaviors. These may include: prostitution, IV drug use, or homosexuality.

Our transplant center does not normally accept organs from such donors unless we feel that the good far outweighs the would-be risk.

Blood tests are done on

potential deceased donors to look for viruses such as HIV, Hepatitis B or Hepatitis C. No test is perfect, and false negative tests may occur – though rarely.

We know from organ, tissue, and blood donor data that there is a small chance (about 1-in-60,000 to 1-in-2,000,000) that an infection could be passed on. We believe that the risks of getting this type of kidney are very small or we would not suggest that you accept the kidney.

When you receive an organ offer call from the transplant center, the

transplant coordinator will tell you if the kidney is from a high risk donor. To protect donor privacy, you will not be given any details.

You will have an option to accept or decline this type of kidney. Because of time constraints, you will need to decide quickly. You may want to think about these options and discuss questions and concerns with your transplant coordinator or surgeon in advance.

You will **NOT** lose your place on the wait list if you choose to decline a kidney from a high risk donor.

Social Workers Can Help with Advance Directive

If you do not have an Advance Directive on file at UW, our team urges you to complete one during your wait time.

This is a paper where you state your wishes about future health care and choose who should make medical decisions if you

are unable. Please contact one of our transplant social workers to guide you through this process.



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

PHONE: (608) 263-1384
FAX: (608) 262-5624

We're on the Web!
See us at:
www.uwhealth.org/transplant

Important Phone Numbers to Keep Handy

My Transplant Coordinator's Name: _____
My Coordinator's Phone Number: (608) _____

My Social Worker's Name: _____
My Social Worker's Phone Number: (608) _____

Living Donation Outreach Educator: (608) 261-1993

Financial Counselor/Insurance Questions: (608) 263-1503 or 263-1502



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



PATIENT NAME
STREET ADDRESS
CITY, ST 22134