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Preparing for the Holiday Season!

It's the holiday season. Time, once again for celebration, gifts and thankfulness. The staff of the UW Transplant Program wants to touch base and share new information with our kidney transplant wait list patients. We hope this newsletter finds you doing

well and enjoying this beautiful time of the year.

Please take a few moments to catch up on transplant news and tips for making the wait for your transplant go more smoothly.

In this issue, we will introduce our newest transplant coordinator, Terri

Fass, and share some updates about flu vaccines and nutrition. We also remind you that it is never too late to consider a living donor transplant. Lastly, please read about how you can be a part of the 2010 U.S. Transplant Games being held in Madison. Enjoy!

Never Too Late to Consider a Living Donor!

On November 15, the UW Transplant Program celebrated the kindness of 193 living organ donors who helped a loved one receive a transplant between July 2007 and June 2009. The UW Transplant Program thanked donors for their "Gift of Life" by presenting a Wisconsin Governor's certificate and medal.

It is sometimes hard for transplant doctors and staff to understand why more patients don't pursue a living donor transplant. Research shows very clearly that the kidney transplant lasts much longer, twice as long on average, and has fewer problems when it comes from a living donor. Sometimes patients hesitate to change course

after being on the wait list for a period of time. This is almost like "grocery checkout psychology."

People in a store who have waited and are nearing the front of a long line almost never change lanes when a new checkout opens. Instead, people at the back of the line – with a shorter wait time – shift lanes and get checked out quicker.

The mindset seems to be, "I've earned this spot by waiting and I'm not going to take the risk of changing lanes."

There is a down side to this behavior. Not considering a living donor transplant or "changing lanes" means the patient misses a chance to have a better, longer-lasting kidney.

Remember that patients who are active on the wait list, or on wait list hold status, continue to accrue wait time. The wait time increases even while living donors are screened. A patient will **not** lose their place on the kidney transplant wait list during the living donor evaluation process.

So wait list patients should not be afraid to try "changing lanes." If a new chance for a living donor becomes available – at any time during the wait for a transplant - it is worth trying to get the longer-lasting kidney transplant. Patients won't lose their place in line!



Keeping the Living Donor Option Open

Patients who are over age 65 gain an even larger advantage from living donor kidney transplant than younger patients. Five years after transplant: 83 percent of seniors with a living donor transplant still have a working kidney; 53 percent of seniors with a deceased donor transplant still have a working kidney.

Working with patients and their families, we also know that many patients have emotional reasons for not asking for living donors, or accepting a kidney from a living donor when it is offered.

Often patients don't want to burden or put loved ones at risk. Yet research shows that kidney donation is quite safe and donors have very few problems.

Loved ones may not offer to donate a kidney even though they may be interested. Mistaken ideas or wrong information about living donation may be a common reason that potential donors don't come forward. Potential donors may not want to bring up medical issues

and feel they might be prying, or they may be afraid the kidney patient will become upset if they talk about their health. Donors often say that they were waiting for the recipient to ask. These communication gaps can make patients miss a chance to have a living donor transplant.

Our program has a Living Donation Outreach Educator who can help bridge that communication gap. She can spend time with wait-list patients to help discuss living donation with family and friends. Meetings can be held at your home or over the phone. New research shows that group education of families, relatives and friends of patients helps everyone to

be more informed about transplant choices. By knowing more, more people may feel empowered to come forward as possible donors.

If you would like some help communicating about living donor transplant, contact our Living Donation Outreach Educator, Kelli Willard West at: 608-261-1993 or kwest@uwhealth.org.

Additionally, you can request a copy of the booklet, "Starting the Conversation – How to Talk about Living Kidney Donation."

2010 U.S. Transplant Games Resources

- For more info or to join Team Wisconsin, email teamwisconsin@kidneywi.org
- For general info, check out www.kidneywi.org or www.transplantgames.org
- For updates and fundraising opportunities, see Transplant Wisconsin Inc. at www.transplantwisconsin.org



Get Involved! 2010 U.S. Transplant Games in Madison

The National Kidney Foundation sponsors the U.S. Transplant Games every other year. Madison, Wisconsin is honored to host the 2010 games Thursday, July 29 through Wednesday, August 4, 2010.

Any man, woman or child who has received an organ, bone marrow or stem cell transplant can compete. Living donors can also compete in certain events for the first time in 2010.

So why is this important for kidney wait-list

patients? This is your chance to volunteer your time and get involved! You will be interacting with many people who have received a kidney transplant and relate to your experiences. The best part? You will witness the power of transplant, be inspired by all of the participants and share in their success!

Further, the event pays tribute to the more than 4,000 American families who donate the organs and tissues of their family members each year. The Transplant Games call attention to the critical need

for more organ donors. The 2010 U.S. Transplant Games in Madison, Wisconsin will require more than 3,000 volunteers to help with a range of tasks from registration, social activities and coordinating athletic events. It promises to be a fun, educational and rewarding experience.

You can also help support local athletes through Team Wisconsin.

For more information visit: www.transplantgames.org

Staying Active on The Wait List – Updates Needed

Update your transplant coordinator as soon as possible when:

- Phone numbers or address changes.
- 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 yearly.
- Blood samples must be sent **monthly** to the UW Histocompatibility Lab – coordinate with your dialysis unit or Nephrologist.
- Monthly blood samples **must** include **two** forms of patient ID on the tubes (name and birth date).

- Some patients need to repeat a cardiac stress test yearly.
- Men over age 50 need annual PSA blood tests.
- 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.

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 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 (www.mapquest.com) 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.
- Charter flights land at a private air terminal where there is no onsite taxi service. Local taxicab 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.

Be Informed – High Risk Donor Consent

You may be offered an organ from a deceased or living donor that is thought to be “high risk” for spreading certain infections, as defined by the Centers for Disease Control (CDC) guidelines. Donors are noted as “high risk” if they were known to engage in certain high risk behaviors.

You **WILL** have an option to accept or decline this type of kidney. You will **NOT** lose your place on the wait list if you choose to decline a kidney from a high risk donor. Your educational binder has more information on this type of donor.

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.

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!

Meet Our Newest Transplant Coordinator

Terri Fass received her Bachelor of Science Degree in Nursing from UW-Madison. She has worked in various areas throughout UW Health. She began her career on the transplant floor and participated in the care of some of the first pancreas and liver transplant recipients in the 1980's.

She also worked for the float staff, radiology department and most recently the oncology department at UW Health, managing patients enrolled in cancer clinical trials.

Terri joined the pre-kidney coordinator staff in July of this year and is very happy

to return to the transplant team.

Terri is married with two children ages 20 and 16. In her spare time she enjoys spending time with family, swimming, walking her dog, and assisting her husband with their family bicycle business.



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

Super Sips – Dietician Advice about Beverages

Daily Recommended Intake

800-1000 mg phosphorus
2000-3000 mg potassium

Target Blood Levels

Phosphorus
3.5 to 5.5 = NORMAL
Potassium
3.5 to 5.0 = NORMAL
5.1 to 6.0 = CAUTION
6.0 + = DANGER

Recommended Drinks

water; clear diet sodas; drinks sweetened with artificial sweeteners

Drinks to Avoid

regular or diet dark colas; beer; fruit juices and fruit-flavored drinks high in potassium; sport drinks; drinks with phosphoric acid
<http://www.davita.com/diet-and-nutrition>

A renal-friendly diet is one in which phosphorus and potassium levels are controlled. Phosphorus is controlled to avoid losing calcium, thus weakening the bones. Potassium is controlled to avoid heart and muscle problems.

If blood potassium is too high when you are called

in for a transplant, you may need dialysis before surgery. Because of short timing, you could miss your chance to receive the kidney.

The majority of phosphorus and potassium should come from healthy foods. Many

dietitians recommend drinks that are low in potassium and phosphorus.



Be Aware of What You Drink!

Each 8 oz (1 cup) serving contains:	Phosphorus (mg)	Potassium (mg)
Diet Sprite/ Diet Ginger ale	0	2
Coffee	7	115
Home brewed tea	2	88
Lemonade	18	8
Cranberry/Apple/Grape Juice	10	60
Coke/Dr. Pepper/Pepsi	25	13
Beer	33	64
Gatorade	24	37
Powerade	2	44

Sources:

http://www.kidney.org/atoz/atozTopic_Nutrition-Diet.cfm

Data from the USDA Nutrient Database at <http://www.nal.usda.gov/fnic/foodcomp/search/>

Transplant Support Groups Help Patient Education

The UW Health Transplant Program strongly believes that patients do better when they know more about their disease and what to expect with the transplant. Knowledge is power!

Support groups can be a useful way to share and gather information from others. There are transplant support

groups spread around the Midwest. There may be one in your local area.

Support groups are organized and run by patients. Some members are waiting for a transplant and some have already received a life-saving organ.

For a list of transplant support groups in your area, please go to the

website:

<http://www.uwhealth.org/transplant/kidney-transplant/10362>

Click on the link to *Patient Education Resources*, then *Transplant Health Facts for You*, finally linking to Support Groups for Transplant Patients.

If you need a written copy of the list, please contact our staff.



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 document on which 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.

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

If you haven't had time to visit our frequently updated website at uwhealth.org/transplant, we invite you to give it a try! There is a lot of

information on the website – from FAQs (Frequently Asked Questions) to videos and from current statistical information to patient stories. We've got

it all! This is a great way to feel "connected" and get updated transplant information. If you would like to share your story or comment on

other people's stories, check out our new community web site at our.uwhealth.org.



Other Recommended Websites

National Kidney Foundation of Wisconsin (NKFw).

The mission of this organization is to prevent kidney and urinary tract diseases, improve the health and wellbeing of individuals and families affected by these diseases and increase the availability of all organs for transplantation. www.kidneywi.org.

Renal Support Network.

This is a nonprofit, patient-focused, patient-run organization. It provides non-medical services to those affected by chronic kidney disease (CKD). RSN strives to help patients develop their personal coping skills, special talents and employability. RSN educates and empowers patients and family members to take control

of the course and management of the disease. A vital role of RSN is to provide lawmakers and policymakers with the patients' view on the needs and abilities of people with CKD. www.rsnhope.org

Kidney Space. Online chat forum sponsored by the Renal Support Network. www.kidneyspace.com

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
Kelli Willard West, MSSW, APSW

Financial Counselor/Insurance Questions: (608) 263-1503 or 263-1502
Lynn Anderson or Patricia Eddings

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.

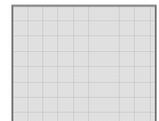


Need Help to Stop Smoking?

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