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Happy Spring to All!

It's time, once again, to connect with those of you anxiously awaiting your kidney transplant. We at the UW Health Transplant Program hope this newsletter finds you doing well and enjoying the new beginnings of Spring.

Hopefully you are able to take time out of your schedule to enjoy our

biannual update. Refreshing your knowledge regarding transplantation and all of the "ins and outs" is important... especially in our ever-changing environment.

In this issue, we will introduce our newest transplant coordinator, Jody Schwerdtfeger, and

our charming mascot, Dottie the Dot.

Additionally, our readers will learn more about blood-type incompatible transplants, nutrition, and the 2010 U.S. Transplant Games being held in Madison.

Enjoy!

Don't Wait to Lose Weight!

Excess weight leads to poorer transplant outcomes. Obesity is related to delayed transplant function, more infection, heart disease and diabetes. Surgery also takes about 30% more time for an overweight patient, compared to one at ideal body weight.

Congratulations and good work if you are already at an ideal body weight. But how do you know if you have higher risk due to weight?

Body Mass Index (BMI) is a measure of body fat based on height and weight. It applies to both adult men and women. You can find your BMI by entering your weight and height online at:

www.nhlbisupport.com/bmi

Prior to transplant aim for a BMI < 30. **Sometimes this is easier** said than done!

BMI Categories:

- ⇨ Underweight =< 18.5
- ⇨ Normal = 18.5 to 24.9
- ⇨ Overweight = 25 to 29.9
- ⇨ Obesity => 30

Losing weight can be challenging. **Making change now means you will be in a better, healthier place for your transplant and beyond.**

Behaviors That Will Help You Lose Weight and Maintain It

(from "Tips to Weight Loss," NIH Pub. No. 05-5210)

- ☑ **Be a SMART planner.** This means being Specific, Measured, Appropriate, Realistic, and Time-bound about what you plan to achieve.

- ☑ **Keep an eye on the size!** Try using smaller plates; they will help you take smaller portions.
 - ☑ **Make yourself an offer you can't refuse.** Be creative, set up rewards for yourself frequently.
 - ☑ **How much is enough activity?** Get at least 30 minutes of moderate physical activity per day.
 - ☑ **Balance your (food) checkbook.** Keep a diary of what you eat and daily physical activity.
 - ☑ **Am I full yet?** Take a few minutes before digging in for the next helping.
- Feel free to ask your dietician or doctor for more ideas about weight loss.



Celebrate Transplant - 2010 U.S. Transplant Games

Sponsored by the National Kidney Foundation

Where and when?

- Madison, Wisconsin (Our own back yard!) We are very excited and honored to host the games!
- The games will be held Thurs. July 29 to Wednesday August 4, 2010.

Who can compete?

- Any man, woman or child who has received a life-saving organ transplant, including kidney, lung, heart, liver, pancreas or bone marrow.
- Athletes must be at least one year post-transplant.

What events are available?

- 5K race, badminton, 3-on-3 basketball, bowling, cycling, golf, racquetball, swimming, table tennis, tennis, track and field and volleyball.
- Gold, silver and bronze medals are given for first, second and third place in each event and age group.

Why do we have the Transplant Games?

- It is so much more than fun and games!
- Showcases the success of transplant.
- Calls attention to the critical need for more organ donors in the U.S.

- Recognizes and pays tribute to the more than 4,000 American families who donate the organs and tissues of their family members each year.
- Establishes a commitment to patient wellness, increasing longevity and improving transplant.

Don't want to compete? Volunteer!

- We will need more than 3,000 helping hands.
- Information and website link coming soon.

SEE WEB LINKS TO THE LEFT

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 additional fundraising opportunities, see Transplant Wisconsin, Inc. at: www.transplantwisconsin.org

FAX UPDATED MEDICAL RECORDS

→ → → → →

Fax medical reports 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.

Staying Active On "The List" – Updates Needed

Update your transplant coordinator when your:

- Phone numbers or address changes.
 - Insurance changes.
 - Health changes or you are suffering from any illnesses or open wounds.
 - Admitted to a hospital for any reason.
- Please remember....
- Transplant re-evaluation may be scheduled every 1-2 years.
 - Blood samples must be sent **monthly** to the UWHC Histocompatibility Lab – coordinate with your dialysis unit or nephrologist.
 - Monthly blood samples **must** include **two** forms of patient identification 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 colonoscopy.

Blood Type Incompatible Transplants?

Do you know someone who wants to donate a kidney to, but they are the wrong blood type? You're probably thinking, "There is no way this could work."

The UW Health Transplant Program has a special program for these cases called "Blood –Type Incompatible Desensitization Protocol." This is a Medicare-approved treatment at UWHC.

This program is not designed to work for every patient who has a blood-type incompatible donor.

The UW Health Transplant Program has completed eight transplants for patients with a blood type incompatible living donor. We are happy to report that all of these transplants have been a success!

All of these kidney recipients underwent "desensitization" in order to receive the

incompatible blood-type kidney.

How do we do this? All transplant patients take immunosuppressant medicines after transplant to "trick" the body into accepting the new kidney. Desensitization simply starts the "tricking" process earlier – before transplant surgery.

Desensitization treatments involve a combination of:

- Plasmaphoresis, a treatment done as an outpatient at UWHC, before and after the transplant. This procedure helps filter antibodies out of the blood. Antibodies are the "soldiers" in the blood that fights any foreign substance. Filtering reduces the reaction the patient may have when receiving a

blood-type incompatible kidney transplant.

- IV immune globulin is a medication given directly into the blood stream. It keeps antibodies from rebounding, or coming back after plasmaphoresis.

- Oral immunosuppressive medications are taken before and after transplant. These medications help to trick the recipient's body into believing the new kidney is not a foreign tissue.

The kidney donor does not require any additional treatments or procedures. The donor will undergo the same routine work up and post care as a 'standard' transplant.

See www.uwhealth.org for more information. If you need help finding a living donor, please feel free to contact the Living Donation Outreach Educator at: 608-261-1993 or kwest@uwhealth.org



Our Newest Pre-Kidney Coordinator

Jody Schwerdtfeger graduated from UW-Madison in 1995 with a Bachelor of Science in Nursing. She worked in the Chicago area at Northwest Community Hospital and Northwestern Memorial Hospital in the orthopedics, neurology and

the ICU. Jody started at UW Hospital and Clinics in 1999 and worked in the ICU and Emergency Department. She joined the transplant program in February of this year and is very happy with the change.

Jody has three children, ages 8, 6 and 4. In her spare time, Jody likes to spend time with her family and friends, read and run. She is running the Madison Marathon in May as a fundraiser in memory of her mom who died of lung cancer in 2006.



Need Help to Stop Smoking?

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



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 and 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 and pharmacy, along with phone numbers and addresses*

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 Hospital and Clinics, 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 and Clinics. 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 a charter plane and pilot ready on-call 24/7.
- Reminder – UW Hospitals and Clinics is a non-smoking health care setting. Smoking is not permitted by anyone, including patients, anywhere on 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.

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.

Web Resources

An excellent resource for patient information is the National Kidney Foundation of Wisconsin website: www.kidneywi.org. Look for info about the NKF Kidney Walk in Brookfield, WI on September 20th.

We also encourage patients to explore the Renal Support Network website: www.rsnhope.org. This site offers a host of different programs, including:

- A phone support line at 1-800-579-1970
- An online chat forum at www.kidneyspace.com
- A list of patient lifestyle meetings, including one in Iowa this summer.

Social Workers Can Help with Advance Directive

If you do not have an Advance Directive on file at UWHC, 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.



Meet Dottie the Dot

She's cuter than Bucky Badger! Dottie the Dot is Wisconsin's newest A-list celebrity and one of the few organ donation mascots in the nation. As the face of organ donation in Wisconsin, Dottie has her big, fluffy mascot hands full, spreading awareness of Wisconsin's "Got your dot?" organ donation message to every corner of the state.

Dottie is a custom-made mascot, created by UW Health. One of the goals of the "Got Your Dot?" promotion is to invite one million more Wisconsinites to

say yes to donation and get an orange dot by 2010.

Since her first public appearance last Fall, Dottie has traveled the state to public venues such as parades, sporting events, race/walks and health fairs.

When Dottie is on the scene, she's accompanied by organ donation advocates with a thorough knowledge of our current, critical shortage of donor organs. Dottie's escorts will help make people aware of the importance of donation and how they can sign up to be donors themselves.

You can also have your very own Dottie the Dot plush doll. You can purchase a Dottie doll for \$10 at the Transplant Clinic, or send an email to rschwab@uwhealth.org. All proceeds go to organ donation education and awareness in Wisconsin.

If you would like to request Dottie for an event, join the Dottie Duty volunteer team, or if you have any questions about the Dottie campaign, contact: dottiedot@uwhealth.org



Know Your Numbers... Data on Average Wait Times

The average waiting time for a UW Transplant Program kidney wait list patient is 12.5 months. The regional average waiting list time is 31 months, which includes transplant centers in the states of Wisconsin, Illinois, Minnesota, North Dakota and South Dakota. The national waiting list average time is 41.6 months.

The UW Health Transplant Program is able to achieve shorter average wait times largely because the UW Health Organ Procurement Organization (OPO) is so successful at organ recovery. The OPO works closely with

area hospitals to identify candidates for deceased organ donation and address the needs of deceased donor families. The UW Health OPO is a nationally recognized leader in the field.

Another key option for reducing kidney transplant wait time is using a living kidney donor for the transplant. Living donor kidney transplant also shows better patient outcomes than deceased donor kidney transplants. The UW Health transplant program data gives us an estimate of 8-12 years of kidney function for patients who receive a

deceased donor transplant. Contrast this with an estimated 12-20 years of kidney function for patients who receive a living donor kidney transplant.

Remember that the UW Health Transplant Program has a Living Donation Outreach Educator who can assist patients with strategy for finding a living kidney donor. Many patients find it difficult to invite family and friends to consider kidney donation. Call or email Kelli Willard West if you would like some help in this area: 608-261-1993 or kwest@uwhealth.org

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.



600 Highland Avenue
Room F8/152
Madison, WI 53792-1736

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 53792-1736



PATIENT NAME
STREET ADDRESS
CITY, ST 22134