

WHILE YOU ARE WAITING

SPRING 2008; EDITION 4



Hello to everyone! Spring has finally sprung in Madison, Wisconsin! Hopefully this letter finds all of its readers enjoying this season of 'new beginnings'. If you are reading this newsletter for the first time, we welcome you to our Transplant Program. This correspondence is designed specifically for those waiting for a kidney transplant at the University of Wisconsin Hospital and Clinics. We hope to provide information to update patients and their supporting family and friends on what is new at our Transplant Center. We also use this biannual mailing to remind everyone of important topics and matters regarding receiving a transplant and remaining active on the waiting list.

DID YOU KNOW?

- ❖ As we enter a new era in kidney transplant, we are discovering new ways to overcome blood type incompatibility and crossmatch incompatibility. If you have had an interested donor disqualified in the past, due to either of these reasons and you are interested in pursuing this option, please call your coordinator to further discuss.
- ❖ Skin cancer is the most common cancer following transplant. Protecting your skin today will help decrease your chances of developing skin cancers in the future. Applying a very thick coat of SPF at least thirty minutes before sun exposure and reapplying every 2 hours thereafter are recommended. Lotions with an SPF >30 with UVA and UVB protection are preferred.
- ❖ When the Transplant Coordinator is notified that a kidney is available for you, we will have approximately ONE hour to find you! You may receive a phone call ANYTIME of the day or night. Make sure our office always has your current contact information.
- ❖ If you needed a cardiac stress test as part of your initial kidney evaluation, please call your coordinator to see if you need to repeat this test, especially if you have not done a stress test in over a year. Depending on your clinical situation, you MAY need to have this done annually and your pre-transplant coordinator can guide you.
- ❖ Annual medical updates are necessary to keep you active on our waiting list. Men over 40 years old should have annual PSA blood tests. Women over 40 years old need annual mammograms. Patients over 50 years old need a colonoscopy; so if you just turned 50, and you are on the waiting list without a CURRENT colonoscopy, please call your coordinator to discuss. All females, adolescent and older, need an annual pap smear. . All patients need annual physical reports faxed to our office.
- ❖ A transplant re-evaluation may be scheduled every 1-2 years while you are on the waiting list. This length of time may depend on your current health conditions. Do not hesitate to call your coordinator regarding this update if you have not heard when your next visit is scheduled.

- ❖ You can access transplant education videos developed by our transplant team by going to the web address listed below and then clicking on "patient education videos and quizzes". Currently, new videos are being added to the program, so keep looking for new topics over the next few months. These are great tools to refresh your memory on important transplant topics. There are even "tests" to check your knowledge!
<http://www.uwhealth.org/transplant>
- ❖ University Hospital is an official "no smoking environment" since 4/3/08. Smoking is not permitted on the hospital property any longer by patients, visitors or employees.
- ❖ 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 according to the Center for Disease Control (CDC) guidelines. Donors are considered "high risk" because of what the CDC deems to be a high risk behavior such as prostitution, intravenous drug use, or homosexuality. It is not the norm to accept organs from such donors unless we feel that the good far outweighs the would-be risk. Blood tests are done on potential donors to look for viruses such as HIV, Hepatitis B or Hepatitis C. No test is perfect, and false negative results might occur, although rarely. Using data from organ, tissue, and blood donors we know there is a small chance, (between 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. **The transplant coordinator will inform you at the time that the kidney is offered if it is from a high risk donor. You would then decide whether to accept this type of kidney. If you choose not to accept the kidney, you will not lose your place on the waiting list.**
- ❖ The United Network for Organ Sharing (UNOS) provides a toll-free patient services line to help transplant candidates, recipients, and family members understand organ allocation practices and transplantation data. You may also call this number to discuss a problem you may be experiencing with your transplant center or the transplantation system in general. The toll-free patient services line number is 1-888-894-6361.

A NOTE FROM OUR NUTRITIONIST:

Weighing in on Weight while you Wait

By Karen Kritsch, PhD, RD, UW Health Transplant Nutrition Specialist

The closer you are to a healthy body weight before transplant, the better. The UW I Transplant Program uses body mass index (BMI) as one indicator of readiness for transplantation. BMI is a measure of body fat based on height and weight that applies to both men and women.

Your weight prior to transplant makes a difference. Having excess body weight:

- extends transplant surgery time by an average of 33%
- increases the risk of delayed transplant function
- increases the risk of new-onset post-transplant diabetes
- increases the risk of wound infection and lengthens healing time
- increases the risk of post-transplant heart disease

Go to the BMI calculator to determine your BMI.

<http://www.nhlbisupport.com/bmi/bmicalc.htm>

Now is the time to make some changes to improve your eating choices and to increase activity. While at this site, click on 'Aim for a Healthy Weight', 'Assessing Your Risk', or 'Recipes' to gain more information about losing the weight while you wait.

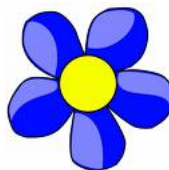


BE PREPARED FOR YOUR PHONE CALL FOR TRANSPLANT!

- ❖ What to remember to pack
 - ❖ Driving Directions
 - ❖ Loose fitting clothes (ie. Elastic waist pants/shorts, t-shirts)
 - ❖ Non-skid slippers or shoes with closed toes
 - ❖ Your **complete** medication list and pill bottles
 - ❖ Dialysis supplies to get through 24 hours if on Peritoneal Dialysis
 - ❖ Personal Toiletries
 - ❖ Your insurance cards
 - ❖ Phone card and/or cell phone
 - ❖ List of your physicians/health care providers/pharmacy and their phone numbers/addresses
- ❖ Keep your pager/cell phone on and charged at all times.
- ❖ Keep in mind that at the time of discharge, depending on your insurance, you may need to pay for a one month supply of medication, some of which may be quite expensive. Be prepared for this potential expense and think ahead about how you will pay for it.
- ❖ If you live a distance from our Transplant Center, have a plan in place for transportation that will be available to you at any time of the day or night.

PLEASE REMEMBER...

- ❖ ...if you have a potential living related or unrelated donor option, please pursue this avenue; our organ shortage worsens every day. If you have questions about how to ask someone to consider live donation, please contact your transplant coordinator or our transplant social workers.
- ❖ ...if you receive a blood transfusion, be sure that the blood is filtered to avoid developing antibodies. **CALL YOUR COORDINATOR IF YOU RECEIVE ANY BLOOD PRODUCTS.**
- ❖ ...if you live a distance away from our Transplant Center, map out your travel plans. You may Mapquest your address to ours at 600 Highland Avenue/Madison, Wisconsin 53972 via the internet.
- ❖ ...if your travel plans to our hospital include air travel, please have flight schedules available and charter pilots on call 24/7.
- ❖to check with your dialysis unit (or nephrologist's office, if you are not on dialysis) to assure that they are sending your monthly blood sample to our UW laboratory. **PLEASE BE CERTAIN THAT THERE ARE TWO PATIENT IDENTIFIERS ON THIS BLOOD TUBE (IE; NAME AND DATE OF BIRTH).** If there are not two identifiers, the blood sample is thrown away.
- ❖ ...notify your transplant coordinator with any changes in your phone numbers, addresses, insurance, or health status.



IMPORTANT PHONE NUMBERS TO KEEP HANDY

(CUT HERE)

UNIVERSITY OF WISCONSIN HOSPITAL TRANSPLANT DEPARTMENT

MY COORDINATOR'S NAME _____

MY COORDINATOR'S PHONE NUMBER (608) _____

GENERAL TRANSPLANT OFFICE PHONE NUMBER 608-263-1384

TRANSPLANT OFFICE FAX NUMBER 608-262-5624

FINANCIAL COUNSELOR/INSURANCE QUESTIONS 608-263-1503