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HAPPY HOLIDAYS FROM US TO YOU!

The holiday season is upon us! Our staff continues to be as busy as Santa's Elves at the UW Transplant Center. We would like to take this time to wish all of our patients and their families

a happy and safe holiday season. This bi-annual newsletter is sent to all of our kidney transplant patients to provide an update on the latest happenings in our program. We understand that waiting for your transplant can be a

stressful time and we hope that this newsletter will diminish some of that anxiety and provide you with a small refresher course to prepare you for your eventual kidney transplant! Merry reading!

OUR NEWEST PROGRAM~NATIONAL KIDNEY REGISTRY

Approximately one third of kidney transplant patients who have a willing living kidney donor, will not be able to accept the kidney due to incompatible blood type or incompatible antibodies. In the past, this would mean the potential transplant recipient would wait many years on the kidney transplant waiting list until a compatible, deceased donor kidney became available.

Exciting News!! UW Transplant Program is joining the **National Kidney Registry**. This is a national exchange program designed to help those potential kidney transplant patients that have potential live kidney donors, but have found out that their intended donors are not compatible.

This innovative program will help with the exchange of donor and recipient pairs with other pairs in a similar situation, which makes the transplant possible. Live donor kidneys will be shipped in (flown or driven by a courier service), while your loved one's kidney would be shipped to another transplant center. Therefore, many living kidney donors would still be able to donate and their loved one would receive a kidney in return.

Benefits of participating in an exchange program include:

- Receive a kidney sooner
- Receive a living donor kidney
- Receive a better matched kidney

For more information on the kidney exchange program, please go to www.kidneyregistry.org

Please keep in mind both you and your living donor must be approved at University of Wisconsin Hospital and Clinics prior to placement in the kidney exchange program. You may also call your transplant coordinator at 608 263 1384 or the kidney exchange coordinator at 608 263 4298.





Yes, I will

RETURNING TO WORK AFTER TRANSPLANT

After your transplant you will have more energy and you may start to think about what it would be like to return to work.

Research shows that working after transplant help one become more independent and improves quality of life. Working may even help you live longer!

Formulating your plan to enter the working world takes creativity, forethought, and resourcefulness- particularly in this economy where jobs can be hard to come by.

Returning to work might mean simply returning to your job you left before transplant. It may mean 'creating a job' such as

babysitting grandchildren. Volunteerism is also a great idea when trying to enter into the work force.

You know better than anybody how your feel. If you have concerns about how a particular symptom will affect your ability to work, plan to bring this up at your next check-up and discuss with your medical team.

Many times patients wonder 'how do I explain my illness to a future employer?' Please realize that you don't 'have' to explain anything to anybody-it is against the law to discriminate against a person based on their health status.

If you have been out of

the work force, it helps to rehearse what you are looking for in a job. What are your skills? What have you been doing lately to prepare for permanent employment? Are you volunteering?

Connecting with your local Department of Vocational Rehabilitation (DVR) can help you think through options, and get additional training.

Life Options is a terrific resource, including an 'employment guide'. Visit www.lifeoptions.org or call (800) 468-7777 for more information.

The National Kidney Foundation also has a rehabilitation brochure series- this can be found at www.kidney.org or call (800) 622-9010

OUR NEWEST PRE-TRANSPLANT COORDINATOR-BECKY DILLIS

Becky Dillis received her Bachelor of Science degree in LaCrosse, WI in a satellite program of UW-Madison. She worked on the inpatient transplant floor for two years before transitioning to transplant clinic.

Becky joined the post-transplant kidney care team in September 2010. She feels fortunate to continue her work in the transplant field.

Becky was recently married this summer and is the proud mama of a 140 pound Great Dane puppy. In her spare time, she enjoys skiing, horse-

back riding and reading.



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

Remember to check our website for updated transplant information.



Staying Active on The Wait List – Updates Needed

Update your transplant coordinator as soon as possible when:

- Your phone number or address changes.
- Your 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 **every 28 days** 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 handle 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 of receiving the call.
- 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 taxi 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.

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!*

Tips for Talking About Living Kidney Donation

Inviting people to consider kidney donation is not easy. It can feel awkward and even scary. Asking friends or family to donate a kidney is not like asking for any other kind of help.

Patients often don't know how to start this conversation. There are ways to make it more comfortable. The booklet *Starting the Conversation – How to Talk About Living Kidney Donation* from **Transplant Experience** offers suggestions.

These “Know - No's” can also help patients prepare.

KNOW	Your Disease
	<ul style="list-style-type: none"> • Be able to explain your kidney disease and how it impacts you. • What is the long-term outlook with dialysis compared to kidney transplant?
KNOW	About Living Donation
	<ul style="list-style-type: none"> • Understand the benefits of living donor kidney transplant and how the process works. • Make your transplant choices based on facts - not gut reactions.
KNOW	Where to Get More Information
	<ul style="list-style-type: none"> • Carry your transplant coordinator's phone number in your wallet. • Look at the transplant center website. • Talk to other transplant patients, your doctor and others.
KNOW	Your Communication Style
	<ul style="list-style-type: none"> • How do you best share information with people? • Are you talkative or quiet? Are you open or private? Do you like being in a group of people? Do you socialize online more than face-to-face? • Are you at ease having others speak on your behalf?
NO	Thinking People Don't Want to Donate
	<ul style="list-style-type: none"> • Not all living donors offer right away, some wait to be asked. • Many people don't know about living donation and may need more information. • People may think only blood-relatives can donate and don't know that friends could donate. • Some people will not ask about medical issues because they are trying to honor your privacy. • Plan ahead. How will you respond if people offer to donate? Be able to respond to questions and share further information about living kidney donation.



DOUBLE KIDNEY OFFER

When a deceased donor kidney offer is made there are many decisions that go into this process. One of the decisions that is made by our transplant surgeons is whether to offer TWO kidneys at the same time to ONE recipient.

This decision is made when the surgeon feels that the kidney function of only one kidney will not be adequate for transplant.

As you might remember, when you were evaluated you were asked to sign a consent form to accept or deny Extended Criteria Donors (ECD). These are kidneys from an older subset of kidney donors. The other subset of kidney donors are called Standard Criteria Donors

(SCD).

It was the decision of UNOS that if two kidneys are offered then the organ offer will be considered a SCD offer. In other words, the age of the donor is no longer a factor in the offer.

Since 2004, we have performed 18 such transplants. The graft survival of these transplants is comparable to Standard Criteria outcomes.

As you can summarize, these offers do not happen very often, but when this scenario arises, you are given this information and asked to accept or deny the offer. You will be aware that two kidneys are being offered

at the time of your phone call.

We believe that these are good kidneys and offer very acceptable results based on our analysis of recent data.

The ultimate decision to accept this type of offer is yours. If you choose to deny this offer, you do NOT lose your place on the waiting list.

Our hope in writing about this is to educate those on the waiting list. If this situation arises, a well thought out decision can be formulated ahead of time.

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.



SURROUND YOURSELF WITH SUPPORT!

Transplant support groups are available for you and your family. These groups are a great source of information both before and after your transplant!

If you live outside of the areas listed, it is recommended that you contact a local transplant center and inquire about the groups in your area.

Wisconsin

Appleton: NorthEast Transplant Support- NETS-St Elizabeth's Hospital - Contact: Linda Ourada (920) 731-8845.

Green Bay: Contact: Teri Patz (920) 436-4910.

Janesville: Mercy Dialysis. Contact: Kay Griffith, MSW. (608) 741-3814.

LaCrosse: Coulee Region Transplant Support Group Meetings at Rose Conference room Franciscan Skemp Healthcare LaCrosse, WI (608) 782-2560 or e-mail NiteFrogger@cs.com

Madison: Published newsletter six times per year, *The Borrowers*. To be added to mailing list, contact: Mike Armbrust, TX Coordinator, UWHC Transplant Program, 600 Highland Ave., Madison, WI 53792-7375.

Marshfield: Contact: Leah Breu, R.N. (715) 387-5308. Marshfield Clinic

Wausau: The North Central Wisconsin Disease Support Group. Contact: Richard Stefsek (715) 848-2953. May also contact Chris Litrenta, CSW at Wausau Kidney Center (715) 845-8454 for information and support.

Illinois

University of Illinois: Marianne Baker, Social Worker (312) 413 3121.

Naperville: Organ Transplant Support Group. rpmcOTS@aol.com, (630) 527-8640 Newsletter - *Miracle Messenger*.

Loyola University Medical Center: Denise Calvert, MS, RN/ Janet Coutee, BSN, RN/ Billie Kostro, MSN, RN, (708) 216-3454.

Iowa

Dubuque: Dubuque Finley Hospital, Contact: Tammy Marti, RN (319) 582-1881. Tammy.Marti@finleyhospital.org

Iowa City: Anxiously Awaiting - University of Iowa Hospitals & Clinics. Contact: Sara Vance (319) 356-8877 University of Iowa Hospitals & Clinics: Karin McKeone, MSW/ Kelly Corcran, MSW, (319) 356-2207. www.uiowa.edu.

Sioux City: Transplant Support Group. Marian Health Center. Diana Reeses, (712) 266-8923

Michigan

Transplant Recipients International Organization (TRIO): Southwest Michigan Chapter (619) 423- 6450.

Lakeshore Transplant Support Group: Hackley Hospital. Gary Passon (616) 846-9558.

Minnesota

New Beginning Transplant Awareness/Support Group: Johnny and Lisa Reid, (601) 268-1759, Larry and Joyce Norris, (601) 545-2193.

This information is subject to change, and is not an all-inclusive list. Contact your local hospital, dialysis unit or social work department to obtain more information about support groups in your area.



Important Phone Numbers to Keep Handy



University of Wisconsin
Transplant Program

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:

uwhealth.org/transplant

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

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

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

To order Tissue Typing Kits: 608-263-8815

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.

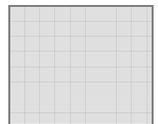
1-800-QUIT-NOW or for Spanish-language **1-877-2NO-FUME**

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



University of Wisconsin
Transplant Program

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



PATIENT NAME
STREET ADDRESS
CITY, ST 22134