

a publication for transplant recipients and their families

# renew

vol.1, no.1

inside

tree of life  
medicare and  
medication issues  
tree planting  
ceremony

## the sunny side of transplant

Darnell M. Waun, RN, MSN  
Patient Educator

**In South Texas, sun exposure is always a risk for transplant recipients. However, as we move into the summer months, sun exposure becomes an even bigger risk. The anti-rejection medications necessary for the survival of your transplanted organ also increase your risk of skin cancer.**

There are many reasons a person can get skin cancer but sun exposure and sun damage play the major role. The effects of sun exposure over a lifetime play a significant role in increasing this risk. Sunburn causes damage to the skin and also increases the risk for developing skin cancer.

Prevention of skin cancer in transplant recipients means simply changing some basic behaviors:

1. Avoid the mid-day sun and shorten the time in the sun if you must be out. Avoid the hours of 10 a.m. to 4 p.m.
2. Regardless of your racial background, skin color, tanning ability or age, always protect your skin from UVA and UVB exposure (UVA and UVB refer to light rays from the sun that are damaging to the skin) by using a Sun Protection Factor (SPF)-30 or higher sunscreen product.
3. Wear long sleeves and pants and broad-brimmed hats. Baseball caps do not provide adequate protection for your ears and neck.

**sunny side** continued on inside >



# tell everyone be a donor

**Ann Hardee, RN**  
GI Nurse Coordinator

Transplant recipients and their families are particularly sensitive to the importance of the Gift of Life made possible by organ donation. Think about that unforgettable moment when you received the call that an organ was available for you and how your life has changed since that day. Because you are “walking the walk”, you are the best advocates for the importance of organ donation and its impact on quality of life. You are living proof that organ donation makes a difference.

You can spread this message in several ways. First, tell your story whenever you have the opportunity. No story is as powerful as one coming from someone who has experienced transplant first-hand. Second, be a role model for healthy living. Stay active, exercise regularly, and be compliant with your post-transplant medication and follow-up appointments. Third, be a donor yourself and encourage your family and friends to do the same! The Glenda Dawson Donate Life-Texas Registry web site is [www.DonateLifeTexas.org](http://www.DonateLifeTexas.org).

People will have a greater appreciation for, and understanding of, organ donation because of you. Take this responsibility seriously and make a difference for those on the waiting list who are anxious to join your ranks as transplant recipients.

## hepatitis C

**Eric Lawitz, MD, CPI**  
Medical Director  
Alamo Medical Research

Hepatitis C is a virus that was discovered in 1989. It takes years and decades to cause its damage; however after 20 – 30 years of infection, 20 – 30% of infected patients will develop cirrhosis. Once cirrhosis develops there is risk of either liver cancer or liver failure. Hepatitis C is the leading cause for needing a liver transplant today. To try to avoid the need for liver transplant, there are effective therapies for Hepatitis C. The most common type has cure rates of between 40 – 50% after taking a year of Pegylated Interferon subcutaneously weekly and Ribavirin orally daily. Newer therapies are in development and appear to be very promising in bringing cure rates significantly higher. The most important and powerful class coming is Hepatitis C specific protease inhibitors. By adding these oral agents to existing standard therapy we deliver a “triple therapy” that has been shown to increase cure rates from over 40% to as high as 75%. These not only work in patients that have not been treated but also in those that have not gotten a cure on their previous standard therapy. Locally in San Antonio we have Alamo Medical Research who’s Medical Director (Dr. Eric Lawitz) has brought the most promising Hepatitis C agents to South Central Texas. Alamo Medical Research can supply these agents specifically targeted against Hepatitis C to those who have never been treated or those that have not been cured with standard therapy. As always these investigational agents are supplied at the developing company’s expense. All medications, labs, visits, and liver biopsy (if needed) are supplied at no cost to patients. *Dr. Lawitz and his clinic look forward to trying to cure your patients Hepatitis C today. Call (210) 253-3426 for further details.*

# Dear Ann Livers,



**Q:** I am a transplant recipient living on the Gulf Coast and am concerned about the possibility of a Hurricane or other natural disaster that requires me to evacuate.

**A:** When a disaster occurs,

transplant recipients and their families must plan ahead and be prepared for this possibility because of the highly specialized nature of your care. Create an evacuation plan ahead of time and prepare a personal transplant emergency kit that will fit into a backpack that includes the following:

Keep your medication supply well-stocked at all times! Make sure you have all of your original medication bottles easily accessible so you can pack them quickly. Don’t forget your weekly medication box.

Plan where you will evacuate to ahead of time and identify medical resources capable of meeting your needs at that location and write down their addresses and phone numbers.

Make a list of your doctors and hospital names and phone numbers, all your medications, insurance information and emergency contacts.

Pack your personal self-monitoring equipment (BP Cuff, thermometer, glucose monitoring equipment, insulin administration supplies, extra batteries, etc.). If you have a cell phone, be sure to pack your charger.

Pack some face masks and hand sanitizer in case you are in an environment that would be high risk to immune suppressed recipients.

Have vital records such as wills, birth certificates, passports, etc. in a waterproof bag and ready to put in your evacuation bag.

Notify University Transplant Center of your evacuation location and contact phone number at (210) 567 – 5777.

The things I have just mentioned are specific to your transplant needs. Follow the directions of your community disaster plan for all other aspects of evacuation planning.

## save the date

### Genesis Support Group

1st Tuesday of the Month  
12:30 – 1:30 p.m.  
Foundation Room—3rd Floor  
University Hospital  
Contact Ryan Pflipsen, LCSW  
210 – 567 – 5777

### National Minority Donor Awareness Day

August 1, 2009  
www.omhrc.gov

### San Antonio Walk for PKD

September 19, 2009  
Joske Pavilion  
Brackenridge Park  
San Antonio  
www.PKDCure.org

### Vital Alliance Run/Walk

October 24, 2009  
Joske Pavilion  
Brackenridge Park  
San Antonio

### National Donor Sabbath

November 14 – 15, 2009

### Gift of Life Holiday Gala

December 3, 2009  
6:00 p.m.  
Norris Conference Center  
San Antonio

### Texas' ONLY Living Donor Liver Program

Living donor liver transplantation may be a viable option for some patients on the waiting list. This procedure often enables patients to be transplanted prior to further worsening of their liver disease. For more information please contact the Living Donor coordinator at 210-567-5777 or Toll-free at 1-888-336-9633.

# Tree of Life

About 40 people gathered on the 12th Floor Transplant Unit on April 21 for an emotional program celebrating the patients who became organ donors at University Hospital.

Marinela Calderon and Antonio Garza were among the families present for the annual Tree of Life ceremony. Their 18-year-old daughter Heather died last year after falling from a cliff. Mrs. Calderon says she finds comfort in knowing that Heather's lungs are still breathing for someone else. "It's hard for me to let my broken heart mend. But I know that Heather's heart is showing love to another family."

Drs. Glenn Half and Ronald Stewart provided remarks to the group on the impact of donation—from the transplantation and trauma perspectives—and thanked the families for making the courageous decision to allow their loved ones to give the gift of life to others.



Dr. Ronald Stewart thanks the donor families



Family of Heather Garza



Marinela Calderon, mother of Heather Garza, talks about Heather's wish to be an organ donor

## sunny side from front

- Remember that reflection of the sun off water when fishing, swimming or boating gives the same risk as direct exposure.
- Check your skin, or have someone help you, monthly and report any changes to your primary care doctor immediately. Our center recommends a skin check by a physician annually with referral to a dermatologist if necessary.

Some types of skin cancer, particularly squamous cell, can be more dangerous and may spread to other parts of the body.

An article in the 1999 Journal of the American Academy of Dermatology reports that squamous cell cancer is 65 times more common in transplant recipients than in non-transplant patients. Avoid the "It can't happen to me" mind-set and follow your doctor's directions if you have any changes on your skin.

You are the Key!! Understanding that you are at increased risk for skin cancer, using effective sun protection methods, knowing how to recognize skin cancers, and seeking prompt treatment can literally save your life!



## celebrating our transplant nurses

### left to right

John Williams, RN, Cheryl James, UC, Cris Cabagay, RN,  
Liz Moreno, RN, Marissa Red, RN, Florida De Veas, RN,  
Michael Payne, RN



# medicare and medication issues

**Ryan Phlipsen, LCSW**  
*Transplant Social Worker*

One of the most confusing issues for transplant recipients is how to pay for essential, but expensive, transplant medications that are required to prevent rejection of your newly transplanted organ. This article addresses Medicare coverage.

Medicare has several different “plans”:

- Part A pays for your inpatient hospital stays.
- Part B, in addition to paying 80% on your anti-rejection medications, will also pay for your outpatient clinic visits.
- Part C is referred to as an Advantage or Replacement Plan. These plans sometimes have separate drug coverage in place of Medicare Part B & Part D coverage and will be discussed in a future newsletter issue.
- Part D is the prescription portion of Medicare

Part D covers all of your medications as long as they are on your particular plan’s approved drug list. At University Hospital we have an agreement with the Part D plan called CCRX. If you have CCRX as your Part D plan, the 8th Floor Transplant Pharmacy is able to assist you with filling your prescriptions & obtaining refills. If you have a Part D plan other than CCRX you will need to fill your medications at an outside retail pharmacy or utilize a transplant specialty pharmacy that can assist in coordinating you Part B and D benefits.

If you had Medicare at the time of your transplant, your anti-rejection medications are covered by Medicare under Part B at 80%. The additional 20% would be an out-of-pocket expense to you unless you have a supplemental policy or Texas Kidney Health Care (for kidney patients who meet their inclusion criteria only). All of your other medications are covered under your Part D plan as long as the medication is on that plan’s approved drug list. Calling Medicare at 1(800) MEDICARE or going to

their web site at [www.medicare.gov](http://www.medicare.gov) can assist you with determining which Part D plan is best for you based on the drugs you are taking.

**BE AWARE**, Medicare B & D have monthly premiums. These change year to year based on the national cost of living figures. For 2009 the Part B premium is \$96.40 & the Part D premium depends on the particular plan you chose. The annual enrollment period for Part D is usually November 15 through December 31 for coverage to begin January 1 the following year. Enrollment for Medicare Part B is accomplished through the Social Security Administration. For those people who initially decline Part B, perhaps due to coverage with an employer, you can apply for Part B coverage during the special enrollment period during the eight months after you no longer work. Lastly, general enrollment for Medicare Part B is January through March each year with benefits beginning July 1 of that year. You can call the Social Security Administration at 1(800)772-1213 for more details and to enroll.

There are three ways to obtain Medicare:

- You qualify at your age of retirement (age 65 or older based on federal guidelines regarding retirement age).
- You can get Medicare two years after beginning to receive SSDI payments based on another qualifying disability.
- End-stage kidney disease patients can start to receive Medicare three months after starting hemodialysis or the month they receive a kidney transplant. This form of Medicare usually lasts until three years post-transplant.

As long as you have made contributions to Social Security, you may be eligible for Medicare. If have a question or want a topic considered for a future social work article in the newsletter please call Ryan Phlipsen, LCSW at (210) 358 – 4435.

# lifescapes

Kristopher Ayala (Kidney 2007) is a Sophomore at Texas Tech University in Lubbock studying Construction Engineering. He transferred there after spending his Freshman year at North Texas State University. Kris was one of 37 recipients who participated in the updated photo shoot to replace pictures in the transplant hallways.

Ok Cha Martin (Liver 2007) and her husband Robert spent 10 days in February traveling through Italy visiting Rome, Florence and as much of the Italian countryside as time allowed. Next stop...home to Ok Cha's native country of Korea for a visit with family and friends later this year.

Jayne Robinson (Liver 2007) married Michael Tumlinson, Jr. on May 9, 2009. The happy newlyweds are making plans to take a cruise this Fall for their honeymoon.

*If you have a story or picture of you "living your life" after transplant that you want to share with fellow recipients in future newsletters, send them to Darnell.Waun@ubs-sa.com.*

## from the medicine cabinet

**Heather H. Dobie**  
RPh, PharmD

### Keep It Current!

For the first six months after your transplant, it's common for your doctor to make changes to your medications. These changes are made based on many factors, such as the results of your blood tests, how you feel, how you look, etc.

When a change is made, update your medication list right away (before you forget), or ask the nurses to make a new one for you. If they're busy, ask if they can mail you a revised copy the next day. Make sure they have your current address on file before you leave. Throw your old list away, or file it separate from the new one, to decrease the chance of making mistakes. You may also have the medication sheet "exported" to you by email if you give the Patient Educator your email address before discharge. This allows you to make changes on your sheet and print it out at home.

Also remember to:

1. Change your pill box (adding to or taking away doses as needed)
2. Call to update the information on your medical alert ID if you have one.
3. Don't cut a pill unless you check with a Pharmacist first...some meds are dangerous if cut.
4. If your prescription is increased beyond your current medication supply, get a new prescription for your pharmacy to submit to your insurance.

If a doctor other than your Transplant doctor changes your medication, it's a good idea to check with the Transplant Pharmacist at 210-358-4630 to ensure this will not affect your transplant drugs. A drug that may be fine for a non-transplant patient may cause harm to a transplant recipient. While the new drug may be safe to take, it might require extra blood level checks, a dose adjustment, or a special time to take your dose.

Keep it current and you'll avoid medication mistakes.

# tissue donation

## saving lives and restoring quality of life

**Mariluz Martinez**  
UTHSCSA Allograft Resources

### Did You Know?

It is estimated that one in twenty Americans will need some type of tissue transplant. In some cases, doctors will use tissue, which has been donated by someone who died, to save the lives of people with heart disease or to replace limbs that someone might lose due to bone cancer. Donated tissue can also be used to treat problems from sports injuries and dental disease. Human donated tissue is more beneficial since it is natural, does not require blood type matching and is more compatible than metals or synthetics. In addition, it can be precisely shaped for transplantation which allows for shorter surgeries.

One tissue donor can donate heart valves, bone, veins, skin and corneas, which are the contact lens part of the eye. This will help save the lives and restore the quality of life for more than 50 individuals. Tissue donation surgery includes careful reconstruction of the body and does not interfere with funeral arrangements, including open-casket services. Donor families are not charged for any costs associated with tissue donation.

### What Your Gift Means To Others:

Tissue	Benefits to Recipients
Heart Valves	60% of valves are used for children under 10; Almost no rejection, allows children to grow into graft, rarely requires use of long-term anti-coagulant therapy; Only treatment for endocarditis
Bone	Prevents amputation, promotes and allows healing, Restores mobility
Fascia	Returns mobility, restores independence in daily living activities
Ligaments	Returns mobility, restores independence in daily living activities
Tendons	Saves lives and limbs, reduces pain, increases mobility
Veins	Saves lives and limbs, reduces pain, increases mobility; Used when patients have infection
Skin	Saves lives, promotes healing, reduces infection, and restores appearance

Allograft Resources, a component of the University of Texas Health Science Center University Transplant Program, works with tissue donors at various hospitals in San Antonio. Its mission is to enhance the lives of others by providing quality human tissue grafts for transplantation, research or education through the compassionate support of families, outreach and education to communities. The level of medical, technical and administrative performance within the facility meets or exceeds the required standards set by the American Association of Tissue Banks (AATB) which earned Allograft Resources accreditation with the AATB on September 27, 2007.

# 20th annual tree planting ceremony

Deborah Ramirez-Cotter  
Organ Procurement Coordinator

The 2009 Tree Planting Ceremony conducted by Vital Alliance, a San Antonio Organ, Eye, and Tissue recipient organization, was held at Eisenhower Park in San Antonio on Saturday, April 4th. Over 400 donor family members shared in this special event that recognizes the "Gift of Life" that both living and deceased donors have given to their recipients during the past year. Speakers included Diane Cibrian, San Antonio Councilwoman, Liz Montanez, Double Lung transplant and Oralia Gomez, two-time donor family who shared their personal experiences with transplant with those in attendance. This year a transplant choir was formed under the direction of Sandra Haggarty, double lung transplant recipient, who performed a special tribute to donors and their families. This annual event is held each Spring. Watch for the 2010 dates to be announced in the next newsletter.

A donor family honors their loved one  
by planting a tree in Eisenhower Park.



4502 Medical Drive MS 18  
San Antonio, TX 78229