

a publication for transplant recipients and their families

renew

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inside

NurseLink

Make a Difference

Award-winning
Staff



Healthy New Year's Resolutions

Heather H. Dobie,
RPh, PharmD, Clinical Pharmacist

This New Year, we wish for you continued Health and Happiness. If you're reading this newsletter, then you're on the right track to a healthier "you" already! Keeping yourself informed is a key component of good health care. Another way you can be "in the know" is to check out the University Transplant Center website regularly at www.universitytransplantcenter.com or Facebook at www.facebook.com/universitytransplantcenter. Consider joining a Transplant Support Group, too. (Call 210-567-5777 for more information.)

This is the time of year to develop New Year's Resolutions. The list below is a minimum of what I think every transplant recipient should have for better long-term health outcomes. These inexpensive tools can have big payoffs, so resolve to try and acquire these things in 2012. Hint: your actual birthday, your "transplant birthday", and holidays are good times to ask for these items from loved ones:

—**An answering machine.** An answering machine is a necessity if you don't have a cell phone with voicemail. The Transplant Team **MUST** be able to get in touch with you at any time. Many people (you know who you are!) have voicemail on their cell phone, yet don't know how to check their messages or forget to check them (come on, you've told me!). Regardless, if you don't have either an answering machine or voicemail, then ensure that if someone takes a message for you, that they actually give you the message. Explain to them that if anyone from University Transplant Center calls that it's important, and that you need to know about it in a timely manner. Whatever means of receiving messages you have, be familiar with how to retrieve them, and check them at least daily. Someone on the transplant team may be trying to reach you with a medication dose change, lab results, referral information, or instructions to come in earlier than planned for follow-up.

University **Transplant** Center
Experts On Life.

Healthy New Years Resolutions continued

—**A Medical Alert I.D.** If you need medical attention in an emergency, then emergency responders check these I.D.s for your medical history, drug and food allergies, current medications, emergency contacts, etc. I.D. choices are numerous, including charm bracelets and necklaces. And for you guys out there...sports bands, leather “bracelets,” sports watches, dog tags, and shoe tags are available, too. For exercise enthusiasts, wrist sweatbands do NOT have your medical information connected to them. Wear the band OVER your Medic Alert jewelry. One site you can check out is www.medicalert.org or via phone at 1-888-633-4298. Many pharmacies carry products, too. Remember to keep your information up-to-date with the service you choose.

—**An updated Medication List.** Some people consider a handwritten Med List with changes updated in pencil or pen acceptable. In an emergency (where you may not be able to speak for yourself) another person may not be able to read your handwriting. To prevent possible serious medication misadventures, you can ask for an updated Medication List from University Transplant Center anytime. You can manage and print your own sheets, including wallet-sized, by setting up a free account at www.medactionplan.com/mymedschedule/ or by asking a transplant professional to export your current list to you via email.

—**A digital thermometer.** Many transplant recipients call the Transplant Pharmacy asking what over-the-counter medication they can take for cough/cold symptoms. An important piece of information to share with the pharmacist, before a decision can be made, is if you have a fever. Using the back of your hand to check your temperature is not recommended. A digital thermometer is easily obtained at a local pharmacy or from the transplant center.

—**Home monitoring devices.** With advances in technology, there are more and more home monitoring devices available to the consumer. These devices help you monitor your health progress between doctor visits. Examples include: blood pressure monitor for high blood pressure, blood glucose monitor for diabetes, digital scale for heart failure, etc. These are great gifts to ask for! And remember to keep track of your “numbers” from these machines—to take to your medical appointments. Come see us at the pharmacy if you need a new log.

For other ideas for “tools” for better health, talk to your Transplant Team. So have a Happy Healthy New Year throughout 2012!

UTC Stats (1/1/2011 – 12/31/2011)

Transplants: Kidney Liver Lung Pancreas
65 49 34 4

Outcomes Data (7/1/2008 – 12/31/2010):

Source: Scientific Registry of Transplant Recipients @ www.srtr.org

		Kidney	Liver	Lung
1-Year Graft Survival	Expected:	93.64	83.36	84.19
	Observed:	95.56	79.34	82.94
	National:	93.60	85.95	83.39
1-Year Patient Survival	Expected:	96.35	85.61	85.14
	Observed:	98.40	82.50	83.33
	National:	96.77	89.19	84.49

We are proud to share with our patients and partners that our transplant outcomes exceed, or are not significantly different from, the national and expected statistics. If you have questions about these statistics you can view them at the website above or contact us at 210-567-5777.

Dear Ann Livers,



Q: I am having difficulty getting back into the “groove” after my transplant. My family’s normal routines just don’t seem to be getting back to normal. Why is this, and what can we do to make this better?

A: The entire transplant journey is a life-changing experience for the recipient and our entire family system. A system is defined as a set of elements interacting in such a way that the whole is more than the sum of its parts. As a result, we need to understand how the impact of this experience affects ALL the parts. If one or several parts are not functioning normally it throws off the balance of the whole system.

Starting with the words “You need a transplant”, our family and support system begins to change. We are beginning our journey of dealing with a terminal end-stage disease process which can be an overwhelming challenge for everyone involved. We have discussions with our family, many times surrounding the topic of our mortality, that most people find difficult to engage in. The transplant process presents risks to the comfortable “status-quo” in our daily lives...most of us don’t like change. The uncertainty or “lack of control” over our lives and future is overwhelming to many people. Many times financial stressors arise from not being able to work, changes in the status of medical insurance, or the cost of travel to appointments or required medications.

As we become physically sicker and unable to continue our traditional “roles” in our household, our family and support systems start to pick up those tasks to maintain the stability of the family unit. This creates change in the responsibilities of each family member involved. For many people, this is a slow and subtle process, that we often don’t even recognize, that I compare to aging. Much like looking in the mirror each day, I don’t notice the change in my appearance as I age...so too are the changes in our family system as we move through the transplant journey!

Change is an external thing or event that happens TO us. Transition is incorporating that change, like a thread, into the fabric of our daily lives. In order to successfully transition to life after transplant, we must understand the system that we are living and working in and how that system has been impacted by an extended life-threatening illness, a life-changing surgery, and dealing with a chronic condition post-transplant.

To help get through this process, whether waiting for or recovering from a transplant, I recommend the following:

Open communication about the changing needs and concerns of the recipient AND our family throughout our transplant journey, including as we recover, is essential.

Some find that professional counseling is helpful as it brings in an “outside perspective” to the discussion.

Save the Date

Genesis Support Group

1st Tuesday of the Month
12:30 – 1:30 PM
Foundation Room – 3rd Floor
University Hospital
Contact UTC Marketing Department
210-567-5777

American Lung Association Fight for Air Walk

February 11, 2012, Check-In 7:00 AM
Run/Walk Start Time: 8:00 AM
Sea World San Antonio
www.fightforairrunwalk.org

27th Annual Cystic Fibrosis Foundation Tower Climb and Run

February 25, 2012, Check-In 6:30 AM
Competitive Run/Climb Start Time: 7:30 AM
Non-Competitive Climb Start Time: 8:00 AM
Tower of the Americas
Hemisfair Park – San Antonio
www.lonestar.cff.org/towerclimb
210-829-7267

23rd Annual Vital Alliance Memorial Tree Planting Ceremony

April 14, 2012, 10:00 AM
Selma Stage Stop
IH 35 North, Exit 173 Northbound
Selma, Texas
Gates open at 8:00 AM
www.vitalalliancetexas.org

Circle for Life

April 28, 2012
Ride Start Time: 8:00 AM
Start Location: Javelina Harley-Davidson
Boerne, TX
Rally/Finish Site: Sunset Station
San Antonio, TX
www.thecircleforlife.com

Finally, transplant support groups are a great resource as you and your family share concerns, challenges, and successful strategies with people who have had a similar experience. University Transplant Center provides a support group called **Genesis** that meets monthly (See the Save the Date column in this newsletter).

The bottom line is: From start to finish, transplant is more than a “surgery”...it is a life-changing event for everyone involved. Don’t hesitate to get the professionals at the transplant center involved with this part of your recovery if needed.

NurseLink ...For Your Information...

Elvia Shope, RN

Clinical Staff Nurse, Transplant Telemetry

University Health System (UHS) provides a 24-hour per day bilingual nurse telephone line called **Nurselink**. It has been in service for fifteen years and its primary function is to be a resource guide for UHS patients and the community. It is staffed by qualified Registered Nurses who answer the phone 24 hours a day/7 days a week.

Upon discharge from the Transplant Clinic or Inpatient Transplant Unit, Liver, Kidney and Pancreas transplant patients are given home discharge instructions which include calling **Nurselink** at 210-358-3000 for medical concerns that occur after normal business hours, and on weekends and holidays. Lung transplant recipients call 210-358-8001 after normal business hours.

Remember...Call 911 if you have a life-threatening emergency.

What happens when you call Nurselink?

- Always tell the nurse that you are a transplant recipient.
- The nurse will speak with you, listen to your concerns and take pertinent information that will assist in finding the correct doctor to address your concerns. The nurse will contact the doctor or associate who will review your concerns and personally call you back with guidance for your care in a timely manner.
- **Nurselink** may direct you to go to the nearest Emergency Room, same-day appointment or walk-in clinic to be evaluated.
- **Nurselink** will also assist in obtaining a Primary Care Physician in San Antonio.
- The Transplant Clinic (210-358-4500) has staff answering all calls **during normal business hours** (7:30 AM to 4:00 PM) for questions regarding transplant-related issues, prescription refills or rescheduling appointments. **After-hours**, if you leave a message on the Transplant Clinic answering machine, you should expect a call back the next business day. Call **Nurselink** if you feel your medical concern requires attention before that.

A beautiful mosaic was presented to the Transplant Center in memory of **Jenifer Sledge** (Bilateral Lungs, 2011) by her mother Deehona Minton on 30 September 2011. The mosaic is a reminder that each patient and family brings the mosaic of their life experience to the transplant journey and we, as a transplant team, honor that through the precious gift of HOPE.



Sandra Haggray (Bilateral Lungs, 2007) and her daughter, Esther, were in a local production of "The Wiz" at the Carver Community Theater in San Antonio.

Christena Crawford (Bilateral Lungs, 2010) attended the annual convention for The International Association of Workforce Professionals in St. Louis on 26 – 29 June 2011 and proudly carried the Texas flag in the Opening Ceremony. In her remarks, she stated "I'm pleased to be able to carry the flag of the great state of Texas because I received the gift of life. I encourage everyone to sign us as organ donors." Chris and her husband George actually met at an IAWP convention and danced the night away thanks to her new lungs!!



Joan Werneman (Lung, 2010) and her husband Kaj headed to Walt Disney World and Universal Studios in Orlando, Florida with their 2 sons, their wives, and 5 grandchildren for lots of fun but, most importantly, creating beautiful post-transplant memories.

Prestigious Awards go to two University Transplant Center Professionals

Erin Sidle,
Marketing Communications Coordinator

On October 21, 2011, Micaela “Mike” Buecher, RN, CCTC, one of our Renal Nurse Coordinators, was presented with the Transplant Nursing Excellence Award by the International Transplant Nurses Society recognizing her 30-year career in transplant nursing. Jennifer Milton, BSN, RN, CCTC, MBA, University Transplant Center Administrative Director, described the enormity of her contributions with these words: “Her passion for learning about transplant has never dampened. Her career has spanned a time of unbelievable innovations and advancements in donation, transplantation, and immunosuppression coupled with massive changes in the regulatory and financial operations in transplantation.” Mike has had a profound impact on literally generations of transplant recipients. Congratulation Mike!

On December 2, 2011, Dr. Luis Angel, MD was recognized by the Lone Star Chapter of the Cystic Fibrosis Foundation for his contributions to “making a real and powerful difference in the lives of people with pulmonary disease as Director of Lung Transplantation, Interventional Pulmonology and Pulmonary Critical Care at University Transplant Center.” In addition to his strong clinical credentials as an international lung transplant expert, Dr. Angel is best known by his patients for his caring and nurturing demeanor and his total commitment to their positive outcomes. Well Deserved Dr. Angel!



Mike accepting the Transplant Nursing Excellence Award.



Dr. Angel and Steven Tyson at the award ceremony.

MAKE A DIFFERENCE... VOLUNTEER

Tom Morrissey
Heart Transplant Recipient, 2006
President, Vital Alliance

Are you looking for a way to positively impact the future of organ, tissue and eye donation and honor those who have given the “Gift of Life”? As of December 2011, more than 112,500 people are waiting for life-saving transplants across the United States and over 12,000 of those waiting are your Texas neighbors (1)! Every 12 minutes another name is added to the transplant waiting list and an average of 18 people die each day from the lack of available organs for transplant (2). Each of us, particularly those of us who have received transplants and our families, can make a difference in these statistics through volunteering.

VITAL ALLIANCE is a nonprofit organization composed of volunteers representing recipients, donor families, and representatives from organ, eye, and tissue organizations, as well as the medical community. Our mission is to increase community awareness and medical knowledge about organ, tissue, and eye donations. No story is as compelling as those of recipients and families who have received the “gift of life” and those special families who have given the “gift of life”.



Tom Morrissey

You have one of those stories to share with others to increase awareness of the significance of organ donation.

VITAL ALLIANCE sponsors events such as the annual Donor Memorial Tree Planting Ceremony every Spring, Community Health Fairs, National Donate Life month events in April and an annual Organ, Eye & Tissue Donor Awareness Run/Walk every Fall. Volunteers are needed for participation in **all** of these events.

If you are interested in volunteering with **VITAL ALLIANCE**, contact us through our membership page at www.vitalalliancetexas.org or contact me at 210-632-9371 or tom.morrissey@vitalalliancetexas.org.

References:

- (1.) www.optn.transplant.hrsa.gov
- (2.) www.txorgansharing.org



4502 Medical Drive MS 18
San Antonio, TX 78229

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Editor: Darnell Waun, MSN, RN

Darnell.Waun@ubs-sa.com

Transplant Action Item



CONTACT MY DONOR FAMILY

This is the time of year when many people make “resolutions.” Many times these revolve around things that we have meant to do but just put off or didn’t get to for one reason or another. Perhaps one of those things is making contact with your donor family. April is “National Organ, Eye and Tissue Donation Awareness Month.” It is a wonderful time to let the people who made the decision to give you “The Gift of Life” know that you are thinking of them and are grateful for the impact they have made on your life. University Transplant Center has a program to facilitate this communication with your donor family. If interested, contact Deb Cotter at ramirezcotte@uthscsa.edu or 210-567-6623 for more information.