

TX News Notes

1/24/07

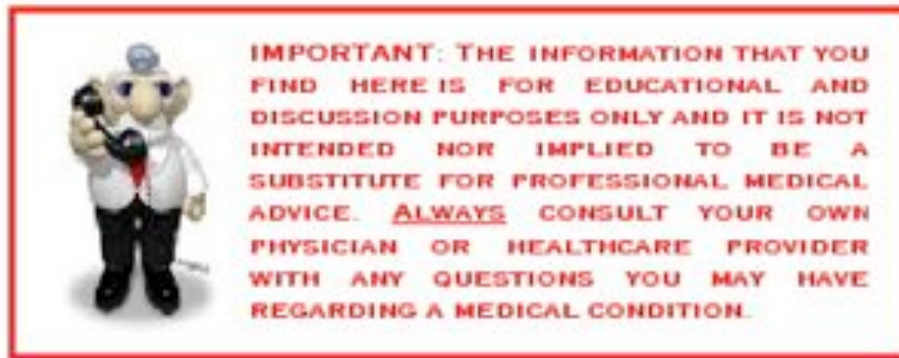


Get some exercise!

What's Here:

News/Calendar

- Article:* A life that beats the odds
Table: Some of the longest surviving transplants
Article: April is Nat'l Donate Life Organ & Tissue Donor Awareness Month
Opinion: What can you do??
Shopping: Lots of interesting things
Feature: Let's play: Top 10 Ways to Spot a Lung Transplant Patient!



Did you smile at your support person today??



NEWS

A cautionary note about the idea of microwaving sponges to kill germs:

Clean your sponge by microwaving it
WSLS NewsChannel 10
Jan 23, 2007



According to a new study, you can sanitize your sponges at home by putting them in a microwave for a matter of minutes. But not all sponges should be put in your microwave.

Researchers caution that the sponge should be wet before putting it in the microwave. And Sponges made of metallic material should not be put in, because they can spark a fire. One woman called Newschannel 10 saying her sponge caught fire after she put it in her microwave.

University of Florida researchers soaked a sponge in raw wastewater, filled with fecal bacteria. They claim a household microwave killed nearly all of the bacteria, viruses, and parasites - 99 percent were dead after two minutes.

http://www.wsls.com/servlet/Satellite?pagename=WSLS%2FMSGArticle%2FWSLS_BasicArticle&c=MSGArticle&cid=1149192807321&path=!features!notonthemenu

Flu activity this week:

<http://www.cdc.gov/flu/weekly/usmap.htm>

General articles of interest – related to lung transplant – updated weekly:

http://groups.msn.com/LungHeartTransplantREAD/_whatsnew.msnw

Heartburn drugs linked to hip breaks

<http://www.concordmonitor.com/apps/pbcs.dll/article?AID=/20061227/REPOSITORY/612270357/1013/48HOURS>

Welcome to www.newlungs.com, a complete guide to lung transplantation from a patient's point of view. Each of the questions is accompanied by a link--click the bouncing ball on the left to get the answer. It's that simple.

<http://www.newlungs.com/>



Asthmatic beach-goers: Beware the "red tide" of Florida

Are you an asthmatic planning a Florida vacation get-a-way this winter? If so, you might want to watch for the notorious "red tide" that forms in the Gulf of Mexico each year, and be sure to bring your medication. Though not immediately dangerous to most people, a recent study has found what allergic visitors to the coast have known for years -- red tide irritates asthmatic lungs.

<http://www.thatsfit.com/2007/01/11/asthmatic-beach-goers-beware-the-red-tide-of-florida/>

FROM THE LATEST SUPPORT GROUP MEETING

We had the pleasure of seeing and hearing Dr. Charlotte Cabello on Thursday at the Transplant Support Group session. Charlotte is Patient Care Director for post-transplant on 7 Hudson South. She gave us an overview of what to expect after our transplant and answered our questions. She emphasized the need for each of us to take responsibility for our recovery and subsequent health care. Our caregivers can offer support - but we will need to learn our meds, anticipate side effects, know what we can expect physically, mentally and emotionally during our recovery. Also important we will get learn our daily schedule as well as what's important, what to ask, who to ask and when to ask it!

For more information, take a look at these Columbia University Department of Surgery websites:
Lung Transplantation Patient Care Guide - Post-Transplant Recovery:

http://www.columbiasurgery.org/programs/tx_lung/guide_recovery.html

Lung Transplantation Patient Care Guide - Resuming Life After Lung Transplantation:

http://www.columbiasurgery.org/programs/tx_lung/guide_after.html

-Up Care After Lung Transplantation:

http://www.columbiasurgery.org/programs/tx_lung/guide_followup.html

REMEMBER: The Feb. 6 support session [with Dr. Jessie] has been postponed. There will be NO session on that day – so our next session will be Feb. 13 with Dr. Arcasoy. But don't forget the Caregivers' Support Group on Feb. 8!

CALENDAR

Mon., Feb. 5, **SESSION CANCELLED**

Thurs., Feb. 8, 4-6 pm, Caregiver's Support Grp, Milstein, 7 Hudson S, Reemsta Conf. Rm.

Tues., Feb 13, 4-6 pm, Dr. Selim Arcasoy

Wed., Feb. 21, 1:30-3:30, Theresa M. Daly

Thurs., Feb. 22, 4-6 pm, Caregiver's Support Grp, Milstein, 7 Hudson S, Reemsta Conf. Rm.

Mon., March 5, 4-6 pm, Dr. Mathew Bartels

Thurs., Mar. 8, 4-6 pm, Caregiver's Support Grp, Milstein, 7 Hudson S, Reemsta Conf. Rm.

Tues., March 13, 4-6 pm., Dr. David Fedoronko

Thurs., Mar.22, 4-6 pm, Caregiver's Support Grp, Milstein, 7 Hudson S, Reemsta Conf. Rm.

Schedules for both groups:
<http://www.lackritz.net/Schedule>

As always, check with Phyllis for
full information: 212-305-6266

A life that beats the odds

By Warren King
Seattle Times medical reporter
Monday, October 16, 2006

WENATCHEE — Sometimes, when he least expects it, Doug Hoxworth gets a karate attack from behind. It's swift and sure, and comes complete with a yell. But it's not such a bad thing.

Carson, Hoxworth's 4-year-old grandson, is the attacker, and the boy pretty much makes Hoxworth's day. So do his granddaughters, Mackenzie and Emma. Or just a call from one of his four daughters, or a poker game with his sons-in-law.

"They're all pretty much everything for me," Hoxworth says of his doting family.

They're lucky to have him. Twenty-one years ago, when they were living in Seattle, Hoxworth, his family and his doctors didn't know whether he would live even another year. He was only in his mid-30s but was threatened with a deadly lung disease that only a rare operation could cure.

Today, Hoxworth is believed to be the fifth-longest survivor in the world of a combined heart and lung transplant, a procedure that is rarely performed anymore. He has lived more than 20 years with the transplanted organs. At the time of his operation, only 33 other people had undergone the procedure at Stanford University in California, where he had the transplant. In the U.S., 1,092 have now had successful heart-lung transplants since the first success in 1981. **The longest survivor has lived 22 years.**

In the early days, the heart was transplanted along with the lungs because surgeons hadn't perfected a technique for lung transplants. Today, single or double lungs are transplanted for lung disorders, and heart-lungs only for patients with failure of both organs.

For Hoxworth, now 59, the journey has been both joyful and excruciating. The years since his transplant have been full of the events and memories that a tight family and many friends bring but burdened with the exhaustion and frustration that come with pain and the side effects of medication. Most recently, he is fighting kidney failure and prostate cancer.



CRAIG FUJII / THE SEATTLE TIMES

Doug and Susan Hoxworth, at home in 1988 with three of their four daughters — from left, Lisa, 17; Sara, 12; and Katy, 8. On May 14, 1986, Hoxworth had received the heart and lungs of an 18-year-old who died in a motorcycle accident.

His attitude has helped immeasurably in seeing him through. "You can't dwell on it and feel sorry for yourself. ... You just say, 'Whatever they throw at me, I can take it,' " Hoxworth says.

Transplant experts say Hoxworth has it right. They credit that outlook and self-discipline, in part, to his long survival. "You have to give a lot of credit to his desire to live and the discipline of his lifestyle. He had to comply with a difficult medication regimen," says **Dr. Bill Frist**, who performed Hoxworth's transplant at Stanford in 1986. He is now a senator from Tennessee and the Senate majority leader.

"I don't have time to die"

Back in 1985, Hoxworth was a healthy, vigorous machinery-maintenance supervisor for a Bothell contact-lens manufacturer when he suddenly began tiring easily and having trouble breathing. He was diagnosed with primary pulmonary hypertension, in which arteries that carry blood from the heart to the lungs narrow, eventually crippling the heart. There is no known cause for the form of the disease he had.

Doctors told him he probably had less than a year to live. A transplant was the only possible cure, they said. But a Seattle cardiologist didn't encourage the surgery because it had limited success. With little hope, Hoxworth and his family decided to take a last trip together to California.

Along the way, his youngest daughter, Katy, then a gregarious 4-year-old, struck up a conversation with a woman beside a Disneyland hotel pool. The woman turned out to be the wife of a doctor — an expert on pulmonary hypertension. Within 15 minutes, the doctor was talking to Hoxworth and offering help. Soon he had Hoxworth try a drug he was researching, but it didn't help. So the doctor got him on the waiting list for the transplant at Stanford, the closest medical center to Seattle that was then performing the procedure.

Hoxworth and his family moved to a small house in Sunnyvale, Calif., near Stanford, and waited for a donor. For eight months. "I don't have time to die," he said in a 1985 interview with The Seattle Times. "I've got too many things left undone ... and I've got a lot of fishing I want to do."

Two potential donors came up. One turned out to have a lung infection. For the second, Hoxworth had a cold and couldn't have the operation. Finally, on May 14, 1986, at age 38, he received the heart and lungs of 18-year-old Michael Fencl, who had died in a motorcycle accident.

Side effects of side effects

Looking back, Frist and Dr. Bruce Reitz, who performed the world's first successful heart-lung transplant at Stanford in 1981, said several factors contributed to Hoxworth's long survival: the young age of the donor, Hoxworth's relative youth at the time and a good tissue match.

And his medications have been essential.

Hoxworth figures he has been on 40 different drugs over the years. They have included several drugs to prevent his body from rejecting the transplanted organs, plus others to fight infections, thyroid problems, depression, acid reflux and a variety of other problems. Now he takes medications to fight prostate cancer and kidney failure.

"Sometimes I take one to counteract the side effects of the other to counteract the side effects of the other," he says, with only a slight chuckle. The drugs have also been the major factor contributing to his kidney failure.

Prednisone, a powerful steroid to prevent rejection, has been the hardest to handle, he says. Side effects have included memory loss, blurry vision and moods that swing from quick temper to getting weepy over a simple phone chat with a loved one. He was never able to return to work.

"Stubbornness can be good"

Family has been key to Hoxworth's coping, he says. Wife Susan's support through the ups and downs has been unwavering. She has overseen his medications, understood his condition, fended off his anger. "Susan is my lifeline," Hoxworth says.

Soon after the transplant, Susan took a job as an assistant in a Wenatchee dental office to help support the family of four daughters beyond Social Security and disability payments. As he recovered, Doug found his parental role increasing. He drove his children to their activities and helped negotiate their teen years.

One of his fondest memories is playing golf with a 10-year-old Katy, who showed natural talent. After a round they would go out for lunch and chat and laugh together. "No matter how he feels, he doesn't complain," says Katy Boreson, now 26. Her experiences with her father helped her decide to become an intensive-care nurse at a Seattle hospital. His other daughters also marvel at how their dad has held up and made the best of the hand he was dealt.

"He shouldn't be here, but he is," says his second daughter, Mary Gatewood, now a 34-year-old marketing specialist for a medical-device manufacturer in Kirkland. "Stubbornness can be a good thing. We don't give enough credit to what our minds can do."

Living in the present

Hoxworth says his ability to keep his problems in perspective has helped keep him going.



Now: 20 years after transplant Doug Hoxworth, 58, of Wenatchee, with wife Susan and daughter Katy Boreson, left. His medical battles continue.



Then: Before the operation Susan and Doug Hoxworth and Katy in 1985. "I don't have time to die," he said at the time.

The small stuff, he says — a stubborn car engine or running late to an appointment — fades like the wind. Even the big problems — his recent life-threatening illnesses or the family's current financial troubles — he mentally puts aside.

He'd rather live in the present. At the same time, though, setting goals has been vital. First, it was living to see all his daughters graduate from high school. Then it was college. Then it was to see how they turned out as adults.

Now he's shooting to make his 60th birthday in May.

The Hoxworths knew several other transplant candidates who never made it. Doug Hoxworth calls his transplant "the luck of the draw," but he has been an exceptionally conscientious patient in taking care of himself, his wife says.

And then there's Michael Fencl.

Hoxworth was not told by doctors who his donor had been. But one of Fencl's friends knew he had been an organ donor, and she attended the same California high school as Hoxworth's daughter Lisa.

The friend told Lisa she knew the identity of her dad's donor. The Hoxworths arranged through a television crew doing a documentary on transplants to meet Fencl's mother. The family still remains close to his mother. "I think about him all the time," Hoxworth says.

"I talk to him. I say, 'Thank you, Michael.' "

Some of the longest surviving transplants

Organ	TX Date	Yrs	Surgery Location
Kidney	1-31-63	43	Univ. of Colo. — Denver
Liver	1-22-70	36	Univ. of Colo. — Denver
Heart	8-30-78	28	Stanford University
Pancreas	5-21-83	23	Univ. of Minn. — Minneapolis
Heart-lung	11-21-83	22	Univ. of Pittsburgh
Double lung	10-8-90	16	Stanford University

Sources: UCLA Immunogenetics Center, United Network for Organ Sharing

April is National Donate Life Organ and Tissue Donor Awareness Month

Will You Give the Gift of Life?

by Kay Coles James

The gift of life is the greatest gift one can ever give. And you may have the power to give that priceless gift to a relative, a friend, or someone you do not even know and may never meet.

The need for organ and tissue donations is tremendous. According to the Department of Health and Human Services, roughly 63 Americans receive an organ transplant every day. More than 77,000 people in desperate need of life-saving assistance are on the national transplant waiting list. Tragically, each day about 16 people will die because the organs they need are not available in time.

Organ donation can literally restore sight to the blind. It can offer a second chance when a weak heart begins to fail. Your bone marrow might be the miracle match for a child stricken with leukemia.

For me, organ donation is a personal mission. One of my closest advisors and dearest friends is alive and enjoying a rich full life today thanks to a donated kidney. That donor and their family have my deepest gratitude; it makes me passionate about encouraging others to follow in those unselfish footsteps.

At the U.S. Office of Personnel Management, our goal is to make the federal government a model employer in every way. The OPM team has launched HealthierFeds campaign to educate federal employees and retirees on healthy living and best treatment strategies.

Our focus this month is organ donation.

I am quite proud of the way the federal government helps its workers become part of the chain of life. Our compassionate leave policies make special accommodation for organ and bone marrow donation.

The government's health program, the Federal Employees Health Benefits (FEHB) program, lets employees choose from among a dozen or more insurance options. While specific benefits may vary among plans, the FEHB covers non-experimental transplants such as cornea, heart, kidney, pancreas, lung, liver, and small intestine transplants. Coverage includes related medical and hospital expenses of the donor, even if the donor is not an FEHB member. You may want to check out your own health insurance to find out how it treats transplants.

The President has declared April "National Donate Life Month." During this spring season of renewal, I would urge every American to consider signing up as an organ donor.

Please visit the Department of Health and Human Services organ donation website at www.organdonor.gov. You can find information and even download an organ/tissue donor card and sign up to become a donor. Remember, giving and sustaining life are the best gifts of all.

Kay Coles James is the Director of the U.S. Office of Personnel Management (OPM)

Get Attention!



What can you do??

You can contact your local media and tell them, "This is your 'Heads Up!' for National Donor Awareness Month - April 2007. There are a lot of people on waiting lists for organ donation. [I am one of them.] Any story you do, helps raise awareness."

Let them know that there are people in the area who have already donated organs or received organs. But a great many more are waiting, while time runs out. They can request free materials and speakers. Encourage them to do a series of short info clips during the morning and evening news throughout the month:

- interview some transplantees
- talk to a physician about WHO can be a donor
- interview a transplant surgeon for an overview of the process from listing to surgery
- talk to a transplant person's "support" person
- talk to someone awaiting transplant - or several people kidney/liver/heart??
- a living donor
- a donor's survivor

and suggest that they try to include a minister/priest/rabbi to dispel myths about religious prohibitions vis-a-vis transplant.

You should suggest that they include info about two important websites:

The New York State Donor Registry: <http://www.health.state.ny.us/nysdoh/donor/>

The United States Official Organ Donation Information Site: <http://www.organdonor.gov/>

The local media [or your company] could sponsor a challenge to encourage organ donation registry on local campuses and in local industries. Have your local TV channel issue a challenge to local fire, police, teachers, coaches, OTHER NEWS/MEDIA PERSONNEL, Chamber of Commerce, politicians, hospital workers, to become donors. Get them to spend a day at a local mall to register shoppers, salespeople, everybody. Have a newsperson stand in front of City Hall to talk to passers-by. There are a lot of slogans:

- LIFE - Pass It On
- Don't Take Your Organs to Heaven - Heaven Knows We Need Them Here!
- Recycle Yourself - Be an Organ & Tissue Donor
- Organ Donation - The Only Cost is a Little Love
- Make a Miracle - Be an Organ & Tissue Donor
- Dare to Share - Be an Organ & Tissue Donor

The bottom line here is that everybody "waiting" needs help - and the first step to that help is awareness. If we help ourselves by promoting awareness - our communities will step up to help us.

For additional information: http://www.donatelifeny.org/organ/n_donate.html



A Suggestion from Ofelia [and daughter Vanessa]

Handler's ergonomic body fits easily in the palm of your hand. A button deploys a strong lightweight gripping arm of zinc alloy and over-molded with hardened non-slip rubber gripping any diameter door handle with up to **60lbs** of pull with minimal effort. The handler not only keeps germs off your hands, it keeps germs off itself. It is made with Nano Silvers that instantly kill most common types of germs.

Wgt: 5 ounces Ht: 2.4 inches Made of: Polycarbonate, rubber, zinc alloy, nano silvers
Price: \$10.95 plus ship

<http://www.handlerusa.com/home.php>



Some of you have asked about ear loop masks [rather than the tie-on kind]. I bought mine from: AbsoluteSci.com, Absolute Scientific Products, Inc - online. I bought in bulk – because it was a great deal – and only cost a bit more for zillions [actually 500 masks] – than it would have cost me for 50 at the local drug store. It is so-o-o many that I don't think I'll ever have to buy again!

<http://www.absolutesci.com/shopexd.asp?id=20498>

And while we are talking shopping, here's the link for the "Ask Me About My Lung Transplant" t-shirts:

"Ask Me About My Lung Transplant" hi-lighted with a green organ donor awareness ribbon dangling from the text. Each design is slightly different as they display your lung transplant message. Bring awareness of organ transplant and promote the importance of organ donation on t-shirts - as well as mugs, hats, bags, buttons, and stickers.



<http://www.cafepress.com/donorawareness/1202941>

Let's talk carrying around our pills!

Pack-m-Ups® pill organizer

Pack-m-Ups® pill organizers are press-and-seal - easy open and close. Use them connected as a weekly pill organizer, or separate them to carry just what you need. They are durable, flexible, and hygienic. Use a pen or marker to remind yourself of the day and time to take your pills.



- Moisture-resistant seals stay closed in a bag or suitcase.
- Clear, re-sealable pouches let contents be seen for security checks.
- Dimensions: 2 7/8 IN x 3 5/16 IN (7.302 cm x 8.414 cm), 2.0 mil thickness

<http://www.packmups.com/>

Apex Medi Planner II

Price: \$7.79 [Everyday Free Shipping]

- Simplify taking multiple medications with the MediPlanner II organizer
- 28 extra large, easy to open compartments
- Raised lettering and Braille markings



THIS LOOKS LIKE THE ONE THAT THEY GET FOR YOU BEFORE DISCHARGE

<http://www.drugstore.com/products/prod.asp?pid=87255&catid=32880&trx=PLST-0-CAT&trxp1=32880&trxp2=87255&trxp3=1&trxp4=0&btrx=BUY-PLST-0-CAT>

Easy-to-use pill dispenser with clock & talking reminder

Timex Healthcare Daily Medication Manager

Price: \$14.99 [Everyday Free Shipping]

- Set Your Dosage Time Up to 4 different times per day
- Set Your Alarm Style Talking, Visual or Beeping
- Missed Pill Alert Easy-to-read digital display.
- Easy to program, large, easy to see buttons.

Contains: 1 Timer/Reminder unit, 1 Pillbox, 2 LR44 Batteries, Detailed Instructions. Uses 2 AAA - not included.



<http://www.drugstore.com/products/prod.asp?pid=154671&catid=32880&trx=PLST-0-CAT&trxp1=32880&trxp2=154671&trxp3=1&trxp4=0&btrx=BUY-PLST-0-CAT>

And finally, we should talk Medic Alert Bracelets

American Medical ID features custom-engraved medical identification bracelet and necklace styles. Medical IDs are recommended by physicians and healthcare organizations throughout the world.



<http://www.americanmedical-id.com/home/>

BIG FINISH: TOP 10 WAYS TO SPOT A LUNG TRANSPLANT PATIENT!

1. He is wearing a mask!
2. She has prednisone cheeks!
3. She has color in her face - pink not bluish-gray! [Elaine V.]
4. He wears a hat, sunglasses and SPF 50 suntan lotion!!! [Deb P.]
5. The person is wearing a cow bell so that the support person can keep track of movements all over the country. [Andy J.]
6. He/She seems to smile an awful lot. Seems they enjoy every minute of every day! [Donna Z.]
7. Someone that's happy and enjoying life, and doesn't complain. [Gary G.]
8. Gets really cocky and says to support person, "Want me to get it? I walk faster than you." [Dave B.]
9. His car's license plate holder says... "TRANSPLANTATION WORKS ... LUNG RECIPIENT..." [Mickey M.]
10. She carries Purell and opens doors with her butt and elbows.