



Summer 2009

Renewal

Sharing the journeys of Mayo Clinic transplant patients, donors and staff

Kidney-Liver Transplant Cures Rare Disease

It was a Valentine's Day present like no other. On Feb. 14, 1999, Jon Anglemyer received the call from Mayo Clinic telling him the wait was over — a donated kidney and liver were available.

That call — and the successful kidney-liver transplant that occurred two days later — were the turning point in Anglemyer's search for a cure for hyperoxaluria, a rare, genetic kidney disease.

With hyperoxaluria, too much of a substance called oxalate is present in the urine. It's a natural byproduct of metabolism. But too much causes kidney stones, which Anglemyer had experienced as a teen and young adult. Because he was otherwise healthy, no one suspected the kidney stones were caused by an underlying, life-threatening illness that was destroying his kidneys.

Quietly, the illness had taken its toll. In 1996, in his senior year studying biology at East Carolina University in Greenville, N.C.,



Jon Anglemyer with wife Melissa, daughter Holly Dawn and son Bruce in 2008.

Anglemyer had a dream internship. He was training dolphins at Walt Disney World in Orlando, Fla.

"I came up from a dive and had a bad taste in my mouth with flulike symptoms," says Anglemyer. Because he didn't want his illness to interfere with an upcoming trip to the Florida Keys, he went to urgent care.

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Generic Drugs: How Transplant Patients Can Choose Appropriately



Generic drugs are usually a safe, economical alternative to their more expensive brand-name counterparts. Though not all transplant patients have had the option to consider generic drugs in the past, generic alternatives to two immunosuppressants, Cellcept and Prograf, may become available this year. While the cost savings may be attractive, transplant recipients should exercise more caution than the average patient when weighing their medication options.

“Changing to generic medications is very appropriate in general because of the cost savings, but transplant medications need more careful consideration,” says Paul Groehler, Pharm.D., a transplant pharmacist in Mayo Clinic’s Specialty Pharmacy.

Generic drugs undergo rigorous testing by the Food and Drug Administration to ensure they are equivalent to their brand-name counterparts. In the general population, a small variability in the active ingredient or a difference in the inactive ingredients usually does not cause a problem.

According to Groehler, immunosuppressants are “critically dosed,” or very closely matched, to a patient’s individual circumstances. This means a small difference in the dosage or other ingredients may cause significant changes in blood work for a transplant patient. Since pharmacies are required to offer patients generics without necessarily consulting the patient’s physician, this could mean transplant patients receive a generic immunosuppressant without the guidance of their transplant physician or coordinator.

He also notes that it is not only important to recognize changes in your drugs and consult your coordinator when switching from brand name to generic, but also between generic manufacturers. If a switch to generic is appropriate, stay with the same generic manufacturer, Groehler says. “Familiarize yourself with how your immunosuppressant drugs look: their size, shape and any markings on them. If you notice any changes, make certain your coordinator is involved,” he says.

Finally, he notes, “Communication is key. By communicating with your transplant team and having lab work done regularly, the change to generic immunosuppressants can be safe and effective.”

Renewal

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Mayo Clinic has offered transplantation as a treatment option for adult and pediatric patients since 1963. Mayo Clinic organ transplant programs have earned worldwide recognition for their expertise and success. In 1998 the separate organ and tissue transplant efforts united under the umbrella of the Mayo Clinic Transplant Center. This cooperation enhances the ability of Mayo physicians and scientists to share expertise and resources, offer comprehensive integrated transplant services, and to conduct innovative research in transplantation.

Kidney-Liver Transplant Cures Rare Disease - *continued*

Dawn Milliner, M.D.



Anglemyer and daughter Holly Dawn named for Mayo Clinic's Dawn Milliner, MD, and a family friend.

The next day, a call from the care provider was jolting. Blood work showed his symptoms weren't caused by the flu. "They said, 'Go to the hospital. Your kidneys are gone,'" Anglemyer recalls.

He returned to Greenville to finish his degree and attend to his health. Three times a week he went to a hospital after class to receive kidney dialysis.

Anglemyer graduated and began work on his master's degree, but his symptoms grew increasingly troublesome. "I was very weak in my hands and feet," he says. His doctors recommended a kidney transplant. A dialysis nurse, who had become a friend, donated her kidney for the transplant in March 1997.

But a new kidney wasn't the whole solution. "I went from bad to worse," says Anglemyer. "I was bedridden. I lost all strength and was living in a rehab facility."

Baffled, his doctors kept digging for the reason behind his second kidney failure and continued poor health. "They put two and two together," he says, finally pinpointing hyperoxaluria as a possible cause, even though his family had no history of the genetic illness. His doctors recommended that he go to Mayo Clinic.

The Mayo Clinic Hyperoxaluria Center in Rochester, Minn., is one of the most experienced centers in the world for hyperoxaluria, treating and following more than 50 patients a year. Few medical centers offer this specialty because the illness is so rare.

"The likelihood of any individual having this disease is about one or two out of a million," says Dawn Milliner, M.D., a nephrologist and director of Mayo Clinic's Hyperoxaluria Center, which is funded by the Oxalosis and Hyperoxaluria Foundation (OHF).

In October 1997, Dr. Milliner confirmed Anglemyer's diagnosis of hyperoxaluria. Dr. Milliner and her team recommended a kidney and liver transplant. In primary hyperoxaluria, the liver produces far too much oxalate. The kidneys eliminate the excess oxalate, but they are damaged in the process.

"That's why a new kidney alone does not solve the problem," says Dr. Milliner. "A new liver that makes normal amounts of oxalate also is needed."

While Anglemyer waited for donated organs, he coached a swim team in Rocky Mount, N.C. By December 1998, he was at the top of the transplant list and moved to Rochester. He waited again for the call that came on Valentine's Day.

The kidney-liver transplant cured his illness. On Valentine's Day 2009, Jon marked the 10th anniversary of the transplant.

"It's all turned out how I hoped."

"It's all turned out how I hoped," says Anglemyer, who works as a liaison between fish dealers and fishermen for the North Carolina Division of Marine Fisheries. "My quality of life is excellent."

Jon and his wife, Melissa, were married in 2003. Grateful for Jon's good health, the couple encouraged their friends and family members to give donations to the Oxalosis and Hyperoxaluria Foundation in lieu of wedding gifts.

The family, which now includes Bruce, 4, and Holly Dawn, 2, four horses and three dogs, lives on acreage outside Grimesland, N.C. Holly's middle name was selected in part to honor Dr. Dawn Milliner. "I can't say enough about the care I received and how wonderful Dr. Milliner is," says Jon, who continues to see the Mayo Clinic physician for annual checkups. "She's the best."

For more information about kidney transplant at Mayo Clinic, visit www.mayoclinic.org/kidney-transplant/.



New Lungs, New Life

Stephen Cassivi, M.D.



Five years after a double-lung transplant to relieve debilitating symptoms of emphysema, Keith Winkelman is happy to share simple pastimes with his 16-year-old son, Michael.

"I can go out now and throw the ball around with my son, and I was able to go hunting last season with a special permit [for disabled hunters]," says Winkelman.

Transplant became an option for 54-year-old Winkelman, of Camp Douglas, Wis., in 1998 after a particularly bad case of pneumonia led to being put on oxygen to cope with his newly-diagnosed emphysema. His physician at Franciscan Skemp—Mayo Health System in La Crosse, Wis., suggested he travel to Mayo Clinic in Rochester, Minn., to consider lung volume reduction surgery, a procedure where small wedges of damaged lung tissue are removed. At Mayo, Winkelman was told he was not a candidate for that procedure, but he was referred for evaluation for a lung transplant. Following a week of testing, he was listed for a double-lung transplant.

"This is an excellent example of how the seamless teamwork between Mayo Health System physicians and Mayo Clinic Rochester specialists can really contribute to a patient's better outcomes," says Stephen Cassivi, M.D., the surgical director of the Mayo Clinic Lung Transplant Program who performed Winkelman's double-lung transplant.

"The nature and severity of Keith's disease was properly identified by his physician, Dr. Daniel Dietz, at Franciscan Skemp," says Dr. Cassivi. "He arranged for a prompt and expeditious review that, in short order, resulted in Keith being evaluated by our Mayo Clinic Lung Transplant team. Keith's subsequent success as a lung transplant recipient was made possible by that Mayo Clinic teamwork on both sides."

Winkelman received his transplant on Jan. 21, 2003. "It was scary to wake up from surgery and see my oxygen at 100 percent, but not have a [oxygen] tank nearby," Winkelman says. He stayed in Mayo Clinic's Saint Marys Hospital for 11 days, and then spent the next three months in Rochester for rehabilitation at the clinic.

"I spent four-and-a-half years reliant on someone else. A lung transplant gave me back my freedom," Winkelman states. He says that prior to transplant, his family had to pack 40 tanks of oxygen in their minivan for him just to go away for the weekend. Since the transplant, he took his first airplane trip to California for a vacation.

Transplant relieved Winkelman of emphysema and oxygen, but it has resulted in other complications, including osteoporosis and diabetes brought on by anti-rejection medications.

"He's been able to lead a much better life not tied to oxygen. He traded almost certain death for the complications he has now," reflects his wife, Laurie. "This is not a cure-all; it's a trade-off."

Winkelman says that anyone considering transplant should understand that one trade-off is following the required medication regimen. He says, though, that he has become accustomed to his routine, because it is important to follow his care team's recommendations and guidelines.

"If anyone looks at the life they have—if they have trouble breathing like I did—this is kind of like a miracle," he says. "Now I have two birthdays: the day I was born and the day I was transplanted. I owe that to my donor's family; without their sacrifice and extreme generosity, all this would never have been possible."



Keith Winkelman is pictured here with his family, and in California with his son on their first post-transplant vacation.

For more information about lung transplant at Mayo Clinic, visit www.mayoclinic.org/lung-transplant/.



Living Donor Transplant: Two Stories

– Jeff Carlson

After being diagnosed with Polycystic Kidney disease (PKD) in 1984, I knew that I would eventually need a kidney transplant. PKD ran in my family; my father and one of my older brothers had it. As my health slowly subsided, I became fatigued and took several naps a day. I also went through several episodes of having the cysts in my kidneys rupture, causing intense pain that landed me in the emergency room.

My father underwent a cadaver transplant in 1999, but died two months later of a fungal infection in his lungs. My brother received a living kidney from our oldest niece in 2003 at Mayo Clinic in Rochester, Minn., and both are doing well today. When I began to look for a donor a couple of years ago, none of my immediate family members matched. Talking one day with Brad Erhardt, a good friend and former coworker, I told him that I would need a kidney transplant soon.

“I’ll give you a kidney, if you need one,” Brad said. Those were the wonderful words I needed to hear. Brad never hesitated as he offered to donate one of his kidneys to me, and his blood type was the same as mine. Three other friends offered to donate, too, but Brad was deemed the most compatible. Once my kidney function decreased enough, the surgery was scheduled.

The surgery and recovery went remarkably smooth for both Brad and me. I had the transplant on June 6, 2008, and returned full time to my job as a police officer on August 20—just 10 weeks later!

Our local newspaper did a story about the surgery and came back later to do a follow-up story. I agreed to do the newspaper story not for personal recognition, but to promote organ and tissue donation in general and to show that a person does not have to be related to you to donate an organ.

My life has changed dramatically since the transplant. When I returned to my room after the transplant, my wife immediately saw the difference in my appearance—my color in my face was back and the bags beneath my eyes were gone! I credit the wonderful staff at Mayo Clinic for the professional care I received there. I could have chosen a hospital closer to my home in Aberdeen, SD, but I am glad I chose Mayo.



Jeff Carlson, kidney transplant recipient, and Brad Erhardt, living kidney donor, credit much of their successful recoveries to their wives, who provided the men and each other a wonderful support system while in Rochester and recovering at home. Pictured left to right are Dawn Erhardt, Brad, Jeff, Victoria Carlson.

– Brad Erhardt

It has been nine months since I donated a kidney to my friend Jeff, and I still have people asking me if I have to be on a special diet or if I’m healed fully. To tell you the truth, I feel pretty darn good. The only problem that I incurred over this whole ordeal was about 30 extra pounds!

Jeff Carlson and I have known each other for about 18 years now. We were police officers in Aberdeen, South Dakota, but we usually worked different shifts. We really became good friends when we became instructors for Motorcycle Safety Foundation classes. I have known that Jeff would need a kidney for a long time, and had seen his health decline over the five years we taught together from 2002-2007. The day I told him that I would give him a kidney doesn’t stick out in my memory, but the day he told me that he needed a kidney or would have to start dialysis (and work as a probation officer instead of a police officer) is very clear!

We both reported to Mayo Clinic’s Rochester Methodist Hospital at about 7 a.m. on June 6, 2008. I went up to surgery first, and Jeff followed a couple of hours later. I remember seeing Jeff in recovery about 5 p.m. that night. The nurse had me up and walking (slowly) by 11 p.m. that day. The next morning, I was up. At around noon, I went to see Jeff. I was out of the hospital on the afternoon of Sunday, June 8, 2008. I stayed in Rochester for another couple of days with my sister who works at Mayo Clinic. The doctors just wanted me to be close in case I needed care, though I never did.

The thing that I want people to know the most is that the care I received at Mayo was superb. I can only describe the nurses who took care of me as “angels”.

While I was at home recovering, I would sleep a lot. I would also take walks at least once a day. I took three weeks off work as a probation officer for the State of South Dakota, and then went back for half days the first week of July. My support system at work was great, and we were fortunate in my office to have a summer intern who took over my cases while I was gone.

I think that I was able to recover quickly because prior to the surgery, I was in good shape. I ran two miles at least four times a week. After the transplant, I was back in the gym by the end of July, only two months after the surgery. I finally made it back to running two miles this past February.

I have been a blood donor for all of my life, and this experience helped me understand the importance of blood donation even more. In August, 2008, I gave my 80th unit of blood to reach the 10-gallon mark!

For more information about kidney transplant at Mayo Clinic, visit www.mayoclinic.org/kidney-transplant/.
For more information about organ donation at Mayo Clinic, visit www.mayoclinic.org/transplant/organ-donation.



If you’d like to write your transplant story, “in your own words,” please contact Julie Moenck at moenck.julie@mayo.edu.

Staff Profile:

Paul Deziel, Physician Assistant, Transplant Infectious Diseases



Paul Deziel works with patients throughout their transplant journeys.

While the risk of infection following transplant is elevated, Paul Deziel, a certified physician assistant in Infectious Diseases for Mayo Clinic's transplant center in Rochester, Minn., reminds recipients that it is manageable.

"Wash your hands frequently and try to stay away from sick people," he says.

These reminders may sound simple, but they can keep transplant recipients from having to make an appointment with Deziel. "I get to have continuity with patients," he says. "I see them in hospital and in clinic. Unfortunately, though, when they see me or my colleagues, there's usually a problem."

A physician assistant is a dependent licensed practitioner, which means he practices under a licensed physician. The physician assistant can prescribe medication, take medical histories, perform physical examinations, order and interpret tests and educate patients. Deziel might do all of these in a typical day at Mayo Clinic, as he sees patients in both the clinic and hospital settings.

In the outpatient or clinic practice, Deziel evaluates pre-transplant patients who need clearance from the Infectious Diseases perspective. This includes all heart, lung and liver recipients, and kidney, pancreas and allogeneic blood and marrow recipients as requested. Deziel also goes on rounds with the Transplant Infectious Diseases service to visit patients while they recover in the hospital following transplant.

"Infectious Diseases in transplant is like Infectious Diseases in fifth gear," relates Deziel. "Many of the infections we see are not of concern to the general public because our immune systems are not compromised. It takes a special dedication to know the intricacies of transplant infections."

In addition to knowing the ins and outs of transplant infections, Deziel keeps in close contact with other subspecialties that work with transplant, including Dermatology, Pulmonology, Cardiology, Endocrinology and others.

"Everyone here is collegial and contributes to the team. It's not just one person or one group working with a patient; it's all of us. It's really a very rewarding experience," he says.

Deziel has been a physician assistant for 25 years and has worked at Mayo Clinic since 2001.

Stay Healthy this Summer!

Remember to:

- Wash your hands frequently, or use an alcohol-based hand sanitizer if your hands are not soiled.
- Wash all raw fruits and vegetables before eating.
- Wear water shoes or sandals when walking along the beach or wading into water from the shore.
- Wear good-quality gloves, long sleeves, long pants, socks and shoes when gardening.
- When fishing, handle fish only with gloves, and wear gloves when cleaning fish. Preferably have someone clean the fish for you.
- Don't share towels, glasses or eating utensils.

Review your infection prevention guidelines from your transplant coordinator for more tips. Ask for a new one if yours has disappeared!

Gift of Life Breaks Ground on Second Transplant House



Patient-guests help break ground on second Gift of Life house.

Gift of Life Transplant House in Rochester, Minn., provides 30,000 guest nights per year to transplant patients and caregivers. High demand for this service currently results in referring patients to local hotels for accommodations.

On December 3, 2008, Gift of Life Transplant House board of directors, staff and patients took a step to change that by breaking ground for a second Gift of Life House in Rochester.

The mission of Gift of Life is to provide transplant patients and caregivers a supportive homelike environment with high-quality affordable accommodations. The house helps transplant patients achieve optimal recovery in a “home that helps and heals.”

The new facility will be a handicapped-accessible, 36-unit home located on the property adjacent to the existing Gift of Life property. Amenities will include kitchens, dining areas, a surrounding porch, gardens and parking. Common spaces will be large for social gatherings, while other spaces will be set aside for reflection and solitude. Most importantly, the new house will continue Gift of Life’s mission to help and heal.

For more information on the Gift of Life House and the 2008 Capital Campaign, please visit www.Gift-of-Life.org or call (507) 288-7470.



Join a Transplant Facebook Group

A Mayo Clinic heart transplant recipient, Bob Aronson, has a Facebook group for transplant patients, caregivers, donor families and anyone else interested in organ transplantation.

If you already have a Facebook profile, search for “Organ Transplant Patients, Friends and You,” and join this group. If you don’t have a Facebook profile, visit www.facebook.com and sign up. Facebook is a free social networking site that helps you connect with other people.



Attend Patient Education Classes and Support Groups

As a Mayo Clinic transplant patient, you have access to several key patient education classes on the Rochester campus. All classes are hosted in the Transplant Education Room on [floor or unit]. Please contact your coordinator for more information.

Kidney/Pancreas

- Dismissal class, Monday 10-11 a.m.
- Donor class, Monday/Tuesday/Thursday 11 a.m.-12 p.m.
- Candidate class, Tuesday/Wednesday/Friday 10-11 a.m.
- Post-transplant nutrition class, Monday 8:30-9:30 a.m.

Liver

- Pre-transplant class, Wednesday 8-10 a.m.
- Post-transplant class, Wednesday 2:30-4:00 p.m.

BMT

- BMT Line teach Monday 2-3 p.m., Wednesday 11:30 a.m. - 12:30 p.m.
- Pre-transplant class Tuesday/Friday 2-3 p.m.

General

- Guided Imagery Tuesday 3-4 p.m.
- Food Safety Wednesday 1-2 p.m.

Heart/Lung Support Group

- Monday 4-5 p.m.
St. Marys Hospital, Mary Brigh building, room 4-510
All heart and lung patients, pre- or post-transplant, are welcome to learn, share and support each other at this respectful and confidential gathering. For more information, call the Heart and Lung Transplant Center at 800-422-6296.

In addition, heart and lung transplant patients receive individualized counseling based on their particular needs. Please consult your coordinator for details.

Share Your Mayo Clinic Story

A new blog for Mayo Clinic patients, friends and staff is available at sharing.mayoclinic.org. It is a global meeting place for patients, families, friends, employees and students of Mayo Clinic; a place where those touched by Mayo Clinic can tell their stories, and where staff can share “behind-the-scenes” insights.

Visit sharing.mayoclinic.org to read recent entries, browse by topic or share your own story.



For More

Information...

For more information on the Mayo Clinic Transplant Center, visit us online at

www.mayoclinic.org/transplantcenter-rst

If you would like your name removed from this mailing list, please call Kathy Schwab at 507-266-2795 or e-mail schwab.kathy@mayo.edu.