MAYO CLINIC

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Renewal

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

Advice From The Heart: Never Forget to Live Life

Every morning, Patti Finnegan wakes up and is thankful for the blessing of a new day to live her life — a blessing she once took for granted.

A working mother of four teenage children, Patti never thought twice about how tired she felt. But in 2003, when she went from being tired to severely fatigued and even short of breath, she decided to consult her doctor. At SSM St. Mary's Health Center in St. Louis, Mo., Patti was diagnosed with liver failure and right-side heart failure. She was scared and uncertain of her future. For awhile, Patti was able to manage the fatigue, weakness and breathing difficulties with medication, but in 2005 her health continued to deteriorate. Debilitated by her symptoms, Patti had to ask herself, "Is this how I want to live the rest of my life?"

In the meantime, specialists at SSM St. Mary's and Saint Louis University Hospital conducted additional tests, but were unable to find a therapy that improved Patti's symptoms. Paul Hauptman, M.D., Patti's cardiologist at Saint Louis University Hospital, recommended that Patti go to Mayo Clinic for another opinion.

At Mayo Clinic, a team of doctors diagnosed Patti with restrictive cardiomyopathy, a condition in which the heart muscle becomes stiff and cannot fill efficiently during diastole (the period of the heartbeat when the chambers fill with blood). Patti's condition was likely caused by a virus; however, she does not know when or where she contracted it.


Patti Finnegan

"I was floored by the diagnosis because I had everything going for me; I was young, active and ate healthy," Patti says.

Patti's care team at Mayo Clinic immediately began conducting tests to determine if Patti was eligible for a heart transplant and/or a liver transplant. They assessed whether other conventional therapies could improve her symptoms and life expectancy without transplantation, considered her risk factors, and evaluated her willingness to adhere to the lifelong regimented medical program that is necessary after transplantation.

At home in St. Louis, Patti found out the day before Thanksgiving in 2006 that she did not need a liver transplant, but she would need a new heart. She was placed on the waiting list at Mayo Clinic.

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Renewal

Mark Stegall, M.D.
Medical Consultant

Elizabeth Rice
Communications Consultant

Yvonne Hubmayr
Freelance Writer

Monica Granrud
Graphic Designer

Rebecca Finseth
and Diana Xin
Contributing Writers

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.

Advice From The Heart: Never Forget to Live Life

Brooks Edwards, M.D. (left)
Soon Park, M.D. (right)

By the first week of December, Patti's condition had grown progressively worse; she could barely maneuver up and down stairways.

"I tried so hard to mask the symptoms from my family and co-workers because I did not want them to worry," says Patti. But she was getting close to her breaking point.

Patti was hospitalized and spent two weeks in the Intensive Care Unit at Saint Louis University Hospital. Her condition deteriorated so quickly that she was airlifted to Mayo Clinic on Dec. 20, 2006. Her physicians found that fluid had been building around her heart. Shortly thereafter, Patti underwent an emergency procedure to drain the fluid.

Brooks Edwards, M.D., Patti's cardiologist at Mayo Clinic, recalls how "desperately ill" Patti was before her transplant.

"She was terribly weak, but had a tremendously strong will and would never give up," says Dr. Edwards. "There were days she seemed too sick to get out of bed, but despite that, she would walk the halls, trying to maintain her strength. She has a will of steel."

Patti's condition was so dire that on March 20, 2007, when the great news came that a matching heart had been found, she was too ill to even remember.

As Patti was wheeled into the preparation area for surgery, she focused on the picture of her and her four children that was attached to the side of her bed.

"My kids are my inspiration, they kept me alive," says Patti.

Patti's children, Alex, Kelsey, Allan and Katie, are shown here with a plaque dedicating a new outpatient physical therapy clinic for SSM Rehab to Patti at a ceremony held in April 2007.

Soon Park, M.D. was the cardiovascular surgeon who performed Patti's transplant. Everything went exactly as planned during her surgery, but now the next battle began.

After receiving her new heart, Patti began her long road to recovery. She struggled with anxiety and disruptive sleep patterns, but her most serious complication came when her blood pressure dropped dangerously low.

"Dr. Edwards sat by my bed side and held my hand," says Patti. "He kept reassuring me that I would make it – even when I was not so certain."

Once Patti's condition had stabilized, she was moved from the Intensive Care Unit and into the Cardiac Care Unit. There, the focus shifted to Patti's appetite. She struggled for days to eat any type of solid food. She desperately needed the nutrients and energy to fight off infection. One afternoon, Dr. Edwards sat down by Patti and asked her," If you could eat anything in the world, what would it be?" Patti decided on a Big Mac and chocolate shake from McDonald's.

"While it is not the heart-healthy menu we routinely advocate, I was just happy to hear Patti was hungry," says Dr. Edwards. "After finishing rounds that day, I stopped at McDonald's and picked up her special request and returned it to her at the hospital. Surprisingly, she ate almost everything!"

Having been in the physical therapy profession for many years, currently as the director of acute therapies at SSM St. Mary's, Patti was committed to getting back on her feet. Patti says that her physical therapist at Mayo Clinic described her as a "star patient," always giving 100 percent at her sessions.

About four weeks after her transplant, Patti was stable enough to leave the hospital. She moved into the Gift of Life Transplant House, where her visiting family members could help her recover, yet she remained close to Mayo Clinic for her frequent appointments. Patti found that those who were staying at the Gift of Life Transplant House were a wonderful support group that kept her humble throughout the recovery process. She found strength in the fact that everyone in the house was striving for the same goal — "to get better and go home."

Patti left the Transplant House and moved home to St. Louis in June 2007. But as excited as she was to finally go home, she was also very nervous.

"Rochester had been a 'safe harbor' for me regarding my health, and I needed to learn to gain trust and confidence in my health system at home," says Patti. "But I took comfort in knowing that my doctors in St. Louis sent me to Mayo Clinic when I needed it most. The level of patient care I experienced at Mayo was better than I could have ever dreamed."

Today, Patti enjoys waking up in her own home with her children and having "regular days." She says she never realized how much she would miss her "regular, old routine," until she did not have it anymore.

Besides being the best mother she can be, Patti plans to devote much of her time and energy to promoting organ donation and heart health for women. One day, Patti would like to meet her heart donor's family. She plans to bring her children along and thank the donor family for their gift of life … a gift that allowed her children to still have a mother.

In the meantime, Patti's motto and her advice to everyone she meets is, "Never forget to live life,"– advice that comes straight from her [new] heart.

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

In Remembrance: Sister Margeen Hoffmann

Sister Margeen Hoffmann and Sister Jean Frances Gregoire on July 4, 2007.

> *"She was the best. She had a beautiful, loving way of treating people and always knew the right thing to say."*

The Mayo Clinic transplant community has lost perhaps its most cherished and valuable cheerleader. On Friday, Aug. 3, Sister Margeen Hoffmann died at age 71. For 16 years, those who stayed at the Gift of Life Transplant House will remember her as its feisty, gregarious and generous executive director.

Born April 25, 1936, in New Ulm, Minn., Sister Margeen entered the Sisters of Saint Francis in 1954. A self-described "disaster nun," she directed the emergency response for the city's churches during the Rochester, Minn., flood of 1978. The following year, she moved to Niagara, N.Y., and spent the next decade helping the people of Love Canal cope with the upheaval in their lives after the hazardous waste environmental disaster.

In 1991, Sister Margeen returned to Rochester as a temporary consultant for the Gift of Life Transplant House — and never left. She was executive director for 16 years. The house, founded by Edward Pompeian, a Mayo Clinic kidney transplant recipient, provides a temporary home for transplant patients.

Eventually, Sister Margeen had plans to expand the house, and she knew the right person to advise on purchasing and renovating buildings. She brought in Sister Jane Frances Gregoire as facilities manager. The two women became best friends and Sister Jane Frances was Sister Margeen's caregiver through the final two years of her struggle with leukemia, diabetes and heart disease. Sister Jane Frances succeeded Sister Margeen as executive director.

"I can't begin to measure up to her skills and gifts," says Sister Jane Frances. "She was the best. She had a beautiful, loving way of treating people and always knew the right thing to say. The way she set up this house has made it very easy to continue our mission. She was so proud of our wonderful working board and staff."

In 1996, Sister Margeen was elected to the Board of Directors of the National Association of Hospital Hospitality Houses, an organization that supports hospital hospitality houses across the country. She was its president for two years. In 1996, she received the Medal of Honor for Community-Wide Services from the mayor of Rochester. On her birthday in 2002, the city honored her with "Sister Margeen Hoffmann Day."

Sister Margeen was also known for her fundraising abilities. "There weren't a lot of periods or commas in her sentences," says Sister Jane Frances with a laugh. "She was very frank, but people just couldn't say no to her. She also loved having fun. She danced for dollars at a dinner dance. People would hand her money and she stuffed it down her dress and kept dancing."

In May, Sister Jane Frances took a weakened Sister Margeen to Florida for a most enjoyable vacation.

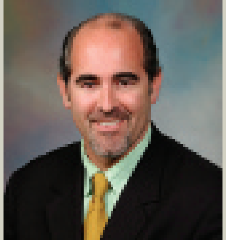
"We got a wheelchair from the Coast Guard with very fat tires and wheeled her right into the ocean," says Sister Jane Frances. "We were up to our waists in water and she just loved it."

Sister Margeen's fun-loving spirit persisted until the end. She will be sorely missed.

For more information about the Gift of Life Transplant House, visit www.gift-of-life.org.

Life Resumes for Runner after Recovery from Kidney Transplant and West Nile Virus

Mikel Prieto, M.D.



Sharon Mulder, kidney transplant recipient, with her husband Roy at the Lincoln Half Marathon in May 2006.

In the late afternoon sun in rural Firth, Neb., a tall shadow joined to a squat one stretches from the gravel road to the tasseled cornfield. The shadows are cast by a runner, Sharon Mulder, age 46, and her dog Peanut. Mulder is a veteran of two U.S. Transplant Games and, after being given a second chance at life, a firm believer in taking good care of her body.

Horseshoe Kidney and Peritoneal Dialysis

Mulder was a young adult when, in 1985, she was diagnosed with horseshoe kidney after seeing her doctor for frequent headaches, fatigue, and nausea and vomiting.

Horseshoe kidney is a common congenital abnormality that forms when the kidneys remain joined at the base, forming a single, U-shaped kidney, instead of separating as they develop. Children born with the condition usually have no signs or symptoms. As in Mulder's case, it often goes undetected for years. Mulder required minimal treatment until 1999 when her kidney function decreased to the point where she needed dialysis.

"I chose peritoneal dialysis because it was so convenient," says Mulder. "I could keep working and also look after my son." Peritoneal dialysis uses the network of tiny blood vessels in the abdomen (peritoneal cavity) to remove waste products and extra fluid from the blood. It requires surgical placement of a catheter into the abdomen. Daytime treatments generally involve connecting the catheter to a bag of sterile fluid that is attached to a pole. The fluid flows into the peritoneal cavity where it remains several hours filtering waste, chemicals and extra fluid. It is then drained into a collection bag.

Mulder, who is a commodity manager for a tool manufacturing company, lives on a farm with her husband, Roy, and their son, Adam, 14. She had very few problems during two and a half years of peritoneal dialysis treatments. Nevertheless, a few months after beginning dialysis, she decided to pursue kidney transplant.

Worth the Wait

Mulder's physician recommended she look into the transplant program at Mayo Clinic.

"My husband and I visited both Mayo and a closer facility and the difference was night and day," says Mulder. "Mayo is a top-notch facility. All of the caregivers are wonderful and I look forward to my checkup every year."

Mulder was listed for kidney transplant in January 2000 and had her transplant on March 19, 2002. The surgery was performed by Mikel Prieto, M.D. Mulder's recovery went well and she was allowed to return home sooner than expected.

A Natural for the Transplant Games

Mulder started running in the fourth grade and, although fatigue slowed her down in the months before and after her transplant, she has never quit. She has run six half-marathons and many other races. She also enjoys strength-training classes and fitness boot camps. She runs three or four miles, four or five times a week, with one of the two family dogs, Peanut and Lucy.

Sharon Mulder competed in the 2006 Transplant Games.

Mulder even remains enthusiastic about running despite her suspicion that the mosquito bite that gave her West Nile Virus in the fall of 2003 happened during a run. There is no cure for West Nile Virus, so physicians can only treat its symptoms. Mulder had nausea and vomiting, headache, stiff neck, ringing in the ears, fever and fatigue and was unable to work full time for several months.

"It took me nine months to recover," says Mulder. "I'm happy that I've regained enough energy to get serious about promoting organ donation. And Peanut and Lucy are happy to be back on their usual runs with me."

Once she had recovered from the transplant and West Nile Virus, Mulder was a natural to compete in the National Kidney Foundation's U.S. Transplant Games.

In 2004 and 2006, Mulder competed in numerous events, including the 400-meter, 800-meter, 1,500-meter and 5k runs; coed 3-on-3 basketball, volleyball and long jump. And she has a stack of gold, silver and bronze medals to show for it.

"At the 2004 Games, we met my donor's family," says Mulder. "They are always in my prayers and in my heart. I had goose bumps all the time at the Games just knowing the reason we were there."

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

Mayo Clinic Staff Profile: Naomi Munene, Certified Diabetes Educator

Naomi Munene, R.N. and Certified Diabetes Educator at Mayo Clinic

Throughout the journey of transplantation, many patients develop lasting friendships with their doctors and caregivers. For Mayo Clinic R.N. and Certified Diabetes Educator Naomi Munene, these relationships are one of the most rewarding parts of her work in the transplant center.

After transplant, certain immunosuppressants such as prednisone may cause patients to develop temporary or ongoing diabetes. "These patients are already totally overwhelmed, and then they're given a new diagnosis — diabetes," says Munene. "Often they have to start taking insulin injections. I try to smooth the way and make it as easy as possible for them."

Patients who had diabetes prior to transplantation may find their diabetes much more difficult to control after the operation. Munene, who has worked in Mayo Clinic's Department of Endocrinology for 35 years, helps patients adjust to having diabetes and helps them acquire the knowledge and skills to self-manage their disease. Self-managing diabetes satisfactorily takes time and energy and can be frustrating.

When patients develop diabetes after transplantation, Munene begins with basics, teaching them only as much as she thinks they can handle at the time. She continually reinforces what they have learned and she provides follow-up care and coaching to patients through telephone calls and return visits. She is always available to answer questions or to troubleshoot if there are problems. Munene emphasizes that patients and caregivers must continue to learn about diabetes and how best to manage it, since there are always new developments that might benefit them.

Tips for Diabetes Management

- Follow your prescribed plan, which may include a meal plan, physical activity or diabetes medication
- Regularly test your blood glucose and record your test results in a logbook
- Use your diabetes educator as a resource

Munene understands the various conditions and stressors in her patients' lives that might affect their blood glucose control, and she is able to take a more personal approach in helping them manage their diabetes.

Although the diabetes management plan varies with each person, Munene recommends:
- Follow your prescribed plan, which may include a meal plan, physical activity or diabetes medication
- Regularly test your blood glucose and record your test results in a logbook
- Use your diabetes educator as a resource

Often, Munene says, her patients become just like family. She enjoys hearing from them and seeing pictures of their families whenever they visit Mayo Clinic. One patient, Mary Jane Bollinger, received a liver transplant in October 1998 and became an insulin-dependent diabetic following her transplant. Bollinger has worked with Munene for the past nine years and is grateful for the outstanding care and friendship that Munene offers her patients.

"She's a very special person," says Bollinger.

> *"It's not just a patient-nurse relationship. I trust her and I feel like I can tell her anything."*

If you have questions about diabetes and transplantation, Munene can be reached at 507-266-3091.

For more information about treatment of diabetes at Mayo Clinic, visit www.mayoclinic.org/diabetes/.

Featured Events

Celebration of Life Picnic

More than 300 people attended the 2007 Mayo Clinic Celebration of Life Picnic, held Saturday, July 7 at Essex Park in Rochester.

2008 U.S. Transplant Games

The 2008 U.S. Transplant Games will be held July 11-16, 2008 in Pittsburgh, Pa. More than 7,000 transplant recipients, donor families, living donors, family members, friends and transplant professionals will come together for this Olympic-style event presented by the National Kidney Foundation.

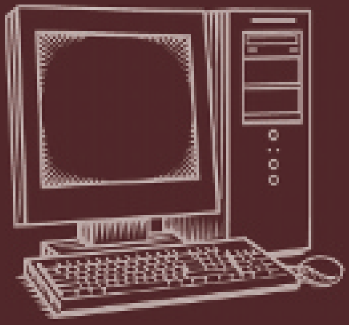
For more information about joining a team or participating in the Games, visit *www.transplantgames.org* or call (866) TX-GAMES.

Join a New Facebook Group: Organ Transplant Patients, Friends and You

A Mayo Clinic heart transplant recipient, Bob Aronson, has started a Facebook group for transplant patients, caregivers, donor families and anyone else interested in organ transplantation. If you have a Facebook profile already, search for “Organ Transplant Patients, Friends and You” and join this group. If you don't have a Facebook page, visit *www.facebook.com* and sign up. Facebook is a free social networking site that helps you connect with other people. The following is a description of the transplant group, in Bob’s words:

”Welcome! This group is for and about people with an interest in organ and tissue transplantation. Please join us in listening, helping, telling stories and sharing experiences. Through interaction with each other, we can encourage donation and have a highly rewarding journey through this exciting time.”

You can also read more about Bob’s heart transplant experience on his blog at *http://bobsnewheart.wordpress.com/*.



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.

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