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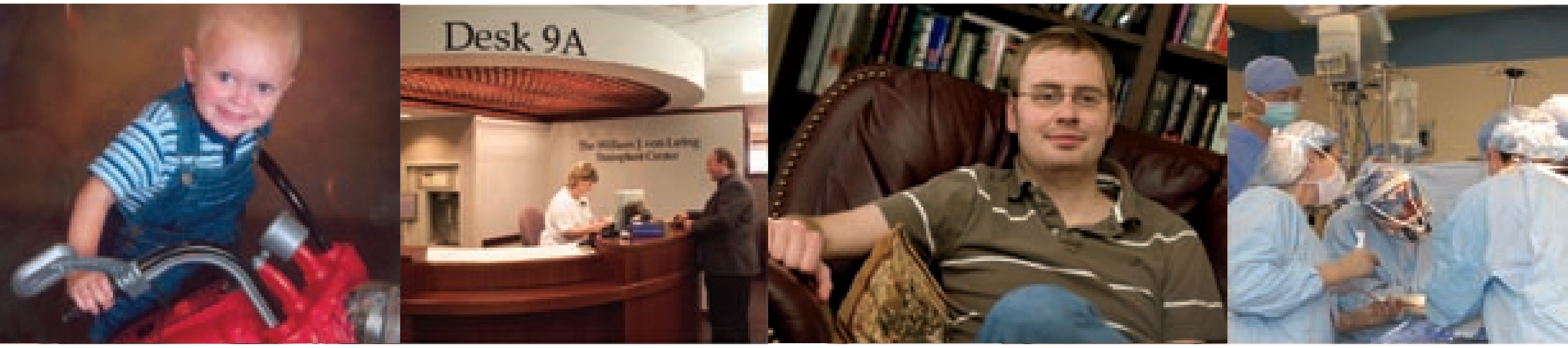


Fall/Winter 2009

Renewal

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

A New Lease On Life: Double Lung Transplant Gives Woman Hope After A Long Struggle

Alejandro Rodriguez and her husband Marcello Diaz at Gift of Life House in August, 2009.

Patricia Alejandra Rodriguez was a 22-year-old newlywed when she started to have respiratory problems. It was 2003, just one year after she and her husband, Marcello, had moved to Italy from Argentina, their native country. After consultations, she says, doctors told her she had psychosomatic asthma and that her illness was likely related to homesickness.

In 2007, however, Rodriguez realized she had a serious health condition. While on vacation in Argentina, she started to feel weak and could not get out of bed. She recalls that a family physician diagnosed a lung problem by observing her abnormal-looking fingernails. A CT scan revealed a serious condition, and doctors in Argentina urged her to get a lung biopsy.

After the lung biopsy and evaluations, doctors in Italy were still unable to pinpoint what was causing the decreased pulmonary capacity. By December 2007, Alejandra required oxygen therapy, and by March 2008 she needed over 2 liters of oxygen per minute. Her illness was advancing rapidly.

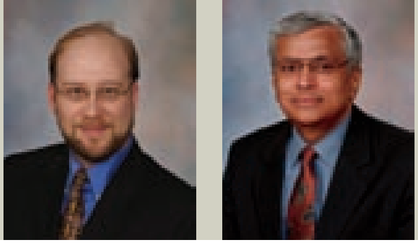
A fight against time

Rodriguez says her doctors determined that the only solution was a double lung transplant. In Italy the wait for an organ would be at least four years. Unfortunately, she could not wait that long.

– Continued on page 2.

On the inside...

A New Lease On Life - *continued*



Stephen Cassivi, M.D. (left)
Udaya Prakash, M.D. (right)

With the support of her employer in Italy, the young couple pursued the referral from her local doctors to Mayo Clinic in Rochester, Minn. “We worked with Mayo’s international appointment office and got a response right away,” says Marcello.

The couple arrived in Rochester in July 2008, and met with pulmonologist Udaya Prakash, M.D. After a series of exams, Mayo physicians diagnosed severe pulmonary fibrosis and also recommended a double lung transplant. Dr. Prakash and the consulting team of physicians concluded that Rodriguez needed to stay in Rochester until suitable lungs were found for transplantation. With the help of both Sharri Kalgren of the Mayo Clinic patient affairs office and an outside immigration attorney, the couple secured the special visa required to remain in the U.S. “Sharri ‘adopted’ us and went the extra mile to help us,” says Rodriguez.

Pulmonary rehabilitation

During the wait, Rodriguez participated in a pulmonary rehabilitation program — essential for patients with chronic respiratory disease. “The Mayo staff motivated Rodriguez and provided moral support,” says her husband. “Thanks to them, she arrived in great shape for her transplant.”

The wait was long, close to nine months. Finally, on the morning of April 23, 2009, Stephen Cassivi, M.D., thoracic surgeon and director of lung transplantation at Mayo Clinic, informed them that donor lungs were available for Rodriguez. The double lung transplant took place later that day. The left lung was replaced just after 8 p.m. and the right one just before 9:30 p.m. Dr. Cassivi and the surgical team operated on Rodriguez for more than seven hours.

“Even after being involved in close to 200 lung transplant procedures during my career, each one remains a very special opportunity to give someone a second chance at life,” says Dr. Cassivi. “We were very fortunate to find a donor for Rodriguez when we did. She was very sick. It is a testament to both the excellent care she received while waiting for her transplant and her own strength of will that she was able to survive until her transplant opportunity came.”

After recovering in Rochester for three months, Rodriguez and Diaz returned to Italy. Although Rodriguez will always remain a Mayo Clinic patient and her progress will be closely monitored by Mayo Clinic physicians, she will continue her general follow-up care in Italy.

> ***“I will always treasure my experience at Mayo Clinic. Despite my condition, I never lost confidence in their ability to help me.”***

“I will always treasure my experience at Mayo Clinic. Despite my condition, I never lost confidence in their ability to help me,” she says. “From the caring physicians and nurses to the interpreters who surprised me with a birthday party, there is a culture of pride and compassion that permeates the institution. No one can do medicine with a human touch like Mayo Clinic.”

For more information about pediatric liver transplant at Mayo Clinic, visit *http://www.mayoclinic.org/lung-transplant/*.

Renewal

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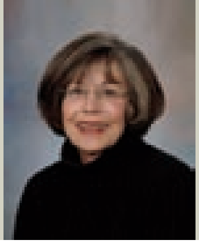
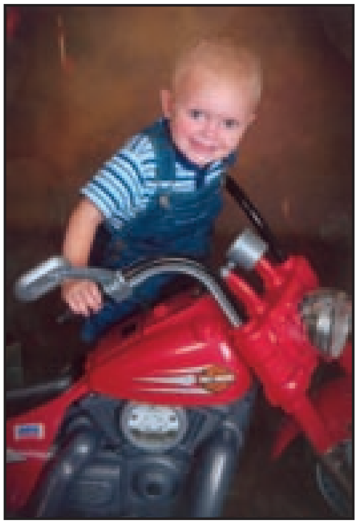
Mayo Clinic has offered transplantation as a treatment option for adult and pediatric patients since 1963. Mayo Clinic organ transplant programs have earned worldwide recognition for their expertise and success. In 1998 the separate organ and tissue transplant efforts united under the umbrella of the 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.

New Liver Brings Giggles and Mischief


Deborah Freese, M.D.


Hunter Little

Tiffany Little and her husband, Mike, wondered why their son Hunter wasn't as happy and cheerful as other 4-month-olds, but they thought that was just his personality. He had constant colds, ear infections and his stomach was distended, but the couple say the physicians they saw insisted that each affliction was "just a phase."

"It seemed like something worse was going on, but I remember we were told he would grow out of it," said Little, of River Falls, Wis.

Further tests found that Hunter's liver enzymes were "off the charts" high, according to Little. Additional investigation led to a diagnosis of alpha-1 antitrypsin (AAT) deficiency. AAT is a protein predominantly made in the liver and secreted into the bloodstream and helps protect the lungs. In most infants and children who have the disorder, AAT deficiency affects the liver.

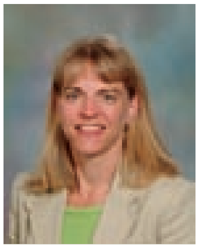
Hunter's condition didn't respond well to treatment with medication, and he was referred to Deborah Freese, M.D., a pediatric gastroenterologist, at Mayo Clinic in December 2007 for liver transplant evaluation.

After an initial workup, Hunter returned home. Christmas was hard, Little said, because they knew their son would have a liver transplant. After a brief hospitalization on Jan. 3, Hunter returned to Saint Marys Hospital on Jan. 6. "We learned then that he would wait in the hospital for a transplant," says Little. He was getting sick fast, she recalls.

Little, who at that time worked in the endocrine lab at Mayo, decided for financial reasons to try to work during Hunter's hospitalization. Family would stay with Hunter while she was in the lab. One evening, she made the 90-minute trip home to River Falls to get work clothes while Mike stayed with Hunter in Rochester. The next morning, she remembers, Mike called to see if she had left home yet, and he said, "You better get here soon. They found a liver." "Hunter had only been on the list six days, so I didn't expect to receive the call yet. We were nervous and relieved, but also sad for the other family who just lost a loved one," she says.

Hunter received a liver transplant on Jan. 19, 2008. Michael Ishitani, M.D., a pediatric liver transplant surgeon, performed the procedure, and Jodi Weckwerth, physician assistant, followed Hunter throughout his recovery.


Michael Ishitani, M.D.


Jodi Weckwerth, P.A.

"I remember very well caring for Hunter in the weeks just prior to his transplant. It seemed as though his condition worsened a bit every day and we knew his liver was failing. There wasn't much good news we could offer his parents at that time," recalls Weckwerth. "He was very fortunate to receive a donor liver as quickly as he did, and he recovered from the operation more quickly than most infants. Within a short time we were able to finally see the 'real' Hunter—playful, inquisitive and smiling! It is a privilege to care for Hunter."

Little says her family felt especially cared for at Mayo Clinic. "Anytime we needed anything, the doctors and nurses were always there. I knew they were taking care of Hunter," she says. She recalls two nurses from the pediatric intensive care unit. "Crystal and Amy will forever be in our hearts," she said, for the care they gave Hunter.

The Littles lived at the Ronald McDonald House in Rochester for about two months following Hunter's release from the hospital on Jan. 27, only seven days after his transplant. Being just a few blocks from Saint Marys Hospital was so convenient for check-ups and the single bout of rejection Hunter dealt with following surgery, said Little.

Little notes that the transplant brought about many changes in their lives, including her decision to become a stay-at-home mom to keep Hunter out of childcare. "I loved my work, but it's important when he's so young to protect him from infection," she said.

Now, two years later, Hunter is a rambunctious 2-year-old who recently tossed his mother's digital camera into a bathtub full of water. "This transplant made him into the child he was supposed to be," said Little. "Looking back, he never smiled or laughed much because he didn't feel well. Shortly after he came out of recovery, he laughed a laugh that I'll never forget, just because he had the hiccups. From then on, we've said he got a giggly liver."

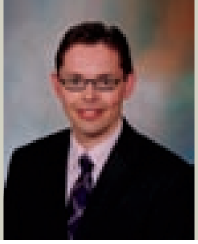
Editor's note: At the time of this writing, the Littles are expecting their second child, a boy who will be named Hayden. Tiffany Little says that they were scared at the thought of a second child being affected by the same disease as Hunter. "We felt in our hearts that we wanted a second child, and that God would decide the outcome of this child and the disease," she says. Little also says that they were reassured by their physician that the odds were very small for another child to have to endure what Hunter went through. "Now we know what to test for and what to watch for, as well as where to go — Mayo Clinic," said Little.

For more information about pediatric liver transplant at Mayo Clinic, visit ***www.mayoclinic.org/liver-transplant/children.html***.

College Student Encourages Others to Save a Life

Save a Life – Be A Donor!

William Hogan, M.B., B.Ch.



Andrew Dorfschmidt, his sister Katy, and the family dog.

Early in the day on Nov. 17, 2005, Andrew Dorfschmidt was a typical 19-year-old, college freshman at South Dakota School of Mines and Technology in Rapid City, S.D., preparing for exams. He had recently had the stomach flu and thought he might have mononucleosis, but he was trying to complete his first semester in college. Dorfschmidt was planning to go home and see his family physician the next week.

Twelve hours later, his parents, Dan and Julie, were spending their evening at home in Bismarck, N.D., a five-hour drive away, when they received a call from his roommate that Andrew was so sick that that friends were driving him to the emergency room. Just 45 minutes later, Dorfschmidt's parents received the shocking call from the medical center that Dorfschmidt had leukemia, had become septic, and had multiple organ failure.

Dorfschmidt's parents immediately made the long drive to Rapid City. When they arrived, their son was on a ventilator in the ICU. Three weeks later, Dorfschmidt had improved with treatment, and his family was able to transfer him to the hospital in Bismarck where he received additional standard chemotherapy and went into remission just after the holidays. "Due to the degree of organ failure, he was unable to start standard chemotherapy for his leukemia immediately. He was started on a modified regiment of chemotherapy until he recovered sufficiently to be able to tolerate standard chemotherapy," says William Hogan, M.B., B.Ch., hematologist at Mayo Clinic Transplant Center.

When Dorfschmidt's oncologist in Rapid City had originally discussed the situation with Dorfschmidt, he was well prepared and informed and had already contacted several other medical centers, including Mayo Clinic in Rochester, Minn. "Dorfschmidt required a transplant to help prevent future recurrence of the leukemia due to a rare chromosomal abnormality that was just one component of his condition," says Hogan.

"After discussing the options, we chose Mayo Clinic because of its well-known reputation, its proximity to home, and our strong belief that Mayo Clinic would do everything it could to get me back on my feet," says Dorfschmidt.

On Jan. 9, 2006, Dorfschmidt and his mom had their first meeting with Hogan at Mayo Clinic. Soon after, Dorfschmidt and his family were back at Mayo for a peripheral blood stem cell transplant with his younger sister Katy, 19, who was a perfect-match donor for the needed cells. Following his transplant, Dorfschmidt stayed at the Gift of Life Transplant House in Rochester until his return home in mid-April.

Dorfschmidt is now healthy and doing well and has returned to college in Rapid City, where he is involved in intramural sports and lives in a fraternity house. His fraternity is very involved in the community, and last fall he helped orient new freshmen to the college campus and Rapid City. He is studying computer engineering at his parents' alma mater, and living as a typical college student with his fraternity brothers, who he says are "irreplaceable."

Dorfschmidt says, "I plan to graduate next year and hope to find a job that I love doing. Most of all, I just hope to stay healthy and hope for the best, and I'm thankful for every day that I am healthy."

Dorfschmidt has a great sense of appreciation from his journey. "The whole experience, now looking back, was the worst roller coaster ride that I've ever experienced and is hard to sum up in a few words," he says. "I am eternally grateful to my sister, my donor; my family, who all donated a piece of themselves; the doctors, who did everything I expected and could hope for; and friends, who sent cards, e-mails, phone calls, or maybe just sat and watched 'Jeopardy' with me."

Dorfschmidt and his family understand the need for organ donation. At the time of his transplant, Dorfschmidt gave extra marrow to be used in research and participated in an educational video to be used for other transplant patients. Katy, who is now a sophomore in college, made sure that she and her parents were tested and are now listed on the national bone marrow registry.

Andrew Dorfschmidt with his sister Katy, his donor, while she is donating her cells.

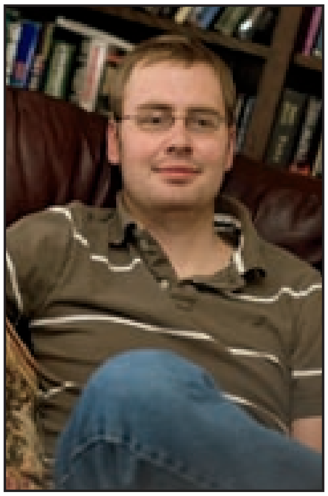
Dorfschmidt's advice for others is very encouraging. "It's hard to sum up the need for hope and determination that one must possess for such a journey, the little glimmers of positive in a gloomy time, the thoughts of what could happen tomorrow to help push forward," he says. "I would not wish it upon anyone, yet I am, in a way, thankful for the outlook and resolve it gave me."

Sounding a little like the typical college student that he is, Dorfschmidt offers this personal motto: "Look forward to tomorrow, be thankful for today; and save a life, be a donor."

For more information about bone marrow transplant at Mayo Clinic, visit ***http://www.mayoclinic.org/bone-marrow-transplant/***.

A Student's Success

Rick Nishimura, M.D.



Ryan Sule

As a freshman at Northern Michigan University (NMU) in Marquette in the fall of 2004, Ryan Sule expected to spend his first night in a dorm room. Instead, he landed in the emergency room after collapsing helping to carry a large television.

Sule was diagnosed with hypertrophic cardiomyopathy, a disease in which the heart muscle becomes thick and cannot pump blood efficiently. It is the leading cause of heart-related sudden death in people under age 30, but Ryan was determined not to fall victim to the same disease that took his mother's life at an early age.

Because his mother had the condition, Sule was at high risk. His childhood doctors, he says, maintained that he was too young and healthy for the disease to be a danger. Sule, meanwhile, struggled with physical activity. "I wasn't good at sports and would get tired very quickly," he says.

Sule was transferred from a hospital in Marquette to Mayo Clinic, where physicians diagnosed the disease and prescribed medication. He went back to school, working on a degree in Human Geography. Sule met his future wife, Jyssica, at NMU, and she has supported him throughout the treatment.

In 2004, Sule had a pacemaker implanted, and in 2006, a second lead was added for extra power to the device. Despite the series of appointments and hospital stays, Sule continued to take online courses to move him toward graduation.

Sule's step-parents, whom he refers to as his mother and father, moved to live near him in 2004 to help with anything he needed. Ryan's siblings, three sisters and two brothers, provided support from a distance. "My brother created a Web site for me to tell my story," Ryan said.

As Sule's condition worsened, his Mayo Clinic physician, Rick Nishimura, M.D., advised him to join the heart transplant list in the spring of 2008.

"Ryan was a healthy kid going to college with no idea of what was going on with his heart. He basically had a type of 'sudden death' with his collapse," says Dr. Nishimura. "Most doctors only see one or two of these cases in their entire practice. At Mayo Clinic, we've seen over 3,500 hypertrophic cardiomyopathy patients."

Sule understood that heart transplant might eventually need to be considered, and it became apparent that there were no longer other options. A big part of his decision to go on the list was that he was now engaged to be married.

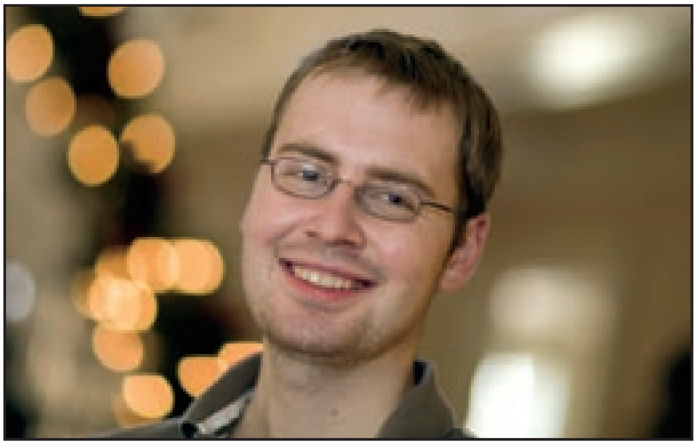
"We didn't want to set a date for the wedding," Jyssica said. "We didn't know when he would get the heart or be ready, and I was willing to wait."

In October 2008, Sule, who had been staying at Gift of Life Transplant House in Rochester, got the call that a heart was available for him. "I started calling everyone. I went outside and ran into my mother as I was calling her. We were ecstatic," Sule recalls.

When Sule awoke following surgery, he was given a marker board to communicate. His first written words were, "Thank you" to the transplant team, and he was off the ventilator within 12 hours. Just a few days after the surgery, he stopped taking powerful painkillers and began taking long walks with nurses.

"I wanted to get my energy back. I wasn't in much pain but I was tired too often," Sule says. "It just takes time, but the recovery is nothing compared to waiting for the heart."

Sule's mother, Karen Hendricks, however, didn't even notice the time. "It just went so quickly. We were hoping, and then he got the heart. It's like your son got a new lease on life, and I don't think anything could be better than that," she says.



Ryan Sule

Sule and Jyssica married on Dec. 20, 2008, in Rochester. He graduated from NMU in 2009. The young newlyweds moved from northern Michigan to Inver Grove Heights, Minnesota, a Minneapolis-St. Paul suburb, to be closer to Mayo Clinic for the first couple of years during his recovery. They enjoy the urban lifestyle of attending Minnesota Twins baseball games, seeing concerts at Target Center and visiting the museums of St. Paul.

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

Staff Profile:
Kathy Schwab, R.N., Compliance Coordinator, Transplant Center

Kathy Schwab, R.N., Compliance Coordinator

> *"I am proud to be a part of efforts where everyone has an opportunity to continually learn and continually teach others. This is part of why I love my job every day."*

Kathy Schwab, R.N., was honored Sept. 30, 2009, as a "Regional Champion" at the Awards Gala of the U.S. Department of Health and Human Services' Health Resources and Services Administration (HRSA) national meeting in Dallas.

Schwab was selected as one of 11 professionals nationally to receive this award for making a difference and positive impact on the field of donation and transplantation through their dedication, passion and diligent work.

Schwab was nominated not only for her work at Mayo Clinic, but also for her participation and leadership on several national collaborative groups that work toward improvements in organ donation, transplants and best-practice sharing. The goals of these collaborative groups include working to dramatically increase the availability of transplantable organs and successful screening, consent, placement and successful transplantation, and spreading these best practices to hospitals across the nation to help them become more effective and prepared in their transplant programs.

Schwab prides herself on being a constant learner in an ever-changing environment. "I am proud to be a part of efforts where everyone has an opportunity to continually learn and continually teach others. This is part of why I love my job every day," says Schwab.

She was nominated by a colleague who stated, "Kathy is always a beacon for donation as her energy and passion to saving lives shines through every day! It is an honor to work with her and a privilege to nominate her!"

Receiving the award was especially exciting for Schwab because, she says, she "was honored by the nomination itself."

Schwab is a registered nurse who works as a compliance coordinator for the Mayo Clinic Transplant Center in Rochester, Minn. She has worked at Mayo Clinic since 1992, serving as a clinical nurse manager for eight years and eight years as a heart/lung transplant coordinator.

2010 U.S. Transplant Games

The 2010 U.S. Transplant Games will be held July 30 through Aug. 4, 2010, in Madison, Wis. 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.

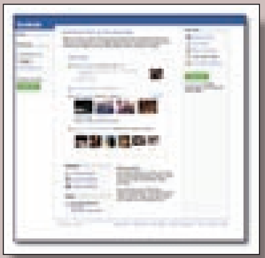
For more information about joining a team or participating in the Games, visit *www.transplantgames.org* or call 866-TX-GAMES (toll-free).

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.

To 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, you can search for "Organ Transplant Patients, Friends and You," and join this group. If you don't have a Facebook profile, you can 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

Heart/Lung Support Group
Mondays, 4-5 p.m.

Saint 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 (toll-free).

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

Gift of Life 5k/10k, September 2009

Gift of Life Transplant House held its first annual Gift of Life 5K/10K on Sept. 13, 2009.

By the numbers:
Funds raised: $1,800
Finishers: 108
Transplant Participants: 5
Volunteers: 32
Lead bikers: 3
Cases of bananas: 2
Bottles of Propel fitness water: 240
Bottles of water: 240
(donated by HyVee)
Bread nuggets: 300
(donated by Bread Baker)
Water stop: 1

Be sure to save Sept. 12, 2010, for the second-annual Gift of Life 5K/10K!

Gift of Life House Grand Opening, Oct. 17, 2009

Gift of Life Transplant House in Rochester, Minn., provides 30,000 guest nights per year to transplant patients and caregivers. As of Oct. 17, 2009, Gift of Life House is able to offer more nights as it has expanded into its completed second location, across the street from the original house.

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 is a handicapped-accessible, 36-unit home located across the street from the original Gift of Life property. Amenities include kitchens, dining areas, a surrounding porch, gardens and parking. Common spaces are large for social gatherings, while other spaces are set aside for reflection and solitude. Most importantly, the new house continues Gift of Life's mission to help and heal.

For more information on the Gift of Life House, please visit *www.Gift-of-Life.org* or call 507-288-7470.

MAYO CLINIC

200 First Street SW
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www.mayoclinic.org

For More

Information…

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Transplant Center, visit us online at
www.mayoclinic.org/transplantcenter-rst

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