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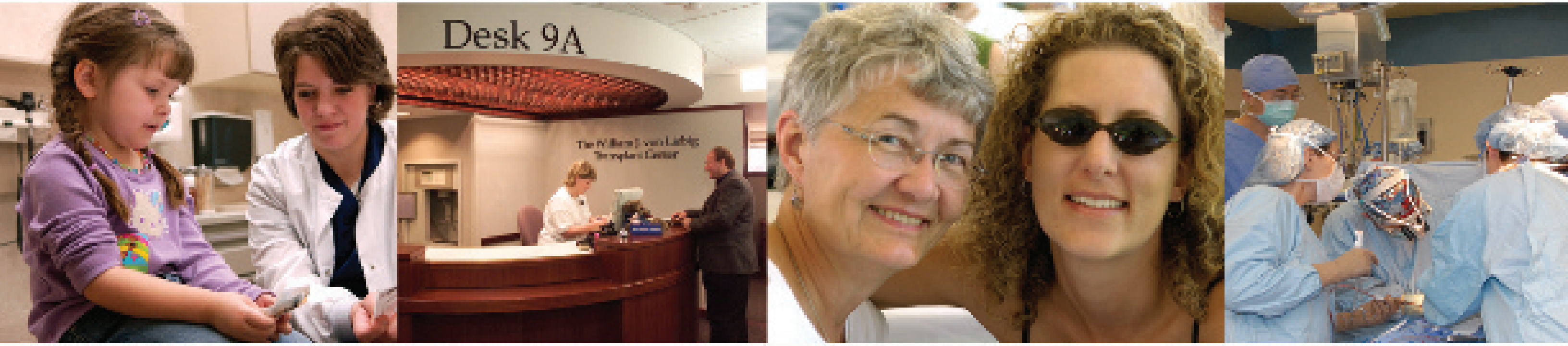

Spring/Summer 2007

Renewal

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

Two men, strangers to each other, but a liver in common

In July 2004, the Mayo Clinic transplant surgery team began a combined heart and liver transplant for 58-year-old Joe Brassell. Waiting anxiously was Thomas Needham, praying that Brassell's combined transplant would be successful. Needham had never met Brassell — and didn't even know his name. But Brassell's transplant was vital for Needham's survival. If all went as planned, Needham would receive Brassell's liver in a domino transplant procedure.

Joe Brassell enjoys spending time with his granddaughter, Jolie.

Joe Brassell's Story

An electrical contractor from just outside Philadelphia, Brassell lived a healthy lifestyle. He went to the gym at 5:30 every morning and jogged three miles a day. But in 2003, during his annual checkup and physical, his primary physician, Dr. Mannino, heard a small clicking noise in Brassell's heart. Brassell was told he had hypertrophic cardiomyopathy, a complex cardiac disease where the heart muscle thickens. He began taking medication to help relax and reduce the obstruction in his heart. But nearly a year later, while vacationing with his family, Brassell began to have worrisome symptoms.

"By the end of our vacation, I couldn't finish a meal and could hardly walk up the stairs," says Brassell. "My stomach was expanded and I had shortness of breath."

Back home in Pennsylvania, Brassell went to his primary physician and learned he was in heart failure. After consulting other physicians in the area, primary amyloidosis was suspected as the cause. However, disagreement about treatments led Brassell to finally ask one physician, "What would you do if you were me?"

"Joe," advised the physician. "I think I would go to Mayo Clinic and get a second opinion."

And that is what he did.

In early May 2004, Brassell and his wife, Dot, arrived at Mayo Clinic. After Brassell met with a team of Mayo physicians, he was told that he did not have primary amyloidosis; instead he had familial amyloidosis, a genetic condition that caused his liver to produce excessive amounts of the amyloid protein. This protein can build up in different parts of the body, especially the heart, and cause permanent damage. Familial amyloidosis is very rare, and the only current cure is a liver transplant to remove the source of the protein production.

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On the inside...

Renewal

Mark Stegall, M.D.
Medical Consultant

Elizabeth Rice
Communications Consultant

Yvonne Hubmayr
Freelance Writer

Monica Granrud
Graphic Designer

Brian Olson
Contributing Writer

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.

Two men, strangers to each other, but a liver in common *- continued*

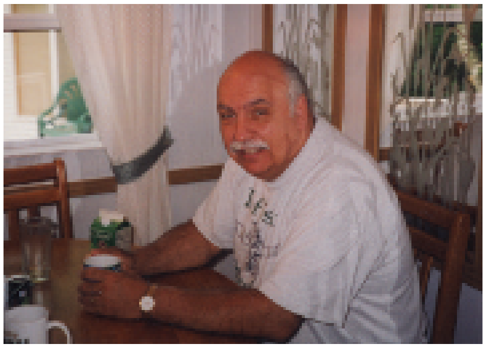
Joseph A. Dearani, M.D. (left)
Charles B. Rosen, M.D. (right)

Because the condition had seriously damaged his heart, Brassell needed a combined heart and liver transplant. Without the transplant, he was told, he had about two months to live.

Here, Brassell's story takes an almost ironic twist. The amyloid proteins in his liver had irreversibly damaged his heart. But, because those proteins take 30 or more years to cause problems, Brassell's liver could be transplanted into someone over 50 years old who likely would not experience negative effects during his or her lifetime. Mayo Clinic transplant surgeon Charles Rosen, M.D., explained this to Brassell and asked if he would be willing to donate his original liver to another patient after the transplant. This rare combination of surgeries is called a domino transplant. In 2006, only eight domino liver transplants were done in the United States. Mayo Clinic surgeons have performed 10 domino liver transplants since April 2000.

Brassell quickly agreed because, he said, he would love to help another person.

Thomas Needham's Story



Just over seven months earlier, Thomas Needham's local physician, after conducting routine blood tests, determined Needham's diabetes was "out-of-control."

Needham, 57, of New Prague, Minn., was referred to an endocrinologist and a liver biopsy showed he needed a transplant. Needham planned to go to the University of Minnesota Transplant Center because of its proximity to his hometown, but insurance considerations led him to Mayo Clinic.

"At first I was a little frustrated because Rochester was 90 miles away," says Needham. "But as soon as I was at Mayo for the first time, I was definitely happy to be there. The testing was very thorough, and the doctors and nurses — every single person, really — were top quality. I knew I could trust my Mayo team and I just felt like everything was right."

At Mayo Clinic, Needham learned that without a transplant he had about two weeks to live. A matching donor became available just two days later and Needham received a combined liver and kidney transplant. But four months later, Needham developed a septic infection that destroyed the hepatic artery on his new liver. He was devastated to learn he would need a second liver transplant as soon as possible.

"The first thing I thought about was going back on the liver transplant waiting list — with 350 people in our region ahead of me," says Needham. "I didn't think I'd live long enough to get another liver."

Dr. Rosen also was concerned about Needham getting a transplant in time. He appealed to the United Network for Organ Sharing, the organization that facilitates organ donation and transplantation in the United States, to get Needham moved up on the liver transplant waiting list. The appeal was rejected twice, but Dr. Rosen didn't give up.

It was then that he told Needham about a patient who was waiting for a heart and liver transplant due to amyloidosis. Dr. Rosen explained that the patient's original liver would likely last another 30 years so he proposed a domino liver transplant. Needham quickly agreed.

"Since I didn't know if I'd make it another two weeks with my current liver, 30 more years sounded great to me," says Needham.

Needham began praying for a heart and liver for a man he had never met.

Transplant(s) Day

Six weeks after Brassell began his wait at Mayo Clinic, and one week after Needham learned about the domino liver transplant option, a matching heart and liver became available for Brassell.

"The moment brought unbelievable happiness," explains Brassell. "I wanted to jump up and down, but then reality kicked in that someone else had died for these organs to be available to me. That's a pretty depressing thought."

Brassell was taken to the operating room at Saint Marys Hospital on Sunday evening. Mayo Clinic surgeon, Joseph Dearani, M.D., performed the heart transplant and Dr. Rosen performed the liver transplant. The procedure ended Monday morning.

During the 18-hour operation, Needham waited anxiously.

"The most difficult part of the waiting process for me was not knowing if he (Brassell) was going to be okay," says Needham. "The only way I'd have a chance at getting his liver was if the surgeons were successful with his heart and liver transplant."

Finally, there was good news. Brassell's transplant was a success and his original liver was a match for Needham. That morning as one transplant was completed, another began. Both were successful.

Trust and hope for the future

Today, both men are healthy and thankful for the care they received at Mayo Clinic.

"There are fine doctors and nurses back home in Philadelphia, but they aren't all at the same hospital," says Brassell. "At Mayo Clinic all the best people really are in the same place."

"I wouldn't have anyone's hands but Dr. Rosen's take care of me. I had complete faith in him," says Needham. "At Mayo it's not just one patient and one doctor — it's a team. Every morning there would be 10 to 12 people in my room, talking to me and keeping me abreast of every aspect of my care. I can't even begin to thank everyone."

Mayo Clinic's primary value, "the needs of the patient come first," meant trust and hope for two men, strangers to each other, but now, a liver in common. To date, Brassell and Needham have not yet met, but they hope to do so soon.

The Ride of a Lifetime

George Chow, M.D. (left)
Michael Ishitani, M.D. (right)

Tyson Wood donated a kidney to his sister, Lacey.

Thanks to my brother I have a normal life once again! My brother is my hero and I am so proud of him!

These words, written by 17-year-old Lacey Wood of Placerville, Calif., were part of an essay that won her 19-year-old brother, Tyson, the ride of a lifetime on the Donate Life float in the 2007 Tournament of Roses Parade. Tyson donated one of his kidneys to Lacey in July 2006, but Lacey's first experience with organ transplantation was more than 15 years earlier.

When she was an infant, a virus attacked Lacey's heart. She received a heart transplant at 18 months old. As a result, she has always considered herself lucky to be alive.

"Lacey truly embraces life and she's always going full speed," says her mother, Colleen Wood. "She's played basketball, volleyball, Little League, acted as student body president ... the list goes on."

But Lacey has never forgotten the gift of life she received as an infant. To honor her donor and help promote organ donation, she has been involved with her local organ procurement organization, lobbied for the California donor registry, participated in multiple Transplant Games and attended several TACKERS Transplant Adventure Camps in Switzerland.

Lacey's passion for promoting organ donation was (and is) fueled by her desire to help the 95,000 people in the United States who need an organ transplant. Little did she know that she'd be one of those people again — before she even finished high school.

Wanted: Kidney

During her sophomore year in 2005, Lacey became severely dehydrated after a bout with pneumonia. Her physicians discovered multiple blood clots and gout, and a biopsy showed she was in kidney failure. Lacey was diagnosed with focal segmental glomerulosclerosis (FSGS), a disease that affects kidney function due to scarring or hardening of tiny blood vessels within the kidney, and she was told she needed a kidney transplant. Lacey and Colleen traveled to Rochester, Minn., for a second opinion at Mayo Clinic.

"When we got here, everything just felt right," says Colleen. "The doctors here confirmed that Lacey needed a kidney transplant, so we decided the best-case scenario would be to have it done at Mayo."

Colleen, Tyson and Lacey's father, Grayson, were tested as possible living kidney donors. While they each wanted to give Lacey a kidney, they agreed that whoever was the best match would be the donor. Tyson was the "winner," as he was a near-perfect match with Lacey.

"I was happy that I was the best match because I really wanted to be the one," says Tyson. "I thought that by being the donor I could get a better insight into what Lacey goes through every day."

On July 18, 2006, at Mayo Clinic, George Chow, M.D., removed one of Tyson's kidneys, and Michael Ishitani, M.D., transplanted it into Lacey. Both procedures were successful.

"Tyson did great, he was back to his normal self in just a couple days," says Lacey. "And as for me, just a month later I was able to do everything again!"

The Ride

About a month after the transplant, while Lacey was trying to think how to honor her brother for his generous gift, she learned of the Ride of a Lifetime Contest. The contest gave transplant recipients the opportunity to nominate their living organ donor to participate in the Rose Parade by submitting an essay summarizing what the gift of life meant to them.

Donate Life Float at 2007 Rose Parade

Three hours before the deadline for entries, Lacey quickly wrote and submitted an essay describing Tyson's unselfish gift. One month later, the Wood family learned that Tyson was chosen as one of five winners from more than 150 entries.

Tyson and Lacey traveled to Pasadena, Calif., in late December. They met other organ donors and recipients from around the country, worked with the Donate Life team to help build the Rose Parade float and attended special receptions honoring the donors. On Jan. 1, 2007, Tyson rode on the Donate Life "Giving from the Heart" float.

Tyson describes the Rose Parade experience as incredible. But, he says, he didn't need any recognition for his gift to Lacey.

"I would do it all over again, if I had to, if I had another kidney. But I am running a little low on those," says Tyson.

Mayo Clinic's 100th Lung Transplant

Stephen D. Cassivi, M.D. (left)
Mark Brutinel, M.D. (right)

Linda Bilodeau enjoys baking cookies with her grandchildren.

August 25, 2006: A Milestone Lung Transplant for Mayo — and for Linda

The smell of freshly baked cookies wafts from Linda Bilodeau's, Chetek, Wisconsin kitchen. She beams at her grandchildren Kyle and Mariah, ages 5 and 3, who can't wait to dip grandma's special Cherry Chocolate Surprise Cookies in chocolate. Linda, age 55, treasures such times more than most grandmothers. Before her lung transplant, she couldn't do much of anything, let alone take care of two energetic children.

A Teenage Decision Comes Home

Linda started smoking at age 16. She says it's the most foolish thing she ever did — that's what caused her emphysema. Diagnosed in 1990, and tethered to an oxygen tank for six years, she was short of breath, weak, and missed out on much that is good about life. By October 2005, it was clear that only a lung transplant could save her. In February, 2006, following evaluation and extensive tests at Mayo Clinic, Linda was placed on the lung transplant waiting list and encouraged to begin an exercise program.

"Our goal is to return the patient to an independent, high quality life, and the fitter they are at the time of transplant, the greater the chances for that," says transplant lung specialist Mark Brutinel, M.D. "Patients are evaluated in our Pulmonary Rehabilitation Program where an exercise program is tailored to individual ability and needs. We also treat underlying non-pulmonary diseases and aggressively manage their lung disease to optimize their health before the lung transplant."

Mayo's Milestone Transplant

On August 25, 2006, Linda became the 100th person to receive a lung transplant at Mayo Clinic in Rochester, Minn. The lung transplant, which was performed by thoracic surgeon, Stephen Cassivi, M.D., took about six hours and went well.

"Our lung transplant team was honored to be able to perform this transplant surgery for Linda. It was also a special milestone for our program, which has continued to grow since our first lung transplant was done in 1990. As anyone who has been involved in lung transplantation knows, each successful transplant takes an enormous amount of meticulous planning, cooperative teamwork and outright hard work," says Dr. Cassivi. "As surgical director of the Mayo Clinic lung transplant program, I am particularly proud of our program's accomplishments on behalf of our patients."

For Linda, the transplant was a very significant accomplishment.

> *"When I woke up, it was like someone had turned a switch back on for me," exclaims Linda. "I could breathe!"*

Linda recuperated at the Gift of Life Transplant House with her husband, Robert, at her side. She worked hard to regain her fitness and was rewarded by being allowed to go home in time to celebrate her October birthday.

Riding Into a Renewed Life

Linda shows her appreciation to her donor by taking good care of herself. She works out every day and checks her lung function, temperature, weight, blood pressure and blood sugar regularly. She says she would have the transplant over again in a heartbeat.

"Now I can take care of my grandchildren for a whole week at a time. And at Thanksgiving, I was able to continue my mother's tradition of making lefse for the deer hunters."

Perhaps she and Robert also started a new tradition that day. Robert had purchased a Harley Davidson motorcycle two and a half years before her transplant, but Linda could never catch enough breath to ride along. On that chilly Thanksgiving Day, Robert quit hunting early to surprise Linda with her first bike ride. She donned her long johns, took a deep breath, and grinned as they rode off into their renewed life.

Members of the surgical team who were involved in the 100th lung transplant.

Miracle Babies Deliver Joy after BMT

Mark Litzow, M.D.

Clint and Barbara Thesing, of Fort Ripley, Minn., feel especially blessed. Their son, Justin, now age 11, was just 6 weeks old when Clint was diagnosed with acute myelogenous leukemia (AML) — a cancer of the blood and bone marrow. Clint's treatment included very high doses of chemotherapy and total-body radiation therapy, which usually results in sterility.

"The recovery of sterility in patients like Clint — who have undergone both chemotherapy and radiation — is quite rare," says Mark Litzow, M.D., a Mayo hematologist. "We did not expect him to father any more children."

But Barbara wanted more children badly. On Sept. 30, 2004, Clint visited his great-grandmother's grave and prayed that she help Barbara come to grips with the realization that Justin would never have siblings.

"Nine months to the day — June 30, 2005 — we had Julia," says Barbara. "We named her after Clint's great-grandmother. God does listen."

Clint will never forget how he learned about the first "miracle" pregnancy. Around 3 a.m., he was awakened from a deep sleep by a tearful Barbara. Not wanting to raise Clint's hopes, she had been tight-lipped about her suspicion that she was pregnant until the home pregnancy test confirmed it — and she awakened him with tears of joy.

And now, this family has been blessed with a second "miracle" pregnancy. The Thesing's third child is due in July 2007.

Weathering the Storm

Clint is a master electrician and self-described workaholic. For three months, he had seen various physicians trying to determine what was causing his lethargy, weight loss, mouth sores and back pain.

"One night he quit breathing and I took him to the ER and insisted on a referral to Mayo," says Barbara. "That's when we met our knight in shining armor, Dr. Litzow. If it hadn't been for him and for Mayo, Clint says we'd be picking flowers off his grave."

The diagnosis was AML. Dr. Litzow recommended blood and marrow transplantation (BMT) and explained the difficult journey upon which the young couple were about to embark.

Barbara and baby Justin stayed in hotel apartments in Rochester, off and on, for the next nine months. Clint, age 28 at the time, received high-dose chemotherapy and total-body radiation in order to destroy the cancer cells and suppress his immune system so his body wouldn't reject the transplanted cells. AML is a cancer of the blood that crowds out normal blood cells, leaving people with the disease vulnerable to infection or anemia.

On Jan. 9, 1997, Clint had an allogeneic BMT. Allogeneic means the stem cells are donated from someone else. Colleen, Clint's younger sister, was the donor. At first, the transplant seemed like a nonevent.

"Is that it?" exclaimed Barbara when she saw the tiny little bag containing Colleen's healthy bone marrow cells.

However, the challenges ahead were anything but tiny. The transplanted stem cells required 10 to 20 days to produce new blood cells. During that time Clint's low blood counts put him at risk for infection and bleeding. He developed many common side effects that occur after BMT: nausea, diarrhea, mouth sores and fever. In addition, he developed graft-versus-host disease (GVHD).

During the BMT, Clint received both Colleen's stem cells and her white cells. That means her immune system was also transplanted into his body. The cells from Colleen are called "graft" cells and Clint's cells in his body are the "hosts." In GVHD, the graft cells (Colleen's) recognize the host cells (Clint's) as foreign and attack them.

The complication can be deadly, and Clint's case was severe. He had stomach cramps, nausea, diarrhea and a blistering rash.

"My skin peeled off my hands like a snake shedding its skin," says Clint. "Those were tough days. We could not have gotten through it without Mayo staff. One nurse, Teresa Miceli, stands out in the crowd. She always saw to it that our family had what we needed, even if I was not her patient that day. The great people at Mayo give it a much warmer small-town feeling than any of the small towns we've doctored in."

The couple also knew that Justin needed them both and, so they focused on him and better days ahead. In part, the better days ahead can be credited to Clint's suffering. Those who get GVHD have less chance of leukemia recurrence, because the donor's immune system can kill leukemia cells that survive chemotherapy and radiation.

10-Year Anniversary

In January, Clint and Barbara celebrated 10 years of life after BMT.

"We always recognize my anniversary," says Clint. "On the first one, I declared myself one year old — I was cancer-free and it felt like starting over."

But daily activities are not always easy for Clint. A rare side-effect of BMT is osteonecrosis of the hip due to treatment during and following transplantation. Clint has already undergone one hip replacement surgery and continues to live with chronic pain in his other hip.

"Clint is such a go-getter and it's rewarding to see him survive a life-threatening illness," says Dr. Litzow. "Not only did he go back to work, but helped in the construction of their new house. You have to admire someone who is living with chronic pain and has that kind of tenacity."

State-of-the-art Research Targets Kidney Transplant Rejection

William Oetting, Ph.D. (left) and Fernando Cosio, M.D. (right)

The University of Minnesota and Mayo Clinic, which have two of the world's largest kidney transplant programs, are collaborating on a research project to improve the diagnosis and treatment of kidney transplant patients. The lead researchers are Mayo Clinic nephrologist Fernando Cosio, M.D., and William Oetting, Ph.D., a researcher with the university's Institute of Human Genetics. Other members of the Mayo research team include Mark Stegall, M.D., Matthew Griffin, M.D., and Walter Park.

Although the success rate for kidney transplant is excellent, many patients face either acute rejection — the inflammation that occurs when the recipient's immune system tries to reject the transplanted kidney — or chronic allograft nephropathy (CAN), a progressive deterioration of kidney function.

"We are using advanced genetic and protein studies to improve the long-term outcome of kidney transplantation," says Dr. Cosio. "We hope our studies will lead to a noninvasive method to monitor the health of kidney transplant patients at regular intervals and improve the diagnosis of transplant rejection."

The team is looking at three major issues:

1. Identifying Risk
The team is trying to identify variations in genes that will help them assess an individual's degree of risk for acute rejection. Currently, all patients are generally maintained on the same anti-rejection medications for life. That means some are being overtreated, which increases both the patient's costs and risk of side effects, while high-risk patients may not be getting enough of the drug for it to be effective. In other areas of medicine, genetic studies already allow physicians to tailor the minimal amount of medication that an individual needs to be effective.

2. Diagnosis
The team is using advanced proteomic technology to try to develop a urine test that can diagnose the type of disease affecting the kidney transplant. Currently, only kidney biopsy can determine this. A noninvasive test would spare the patient discomfort, prevent complications and save money.

3. Understanding the Biology
Before they can develop better and safer treatments, scientists need to understand what is going wrong at the cellular level. To this end, the team is studying the biological mechanisms that cause kidney damage during acute rejection and CAN.

The research team is supported by the Minnesota Partnership for Biotechnology and Medical Genomics. The Partnership is a unique collaborative venture among the Mayo Clinic, University of Minnesota, and State of Minnesota. It seeks to position Minnesota as a world leader in biotechnology and medical genomics applications that will result in important new medical discoveries, thereby improving health care for patients and supporting the development of new business and jobs in Minnesota.

UPCOMING EVENTS

Celebration of Life Picnic

The annual Mayo Clinic Celebration of Life Transplant Patient Picnic will be held Saturday, July 7th at Essex Park (5455 West River Rd NW, Rochester) from 11 a.m. to 3 p.m. Lunch will be served at noon, and a program will follow at 1 p.m.

Lawn chairs and games are welcome. The cost is $6 per person (children 2-5 years are $3.50 each). Food will be catered by Dish It Up!

In case of rain, tune your radio to KNXR 97.5 or KROC 106.9 for an alternate location. If you haven't already registered, contact Teri Witt at 507-266-2814.

2007 World Transplant Games

From Aug. 25 to Sept. 2, 2007, Team USA will compete in the 2007 World Transplant Games in Bangkok, Thailand. Congratulations to Mayo Clinic kidney transplant patient **Jill Morton**, who was selected as an Elite Athlete Program participant to represent Team Florida in Thailand. Good luck, Jill!

2008 U.S. Transplant Games

The 2008 U.S. Transplant Games will be held July 11-16, 2008 in Pittsburgh, Penn.

Opportunity to Share Your Transplant Story

If you will be in Rochester for the picnic and are interested in describing your transplant experience on video or in a written story to share with your family and friends, please contact Elizabeth Rice at 507-538-7982 or rice.elizabeth2@mayo.edu. A camera crew and writers will be available on Friday, July 6th to help you tell your 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.

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200 First Street SW
Rochester, Minnesota 55905
www.mayoclinic.org