



Spring/Summer 2006

Renewal

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

The Tiniest of Heart Transplants

All expectant parents look forward to that moment of exultant joy after delivery when, exhausted but exhilarated, they hear the wail of their newborn baby along with the news that the baby is healthy. That moment never came for Michelle and Tom Prigge when their daughter, Lillian, was born in the early morning hours of Friday, Aug. 26, 2005. Lillian did not cry right away, her skin was tinted blue and she was not breathing normally.



The community hospital where Lillian was born made immediate arrangements to transport her to a nearby medical center with a neonatal intensive care unit (NICU).

Tom and Kimberly Griffin, Michelle's sister, followed the ambulance. There, an echocardiogram showed that Lillian had a severe congenital heart condition — hypoplastic left heart syndrome with aortic and mitral valve atresia. The severity of Lillian's condition meant that she was going to need the kind of highly specialized neonatal cardiac care that Mayo Clinic can provide, so she had her second ride in a medical transport vehicle before she was 1 day old. In the meantime, her mother had recovered enough to warrant an early release from the hospital.

"It was a very stressful time but we had wonderful support from our families," says Michelle. "We live on one of three dairy farms about 40 minutes from Rochester that is farmed by Tom and his father and two brothers. Tom's parents took care of our two-year old daughter, Victoria, and my mom and I drove to Rochester in time to meet Lillian."

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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.

The Tiniest of Heart Transplants

Joseph A. Dearani, M.D.



Stabilization in the NICU

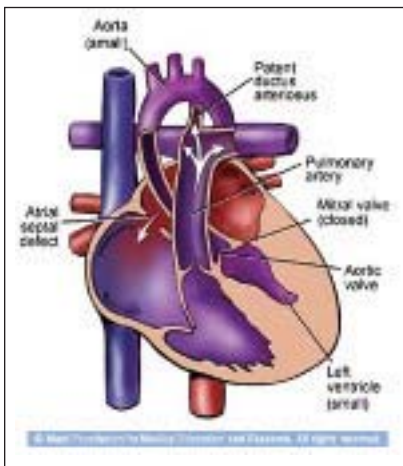
At Mayo Eugenio Litta Children's Hospital NICU, in Saint Marys Hospital, Lillian was stabilized with drugs and a procedure that created an atrial septal defect (ASD) — a hole in the wall between the two upper chambers of the heart that would allow more blood to enter the left chamber. After a weekend of tests, Lillian's health care team unanimously agreed that a heart transplant was the best option to save her life. It was shocking news for the family. They met with Mayo Clinic pediatric cardiovascular surgeon, Joseph Dearani, M.D., who underscored the commitment needed to care for a child who would need immunosuppressive therapy for the rest of her life. Lillian was placed on the national transplant wait list. She was just 3 days old.

Waiting for transplant

In the six weeks between Lillian's birth and her transplant, the Prigge family settled into a routine.

"The best advice we ever had was not to dwell on waiting for the transplant," says Michelle. "We just took one day at a time, celebrating any progress that Lillian made."

Michelle moved into Ronald McDonald House, where she shared support with other families of children with critical illnesses. Tom spent most of his time at home on the farm and with Victoria, and he visited a few nights during the week and most weekends. After four weeks, Lillian was stable enough to be transferred to the Pediatric Intensive Care Unit (PICU) where each patient has a single room, and the family could enjoy a little more privacy.



Lillian's heart condition

Hypoplastic left heart syndrome is a rare congenital heart condition where the left side of the heart is underdeveloped, including the aorta, aortic valve, left ventricle and mitral valve. The job of the left side of the heart is to pump blood that has been oxygenated by the lungs to the rest of the body. In Lillian's case, the ability of blood to move through the left chamber of her heart was made even more difficult by the presence of a severe narrowing (atresia) of the mitral and aortic valves.

The call was, indeed, music to their ears. By 10 a.m., Tom and Michelle were having another conversation with Dr. Dearani, this time about the good match that had been found for Lillian's heart.

"It was bittersweet because we understood that our joy came at the expense of someone else's grief," laments Prigge.

By 2:30 p.m. the complex preparations for transplant were ready.

"I was allowed to hold her while they wheeled us into the operating room," says Michelle. "It was so hard to see the tears rolling down my husband's face as they closed the doors behind us. As soon as they put her to sleep I had to leave her too. But we had lots of family, our pastor, and friends from Ronald McDonald House to wait with us. And the staff were great about informing us about the progress of the transplant."

At 10:30 p.m., Dr. Dearani told the family how pleased he was with the way the surgery went.

"Lillian's operation went well," says Dr. Dearani. "The new heart was functioning normally and we were able to tell the family that we anticipated a smooth recovery."

Lillian was released from the hospital one month after the transplant, though the Prigges were advised to keep her in Rochester for another two months. Victoria and her dad happily joined Michelle at Ronald McDonald House and they were allowed to take Lillian home for Thanksgiving and Christmas. On Jan. 5 they brought Lillian home to stay. At six months old, Lillian's developmental milestones are about two months behind normal, but the Prigges are pleased with her progress.

"The care we got at Mayo was fantastic," says Michelle. "Dr. Dearani is a true gentleman and the whole team was, and continues to be, dedicated to educating us and seeing that Lillian gets the best of care."

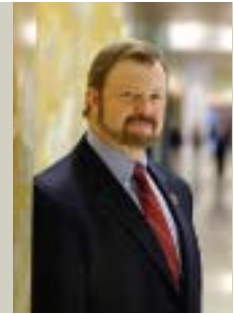
For more information on pediatric heart transplants at Mayo Clinic, visit www.mayoclinic.org/heart-transplant/children.html.

*Heritage Days is an annual event celebrating Mayo's history, recognizing the work of Mayo staff, volunteers and retirees, and acknowledging the community for the support it provides to the organization.



The Prigge family, left to right; Victoria, Michelle, Lillian and Tom.

Overcoming Antibody Barriers to Kidney Transplant



Mark D. Stegall, M.D.



Stacy Neumayer and her half brother, Travis Hurd.

Stacy Neumayer, of Spirit Lake, Iowa, loves to travel and hike — not easy things to do when you're on dialysis. She has had kidney failure since she was 15. By 2001, at age 36, she had had four kidney transplants and had been told she would not be eligible for another one because she had antibodies against all of her potential living donors. The news meant her life would be restricted by four-hour dialysis treatments, three times a week, every week for the rest of her life.

Neumayer accepted her prognosis and, with dogged determination to enjoy whatever time she had left, found a dialysis center where she frequently vacations in Colorado. She loves to hike, and she set about living her life to the fullest. However,

her half brother, Travis Hurd, despite having been tested and told he did not match with Neumayer, passionately believed that he would one day donate a kidney to his sister. He monitored new developments in the kidney transplant field and discovered an innovative clinical program at Mayo Clinic that seemed to be custom-designed for them. It was.

Pulling Down Antibody Barriers

Kidney transplant surgeon Mark Stegall, M.D., had people like Neumayer in mind when he sought a procedure that would overcome the destructive effect of antibodies.

"ABO incompatibility or a positive crossmatch due to anti-HLA (Human Leukocyte Antigen) antibodies were once absolute contraindications for kidney transplantation," says Dr. Stegall, who is also surgical director of the Kidney/Pancreas program and chair of the Division of Transplant Surgery at Mayo Clinic, and chair of the UNOS (United Network for Organ Sharing) Kidney and Pancreas Transplant Committee. "There are more than 7,000 people in the United States in this group and most of them die while waiting for a negative crossmatch deceased donor kidney, yet most of them would be candidates for living donor kidney transplantation."

ABO Incompatible Kidney Transplant

ABO incompatibility refers to the immune reaction that occurs when different blood types are mixed together. The presence or lack of molecules on the surface of the blood cells defines your blood type. Type O has no molecules. Types A and B each have a combination of two molecules, which result in type A (AA or AO molecules), type B (BB or BO molecules), or type AB. When blood types are mixed, the molecules act as antigens that trigger an ABO incompatibility reaction. That's why blood types must be matched.

Mayo began performing ABO incompatibility kidney transplants in May 1999. The procedure involves a preconditioning done to cleanse the blood of antibodies.

Positive Crossmatch Transplant

The HLA major histocompatibility complex (MHC) is a large group of genes, located on a single chromosome, which influences the ability of different cell types to collaborate and produce or suppress immune responses. A blood test determines a person's major histocompatibility antigens. A positive crossmatch means a person has antibodies against donor HLA antigens — a decidedly negative result for anyone waiting for transplant. The antibodies can develop as a result of blood transfusion, pregnancy or organ transplant. Specialized plasma cells (memory B-cells) are long-lived and can quickly recognize and respond if the same antigen invades the body again. Neumayer was told she could not have another transplant because her immune system developed anti-HLA antibodies to each of her four previous transplants.

"We adapted a procedure developed for ABO incompatibility and tried it on patients with positive crossmatch," says Dr. Stegall. "The success of these strategies has allowed individuals with kidney failure to avoid lengthy or indefinite waiting periods for deceased donor transplants."

In 2000, Mayo initiated a clinical trial based on the ABO protocol, which had proven successful. The following January, Neumayer's blood was successfully preconditioned and she received a donor kidney from her half brother on Jan. 9, 2002. When she turned 40 recently, there was no standard milestone birthday celebration.

"January 9th is the day I celebrate," says Neumayer. "That's the day I started to live."

Mayo's Kidney and Pancreas Transplant Program is one of only three centers performing positive crossmatch and ABO incompatible kidney transplants and has performed the most — more than 150. While Dr. Stegall is encouraged by Mayo's early experiences, he is aware that many of the mechanisms of transplant are not well understood and anticipates that furthering knowledge in the field will lead to improvements for his patients. Currently, Dr. Stegall's lab is focusing on three main areas: antibody-producing plasma cells; accommodation — how the kidney transplant acquires resistance to antibodies; and improving long-term survival of all kidney transplants.

"We expect future trials will lead to a greater understanding of the mechanisms underlying antibody-mediated rejection," he says. "Our intent is to provide patients greater access to living donor kidney transplantation and improve the survival of kidney transplantation recipients."

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



Medicare Part D: Do You Get It?



President Lyndon B. Johnson wanted prescription drug coverage to be included in his original Medicare program which became law in 1965. It's taken 40 years, but the government now offers Medicare Part D, a program that supplements Medicare with prescription drug coverage.

"The implementation of the program has caused some confusion," says Stephanie Stewart, a social worker at the Mayo Clinic Transplant Center in Rochester, Minn. "But it is worth your while to enroll if you currently have limited or no drug coverage."

The following information will help you understand Medicare Part D. The information is condensed from the government's Medicare Web site: www.medicare.gov, where you can get more detailed information.

The Medicare prescription drug coverage program:

- Is available for everyone with Medicare, regardless of income, health status, or current prescription expenses.
- Covers both brand-name and generic prescription drugs.
- Requires that you get your prescription filled at participating pharmacies.
- Is delivered by private health plans that are subsidized by Medicare.
- Is like an insurance policy — you pay a monthly premium, which varies by plan, and a yearly deductible (no more than \$250 in 2006). You also pay a copayment or coinsurance — part of the cost of your prescriptions.
- Has varying costs depending on which drug plan you choose. If you didn't join a plan by May 15, 2006, and you don't already have credible coverage (a drug plan that covers at least as much as standard Medicare prescription drug coverage) your premium cost will go up at least 1 percent per month for every month that you wait to join. You will have to pay this penalty as long as you have Medicare prescription drug coverage.
- Has enrollment periods. The next open enrollment period is Nov. 15, 2006 to Dec. 31, 2006, for which coverage will not take effect until Jan. 1, 2007. Once you join a Medicare drug plan you are generally enrolled for a calendar year. You can change or join a new drug plan from Nov. 15 through Dec. 31 each year, and the new coverage will start Jan. 1 of the following year.

Note: If you have limited income and resources, and you qualify for extra help, you may not have to pay a premium or deductible. Apply or get more information by calling Social Security at 1-800-772-1213 (TTY 1-800-325-0778) or visiting www.socialsecurity.gov.

How to choose a plan

1. List the drugs you take and their current costs.
2. Determine your current coverage — most people with Medicare pay for drugs and get their Medicare via:
 - Original Medicare only, or Original Medicare and a Medigap ('Supplement') Policy without drug coverage.
 - Original Medicare and a Medigap ('Supplement') Policy with drug coverage.

- Retiree or union coverage.
 - Medicare Advantage Plan (like an HMO or PPO) or other Medicare Health Plan, which already includes drug coverage.
3. List specific pharmacies that you want to continue using — The Landscape of Local Plans at www.medicare.gov shows plans available in your area.
 4. Consider how important cost, coverage and convenience are to you.
 5. Review plan options — The Medicare Prescription Drug Plan Finder at www.medicare.gov reviews total cost of the drugs you currently take for drug plans in your area. It also provides information on deductibles and premiums.

How to enroll

- Online at www.medicare.gov.
- By calling the plan's toll-free number.
- By mailing in an application to the plan.

Some helpful terms

Premium: The monthly cost you pay to join a Medicare drug plan.

Deductible: The amount you pay for your prescriptions before your plan starts contributing to the costs. No plan may have a deductible of more than \$250 in 2006.

Copayment/Coinsurance: The amount you pay for your prescriptions after you have paid the deductible.

Formulary: The list of drugs covered under a Medicare drug plan.

Coverage Gap: The limit of the plan's benefit, generally above \$2,250, after which you pay 100 percent of your prescription costs.

Scam warning

Please be aware that legitimate Medicare drug plans will not ask for payment over the telephone or the Internet. Never give your bank account or other personal information over the telephone to anyone claiming to help you enroll in a Medicare Prescription Drug Plan.

Information adapted from www.medicare.gov.



Sixteen Not So Sweet When You Have Leukemia – But BMT Outcome Is, Indeed, Sweet



“They told me I had leukemia and we just packed up and left for Mayo,” says Kala.

In October 2002, high school student Kala McKinnon was driving with her parents from her hometown of Warroad, Minn., to Mayo Clinic in Rochester when she spotted her friend in another car. The girls signed “I love you” to each other and waved goodbye as their roads parted, both weeping for the unknown and forbidding territory that lay ahead for Kala. She was 16 and had just been told she had leukemia. More than three years and a blood and marrow transplant (BMT) later, the road ahead looks sweet.

“I had a busy schedule at school, which included hours of volleyball practice, so I didn’t think much about how tired I was or the bruises on my legs,” says Kala. “Then I caught a cold and my mom gave up her doctor’s appointment for me. They sent blood tests away. On one of the worst days of my life, I came home from a friend’s funeral to find that Mom had been crying and my Dad was there — that was unusual because they are divorced. They told me I had leukemia and we just packed up and left for Mayo.”

Acute myelogenous leukemia

At Mayo Clinic, Kala was diagnosed with acute myelogenous leukemia (AML) — a rapidly progressing cancer of the blood and bone marrow. People with AML produce non-maturing, leukemic white blood cells (myeloblasts) instead of mature myeloid cells. The myeloblasts had crowded out healthy cells and left Kala vulnerable to infection, anemia and easy bleeding.

The Mayo Clinic pediatric oncology team placed a long-term central venous catheter in a vein in Kala’s chest to make it easier and more comfortable to give medications and draw blood samples. Then they began intensive chemotherapy treatments to try to induce remission by killing the leukemia cells. The chemotherapy also destroys healthy blood cells, putting Kala at even greater risk for anemia, infection and bleeding. For that reason, Kala was confined to an air-filtered hospital room after each of the three cycles of treatments she

needed until her blood cell counts recovered. For her, that was the most difficult part of the treatments.

“For 30 to 40 days afterward I had to stay in one room when it felt like nothing was wrong — it was so boring,” says Kala. “The other horrible part was losing all of my hair, including my eyelashes and eyebrows. Whole clumps would come out on my pillow. It felt like losing my best friend.”

Relapse and BMT

In March 2003, Kala returned to a warm welcome in her small-town community, which had rallied to help the family however they could. That October, she was crowned homecoming queen. But just when she felt that life was settling back into normality, she developed signs of a relapse and returned to Mayo.

“It came back in December and the only option was a marrow transplant,” says Kala. “None of my family matched well enough so my team searched the National Marrow Donor Program Registry for an unrelated volunteer donor. We were relieved when they found a perfect match. Then subsequent tests revealed that the donor had hepatitis.”

After that emotional roller coaster, a second match was found and preparations for marrow transplant began. Three days before the transplant, Kala received very high doses of chemotherapy and total body radiation therapy to destroy her leukemia-producing marrow. Before that, as a precaution against an emergency that would prevent the donor marrow from arriving, Kala’s bone marrow was also harvested so physicians would have something to replace it, just in case. Kala found the preparations “scary,” but tolerated them well.

The transplant took place on April 29, 2004. Kala was fortunate that she did not get the severe side effects that most patients who undergo radiation and marrow transplantation have.



Shakila P. Khan, M.D.,
Carola A.S. Arndt, M.D.,
Julia A. Gourde, N.P.

“Most patients feel sick and weak and some patients get infections, severe mouth sores, or life-threatening complications,” says Carola Arndt, M.D., a pediatric blood and cancer specialist. “Kala was also fortunate that her recovery was unusually fast.”

Kala had to remain in Rochester for 100 days after her transplant. She stayed at Ronald McDonald House in an apartment room where her parents and grandparents could stay.

“It felt like home,” says Kala. “I got to know some pretty special people, including a little boy who was waiting for a heart transplant.”

Back to Warroad

Almost two years after Kala learned she had leukemia, the catheter, which had been in place throughout her entire experience, was removed from her chest and Kala returned to Warroad. By her high school prom, her hair had grown enough for her to brave going without her bandana for the first time. Kala looks forward to three years from now when, if she stays in remission, her physicians will consider it highly likely that the BMT cured her of leukemia.

Reflecting on her experience, Kala, now 20 and a student at the University of Minnesota, Duluth, notes:

“The worst parts were the first days after learning about my diagnosis, losing my hair, and the actual marrow transplant,” says Kala. “I couldn’t bear to watch that foreign red liquid dripping into my body not knowing what it was going to do to me. Of course, what it did for me was to save my life. I am trying to contact my donor. He’s my hero and I want to thank him.”

***“Kala’s middle name is Joy,”
says Dr. Arndt. “We absolutely
love her and we are delighted that
she continues to do well two years
after her marrow transplant.”***

Kala’s physicians all agree that she is aptly named.

“Kala’s middle name is Joy,” says Dr. Arndt. “We absolutely love her and we are delighted that she continues to do well two years after her marrow transplant.

For more information on bone marrow transplant services at Mayo Clinic, visit www.mayoclinic.org/bone-marrow-transplant/.



Blood and Marrow Transplant Innovations at Mayo Clinic

The Mayo Clinic blood and marrow transplant team is involved in medical research directed toward advancing patient care. These research efforts provide options for patients who may have been denied transplantation elsewhere.

Research efforts include:

- Stem cell transplantation for amyloidosis
- Prevention and treatment of graft versus host disease (GVHD)
- Radionuclides combined with chemotherapy for BMT in patients with lymphoma or myeloma
- Immunotherapy to prevent recurrence of disease after BMT
- Non-myeloablative allogeneic BMT (also called “mini-allogeneic BMT” or “reduced-intensity allogeneic BMT”) for patients who are not eligible for conventional allogeneic BMT, including patients with myelofibrosis, leukemia, lymphoma and multiple myeloma.



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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