



Fall/Winter 2006-2007

# Renewal

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

## From Exhaustion to the Elliptical Machine

### *Journalism Student Thrives with New Heart and Lungs*

Tara Kline hurries from her job as editor of the Rochester Community and Technical College newspaper to her classroom – an ordinary enough task. To Tara, however, the energy to hurry anywhere is still extraordinary two years after her heart and double lung transplant. About the only things that take her breath away now are the elliptical machine, and the realization that she can breathe normally.

oxygenated blood, called cyanosis, turned Tara's lips, fingertips and toes blue. Her heart, which had to pump much harder than normal, was unusually large and functioning poorly. And the blood pressure within the large pulmonary artery, which carries oxygen-depleted blood from the right heart to the lungs, was abnormally high – a serious and potentially life-threatening condition called pulmonary hypertension. In

addition, Tara's echocardiogram showed that she had blood clots in her pulmonary artery. Clotting is a problem for chronic conditions that cause low blood oxygen, because the body tries to compensate by making more red blood cells to carry oxygen. The additional cells make the blood thicker and more susceptible to clot formation. Mayo Clinic heart and lung specialists immediately admitted Tara to Saint Marys Hospital. They treated her with various medications to reduce the blood pressure in her pulmonary artery, strengthen the heart's contraction and dissolve the blood clots. However, they knew that Tara's condition would get progressively worse and, at some point, medications would not be enough. They recommended a heart and lung transplant.

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"Before my transplant I had a desk job and on good days I could work six hours," says Tara. "But on bad days I could barely last one. There were some days when I couldn't even drag myself out of bed. Now I can get through a busy 13-hour day and still have the energy to work out on an elliptical machine. It still amazes me."

## How a Hole in the Heart Can Cause Problems

In April 1997, when she was 18 years old, Tara was diagnosed with a complicated congenital heart condition called Eisenmenger syndrome. She had an atrial septal defect – a hole between the two smaller chambers of the heart – which caused low oxygen levels in the blood. The lack of

## **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.

# From Exhaustion to the Elliptical Machine



*Tara Kline cuddles Rex, who appeared on her doorstep two weeks after she was told she needed a heart and lung transplant.*

## *Wait Rhymes with Eight – Long Years, That Is*

Tara was listed for transplant in November 1997. It took eight long years to find her a match. In the meantime, she required close monitoring. She feels fortunate that she lives in Rochester.

"I got incredible support from everybody on Mayo's transplant team," says Tara. "Over those eight years I got to know all of the heart and lung specialists who specialize in transplant, and they are all exemplary. They even told me I could call them night or day if I had any problems or questions."

According to the United Network for Organ Sharing (UNOS), since 1995, only 30 to 70 heart-lung transplants have been performed each year in the United States.

"Mayo Clinic is one of very few centers in the country doing heart-lung transplantations," says Sudhir Kushwaha, M.D., one of several Mayo Clinic cardiologists who cared for Tara. "Lung transplants are difficult because the patients are very susceptible to lung rejection and infections after the transplantation and there is limited availability of donor organs."

Many factors limit acceptability of the donor organ for heart-lung transplant. A breathing machine keeps the donor's organs supplied with oxygen-rich blood until they can be removed and transported. However, the artificial breathing machine may damage the delicate lung tissue and cause enough injury to make them unacceptable for transplantation. Donor lungs also may be unsuitable because of disease or chest trauma. In addition, lung tissue is delicate and can only be preserved for four to six hours, which restricts the distance the donor organs can be transported.

## *Heart and Lung Transplantation*

On April 29, 2005, at 11:20 p.m., Tara was enjoying a peaceful evening at home in Rochester, watching "The Tonight Show with Jay Leno," when the phone rang. Mayo Clinic was calling. Although she had been expecting the call for eight years, she describes what followed as surreal.

"I was used to my life. I wasn't unhappy," she explains. "No matter how much time it takes, you can never fully accept the magnitude of the final decision about having a transplant. All of a sudden, I was faced with the reality of it. I just wasn't sure I wanted to go ahead with it."

Tara made up her mind after a visit from heart and lung surgeon Christopher McGregor, M.D., who strode into her Saint Marys

Hospital room, early the next morning, exuding confidence.

"I knew that Mayo would only accept the best match, and Dr. McGregor was thrilled that they had finally found a suitable donor for me," says Tara. "He felt sure I would do well. His attitude was a huge boost to my morale but it was still very scary to be wheeled into the operating room not knowing if I would ever come out."

The transplant took four hours. Afterward, Tara's parents were surprised by the immediacy of her color change – her lips were a healthy pink right after the transplant. Because she was heavily sedated, Tara doesn't remember much about the first few days – although she chastises herself with a foggy recollection of getting "quite mean" when the nurses insisted on getting her out of bed.

"The staff at Mayo was fantastic," she says. "They understood how physically and emotionally draining the whole experience was for me. They were kind, patient and attentive – if I had an itch, they'd scratch it – and they made sure I did what I had to do to recover."

Tara required another surgery two weeks after her heart-lung transplant to repair a paralyzed diaphragm – an important breathing muscle. "The surgical procedure to tighten and stabilize the weakened diaphragm was successful," explains lung specialist Mark Wylam, M.D. "Tara has completely recovered and has normal lung capacity."

## *Recuperating with Rex*

After a month in the hospital, Tara went to her parents' house where she spent three months recuperating. Her cat Rex would not let her out of his sight.

"I've no doubt that pets can really help people with chronic illnesses," says Tara. "Rex was certainly an important part of my recovery."

Tara's recuperation has gone well. Every day she performs a test at home to make sure her lungs aren't showing signs of infection or rejection. And her regular checkups at the Mayo Clinic Transplant Center include a biopsy of the heart muscle to check for rejection.

## *A Huge Responsibility*

Tara enthusiastically declares that the quality of her life has improved so much since the transplant that she would not hesitate to go through it all again.

"I've done more in one year than I've done in the past 15 years," she says. "And I'm happy that my family can now move on with their lives. But at first I was overwhelmed by the huge responsibility I felt to the donor and to everyone involved in the program."

Tara wrote to the relatives of her donor six months after her transplant. "It took me a long time to consider what I wanted to write, but I wanted to express my gratitude to them." Today, Tara is studying journalism and plans to use her writing skills to promote organ donation. She often talks to groups about organ donation and particularly enjoys sharing stories and confidences with patients at the Transplant Center. "My mom has to talk me out of feeling guilty about taking a nap. I just feel it's my duty to the donor to make the most of every moment, and I do" says Tara.



# Of Heroes and Gold Medals



*John Greller (center) with Mike and Darlene Van Bendegom.*

John Greller, also known as “The Bear” from his college football days, has no gold medals from the 2006 summer National Kidney Foundation Transplant Games — not because he didn’t win any (he won all three swimming events that he entered). He gave the medals to his heroes.

“The Games are not about winning medals but about celebrating life,” says Greller, of Orange City, Iowa, who received a kidney – his second transplant – from his son, Brian, on Sept. 30, 2005.

“Everybody at the games deserves a gold medal. My heroes are my wife, Janeo, who has been a pillar throughout this journey; our son Brian who has a true servant’s heart; and the Mayo Clinic Transplant Team. I thank God every day that I came to Mayo.”

Greller gave his first gold medal to his wife, also his primary caregiver, for being with him “in sickness and in health,” through 37 years of marriage. He gave his second gold medal to his son, Brian, for giving up his job to take care of his parents in their time of need, and for donating a kidney. He sent his third gold medal to the entire Mayo Clinic team via his social worker, Danielle Peabody. Greller and his wife, are particularly fond of Peabody, because “she was so solicitous” of their needs during their long stay in Rochester. This third medal now hangs in the Charlton 10 lobby of the Transplant Center at Mayo Clinic.

## Another Family of Heroes

Greller, now 61, was diagnosed with diabetes at 28. He had his first transplant, a kidney and pancreas, in November 2001, after his kidneys failed. His donor was a young woman named Jodi, who lost her life in a traffic accident. He and Janeo have since developed a very special relationship with Jodi’s parents, Mike and Darlene Van Bendegom. Greller first competed in the 2004 Transplant Games in Minnesota, where he won two silver medals in swimming events. The first silver medal was presented to Greller at poolside by the Van Bendegom family at those games.

“It was a very poignant moment,” remembers Greller. “We cried in each others arms, not wanting to let go. When we finally did, I took the medal from around my neck and placed it around Darlene’s. I told them I would not be here if it were not for their gift.”

Soon after the Games, however, Greller’s body began to reject the donor kidney. After all they had been through Darlene offered her own kidney to Greller. “It is a testament to how close we have become,” says Greller. “We were very touched by the depth of her generosity.”

*John Greller's third gold medal hanging in the Charlton 10 Lobby.*



## A Second Transplant

Greller had many complications and was very ill following the rejection of his first transplant. He was receiving care from a variety of institutions in Iowa and friends urged him to consolidate his care in one location. Greller decided to seek his second transplant at Mayo Clinic.

“Mayo has an outstanding reputation, and I really like its collegial team approach,” says Greller.

Since Brian Greller’s kidney was a good match, and he was already caring for his parents, he was the obvious choice as a donor for his father. Greller’s second transplant was made more difficult because of eight previous abdominal surgeries to treat a variety of complications from diabetes. The surgeries left scarring that critically narrowed the vein usually used for kidney transplant. A few hours after the transplant, the vein became blocked and the kidney stopped working. Greller’s surgeon, Mark Stegall, M.D., immediately took Greller back to the operating room.

“I bypassed the stricture with a vein graft from a deceased donor,” says Dr. Stegall. “I have performed a thousand kidney transplants, many of them re-transplants like Mr. Greller’s, yet I have never had to do a bypass graft before.”

After surgery, Greller and his wife rented an apartment in Rochester so that he could continue to be monitored by the transplant team. During this time he was able to see his first grandson, who was one month old, for the first time – something he never thought he’d live to do. He returned home to Iowa in November 2005, six weeks after receiving his new kidney. By the summer of 2006, he felt well enough to compete in the National Kidney Foundation Transplant Games in Louisville, Ky.

## Appreciating the Gift of Life

Today, Greller and his family stay in touch with the Van Bendegoms, a friendship born from the donor family’s generosity. Words cannot express the gratitude he feels toward them and toward his own family and his son Brian’s lifesaving donation.

“Providence plays a role in this transplant journey,” says Greller. “Participating in the Transplant Games is a way to say ‘thank you’ to your donor and their families who can see what they’ve made possible. In some cases, a lost life has meant a saved life for a transplant recipient, and the games reflect that. The unique juxtaposition of joy and grief is bittersweet. I am grateful for every day.”

# Alaska Woman Testifies to Change Disability Laws after Liver Transplant

Dawn Pedersen's story since her liver transplant 13 years ago at Mayo Clinic has been a testament to her strong desire to live a healthy life, to her tenacious courage to help others who face similar obstacles, and to carry and live the gratitude she will always feel for the donor who gave her the gift of life.

In 1992, Pedersen was slogging out another summer processing fish at a cannery in Petersburg, Alaska. When she complained of abdominal pain, she was given antibiotics at the first aid station and sent back to work. After spending the rest of the season modifying her diet in an attempt to alleviate the pain, she returned to her hometown, Missoula, Mont., and underwent a liver biopsy.

"A sample was sent to Mayo Clinic and they diagnosed severe liver disease," says Pedersen. "So, in January 1993, I hopped on a train to Rochester, Minn. The first night the pain got so bad that I went to the emergency room at Mayo Clinic's Saint Marys Hospital and ended up having tests all night long."

The next morning, Pedersen was told she would need a liver transplant. She was diagnosed with Budd-Chiari syndrome with underlying systemic lupus erythematosus. Budd-Chiari syndrome is a rare condition where a clot blocks the hepatic vein, the major vein that leaves the liver, and causes congestion. The congestion injures liver cells, eventually causing irreversible liver failure. Lupus is a chronic inflammatory disease of the joints, skin, kidneys, blood cells, heart and lungs. Arrangements were made for Pedersen's father to join her at the Gift of Life Transplant House in Rochester where they waited until a donor liver became available. She only had to wait until June.

## A "Re-birthday"

"The day of my transplant, June 22, 1993, is my re-birthday," says Pedersen. "I was out of Saint Marys Hospital in eight days. They told me that was record time."

After leaving Saint Marys, Pedersen stayed at the Gift of Life Transplant House until she was well enough to go home. In August 1993, she returned to Missoula. She'd gone home but the transplant journey continued — and it wasn't easy.

## Changing a Law to Help the Working Disabled

Pedersen's post-transplant medication cost \$1,200 per month, which was covered by Social Security disability insurance. In 1995, Pedersen decided to return to Petersburg to work the fishing season. She was able to purchase a COBRA plan (Consolidated Omnibus Budget Reconciliation Act), a federal program to continue group health insurance coverage for certain people with temporary special needs.

Following the 1996 season, Pedersen moved to Juneau for full-time work, rather than a seasonal job. However, she said her employment precluded her from disability insurance, and her new company's insurance would not kick in for 12 months. How to pay for her medication consumed her thoughts for a year.

"It would have been much easier for me to stop working, but the transplant made me a productive member of society again. I was only 25. I wanted to work!" says Pedersen.

"That year I spent every dime I had on medication. I would not have made it without a lot of help from my family and from a pharmaceutical manufacturer that donated three months' worth of cyclosporine."

Eventually, Pedersen was referred to a lawyer at the Disability Law Center in Juneau who was working on barriers to employment for the state's disabled population. In 1997, Alaska's governor convened a Disability Summit, and Pedersen was one of many people with disabilities who testified before the Alaska State Legislature. Pedersen was called to testify five times. The summit identified the high unemployment rate among persons who had severe disabilities. Follow-up studies showed that administrative, policy and legal barriers needed to be addressed. One outcome, which had it been in place earlier would have spared Pedersen one very stressful year, was that in 1998, Alaska became the first state to pass legislation authorizing a Medicaid Buy-In program. Now, people meeting the disability requirements can pay a premium on a sliding fee scale based on their income, to continue receiving disability insurance through Medicaid.

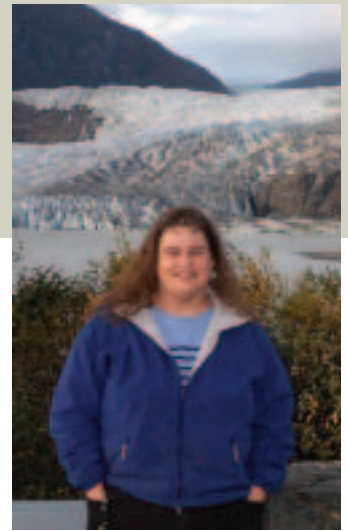
"Dawn faced many problems as she tried to re-enter the job market," says Mayo Clinic Transplant Center hepatologist Eileen Hay, M.B.Ch.B., who has helped Pedersen through many health issues over the past 13 years. "In many ways, her experiences typify the financial difficulties that many transplant patients face when dealing with employment, health insurance, and how to pay for their medications and subsequent trips to Rochester for follow-up care. I think it's terrific that she did something to prevent other people in similar situations from having to go through what she went through."

## Smooth Sailing in Juneau

Pedersen is grateful that her testimony helped result in changes that help other people with disabilities who want to work. She is now an eligibility technician for Health and Social Services in Juneau.

But still, 13 years since her transplant, when she sails and fishes the ocean and lakes or just admires the stunning mountains, glaciers and forests in her adopted backyard, her thoughts return to the donor who gave her the gift of life.

"Even throughout that stressful year without health insurance, I never forgot that without my wonderful and generous donor, I would have died at 25," says Pedersen. "I have also never forgotten Mayo Clinic. When it comes to my health, I won't make a move without Mayo."



*Dawn Pedersen surrounded by Alaska's beauty.*

# Modern-Day Hero: Captain Lien Has the Right Stuff

## 71-year-old Heart and Kidney Recipient Circumnavigates the Globe, a First



*Captain Lien arriving in Hawaii. Photo credit: Honolulu Star-Bulletin. Photo by Dennis Oda.*

When Captain Cook circumnavigated the globe in 1771, he was in his 40s, the Endeavour was 100 feet long, and he had 93 shipmates to keep him company, prepare his food, wait on him and keep watch while he slept. When Captain Ardell Lien circumnavigated the globe, he was in his 70s, the Catalyst was 27 feet long, and he sailed alone. To top it off, Lien had undergone transplant surgery at Mayo Clinic in January 2003. He is the first heart and kidney transplant recipient to sail around the world, an astounding accomplishment that has earned him a place in history.

Lien launched his epic journey from San Diego harbor on May 7, 2005. His mission was to demonstrate that transplant patients can return to a normal life after surgery, and to increase the number of registered organ donors around the world. When he returned to San Diego harbor on Oct. 19, 2006, the 71-year-old Minnesotan had sailed an amazing 31,310 nautical miles in 17 months.

Lien encouraged people he met along his journey to become organ donors, working with Lifesharing, an organization that promotes organ and tissue donation. In the 19 ports that he visited, he met with many organ and tissue recipients and was often featured on the local news. Before his transplant, Lien slept 18 hours a day. He was so weak that he had to crawl up the stairs to his bedroom. Undoubtedly, his astounding accomplishment underscores that organ donation really is the key to a second chance at the gift of life.

Lien began sailing in 1990. Following a career in the Army, which included tours in Vietnam and Korea, he operated commercial fishing and charter boats. Most of his sailing experience comes from six years of living on a 45-foot sailboat with his wife, Maureen, as they sailed between Alaska and Mexico.

### *Alone on the High Seas*

"I thought I was a better loner than I turned out to be," says Lien from his home in Caledonia, Minn. "I'm very happy to be back in the U.S. I was really looking forward to a big hamburger."

Lien carried only three batteries on board the Catalyst, which ruled out having refrigeration. His diet was limited mostly to canned and packaged food, including 40 pounds of pancakes and boxes of canned soup. Still, when he caught a large fish, he released it because he knew he couldn't eat it all at once.

By journey's end, the lone sailor had learned to relax and catch more shut-eye.

"On the last couple of passages, I realized that, with the exception of the shipping lanes, there's very little traffic on that vast ocean," he says. "In the 43 days between the Galapagos Islands and Hawaii, I didn't see one ship."

In South Africa, Lien met up with a hero of his — Sir Robin Knox-Johnston. In 1969, Sir Robin became the first person to sail nonstop around the world alone.

"We had lunch together and mostly talked about the difference between sailing then and now," says Lien. "It's much less daunting now because of the advances made in navigational equipment and access to weather maps."

Lien's cardiologist, Brooks Edwards M.D., and his heart surgeon, Richard Daly, M.D., were on the dock in San Diego to welcome him home. Before Lien sailed, both physicians expressed admiration for his determination to fulfill a dream, but they had given the voyage the green light only on the condition that he return for his annual exam at Mayo Clinic. His wife flew to three ports to see him and to deliver his antirejection medication. Lien also had a three-week respite in December when he flew home from Australia on vacation.

### *A Rich Reward*

Although two mainsails and a jib sail were blown out, and the Catalyst returned much the worse for wear than its captain, Lien says he had few bad days. He had planned his journey to avoid major storm seasons. When asked about his good days, he chuckled, admitting that after endless days alone on the ocean, any day on land was a good one. But he said the best day actually came soon after his voyage ended and resulted from the trip's publicity.

"I found out who my donor family was," says Lien. "My donor's mother read about me in her local paper. She only knew my first name, but she put two and two together and called a friend of hers who lives here in Caledonia, and told her, 'that man took my son's heart around the world.' We had a very nice conversation."

### *Continuing the Odyssey*

Though his around-the-world feat has been accomplished, Lien's mission continues. If he has his way, his solo circumnavigation is just the first leg of a longer odyssey to continue his advocacy for organ donation. He is already planning the next leg — raising funds and arranging to have booths dedicated to organ donation at boat shows around the country.



# Database Coordinators a Gold Mine for Mayo



Database coordinators Norine Huneke (seated) and Jane Fasbender.

Have you ever wondered what goes on down the hall from the big picture window and the row of potted plants in the Transplant Center waiting room? The answer is — plenty! Tucked in the back of a six-person cubicle are two of the most industrious, compassionate, fun-loving database coordinators you could ever hope to meet: Jane Fasbender and Norine Huneke. What they do at their desks directly affects the quality of your care.

Fasbender has been part of the transplant team since 1985, when Mayo began its liver transplantation program. Over two decades, her expertise has grown, along with the other solid organ transplant programs —

pancreas, kidney, heart and lung. Huneke, who started working in the Division of Hematology in 1993, has become an expert in data collection for blood and marrow transplantation.

Mayo now performs more than 720 transplants per year (350 solid organ and 370 blood and marrow transplants) — which generate reams of data.

“Jane and Norine’s skills are a gold mine for Mayo,” says Kathy Schwab, Transplant Center clinical nurse manager. “They have become experts on transplantation data and have developed programs that are unique to Mayo, despite having little formal education in programming.”

## So What Is a Database Coordinator?

A database management system is a collection of computer programs that enables an organization to store, change, and retrieve information from its database. You use one when you search for a book on your library’s computer or get cash from an automated teller machine. At the Transplant Center, your physicians and nurses use a database management system as a vital tool in their mission to provide you with the best care possible. Database coordinators gather data, enter it into a database and use specific programs to sort and extract selected data. They continually enter new data into the system and instruct staff in its use.

## Developing a Quality Data System

As Mayo’s transplant programs expanded, the need increased for a quality database management system to organize the reams of data. Assisted by a key group of programmers and physician input, Fasbender and Huneke organized data to help users enter and extract information efficiently. Data for each of the transplant programs is now organized under multiple tabs, and lab values are fed directly into the system. The pair developed separate pre- and post-transplant computer screens and created summary reports so that physicians can review all available information before the first appointment with a patient.

## Working with Insurance Companies

“One of the most important things we do is to work with the contracting insurance companies,” says Fasbender. “By supplying them with the right data we help patients get the insurance coverage they need to have their transplantation at Mayo.”

## Keeping National Transplantation Lists Current

In 1999, the United Network for Organ Sharing (UNOS) launched its transplant information database system for all organ matching and management of transplant data. When a person is placed on a waiting list for transplant, the information entered into the database determines that person’s priority for transplantation, so it’s critical that the data be accurate and current. The information is also important to Mayo’s transplant programs because the federal government has specific data requirements for funding.

## Ensuring Quality Patient Care

Having an electronic quality data management system saves health care providers hours of searching through charts — time better spent taking care of you. This is particularly important when the Joint Commission on Accreditation of Health Care Organizations (JCAHO) performs an audit. JCAHO sets the standards by which health care is measured in the United States, and requires transplant programs to submit volumes of data to illustrate the high quality of care an institution provides to transplant patients. Mayo has earned the JCAHO Gold Seal of Approval.

## Your Personal Health Data Is Secure

Mayo Clinic follows strict guidelines to ensure patient privacy. Patient data can only be accessed by a special code,” says Fasbender. “Only a few people are granted access to the code by the medical or surgical directors and passwords change frequently. We also have walkaway security installed so that the system shuts down if staff is called away.”

## Challenge, Change — and Chuckles

Fasbender and Huneke are part of a very social office group. Laughter often bubbles out of their cubicles. They appreciate the approachability of all members of the transplant team and are proud to contribute to what they consider to be genuine teamwork within a huge medical center that combines expertise with a down-home personal touch.

They also enjoy the challenging and constantly changing nature of their work.

“It’s never dull,” says Fasbender. “Transplantation at Mayo began in 1963 with the kidney program, followed by all solid organs and blood and marrow transplant. Now we are preparing to launch an islet cell transplantation program. Besides, how many data coordinators have the satisfaction of entering data that so dramatically improves so many people’s lives?”



## For More Information...

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

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