



Summer 2008

# Renewal

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

## Finding Answers at Mayo Clinic: A Reporter's Tale

Always a high-energy person, Lisa Laury loved her job as a long-time TV news anchor in Philadelphia. In 2001, however, she noticed her energy levels were declining and, during exercise, she felt tingling and numbness in her feet. Thus began a journey full of agonizing twists and turns that finally led her to Mayo Clinic.



*Lisa Laury*

Laury was initially diagnosed with POEMS syndrome, a rare blood disorder that affects many body systems. Since the diagnosing physician had little experience with POEMS, he referred her to a neurologist. Patients with POEMS often begin their medical journey with a neurologist because of numbness, tingling, and/or weakness that starts in their feet. As other symptoms and signs appear, they are not often connected with POEMS syndrome, which requires a specific treatment. Laury says she suffered from swelling of the feet, extreme fatigue and weakness, aches and pains and increased blood cell counts.

At that point, she says the neurology specialist told her that she had chronic inflammatory demyelinating polyneuropathy (CIDP), rather than POEMS syndrome. CIDP occurs when the immune system mistakenly attacks peripheral nerves. Laury says he treated her with steroids and

plasmapheresis for a year and a half, but her condition deteriorated. For 18 months, treatment consisted of steroids, plasma exchange and narcotics, but, she says, her health problems multiplied. Since the treatment for CIDP differs significantly from that of POEMS, her condition worsened. Laury says what she really needed was an accurate diagnosis from a hematologist.

"I was in and out of the hospital for nausea, vomiting and digestion problems," says Laury. "I also suffered a paralyzed left vocal chord, which turned my voice raspy and I had to take a leave of absence from my job."

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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.

# Finding Answers at Mayo Clinic: A Reporter's Tale - *continued*

Angela Dispenzieri, M.D.



Not willing to give up, Laury left for Florida hoping sunny weather, some unconventional therapies and examinations by different physicians would help her. But, she says, her condition only worsened.

At one point, according to Laury, a doctor in her medical team recommended she retire from her anchor position permanently and advised that she needed to prepare for dealing with a long-term illness. Laury agreed on one point — she needed to shift her attention from her career for the time being and focus her energy on healing.

Fortunately for Laury, another one of the physicians in her health care team—a gastroenterologist—questioned her diagnosis. He brought up the possibility of POEMS syndrome, the initial diagnosis Laury received. He contacted Angela Dispenzieri, M.D., a Mayo Clinic hematologist and an authority on this rare condition and asked her to see Laury to verify whether his suspicions were correct.

## *Finding the Right Expert at Mayo Clinic*

After three years of health struggles and treatments, Laury met with Dr. Dispenzieri, who agreed with the initial diagnosis: Laury had POEMS syndrome.

“For Ms. Laury, I recommended a high-dose chemotherapy with bone marrow stem cell transplantation (BMT) to fight the disease,” says Dr. Dispenzieri.

BMT is an intense treatment that kills the harmful plasma cells in bone marrow. Laury completed BMT treatment in August 2004 and is pleased with the results.

“Two months after my BMT, my voice recovered,” says Laury. “After three months, my digestion was back to normal. I am still working on strengthening my legs and ankles but I have regained feeling in the bottom of my feet and much of the intense pain in my ankles is gone.” Today, the residual symptoms of her POEMS syndrome are managed by medication, and it remains unknown whether the lingering pain will ever go away.

Dr. Dispenzieri notes that Laury’s problem with fluid retention was resolved and her clotting blood cells and breathing tests returned to normal.

## *The Oprah Connection*

Laury first met Oprah Winfrey in Nashville, Tenn., in 1976 when they were both 19.

“Oprah was already co-anchoring the local evening news in Nashville when I interviewed for a job there,” explains Laury. “We connected and she invited me to stay with her. I could see that one day she would do great things.”

In November 2005, Laury traveled to Chicago to interview Winfrey about her television show’s 25th anniversary. However, when Laury told her story of struggling with illness and the happy ending she found at Mayo, Winfrey wanted to know more and switched from

interviewee to interviewer for an hour-long discussion. Winfrey encouraged Laury to write a book about her medical struggles. Laury says she may plan to do so in the future, hoping that her experience can help others.

## *Appreciation and a New Mission*

Laury is very grateful that she eventually found Mayo and Dr. Dispenzieri.

“As I reporter, I had 101 questions and the staff always answered with courtesy and enthusiasm,” says Laury. “They are professional, thorough, friendly and caring. I just wish we’d found Mayo sooner.”

In January 2007, Laury rejoined the Action News 6 team in Philadelphia as a part-time reporter and anchor. Many of her stories now focus on her mission to help people.

“I feel very blessed for the ability to return to work,” says Laury. “It is particularly special since I reach out to help others with my stories. Just like I needed help, others do too, and this is a way that I can try and give back — by helping others.”



For more information on bone marrow transplant at Mayo Clinic, visit [www.mayoclinic.org/bone-marrow-transplant/](http://www.mayoclinic.org/bone-marrow-transplant/). For more information on the treatment of POEMS syndrome, visit <http://www.mayoclinic.org/poems/>.

# Andy's Gift by Naomi Wagenknecht

Scott Nyberg, M.D., Ph.D.



Andy on his last Christmas in 2005.



Naomi waiting for Andy's family to arrive.



Andy's parents Deanna and Craig Braun with Naomi.

After suffering from lithium-induced kidney failure, I was wait-listed on the National Donor List for almost three years until the call came from Scott Nyberg, M.D., Ph.D, at the Mayo Clinic. He informed me that a perfectly matched kidney had been found for me. We were in Florida at the time and we flew back right away. Eighteen hours later, I received my transplant on January 23, 2006.

At the time of my transplant, we only knew that my donor was sixteen-years old. We prayed for the family that had suffered a great loss, which was the reason this kidney was available for me.

After five days of excellent care at Mayo Clinic's Rochester Methodist Hospital, I stayed at the Gift of Life Transplant House, which provided a protective setting for me to heal and share my experience with others going through a similar experience. I received top-notch care and have the comfort of knowing that my post-transplant coordinator, Michelle Kreps, is only a phone call away.

At my four-month check-up, I gave Michelle a letter that I'd written to my donor's family. I needed them to know how much we appreciated their Gift of Life. A few months passed before we received a letter back from them. When my husband Jerry and I read the letter, we cried as we learned his name was Andy and he loved hunting and the outdoors. There was something very comforting in having names to connect to our prayers.

That fall, I planted 80 red tulips around our house in memory of Andy, and I invited his family to come for a visit when the tulips bloom in the spring. I was yearning to meet his family and thank them in person for their life-saving gift. That January, we received a letter from Jill Halimi, our family services coordinator at LifeSource, telling us that Andy's family was ready to know us. The first time we called Andy's parents, I was too emotional to dial the number so my husband did it for me. A woman answered and upon our greeting, we just cried together over the phone.

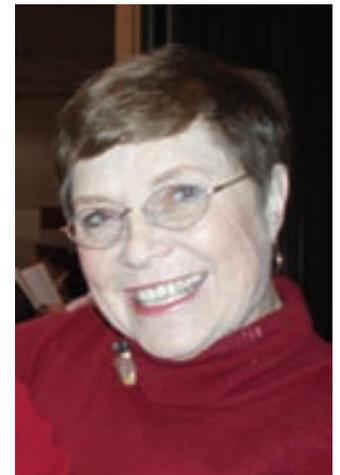
During the phone call, Andy's mom, Deanna, shared with me his story. He was born with a heart defect called Tetralogy of Fallot, which is essentially a hole in the heart. Andy underwent surgery at ages three and again at 16 years old. At the second surgery, he received a new valve in his heart. Not long after the second surgery, Andy suffered Ventricular Tachycardia and was without oxygen for 10 minutes, causing severe brain damage. A few days later, Andy suffered several seizures that left his brain inactive. The next morning, the doctors talked to his parents about Andy being a donor. The phone call was very emotional as I heard the details of their terrible loss. We talked for a long time that day and it is impossible to put into words the emotions that were shared on that call.

On the first anniversary of Andy's death, we sent his family two dozen tulips in remembrance of his life. My husband and I spent most of the day looking at pictures of Andy and mourning the loss of this young man. His kidney was working inside my body and he and his family were in our hearts, as well. We sent letters back and forth during the winter and we were ecstatic to receive the call informing us that the Brauns accepted our invitation to visit when Andy's tulips were in bloom.

That May, Andy's parents and his Aunt Helen traveled five hours to our home. It was a beautiful and emotional day as we talked, hugged and cried. They were touched when they realized the tulips were planted in groups of 16, in honor of Andy's life. Our son Mark arrived to show his appreciation and when he hugged Deanna, I heard him say, "thank you for my mother." Other family members visited throughout the day to meet Andy's parents as we shared stories of Andy over dinner.

We watched a DVD that Andy's friends made showing Andy in all stages of his life, from his years as a baby up until he passed away. The day was over before any of us were ready to let it go.

Deanna says that as long as I am alive, Andy is still with us, which she said is a great comfort for them. I feel the blessing of my new kidney every day of my life. It makes me strive to live every day to the fullest and be the best person I can be in memory of Andy's gift.



Naomi Wagenknecht

For more information about kidney transplant at Mayo Clinic, visit [www.mayoclinic.org/kidney-transplant/](http://www.mayoclinic.org/kidney-transplant/).



*If you'd like to write your transplant story, "in your own words," please contact Elizabeth Rice at [rice.elizabeth2@mayo.edu](mailto:rice.elizabeth2@mayo.edu).*

# Staff Profile

Sara DiCecco and Nickie Francisco-Ziller  
Mayo Clinic Transplant Center Dietitians



Nickie Francisco-Ziller (left) and Sara DiCecco (right).

Sara DiCecco and Nickie Francisco-Ziller know the value of longevity. DiCecco, a dietitian, played a key role in creating the program for the Mayo Clinic Transplant Center 24 years ago. Ziller has been a dietitian with the center for almost 17 years. Their tenure with the center has been rewarding.

“Since we often work with patients from the pre-transplant phase to post-transplant and beyond, we have the opportunity to have long-term relationships with them,” says DiCecco.

Not only does the job provide satisfying and unique relationships, patients trust the two dietitians’ commitment to their well-being over the long term.

“The patients feel like we have been through it all with them, from when they were sick before the transplant and into the future, whatever that may bring. They really feel like we understand what they are going through, and this helps create those close relationships,” says DiCecco.

DiCecco and Ziller focus mainly on liver transplantation, but their job also includes pre- and post-transplant assessments for people waiting for heart and lung transplants. A typical day for these Transplant Center team members starts with inpatient care and consultations with patients waiting for transplants or those who have recently had a transplant. The inpatient consultations vary, depending on the patient’s needs.

“We work with them on all kinds of things, but we primarily focus on education,” says Ziller.

Maintaining healthy eating habits is critical to maximizing transplant success. DiCecco and Ziller guide patients on how best to eat healthy. They talk to patients about eating topics that can help the body prepare for and handle a liver transplant, such as foods to eat or avoid and meal timing. To develop an individual nutrition plan, DiCecco and Ziller consider a patient’s social situation, medical history, existing nutrition plan and current symptoms.

The latter part of their day is spent in the outpatient Transplant Center. These appointments consist of pre-transplant assessments as well as post-transplant follow-up before patients leave Rochester. DiCecco and Ziller work with patients to ensure they are eating properly, and educate them on eating and proper self-care to ensure healthy living post-transplant.

“One of our main goals in the outpatient center is to help them make the transition from being a sick person to a well person,” says DiCecco. If patients have nutritional concerns when they return for checkups, the two dietitians can counsel them.

As part of educating people on the importance of the recovery period and long-term health, DiCecco and Ziller trade off teaching a food safety class on Wednesdays. Discussions can range from cooking foods correctly and keeping the kitchen clean, to making sure food is pasteurized. In addition, they compile patient-centered research aimed at evaluating and possibly improving their program.

## TIPS FOR STAYING HEALTHY POST-TRANSPLANT:

- Eat lots of fruits, vegetables and at least three servings of whole grain foods every day.
- Choose lean meats, low fat dairy products and use minimal added fat condiments (butter, margarine and salad dressings, for example).
- Increase your activity level and maintain an exercise program.
- Take a multi-vitamin and consume plenty of calcium.



# A New Life Without Insulin

*Pancreas transplant as good as a cure for man with severe diabetes*



*"Papa" Gary Hahn with grandson, Dylan, age 2. Four months after his pancreas transplant, Hahn felt well enough to drive to Kentucky when Dylan, his first grandchild, was born.*

From his diagnosis of type I diabetes at age 5, until his pancreas transplant in 2005, Gary Hahn, now 54, never knew the freedom of eating anything he wanted. Mixed in with happy memories of growing up on a farm in Preston, Minn. with five siblings, are those of watching with trepidation as his older brother practiced giving insulin shots into oranges. For 46 years, his days were preoccupied with balancing insulin injections and diet, and dealing with the complications of diabetes. A pancreas transplant changed his life.

"To find out that I have a working pancreas was the most wonderful feeling," says Hahn. "I haven't had one drop of insulin since my transplant."

## *Years of Health Challenges*

Several years after his diabetes diagnosis, Hahn developed serious headaches. In 1963, after visits to several medical centers across the country, Hahn's family took him to Mayo Clinic, only one hour away. The diagnosis was a malignant brain tumor. Mayo surgeons successfully removed the tumor and he remains a Mayo patient, including participation in many research studies.

In 1989, Hahn developed diabetic retinopathy, a complication of diabetes that damages blood vessels at the back of the eye and can cause blindness. A Mayo ophthalmologist used focal laser treatment to stop a leakage of blood and fluid into Hahn's eyes, and warned him that more retinal damage and vision loss was possible.

Hahn went home determined to control his blood sugar better. He lost 25 pounds and began reading about pancreas transplant.

Mayo Clinic is among the top five pancreas transplant centers in the country and has performed more than 300 pancreas transplants since its program began in 1987.

## *The Tipping Point*

Most people who have diabetes recognize the warning signs of hypoglycemia (low blood sugar), such as shakiness, dizziness, sweating, hunger, headaches, seizures, confusion, or tingling around the mouth. However, some who have had diabetes for many years develop a dangerous condition called hypoglycemic unawareness — a person, unaware that blood sugar levels are dropping, can faint unexpectedly. Hahn credits Karen, his wife of 34 years, and their two sons, Brad and Jerad, for saving his life many times when he fainted. In 2004, he had five hypoglycemic reactions, including one on Jerad's wedding night.

Later that year, as he drove on a major city street, he was involved in a traffic accident, but remembered nothing. No one was badly hurt, but Hahn understood the serious implications. His job as an insurance salesman required hours of driving every day. In January, 2005, during his regular check up at Mayo Clinic, he asked about the requirements for pancreas transplant eligibility. When he explained the circumstances surrounding his accident, he was quickly evaluated and on May 1, 2005, his name was added to the waiting list.

## *A Life Transformed*

The Hahns' two sons now serve in the military, far from home. Family is very important to Hahn, and he thinks "the man upstairs" was involved in how his transplant evolved.

"On Aug. 13, 2005, the whole family was together for my niece's wedding shower," says Hahn. "At 9 the next morning, we got the phone call to say that a good organ match had been found for me."

That evening, Hahn underwent a successful pancreas transplant.

"I could not have gotten through this without support and prayers from my family, friends and community," says Hahn. "I also feel fortunate to live so close to such a fantastic medical center as Mayo. My advice to anyone who has diabetes is to take care of yourself — eat right, follow your doctor's orders, and learn how and why to take care of your blood sugars properly."

For more information about pancreas transplant at Mayo Clinic, visit [www.mayoclinic.org/pancreas-transplant/](http://www.mayoclinic.org/pancreas-transplant/).



## Capital Campaign Kicks Off for Second Gift of Life Transplant House



GIFT OF LIFE  
TRANSPLANT HOUSE

### EXPANSION FOR *Life*

The Gift of Life Transplant House Board of Directors, staff, and volunteers are hard at work for the 2008 Capital Campaign, Expansion for Life, to raise funds for a second Gift of Life House in Rochester, Minn.

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."

Gift of Life annually provides 30,000 guest nights to transplant patients, filling the house to capacity. As a result, Gift of Life must often refer many guests to local hotels for accommodations. Last year, Gift of Life served more than 900 transplant patients, yet more wanted to stay at Gift of Life but could not because of lack of space.

The new facility will be constructed as a 36 unit home located on the property adjacent to the existing Gift of Life property. The handicapped-accessible facility will have kitchens, dining areas, a surrounding porch, gardens and parking. Common spaces will be large for social gatherings, while other spaces will be set aside for reflection and solitude. Most importantly, the new house will continue Gift of Life's mission to help and heal.

For more information on the Gift of Life House and the 2008 Capital Campaign, please visit [www.Gift-of-Life.org](http://www.Gift-of-Life.org) or call (507) 288-7470.



## 2008 U.S. Transplant Games

Mayo Clinic was among the sponsors of the National Kidney Foundation's 2008 U.S. Transplant Games, held July 11-16 in Pittsburgh, Pa. At the Games Expo, Mayo Clinic had a booth to greet participants and to provide a platform for sharing transplant stories through social media, for example:



- Photos from the Games can be viewed at [www.flickr.com/photos/mayoclinic/](http://www.flickr.com/photos/mayoclinic/). Or you can search for the tag `transplantgames08` at [www.flickr.com](http://www.flickr.com).
- Some participants shared their transplant stories via video on Mayo Clinic's YouTube channel at [www.youtube.com/user/mayoclinic](http://www.youtube.com/user/mayoclinic). Search for `transplantgames08`.

Please check out these sites to see and hear about people whose lives have been dramatically affected by transplant, and use these social media to help raise awareness of donation by passing these compelling stories along to your family and friends.

## Briefs

### Join a Transplant Facebook Group

A Mayo Clinic heart transplant recipient, Bob Aronson, has started a Facebook group for transplant patients, caregivers, donor families and anyone else interested in organ transplantation.



If you have a Facebook profile already, search for "Organ Transplant Patients, Friends and You" and join this group. If you don't have a Facebook page, visit [www.facebook.com](http://www.facebook.com) and sign up. Facebook is a free social networking site that helps you connect with other people.

### National Kidney Foundation Kidney Walks

Twenty-six million people have chronic kidney disease and another 20 million are at risk. The National Kidney Foundation (NKF) Kidney Walk is an opportunity for dialysis patients, organ transplant recipients, donor families, living donors, the medical community, and the general public to celebrate LIFE and support the foundation's mission.

The NKF's Kidney Walk is intended to help people understand the need for early detection of kidney disease. In addition to raising funds for research and for patients and their families, the Kidney Walk is a great way to bring the community together!

Kidney Walks are held all over the country from early spring to late fall. To determine if there is a Kidney Walk in your area, refer to the schedule at <http://www.kidney.org/news/kidneywalk/walkschedule.cfm>.



For More

## Information...

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

[www.mayoclinic.org/transplantcenter-rst](http://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](mailto:schwab.kathy@mayo.edu).*

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