

Mayo Clinic William J. von Liebig

# Transplant Center

Spring/Summer 2004

## Three successful transplants — One positive woman

### *"You can't be serious!"*

That was Sue Seiler's response on April 7, 2000, when Mayo physicians told her she needed a heart transplant. At 53, she was rarely ill, maintained her trim figure through exercise and healthy eating habits, didn't smoke and never had high cholesterol or high blood pressure. But six months before, Seiler began having symptoms of heart failure.

#### **The diagnosis: Primary amyloidosis**

Seiler and husband, Larry, live in Davenport, Iowa. During an angiogram performed by Seiler's physicians to help diagnose her condition, her heart stopped. She was resuscitated, put on life support and helicoptered to Mayo Clinic.

Seiler was diagnosed with primary amyloidosis — a rare and potentially fatal condition that occurs when abnormal protein deposits interfere with organ function. The abnormal protein, amyloid, is produced by bone marrow cells. It builds up in the body's organs; typically in the heart, kidneys, liver, spleen, nervous system and gastrointestinal tract. The exact cause of amyloidosis is unknown and there is no cure. However, as this story illustrates, there is hope in the possibility of transplant — truly the gift of life.

#### **The heart transplant**

Seiler's heart was in such bad shape that her only hope was a new one — and a long stay in intensive care waiting for one to become available.

"I was blown away and so afraid," says Seiler. "But I began to look at things differently after a visit from another person who had already been through this. She told me that she didn't want to go home and die in front of her children without first fighting as hard as she could for her life."

#### *Those fighting words sent Seiler on a mission.*



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## Three successful transplants — One positive woman *(continued)*



*Sue and Larry Seiler share their experiences with fellow Gift of Life Transplant House guest, Leah McDermid.*

“From that moment, I made a conscious effort to remain positive throughout this journey,” says Seiler. “It was easier to be positive when I thought about it as an opportunity to show my kids and grandkids the good that can come from not giving in when adversity strikes.”

### **Transplant Center Newsletter**

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Mayo Clinic has offered transplantation as a treatment option for adult and pediatric patients since 1963. Mayo 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 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.

For two months, Seiler coped with being cooped up in one room by developing and adhering to a daily schedule. She took several walks down the hall, worked out on the stationary bike brought into her room, and sat at the desk to write. Although she allowed herself naps in the recliner, she forbade herself from getting back into bed during the day.

Seiler received her new heart on May 24, 2000. She credits her speedy recovery to the great care she got at Mayo Clinic, her husband’s attentive caregiving, the support of her family, and the nurturing environment at Gift of Life Transplant House.

### **Blood and marrow transplantation**

Though the heart transplant went well, a long and difficult road remained ahead. Seiler’s hematologist, Morie Gertz, M.D., discussed chemotherapy with her and how that can slow the production of amyloid. He explained that high doses of chemotherapy also will destroy normal blood cells — putting her at risk of bleeding and infection. To help her body quickly replace the normal blood cells, she would need a blood and marrow transplant (BMT).

Seiler had a stem cell transplantation in January 2001. This process required another seven weeks in Rochester. After a week of testing, her own blood stem cells were collected over several days and stored until they could be returned to her bloodstream after chemotherapy treatments. The cells are capable of producing all necessary blood cells.

“After a heart or kidney transplant, you can feel yourself getting better — it’s not like that with a BMT,” says Seiler. “I felt ill and weak and I developed shingles in my eye. The recovery was slow.”

### **Kidney transplant**

Eighteen months after her BMT, antirejection drugs and perhaps amyloid deposits already built up in Seiler’s kidneys began causing her kidneys to fail. Seiler’s physicians encouraged her to discuss the possibility of live kidney donation with her family — they did not want her to begin dialysis, and the usual wait for a kidney is three to five years.

Seiler soon had several offers from her large and supportive family. However, her brother, Steve King, was on his own mission. During Seiler’s recovery from her heart transplant, King stayed three days at Gift of Life Transplant House and was deeply moved by the many

## Three successful transplants — One positive woman *(continued)*

stories of how people were coping with life-threatening illnesses. King turned out to be a perfect match for his sister — in more ways than one. One of his kidneys was unusual in that it had three arteries, which allowed surgeon, Scott Nyberg, M.D., Ph.D., to join them together and make one artery long enough to fit Seiler's needs. Seiler treasures Dr. Nyberg's comment after the transplant in May 2002: "The Good Lord made him just right to fit you."

### Reciprocating support

As they journeyed through Seiler's three transplants, Sue and Larry Seiler drew strength from the healing atmosphere at Gift of Life Transplant House. Whenever they return for Seiler's checkups, they do whatever they can to give something back. They offer to meet with people who are just beginning their transplant journeys — to share their experiences and provide inspiration and reassurance. Seiler tells them they're already getting the best medical care available, and advises them to follow instructions and get in the best shape possible for surgery and leave the rest to their faith. Larry Seiler stresses the importance of caregivers taking time for themselves and not feeling guilty about it. Gift of Life staff know him for his generosity in volunteering his handyman services such as hedge trimming, fixing plumbing problems and installing ceiling fans and light fixtures.

"He is not one to sit and do nothing," says his wife. "And we are so grateful — they are our family away from home."

Seiler feels blessed to have such strong support from her family.

"I could not have gone through this without Larry's dedication," she says. "My two sisters, brother and other family members relieved Larry whenever he needed to go home and attend to his new business. All of my family was unbelievably supportive."

Seiler honors the donor of her heart by working to increase awareness about organ donation. She volunteers for the Iowa Donor Network, often speaking to high school students at driver's education classes to encourage them to specify 'organ donor' on their driver's license.

"Dr. Gertz told me, for the third year in a row, that I have no amyloid in my blood or urine and that the disease is currently under control," says Seiler. "I am glad that others can find hope in this treatment. I have been blessed and this gives me a chance to give something back."

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## About the Mayo Clinic William J. von Liebig Transplant Center

The transplant programs at Mayo Clinic in Rochester are among the busiest in the United States and have achieved some of the nation's highest patient survival rates.

The six transplant programs (liver, kidney, pancreas, heart, lung, blood and marrow) are organized under the umbrella of the Mayo Clinic William J. von Liebig Transplant Center. This state-of-the-art facility offers comprehensive services for transplant patients in one location and brings the collective knowledge of all Mayo specialists to bear on the most difficult transplant problems. Specialists in infectious disease, psychiatry, addiction treatment, dermatology, critical care and anesthesia, and pathology — all with special expertise in transplantation — contribute to the care of all transplant patients at

Mayo Clinic. This collaboration has enabled Mayo to achieve national and international prominence, and advance the field of organ transplantation.



## Sheila Jowsey, M.D.:

### An admiring student of her patients' resilience to stress



*Sheila Jowsey, M.D., a psychiatrist, is a member of Mayo's transplant team.*

The Mayo Clinic William J. von Liebig Transplant Center is a multidisciplinary effort. Each member of the team specializes in a medical discipline area. But Mayo caregivers never forget that they are treating people, not organ systems. They understand the stressful nature of the transplantation journey. In fact, mental health issues such as depression and anxiety, both treatable conditions, are so much a part of the experience that psychiatrists and psychologists are regular members of the transplant team.

Sheila Jowsey, M.D., one of five psychiatrists or psychologists on the Transplant Center team, has a great deal of respect for her patients.

"The patients have so much to teach us about how to cope with illness and the importance of being connected to caring family and friends," says Dr. Jowsey. "All of us can maintain our mental health during stressful times by emulating their ways of being resilient."

#### **Maintaining your mental health on the transplantation journey**

Mental health researchers have identified suffering, uncertainty and enduring change as the three most important circumstances that contribute to psychological

problems related to chronic illness. People undergoing transplant are experts in coping with stress, because they must deal with all three.

Observing the way patients adapt to the transplantation lifestyle, Dr. Jowsey identified four major factors that help people cope with stress:

- **Taking responsibility for your health** — by making a decision to be an active member of the health care team. This means learning about your illness so you know what to expect, taking your medications as advised, eating nutritious meals, getting the required exercise, knowing about problems such as depression and being willing to alert the health care team to potential problems.
- **Having a spouse or significant other** — to love you, listen to you and be your best cheerleader.
- **Connecting with your support network** — make those who love you feel good by letting them do something to help you and your caregiver.
- **Finding meaning** — by contributing to a cause greater than yourself that energizes and inspires you. You may find meaning through your faith or another aspect of spirituality, or by exploring your passion for an intellectual pursuit, a craft or activity.

#### **A new screening tool**

Dr. Jowsey participates in research on the psychiatric aspects of organ transplantation. Currently, her research focuses on identifying patients most in need of psychiatric treatment. She collaborated with colleagues to develop a screening test that identifies psychological characteristics that put people at increased risk for developing problems when a serious illness robs them of their autonomy.

The screening test was well received at a recent American Psychiatric Association meeting when Dr. Jowsey presented it to psychiatrists who specialize in treating seriously ill patients.

"The transplant team recognizes the importance of mental health to a successful transplantation outcome," says Dr. Jowsey. "We anticipate this tool will help us identify those most in need of our services. Our goal is for our patients to emerge from the transplantation experience thriving — and that includes their mental health."



# Happy Anniversary!

## The Gift of Life Transplant House turns 20

As this newsletter goes to press, staff at the Gift of Life Transplant House are hard at work planning a long weekend filled with fun events to celebrate the 20th anniversary of Gift of Life Transplant House. But the home's roots reach back more than 30 years — that's when a young man called Ed Pompeian traveled from Michigan to Rochester for a kidney transplant.



*Ed Pompeian founded Gift of Life Transplant House 20 years ago.*

### **A miracle-studded life**

Pompeian sees his life as a series of blessings joined by small miracles. The first miracle happened as he clung to life, suffering from a severe kidney infection.

"I shared my hospital room with an elderly gentleman who advised my parents to take me to Mayo Clinic," says Pompeian. "His advice saved my life."

At age 21, Pompeian felt blessed when his mother, Helen, eagerly volunteered to be the donor for his living donor kidney transplant at Mayo in 1973. By 1980, he had met and married Jayne, his wife of 24 years. From that blessing grew the next four miracles — children Edward, Aaron, Nick and Adrienne. "I had been on drugs for

many years and tests showed little chance of fathering children," chuckles Pompeian.

Pompeian also credits his later fund-raising successes to miracles, humbly disregarding the likely impact he had on donors eager to be associated with his enthusiasm for a selfless and noble dream.

### **Planting the seed and growing the vision**

After recovering from transplant surgery, Pompeian became an angel of mercy. Over the next 10 years, he visited the transplant floor daily to talk to patients about his experiences. He was a good listener, too. He heard many tales of scared patients spending endless nights in cold, isolated and expensive hotel rooms, the seeds of his vision were planted.

In 1976, Pompeian began to act. He convinced his real estate partner to help him furnish an apartment in a building they owned. They offered it at reduced cost and without a lease to patients waiting for, or recovering from, transplant surgery. By the time they sold the building in 1980, they had outfitted five more apartments. Pompeian then continued his mission of providing appropriate housing for transplant patients by purchasing a nearby complex of 22 kitchenettes.

### **Twenty years ago: the first house**

In 1984, Pompeian eyed a house for sale at 624 West Center Street.

"It was a three-story, eight-bedroom house with beautiful oak woodwork," says Pompeian. "The seller was delighted at the potential of her house becoming a temporary home for transplant patients."

With his real estate skills, Pompeian convinced the seller to finance the house. Intense efforts were made to raise funds for the down payment. The house opened in December 1984 — and Pompeian's vision of providing a compassionate, homelike environment for people undergoing the transplant journey far from home was realized.

### **Purchasing the current building**

Pompeian had tapped into a genuine need that was growing in concert with Mayo's burgeoning reputation for successful transplant programs. In 1988, the Gift of Life Transplant House board leased additional space in the nearby convent at St. John the Evangelist Catholic Church, bringing the number of beds available to 21.

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## Happy Anniversary!

### The Gift of Life Transplant House turns 20 *(continued)*

As medical technologies improved, transplantation became a possibility for more and more people — and they all needed a comfortable home away from home during their transplant journey. When the former home of Mayo Clinic surgeon E. Starr Judd came up for sale in 1994, the board agreed with Pompeian that it would provide the perfect atmosphere and location for patients undergoing or waiting for transplant surgery.

“We needed to raise \$300,000,” says Pompeian. “It sounded daunting but it was a miracle how generous our donors were.”

A 32-bedroom addition and further renovations were completed in 1995. Another addition of 13 bedrooms was completed in 2001. With the house’s original three bedrooms, that brought the total number of bedrooms available to 48. The hard work and determined fund-raising efforts that have continued over the years have kept the home affordable.

“I didn’t do this on my own,” says the ever-humble Pompeian. “I am grateful for the hard work and generosity of countless people in the community who helped me realize my dream.”

The Gift of Life Transplant staff hopes you will be able to join in the fun on Sunday, July 11, as they celebrate 20 years

of providing their guests with high-quality, affordable accommodations in a supportive, homelike environment. And while you’re there, take a moment to shake the hand of Ed Pompeian, a man who has both received the gift of life and donated his time, talents and financial resources to see that those who followed him have a welcoming place to stay.

#### The weekend’s events

**Saturday, July 10:** Mayo Clinic’s Transplant Center picnic (See below for information.)

**Sunday, July 11:** 20th Anniversary Open House, “Sharing the Gift.” Festivities include brunch from 11 a.m. to 1:15 p.m., music throughout the day and a benefactor recognition, including guest stories at 1:30 p.m.

**Monday, July 12:** 20th Annual Gift of Life Benefit Golf Tournament — registration is first come first served. To check on available slots, visit the Web site at [www.gift-of-life.org](http://www.gift-of-life.org) or e-mail the Gift of Life at: [office@gift-of-life.org](mailto:office@gift-of-life.org).

## Upcoming Events

### Annual Picnic

Mayo Clinic’s annual “Celebration of Life Picnic” will be held Saturday, July 10, 2004, at Essex Park from 11 a.m. to 3 p.m. If you haven’t already registered, you may still return your registration form or contact your nurse coordinator. Desserts, lawn chairs and outdoor games are welcome. In case of rain, tune your radio to KNXR 97.5 or KROC 106.9 for an alternate location. Cost is \$7 per person (children 6 and under free) for food catered by the Canadian Honker.

### 2004 Transplant Games

The 2004 U.S. Transplant Games provides a physical demonstration of how organ transplantation restores vitality to so many people — 10,000 people are estimated to participate this year. It is the largest sporting event in

the world for people who have received organ transplants. The games also highlight the need and worth of organ donation.

This year, the games will be held at the University of Minnesota from July 27 – Aug. 1.

Mayo Clinic patients are encouraged to get involved. Events include cycling, golf, swimming, racquetball, table tennis, 3-on-3 basketball, track and field, badminton, bowling, volleyball, and a 5k race.

You can find more information and register at <http://www.kidney.org/>.

# Mayo's youngest candidate for whole-liver transplant



*Trevor Tompkins is the youngest person ever to undergo a whole-liver transplant at Mayo Clinic.*

Trevor Tompkins won't remember his first ride in a helicopter. His mom and dad won't ever forget it. Trevor's journey came in the middle of the night, when he was just four days old. And it began a different journey, for Trevor was soon to become the youngest person ever to undergo a whole-liver transplant at Mayo Clinic.

## **A mellow baby**

At first, Trevor seemed to be just a mellow baby. He was born on Feb. 15, 2003, weighing 8 pounds, 1 ounce. When his parents, Travis and Debbie Tompkins of Augusta, Wis., brought their firstborn son home, they assumed Trevor was just sleepy and otherwise content. But then there were signs that something was wrong.

Trevor didn't have much of an appetite. At an appointment at Luther Midelfort in Eau Claire, Wis., — part of Mayo Health System, the day after Trevor was dismissed from the hospital, his pediatrician noted his slow responses. He admitted Trevor to the hospital suspecting an infection. The initial treatment didn't help, but the quick-thinking pediatrician had ordered a test that revealed a potentially fatal level of ammonia in Trevor's blood. An emergency telephone consultation with Mayo Clinic specialists determined that Trevor had a rare genetic disorder. If not identified and treated quickly, it would have taken his life.

## **Ready for takeoff**

Then came Trevor's helicopter ride — aboard the Mayo One emergency helicopter. His parents followed in a car driven by relatives.

"We couldn't go with him because the chopper was too small to hold all of us," says Debbie Tompkins.

When they arrived, Trevor's parents were frightened by what they saw, but even then Trevor's situation was improving.

"Trevor was already in the NICU (Neonatal Intensive Care Unit) at Saint Marys Hospital," Debbie says. "He had IVs and monitors everywhere: his hands, feet, head, belly button."

Dusica Babovic, M.D., a geneticist who directed treatment of Trevor's metabolic disorder, worked with neonatologists to rapidly lower the levels of ammonia in Trevor's blood through infusions, dialysis and medication. Additional tests determined that Trevor had ornithine transcarbamylase (OTC) deficiency.

"The diagnosis of this condition is easy, if you think about it," says Mounif El-Youssef, M.D., a Mayo Clinic gastroenterologist who joined Trevor's team of specialists. "But, with a condition as rare as this one, the difficult part is thinking to test for it in the first place."

A metabolic disorder, OTC deficiency occurs in approximately one in 80,000 births. Because it hinders the processing of protein, the disorder rapidly leads to a toxic accumulation of ammonia in the body that can cause severe brain damage and death. That damage was minimized because of the quick action and intervention. But due to his brain's exposure to high levels of ammonia, he has some mild developmental delays.

The gene for OTC deficiency is on the X chromosome. In the Tompkin's case, Debbie learned she was a carrier of OTC deficiency only after Trevor had already been admitted to the NICU. If the couple has other male children, they have a 50 percent risk of being affected. However, the knowledge Debbie and Travis, and their doctors, now have will help tremendously in dealing with the condition.

## **The liver transplant**

Trevor's physicians stabilized his condition within a day of his arrival at Mayo. His illness could be controlled by

## Mayo's youngest candidate for whole-liver transplant *(continued)*

medication in the short term, however, to protect Trevor from further damage, the only option was liver transplantation. So Trevor was placed on the waiting list.

Early on the morning of April 17, 2003, Debbie and Travis received a call from Michael Ishitani, M.D., a Mayo Clinic pediatric liver transplant surgeon, that their wait was over.

"Trevor's small size made the surgery challenging," says Dr. Ishitani. "The blood vessels and structures you're working with are very small, so the risk of surgical complications is much higher compared to liver transplants done in adults."

### **A happy, growing and thriving baby**

After the transplant, Trevor did well with only a few

minor complications. On May 22, 2003, more than three months after he was flown to Rochester, Trevor was well enough to go home to Augusta with his parents.

"Bringing him home was awesome, but a little weird," says Debbie Tompkins. "For three months, we lived in his hospital room or one room at the Ronald McDonald House.

There were always people around. Coming home to a quiet house was a big change. Then we thought, 'Finally. Now we get to be a family.'"

Trevor is a happy, good-natured baby who loves to be around people. Although he will be on antirejection medication for the rest of his life, his care team is hopeful that Trevor will continue to grow and thrive.



### **For More Information...**

For more information on Mayo Clinic's William J. von Liebig Transplant Center, visit us online at:

[www.mayoclinic.org/transplantcenter-rst/](http://www.mayoclinic.org/transplantcenter-rst/)



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MC4221-02rev0604