

Mayo Clinic William J. von Liebig

Transplant Center

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The Jay Ryan story: a young man's unplanned odyssey

In June 1996, Jay Ryan was an 18-year-old in the peak of physical fitness who was about to set out on a journey. Rather than the journey evoked by the clichéd phrases of his graduation cards, it was an unplanned odyssey where the sights included a glimpse of death, the destination was a new heart and the homecoming was a new chance at life.

A mysterious viral infection

Jay's transplant journey began with a trip to the Boundary Waters in northern Minnesota where he apparently picked up a mysterious viral infection. He returned feeling short of breath and, alarmingly quickly, became critically ill.

"In June I was fit and healthy and weighed 205," says Ryan. "By August I had a new heart, was 147 pounds and could hardly walk to the bathroom."



Jay Ryan enjoys a game of golf.

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At first Ryan's family physician thought he had bronchitis or asthma. However, within two days it was becoming obvious that something was drastically wrong. When a chest X-ray in the emergency room revealed a supersized heart, Ryan was admitted to a hospital in St. Paul. That's where he spent his 19th birthday — struggling to breathe and not knowing what was wrong, or what was going to happen to him.

The road to transplant

In desperation, Ryan was referred to Mayo Clinic in early July where cardiologist Brooks Edwards, M.D.,

immediately admitted him to the hospital and launched the battery of tests to prepare him for heart transplant.

Unlike many transplant recipients, Ryan did not suffer the agony of a long wait for his transplant.

"I was home from the Boundary Waters only a few days when I told my mom I just couldn't breathe," says Ryan. "I don't remember anything else until I woke up after my transplant."

But these were agonizing days for Ryan's family. His condition was grim. His heart stopped and after he

The Jay Ryan story: a young man's unplanned odyssey *(continued)*

was resuscitated he was kept alive with a left-ventricular (LV) assisted device — a machine that does the work of the heart. He stayed on the machine for more than two weeks, longer than any patient before him. A heart became available in the wee hours of Aug. 2.

“Our care team was delighted that a heart became available for Jay because it was clear that his ability to survive on the device was running out,” says heart surgeon, Christopher McGregor, M.D. “For our patients today, the outlook is much better because improved devices now last for many months.”

The transplant surgery went well. Ryan commends Dr. McGregor for his meticulous surgical skill and demanding standards. Ryan's recovery went exceptionally well. He missed only one semester of college and was back playing baseball nine months after transplant. Clearly his positive attitude played a large role, although he credits the dedication of people like his first nurse coordinator, Kathy Schwab, who promised to take care of him “like a second mom.” Ryan cannot say enough good things about the care he received from the transplant team and from the Gift of

Life Transplant House where he stayed for six weeks after surgery.

Enjoying the gift of life

Ryan grew up on the same street as Sarah Rickert. In high school, they went to the junior prom together — but only as part of the routine exchange of dates among a close circle of high school friends.

Throughout the course of Ryan's illness, however, Sarah stuck by his side and the bond between them deepened. When he got out of the hospital, the couple began dating. They attended the same college and after graduation, in 2001, they married.

Ryan is now a salesman for a printing company and stays fit playing softball, golf and doing yard work with Sarah. To look at him, you'd never suspect he had a heart transplant.

“Getting the heart was the most phenomenal gift a person could get,” says Ryan.

“I feel blessed. I've had very few setbacks. I had a minor stroke due to the LV assisted device but all that causes is a little numbness in my hand. And I had a few problems with post-transplant lymphoma disease but since my medication was changed three years ago, I haven't had any more tumors.”

“Immunosuppressive drugs can raise the risk of developing non-Hodgkin's lymphoma,” says Thomas Habermann, M.D., Ryan's hematologist. “The good news is that lowering the dose of immunosuppression results in tumor regression in one-third or more of patients — but that means increasing our vigilance for graft rejection.”

Always upbeat, Ryan lives by the words of Cal Stoll, a former University of Minnesota football coach and fellow heart-transplant patient who visited Ryan after his transplant.

“Cal told me, ‘If you think you're broken, you *are* broken,’” says Ryan. “You've got to play the hand you're dealt with and the best piece of advice I could give anyone waiting for a transplant is to maintain a positive attitude.”

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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.

Transplant nursing — there's nothing cooler



Carolyn Unruh, kidney/pancreas and liver transplant nurse.

Carolyn Unruh, an 11-year veteran of transplant nursing and a registered nurse in Mayo Clinic's Kidney/Pancreas and Liver Transplant Program, can't understand why more nurses don't choose transplant nursing as a career goal.

"It doesn't get much cooler than transplant," says Unruh who explains with an anecdote:

We had a very ill patient who was on the floor for a long time waiting for a liver. She was quite confused and, after transplant, her recovery was longer than normal. But a year later when she saw me on the floor, she practically broke into a run. She absolutely beamed and said, "Look at me. I'm all better!" What could be cooler than caring for a patient over a long period and then seeing their quality of life returned to them?

A rapidly changing field

Kathy Neswold, a nurse of 17 years — 10 of them in the Heart-Lung Transplant Program — was 12 when she decided to become a nurse. Her inspiration was the good feeling she got from tending to her grandfather's basic needs after he chose to die at home. Now married with two children, she still enjoys basic nursing care but also finds satisfaction in new challenges.

"In our field you have to be able to continually embrace change," says Neswold. "There is always a new dressing, a new computer application or a new piece of equipment to keep you on your toes."

The changes reflect the ongoing barrage of rapid advances made to improve care for transplant patients. Some are lifesaving changes while others improve the quality of life while waiting for transplant.

Kristin Cox, a registered nurse who started in Mayo's Blood and Marrow Transplant (BMT) Program following graduation two years ago, lauds the BMT outpatient program as a positive change that occurred before her time.

"The outpatient program wasn't offered until about 10 years ago," says Cox. "It was an important innovation because BMT is a very challenging process and our patients eat and sleep so much better without all of the disturbances of a hospital environment."

BMT requires one to 10 days of high-dose chemotherapy or total body irradiation — sometimes in combination — to kill the targeted cancer cells. However, the treatment kills all cells that are growing and dividing so it also severely lowers blood count levels. In the 10 to 20 days it takes for the transplanted stem cells to produce new blood cells, patients are at risk for infection and bleeding. They are treated with antibiotics, and red blood cell and



Kathy Neswold, heart/lung transplant nurse.

platelet transfusions. Patients commonly experience some combination of persistent nausea, fever, diarrhea and mouth sores until their blood counts recover.

– Continued on next page.



Kristin Cox, blood and marrow transplant nurse.

A select group of patients waiting for heart transplant can also enjoy the comforts of home thanks to innovation. Improvements made over the last decade have resulted in a mechanical heart, called a ventricular assist device (VAD) that can support the circulation for a prolonged period. Neswold tells how the device renewed her faith in transplant after losing several severely ill and elderly patients:

I think God sent a particular patient to help me through a difficult time. The patient is well-known in our unit for his upbeat attitude, fondness for telling jokes and his ongoing kindness and generosity toward the nurses. He had to wait two or three months for a heart yet he greeted us with a smile every morning. Eventually, he had to have a ventricular assist device and it saved his life. I was so thrilled that, since then, VAD has become my passion.

Soon afterwards, Neswold became VAD-certified — a process that requires demonstrated proficiency in running and maintaining the device, hand-pumping and patient education.

The challenge of dealing with death

Cox knows how hard it is to get through those periods when there seems to be a run of patients who don't do well.

"I'm grateful that my husband is such a great sounding board because there's no question that the BMT unit is a tough place to work," says Cox. "But it's important to remember that death is a natural and important time for both the patient and the family and helping them cope with it is part of our responsibility."

Cox remembers one such occasion with fondness.

"I had become quite close with the wife of a patient who died on my shift," explains Cox. "When she came into the room, she asked me to pray with her. I was very pleased that she wanted me there with her. It was a very special moment."

Belonging to a special community

All three nurses agree that being part of the unique bond between transplant patients, their caregivers, families and the Gift of Life Transplant House adds value to their jobs.

"The people who have transplants and those who care for them really become like family because we get to know each other well over many visits," explains Cox. "Our patients need a great deal of encouragement as they go through BMT. It's a wonderful feeling to see them three months later — their hair growing back and getting on with their lives."

Unruh sees another advantage in getting to know the patients well.

"When you know your patients so well, you have a better chance of picking up on subtle signs when things go wrong," says Unruh. "It's exciting to know that the physicians can rely on you to alert them when you see something's not quite right."

Neswold views transplant as a profound and even mystical experience.

"This is the best job I've ever had," she says. "We see people get a second chance at life. We see desperately ill children grow up to have their own kids."

What could be cooler than that?

3,000 kidney transplant milestone celebrated with one of the first kidney donors



Beverly Staples, Mayo Clinic's first living kidney donor.

Beverly Staples does not have to think too hard when someone asks her what she was doing the day President Kennedy was shot, on Nov. 22, 1963, — she was in the hospital undergoing tests to determine if she could donate a kidney to save her brother, Gayle Lindahl's life. The surgery, which took place in January 1964, was only the second living-donor kidney transplant performed by the Mayo Clinic Kidney Transplant Program — the program has now performed more than 3,000 kidney transplants.

The 3,000 milestone was celebrated on Nov. 5, 2004, at an event attended by 600 patients and their families and members of the kidney transplant team. Staples was a guest speaker at the event. In her speech, she recalled that the surgery took place about three years before a liver or heart transplant had been done anywhere in the world, and at a time when only twin-to-twin living-donor kidney transplants had been successful.

Despite the uncertainty, all six of Gayle Lindahl's siblings volunteered to donate a kidney. When an older brother was diagnosed with bladder cancer as a result of the extensive testing, Staples became the primary candidate.

"It saved my older brother's life because the cancer was diagnosed at an early stage," says Staples. "As for Gayle, he was on dialysis when he was only 21. The transplant gave him four more years and I haven't had any health problems so I have no regrets. But it did take a giant leap of faith in both God and in the doctors and nurses at Mayo because we were going into uncharted territory."

The largest living-donor program in the country

Although kidney transplant surgery is not to be taken lightly, it no longer requires the 'giant leap of faith' that the new program inspired.

"Mayo has one of the largest and most successful kidney transplant programs in the United States," says Mark Stegall, M.D., surgical director of the program in Rochester. "We complete 250 kidney transplants every year, and nearly 200 of them are from living donors. We have the ability to transplant across blood types (ABO-incompatible kidney transplant) and to transplant patients who have developed antibodies against their donors (positive crossmatch kidney transplant)."

Mayo has the largest living-donor program in the country and living-donor transplant candidates come to Mayo from throughout the United States and around the world.

Thumbs up

Forty years later, Staples vividly remembers a moment any kidney donor would treasure:

"I looked at Gayle through the window of his isolation room and when he saw me he gave me the 'thumbs up.' Then he pointed to the half-filled urine bag hanging from his bed and gave me a huge smile. That's when I knew it was all worth it."

Angels for a Miracle



Violet and Joel Nelson organized “Angels for a Miracle” to give something back following Joel’s double-lung transplant. Joel is now waiting for a kidney transplant.

The song, “I believe there are angels among us,” was well-chosen to help kick off the second annual “Angels for a Miracle” Benefit for Organ Transplant held in April 2005 at Willow Creek Middle School. The benefit raises funds to help defray the costs of non-medical expenses for Mayo Clinic patients undergoing transplant. Indeed, there were angels aplenty that day — donating gifts for the raffle, selling their home-baked goods, or helping out with the live auction, games or informational tables. But perhaps most deserving of the title are the event’s organizers, Joel and Violet Nelson.

For many years, Joel Nelson struggled with Chronic Obstructive Pulmonary Disease. In 1999, he became a candidate for a double-lung transplant.

“I was on the list for three years and two months,” says Nelson. “Then, on Sept. 6, 2002, I received the miracle. It was an emotional roller coaster but it drew us closer as a couple and closer to God.”

After it was all over, the Nelsons recognized the full implication of being given a second chance at life and wanted to give something back. The Nelsons live in Rochester and reflected on how much more difficult it was for those in the program who traveled very long distances to come to Mayo, leaving their children, family and jobs for long periods.

“The goal of building up the Transplant Fund seemed like an ideal way to give something back,” says Violet Nelson.

Mayo originally created the Transplant Fund as an endowment fund to support non-medical expenses, such as travel, food, lodging and day care expenses of transplant patients. Recently, the high demand for grants has forced a reduction in both grant amounts and their availability. “Angels for a Miracle” was just what the doctor ordered.

The Nelsons formed a committee and began organizing a benefit to be held in May 2004. They chose to do a small celebration of the transplant community followed by a walk. They also sold T-shirts and provided a raffle, silent auction, bake sale, concession stand, massages, information tables — and hugs.

“We have many wonderful angels on the committee,” says Violet. “So much talent and eagerness — so many ideas. The event raised more than \$17,000.”

The Nelsons were amazed by the eagerness and generosity the event inspired and decided to conduct it annually.

“We decided to change the name from walk to benefit because some people were not well enough to walk and were put off by it,” says Violet. “We just want people to come, have fun, meet new people and help raise funds and awareness.”

Despite the unseasonable cold outside, which put off all but a few brave walkers, the atmosphere inside this year’s event was warm and festive. With \$15,000 raised, the Nelsons declared it another resounding success.

If you would like to share your transplant experience at next year’s “Angels for a Miracle” benefit, Violet Nelson would love to hear from you. Call her at 507-258-0487.



Ranking the sickest patients for liver transplant

If your transplant team identified you as a candidate for liver transplant, you joined some 17,500 people on the waiting list. In 2002, to assure an objective way of determining who should receive the next available liver, the United Network for Organ Sharing (UNOS), the government-sponsored agency in charge of organ donation and allocation, adopted a point system, called the Model for End-Stage Liver Disease (MELD).

MELD allocates a score between six and 40 based on a formula developed at Mayo Clinic. The formula uses your results on the following three routine lab tests:

- Bilirubin, which measures how effectively your liver excretes bile
- INR (prothrombin time), which measures your liver's ability to clot blood
- Creatinine, which measures kidney function

Your MELD score can change as your liver disease progresses. Your team will advise you how often you should schedule more tests in order to update your MELD score.

When an organ becomes available, a computer compares the characteristics of each patient on the waiting list to those of the donor. It allocates points to each patient and produces a list of patient names ranked in order of their compatibility, degree of medical urgency, distance from the donor and length of waiting time.

Does the person with the highest points always get the donor organ?

When your name comes to the top of the list, the Mayo team receives a call notifying them that a donor liver is available for you. That's when you get that long-anticipated call and give the green light to set up for your transplant.

However, it often happens that the top candidate does not get the donor organ. The organ may be unsuitable because of size difference or the circumstances of death. Sometimes the transplant candidate may be unavailable, have an acute illness that makes major surgery inadvisable, or may not be psychologically ready for immediate transplant.

"Patients with special conditions such as hepatocellular carcinoma, oxalosis, familial amyloidosis, and hepatopulmonary syndrome are assigned scores appropriate to their risk of death or disease progression," says Charles Rosen, M.D., surgical director of the Liver

Transplantation Program. "And patients with other diseases can appeal for higher scores to a special regional review board comprised of physicians from each of the transplant centers in the region and other nonphysician members."

One of the highest patient survival rates in the nation
Mayo Clinic Rochester's liver transplant program has performed more than 1,500 liver transplants since its beginning 20 years ago. Its success is best illustrated by its survival rates, which are among the highest in the country. Mayo's one-year survival rate is more than 90 percent compared with the national average of 86 percent. Mayo's three-year survival rate is more than 86 percent compared with 78 percent for the national average.

You can compare Mayo's transplant results to other programs in the United States on the Scientific Registry of Transplant Recipients Web site at www.ustransplant.org.



Charles Rosen, M.D., surgical director of the Mayo Clinic Liver Transplantation Program.

Upcoming Events

Annual Picnic

Mayo Clinic's annual "Celebration of Life Picnic" will be held Saturday, July 9, 2005, at Essex Park from 11:30 a.m. to 2 p.m. If you haven't already registered, you may still return your registration form or contact Mollie Vogel Luhman at 507-538-7446.

Lawn chairs and games are welcome. In case of rain, tune your radio to KNXR 97.5 or KROC 106.9 for an alternative location. Cost is \$7 per person (children 6 and under free) for food catered by the Canadian Honker.

2005 World Transplant Games

Sixty countries have been invited to compete in the 15th World Transplant Games to be held July 16 to 24, 2005, in London, Ontario, Canada.

Save the Date: 2006 Transplant Games

While it may be too late to register for the 2005 World Transplant Games, now is the time to put next year's U.S. Transplant Games on your calendar. The 2006 U.S. Transplant Games will be held June 16 to 21, 2006, in Louisville, Ky.

Competition is open to anyone who has received a life-saving solid organ or bone marrow transplant. Last July, a record-breaking crowd of 6,000, including 1,500 transplant athletes, converged in Minneapolis, Minn., for the 2004 U.S. Transplant Games.

Start planning now to participate in this celebration of life among recipients, their families and friends. Become a transplant athlete and show the world how successful organ and tissue transplantation can be.

To register, or for more information about both events, visit www.kidney.org. To join a Mayo Clinic team, contact Kathy Schwab at schwab.kathy@mayo.edu.



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/



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