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## Lives in the Balance

**In remarkable ways, members of IWU's community have participated in both the giving and receiving of life-saving organ transplants.**

**By Chris Fusco '94**

In a time of tragedy, the family of Bill and Paula Walsh turned to organ donation for hope.

On the morning of Aug. 15, 1998, Bill and Paula were in Champaign, helping their son Brent move into an apartment near the University of Illinois. Their 18-year-old daughter Shannon accompanied them on the trip.

That night, the two parents were at OSF Saint Francis Medical Center in Peoria, trying to comprehend how their daughter's car had skidded off a two-lane road and crashed into a utility pole, leaving her badly injured.

Shannon Colleen Walsh was about to enter her senior year in high school. A music lover, she played the piano and flute. She worked part time at Schnucks supermarket in Bloomington, which was where she was headed when the crash happened southeast of town at about 3:50 p.m.

At the hospital that night, the situation looked dire.

"When they stopped the ventilator, she couldn't breathe on her own," recalls her father, an associate professor of business administration at Illinois Wesleyan. "They were scratching the foot, flashing the lights in the pupils, but it wasn't there."

Every year, between 12,000 and 15,000 people in the United States die in a manner that leaves them able to donate their organs. It became clear to Shannon's family that she was about to become one of them.

"We were calling for the donor folks," Bill Walsh says. "It was helpful to know at least some good could come from this horrible thing that happened."

The family's act of kindness did not come without its own set of stresses. There were routine but sensitive questions about Shannon's life and paperwork for the organ recovery coordinator to complete. As the process moved forward, the Walshes weren't exactly sure that the machines keeping Shannon's heart beating would allow her to hang on long enough to have her organs transplanted.



IWU professors Hans-Joerg and Moreena Tiede with daughter Annika, who is doing well after receiving a liver transplant. (*Marc Featherly*)

“If her heart wouldn’t keep functioning, we weren’t sure what organs would be usable,” says Bill Walsh. “Her heart stopped one time while we were out of the room.”

The same torturous situation that the Walsh family encountered faces others every day: loved ones—often after unexpected tragedies—become brain-dead, meaning their hearts and lungs function only with the help of machines.

About one percent of Americans die this way, making them eligible to donate their heart, kidneys, liver, lungs, and select tissues if their families consent. The other 99 percent usually can become tissue donors only, which includes the eyes, heart valves and, in some cases, bones.

Meanwhile, a growing number of people are awaiting life-saving organ transplants. Last year, more than 6,400 people on organ waiting lists died, including 320 Illinoisans, according to the United Network for Organ Sharing. The national transplant waiting list now numbers 79,000.

Fewer than half the families presented with the option of organ donation actually do it, and the organ shortage is so great that risky, living-donor transplants reached an all-time high last year. The crisis spurred the American Medical Association to announce it would support a study to examine the controversial concept of offering financial incentives to organ-donor families.

The shortage of organs is partly the result of medical advances.

“People are turning to transplant as an option more,” says Ruth Kucan Keith ’81, an organ recovery coordinator for the Gift of Hope Organ & Tissue Donor Network, which oversees organ distribution in Illinois. “There’s been improvements in surgical technique, the preservation solution to prepare an organ, and drugs that combat the rejection of the organ.

“Insurance companies also are more likely to be covering the transplants. Now, there’s truly a way for people to save their lives.”

The Illinois Wesleyan community is a testament to Keith’s statement. She is one of two IWU alumni who work as an organ recovery coordinator for Gift of Hope, formerly known as the Regional Organ Bank of Illinois. Also, an Illinois Wesleyan alumnus is alive today because of a transplant, and the same goes for the 2-year-old daughter of two IWU faculty members.

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In spring 1997, with her fraternal twin sons nearing the end of their freshman years at her alma mater, Linda Henderson Fischer '70 learned during a routine checkup that she had a heart murmur. She went to a cardiologist, who told her she had cardiomyopathy, a condition that causes the heart to enlarge.

Medication might be able to control the problem, Fischer was told, but the only solution was a heart transplant.

“I had been a little more tired than usual, but that was about it,” she recalls. If a transplant was in her future, she figured it probably wouldn’t happen until she was in her 80s or 90s. She was 49 when diagnosed.



Linda Henderson Fischer '70

For more than two years, life went on as usual for Fischer.

In September 1997, the former *Argus* editor became assistant editor at *Maintenance Technology* magazine in Barrington, which is near her home in Lake in the Hills, a northwest suburb of Chicago.

In October 1999, she awoke one night feeling pressure in her chest.

“I was extremely uncomfortable,” she says. “The paramedics came, and I went to the hospital where they indeed confirmed I had had a minor heart attack.”

Fischer underwent surgery to have a pacemaker installed, but she still felt extremely sluggish afterward. Her cardiologist suggested she go to Loyola University Medical Center for a transplant evaluation.

At first, Loyola’s doctors thought a steady exercise regimen and more medication might help her. She took their advice and believed the routine was working when she watched sons Eric and Kurt Fischer graduate from IWU in May 2000.

About two months later, she learned otherwise. Medical test results showed her heart continuing to perform poorly. She went on the heart-transplant waiting list, receiving a pager on July 19 that would let her know if a heart became available.

The next day, Fischer felt awful at work and went back to the hospital, where she was admitted. Her heart was failing badly, and she was moved up on the transplant list because of her critical condition.

At 11 p.m. on July 22, the phone rang in her room.

“I was trying desperately to sleep, and I was extremely upset at somebody calling me at that hour,” Fischer says. “The voice that spoke to me was one of my doctors who said, ‘Linda, I think we have a heart for you.’”

She hardly could believe it.

“When I went on the list, I went with the feeling that this was going to be a long-term action, that I would be on the list for a while,” she says. “I was trying not to think that most of the people on the waiting list die before they get their organs.”

The all-day transplant happened on July 23, and Fischer went home a week later.

Since then, she describes herself as a textbook transplant case, exercising regularly and taking about 25 pills daily to keep her body from rejecting the heart. Like all transplant recipients, she'll take them the rest of her life.

Fischer volunteers for Gift of Hope, telling her transplant story to community service groups, scout troops, and anybody else willing to listen.

She walked down the aisles at her sons' weddings, in November 2001 and March 2002, respectively, thankful that the family of the 24-year-old man who lost his life gave life to her. Fischer has written his family a couple of letters, but both sides would need to consent through Gift of Hope before they could meet.

“I have a great love for life...the simple things,” says Fischer, who turned 54 in January. “I get a big kick out of watching butterflies, watching animals at the zoo. I'm not getting upset or worried about the little things. It's just not worth it.”

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Annika Tiede has spent nearly a year of her 26 months in this world in hospitals. She's had three major surgeries, including two liver transplants.

To see her on this late-summer Friday at Children's Memorial Hospital in Chicago, you'd never know it.

Annika weighs about 27 pounds, with blonde hair and her grandmother's blue eyes. She's walking, exploring the waiting area and smiling at her parents, IWU assistant computer science professor Hans-Joerg Tiede, 31, and adjunct computer science instructor Moreena Tiede, 32. The family is here for an ultrasound to see if Annika's liver is continuing to work right.

Five weeks after her birth on Oct. 16, 2000, Annika was diagnosed with biliary atresia, a condition that hampered bile flow from her liver to her digestive system. That allowed bile, a highly toxic substance that aids in digestion, to stay in her liver and infect it.

Doctors performed an operation that restored bile flow, but it didn't work for long. At age 7 months, Annika's liver developed two large bile leaks, and doctors put in two tubes to drain the liquid.

In other cases, doctors might have moved forward with a living-donor liver transplant from an adult, but they didn't want to do so with Annika. A key vein in her liver hadn't developed normally, which would make that kind of surgery difficult.

"The portal vein was sort of shrunk together as a result of the condition," her mother says. "It needed to be replaced, and it wasn't such that you could get a piece of vein long enough from a living donor."

But as Annika waited, things got worse. She developed a massive infection that required her to be isolated in the hospital. A living-donor transplant might be her only hope, her doctors said.

Then came more bad news—her parents didn't have the right blood types to be her donor.

"There were just so many things going on at once," Annika's father says. "This wasn't too much out of the ordinary given how everything else was going."

Cliff Snell, 27, a first cousin of Moreena Tiede's from Texas, agreed to be Annika's donor. A week after her first birthday, he was at Northwestern Memorial Hospital, preparing to have about a third of his liver removed and given to Annika.

Doctors cancelled his surgery just seven hours before it was to begin.

A liver had become available from a Chicago-area teenager who had died. A third of it would go to Annika; the rest to a man in liver failure at the same hospital.

Two months after her transplant surgery, Annika went home. Her parents couldn't believe her boundless energy and appetite. They thought the worst was behind them.

Ten days later, they were back in the hospital. A blood clot in Annika's hepatic artery was killing the donor liver. She needed a new one.

This time, however, a living-donor transplant was possible because the portal vein Annika had gotten during her first transplant was functioning normally. In January 2002, Snell returned to Chicago, this time donating a piece of his liver to Annika. Both livers have since regenerated to their normal sizes, and Annika continues to recover.

She comes to Chicago about once a month with her parents to get checked out. She takes about 10 doses of anti-rejection medication a day.

"This past summer was the first time we really had time to be as a family," says Hans-Joerg Tiede, a native of Berlin, Germany. He and his wife's fall semester class schedules have been designed so that one of them will be at home with Annika at all times.

There are still hurdles to overcome—Annika's speech development is behind, for example—and there's always a fear of infection when a patient takes anti-rejection drugs.

Still, the Tiedes feel blessed to have Annika in their lives—something that wouldn't be possible without organ donation. The ultrasound on this day goes well, another step taken on Annika's road to recovery.

“In general, something has to happen to improve organ donation because there are kids in this hospital who died waiting for pediatric heart transplants,” Hans-Joerg Tiede says. “There are people who die every day waiting for an organ. Something has to happen to improve that.”

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When people first ask Lana Brown Casica '95 about her job, they don't quite get it. Like fellow IWU nursing school alumna Ruth Keith, she's an organ recovery coordinator for Gift of Hope, the not-for-profit, federally designated organ procurement group that serves residents in Illinois and northwest Indiana.

“Whenever I tell them my job, immediately they think I must work with the [transplant] recipients,” Casica says. “When I tell them, ‘No, I work on the other end of things,’ they say, ‘Oh, you have to talk to the families....How does anybody do that?’”

Casica, of Peoria, and Keith, of Bloomington—both registered nurses who serve as conduits between donor families and the transplant system—each do that painful task as many as two dozen times a year. It is one of the hardest parts of the 18 to 24 hours straight that they work if a family donates a loved one's organs.

“Once you're at the hospital, you try to get the whole dynamics of the family,” Casica says. “You talk with the doctors and nurses. You try to find the spokesperson that they're relying on. If the family has its own minister or clergy there, we try to talk to them as well, so that they can even help us get the family into a setting where they understand the situation and can move forward.”

Federal law also requires the coordinators to ask families some prickly personal questions, including ones about sexual activity and whether the deceased had smoked, or used alcohol or drugs.

“It's the history of the organs,” explains Keith, adding that some families understandably are put off by it. “All of these things have an impact on how a surgeon would react” to using the organs.



Lana Brown Casica '95 and Ruth Kucan Keith '81 (above) are registered nurses who serve as organ recovery coordinators in Central Illinois.

Working with families is only one part of organ recovery coordinators' jobs. Their duties also include helping test the organs to make sure they're suitable for transplant, working directly with transplant surgeons, and even packaging kidneys.

When they're not handling cases, Keith and Casica train hospital nursing staffs about organ-recovery procedures and speak at public-education events about organ donation.

The job, Keith said, is rewarding on several levels.

"It's not just the lifesaving aspect," she says. "It's also helping donor families through their grief."

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Bill Walsh remembers answering the sensitive questions about his daughter before he said goodbye to her.

"We had to go through a litany of questions," he recalls. "The folks from the donor agency were trying to ask the questions they needed to ask in the most sensitive manner, but they're extremely careful not to be pushy."

Several months later, the Walsh family was notified that both of Shannon's kidneys had been transplanted into two middle-aged adults, saving their lives.

That's helped ease the sting of Shannon's death...a little.

"If there were no upside whatsoever, it would have been more difficult to face," he says. "I'd hate to think of two other families going through the kind of things that we went through...At least somebody could come out a little better off."

Both Bill Walsh and his wife Paula—who serves on the Illinois Wesleyan Associates Board—encourage people to sign the backs of their driver's licenses and become organ donors. Even more important, they say, is discussing the issue with family members, who can stop an organ donation if they aren't aware of a family member's wishes.

"The most important thing is that folks think ahead of time," Bill Walsh says. "To do nothing is what costs lives."

**Chris Fusco '94 is a reporter at the *Chicago Sun-Times*. In December 2000, he donated 60 percent of his liver to his childhood friend Mark Mucha, who later died. His award-winning story about the experience can be read online at [www.suntimes.com/special\\_sections/transplant/](http://www.suntimes.com/special_sections/transplant/).**