
UNIVERSITY OF WISCONSIN TRANSPLANT PROGRAM
50
Years of Courage
1966–2016
★★★
UW ORGAN AND TISSUE DONATION

THE FIRST 50 YEARS: A REFLECTION

This book is filled with many remarkable stories about our patients and the donors and donor families we had the privilege to serve, as well as the contributions of our physicians and staff that advanced transplantation worldwide.

Over the past 50 years, thousands of people have been touched by the UW Health Transplant Program and UW Organ and Tissue Donation. It is likely that those whose lives have been deeply affected would not describe themselves as "courageous." The recipients themselves may say they had little choice but to take the plunge. The staff – physicians, nurses, donation professionals, social workers, our partners in hospitals across the country and countless other staff and volunteers – may say they are simply doing their job when they care for a transplant patient, research new options, comfort a grieving family or recover an organ. Civic leaders in government who work with us to improve donation and transplant laws may say these policy changes are basic life-saving logic. The donor families who made the choice to give the gift of life and share their stories would likely say they are simply keeping their loved one's legacy alive.

Then again, those who display the most courage rarely recognize it in themselves.

Our stories focus on our program's first 50 years, but they also look ahead to the next 50 years – a time when the challenges of today will be met and overcome, and our dedicated team members will be able to save more lives.

Our programs are among the best in the nation, and it is because of people like those featured in this book, and many more – our recipients, donor families, living donors, partners, volunteers and UW Health professionals.

This gathering represents just a fraction of the more than 20,000 recipients, organ and tissue donation family members, living donors, partners, volunteers and staff who are part of the UW Health family.


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Did You Know?

When Ray D. Owen, PhD, was a young PhD student at University of Wisconsin-Madison in the 1940s, he made a discovery that laid the foundation for the transplant of human organs. Owen observed that when he transfused blood between two Guernsey calves that had the same mother but a different father, they did just fine. This was because each calf had learned to tolerate the other's blood cells. Owen had discovered the phenomenon of immune tolerance, which helped other researchers advance the science of transplant.

Top: The transplant team from 1989 gathers for a group shot. Middle: Under the leadership of Munci Kalayoglu, MD, front right, the liver transplant staff – pictured here in 1994 – grew steadily. Bottom: Michael Anderson, PA-C, left, pictured here with Jim Kim, MD, became executive director of UW Organ and Tissue Donation in 2013.

Transplant brings joy to family

Area man receives new heart, lungs

By BARBARA MULHERN
Capital Times Staff Writer

Steven Eckel was sitting in his Cottage Grove home Sunday, disgusted over watching the Green Bay Packers lose, when he received the call that would change his life forever.

Eckel — who Monday became the state's first combined heart-lung transplant recipient — got the call from University of Wisconsin Hospital surgeon Dr. Barry Fields that a heart-lung donor had been found.

Eckel's wife Joane said Tuesday she was "relieved" the year-and-a-half wait for a donor was over. She added that she's hoping her husband will have a normally functioning heart and lungs in the future.

"We've been real lucky," Joane

"My doctors told me I'd kill myself if I kept working," Eckel told The Capital Times two years ago. "When I was a little kid they told me I probably wouldn't live until I was 18; then I was 18 and still alive. I just kept telling myself I'd be OK."

Eckel's wife and children, Molly, 6, and Anthony, who will turn 8 next Monday, are also hoping he'll be OK. Eckel needed the heart-lung transplant because he was born with a form of Eisenmenger's syndrome, which is incurable without transplantation.

Eisenmenger's syndrome is a condition where blood flow to the lungs is impeded by a heart defect that produces abnormally high blood pressure. Eventually, the increased pressure leads to thickening of the artery walls, which further restricts blood flow to the lungs.

It wasn't until mid-1986 that Eckel began coughing up blood and having serious problems because of the disease. The long wait for a donor, Fields said, has been "agonizing."

When asked how long Eckel might have lived without having the transplant, Fields said, "Only God knows that answer." But, he added, coughing up blood is considered to be "the last stage" of the disease.

"Steve is a large man (220

A WORLD-CLASS TRANSPLANT CENTER IS BORN

In the first half of the 20th century, the thought of saving one person's life by transplanting another person's organ into his body was the stuff of science fiction. Yet in 1954, Joseph Murray, MD, and J. Hartwell Harrison, MD, performed the first successful transplant – a kidney transplant between identical twins in Boston. Over the next few decades, major medical centers across the nation began exploring how they could incorporate transplantation into their surgical programs. University Hospital in Madison, Wisconsin was at the forefront of that trend when surgeon William Kisken, MD, teamed up with Fritz Bach, MD, and nephrologist Richard Rieselbach, MD, to begin a kidney transplantation program in 1966.

Kisken and three other surgeons, including urologist David Uehling, MD, began performing more and more kidney transplants. But the program's momentum stalled when Kisken requested that transplantation receive its own divisional status, and was denied. He left the program in 1972 and another surgeon, Jack Hussey, MD, continued the small program with Uehling. During that time, the heart transplant program began in 1973.

National acclaim

When the UW School of Medicine needed a new chairman for the Department of Surgery in 1974, members of the leadership team decided to recruit a transplant surgeon who would be able to grow the transplantation program. They found Folkert Belzer, MD, a young surgeon from the University of California-San Francisco who had already made a name for himself there. Belzer set his sights on turning University Hospital into a world-class transplant program and built a team that was up to the task (see page 8). Among that team: Hans Sollinger, MD, PhD, who established the pancreas transplant program in 1982, and Munci Kalayoglu, MD, who built the liver transplant program in 1983.

Organ procurement

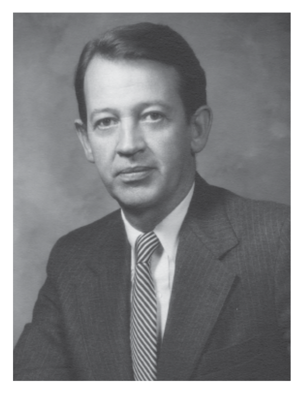
A transplant center is only as successful as its organ procurement organization (OPO). So, as the UW transplantation program grew, so did the organization now known as UW Organ and Tissue Donation (UW OTD). In 1984, the federal government passed the National Organ Transplant Act (NOTA), which called for the creation of an Organ Procurement Transplant Network (OPTN). UW OTD became a part of that network, with Robert Hoffman as its first director. Over the years, the transplant center and the OPO have become nationally renowned for their excellence, and for creating a life-saving relationship with each other.

The program grows

In 1986, John Pirsch, MD, joined the program as the transplant medicine internist; in 1988, Tony D'Alessandro, MD, created the intestinal medicine proram; and in 1989, Robert Love, MD, established the lung transplant program. And with that, the ascent was complete – University Hospital was among the top centers in the country. In the next few years, University Hospitals and Clinics and the UW Medical Foundation joined under the name UW Health, and partnered with UW School of Medicine and Public Health. The newly named UW Health Transplant Program continued its mission: Directing the Future of Transplantation. Over the last five decades, the transplant center's physicians and staff have distinguished themselves through their research, innovations and individualized care for patients, donors and their families. They have built and maintained excellent relationships with physicians from across the country who entrust patients to their expert care.

From left, Takushi Kohmoto, MD; Nilto DeOliveira, MD; and Lucian Lozonschi, MD, are part of the current heart and lung transplant surgical team at UW Health.

THE MAN BEHIND THE PROGRAM



Folkert Belzer, MD

The transplant program became nationally renowned because its surgeons worked together as a team. At the head of that team was Folkert Belzer, MD, chairman of the Department of Surgery at UW School of Medicine and Public Health from 1974 to 1995. Over time, Belzer would be called the "father of organ preservation" because he had developed a solution that kept organs viable for more than 18 hours (see page 11). But Belzer did much more than create the solution – he built a department that encouraged innovation.

"The early transplants were done by all kinds of surgeons – cardiothoracic surgeons, vascular surgeons and urologists," says Mike Armburst, who served as director of UW Health's adominal transplant program from 1984 to 2015. "There was no transplant surgery specialty." Leaders at UW Health wanted to increase the program's presence in the relatively new world of transplant, so they chose Belzer to establish that identity.

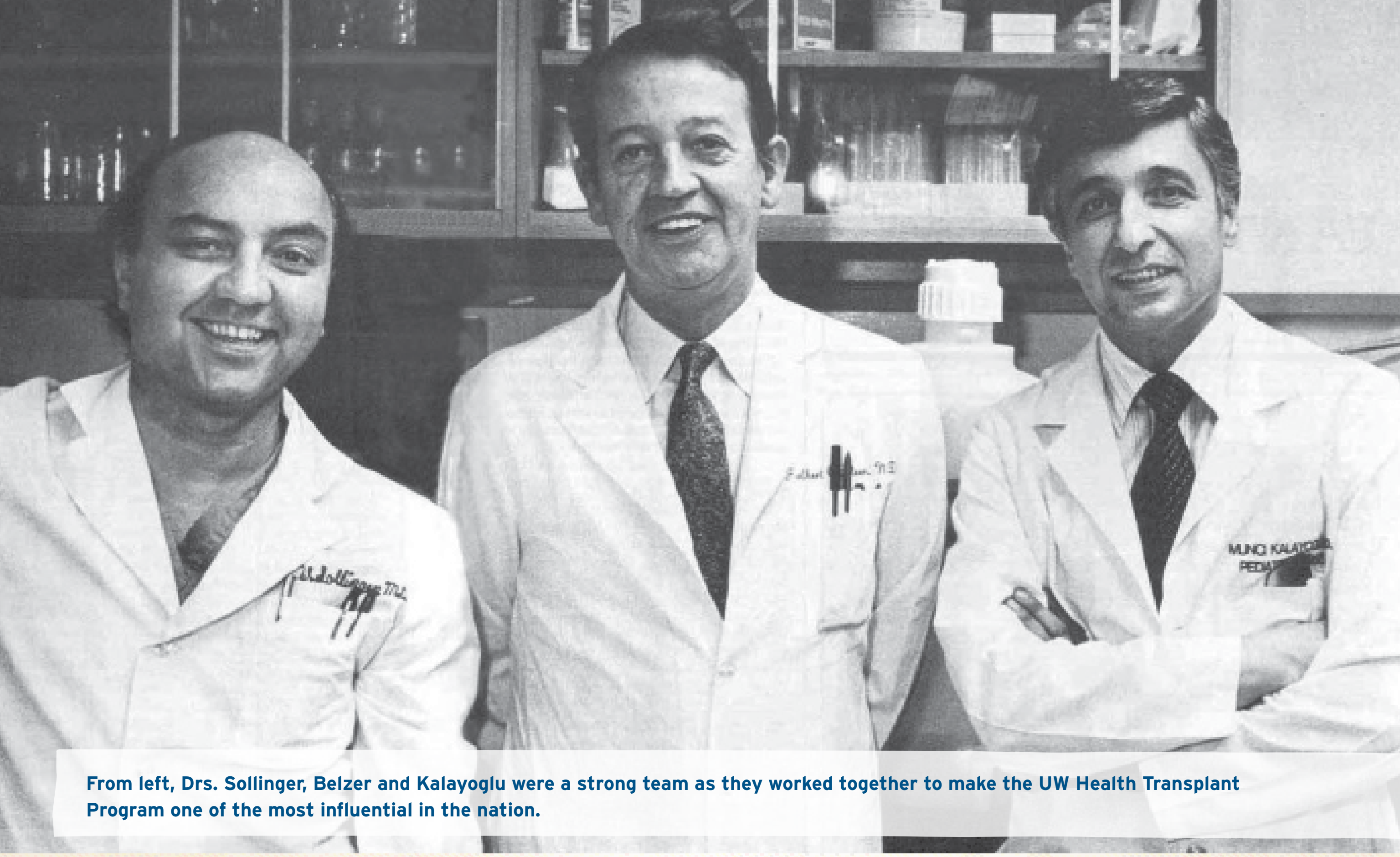
He certainly was up to the task: In his first few years on the job, Belzer built up the volume of kidney donations from both living and deceased donors. UW Health surgeons had been performing about 25 kidney transplants per year in the early 1970s; that volume doubled to 50 transplants in 1975, and by 1981, it had grown to more than 100 cases. Now, UW Health performs more than 250 kidney transplants per year. It consistently is among the nation's top transplant programs, and was the largest in the United States in 2005 and 2006.

With more transplants comes the need for more staff. Belzer began recruiting UW-trained surgeons to join his staff, beginning with Hans Sollinger, MD, PhD, a German surgeon who completed his surgical residency under Belzer and joined the team in 1980. Sollinger convinced Belzer to begin a pancreas transplant program, which became nationally renowned after Sollinger developed a new technique (see page 21).

In 1984, Belzer and Sollinger recruited Turkish surgeon Munci Kalayoglu, MD, to start a liver transplant program. The three became close collaborators regarding both their research and their patients. "We were such a tight group for such a long time," says Sollinger. "It's like a soccer team – you can have the best soccer players in the world, but if they don't get along, it's not going to work. All of us just clicked. We visited each other's offices and talked about our work and our families."

"Hans was like my brother," says Kalayoglu. "His kids were friends with my kids. All three of us would always help each other when we needed it. Belzer was protective of us; if something went wrong, he covered for us."

When Belzer became ill with cancer in 1995, he stepped down as head of both surgery and transplantation and split his job in two, appointing Sollinger chair of the division of transplant. After he died in August 1995, the Department of Surgery created a professorship to honor him. Sollinger went on to lead the transplant program with great success for 14 years.



From left, Drs. Sollinger, Belzer and Kalayoglu were a strong team as they worked together to make the UW Health Transplant Program one of the most influential in the nation.

WARM PRESERVATION FOR KIDNEYS

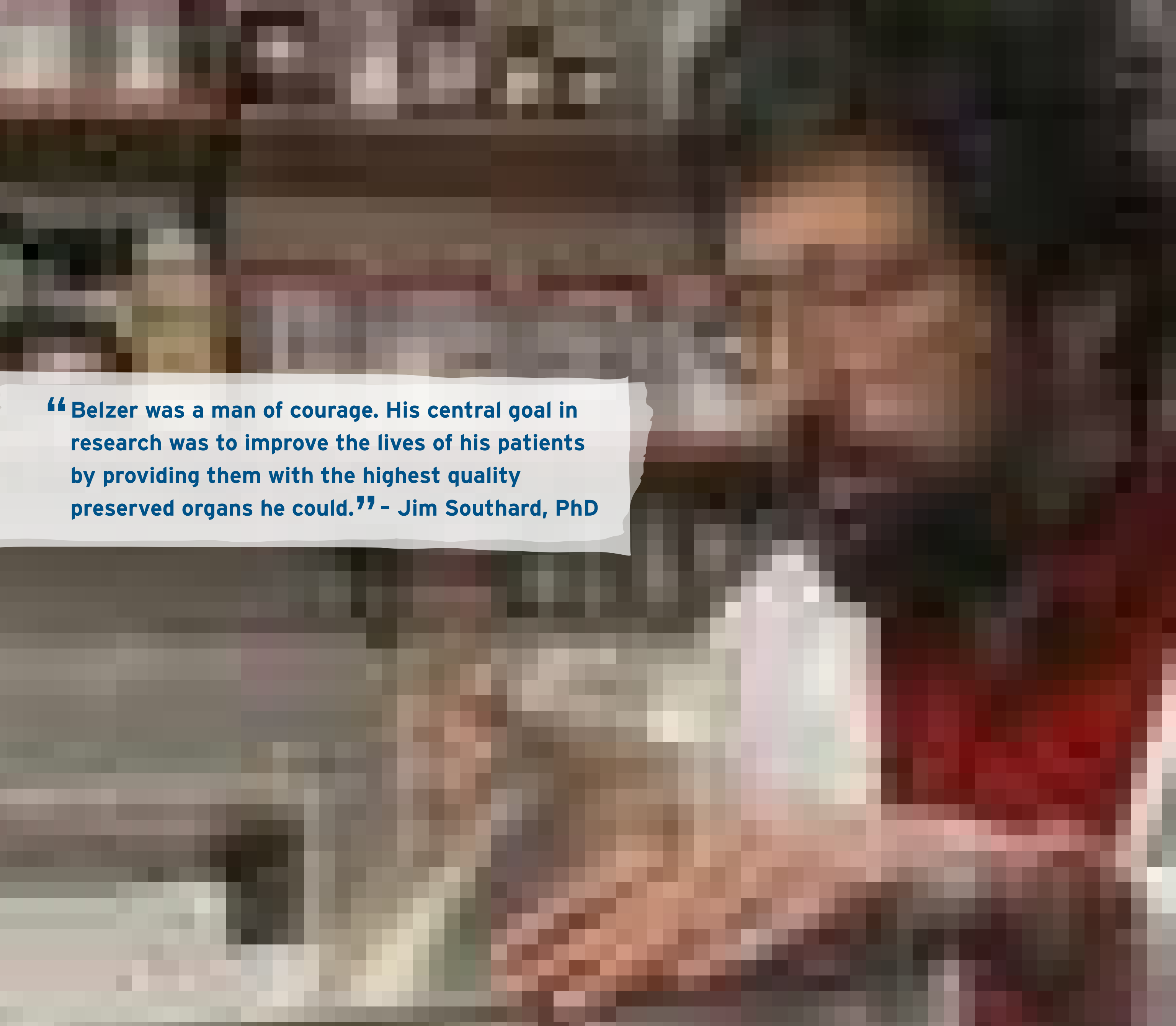
When Belzer first came to University Hospital, he already was known internationally for having developed the first kidney perfusion preservation machine – an apparatus that pumps specially designed plasma through the human kidney to keep it healthy for up to three days.

At that time, kidney transplant was most successful when clinical staff matched the kidney and recipient tissue immunologically to prevent tissue rejection – a process that required more than two days to perform. Belzer was not satisfied with his three-day preservation method because it did not leave much time for transport and surgery. He wanted to preserve a kidney for five to seven days to improve sharing of kidneys across the country. He received a grant from the National Institutes of Health (NIH) for the project and brought Jim Southard, PhD – a biochemist who worked in his lab – on board to make it work.

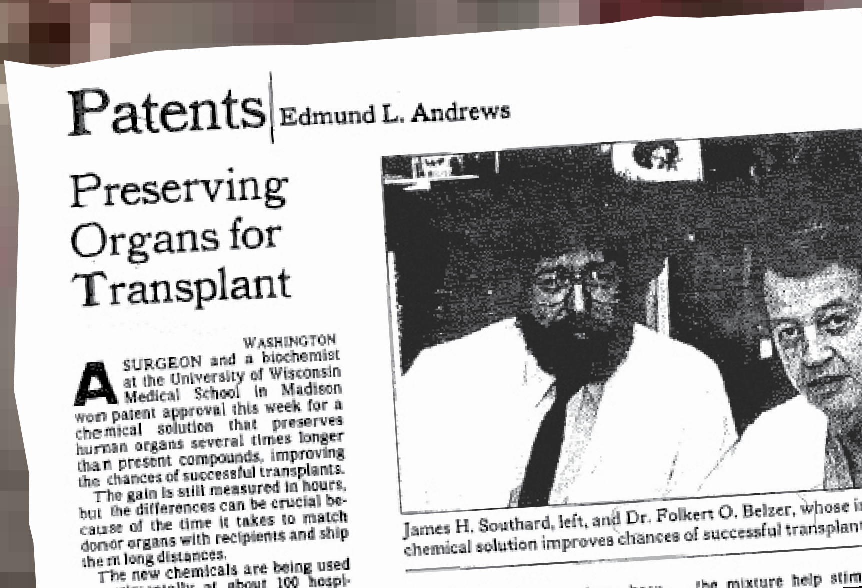
"He and I just hit it off wonderfully," says Southard. "Dr. Belzer, a busy surgeon, took time to be in the lab every day. He would tell me that although surgery was challenging, it became routine, and he needed something to stimulate his mind at night – and that something was research."

After much trial and error, Belzer and Southard created a new, synthetic solution in 1984 that no longer depended on human plasma and could preserve a kidney for up to five days. Belzer started using the solution right away. It was well received on a national level – patented and marketed with the help of the Wisconsin Alumni Research Foundation (WARF) – and many transplant centers across the United States began using it on a regular basis.

> “Belzer was a man of courage. His central goal in research was to improve the lives of his patients by providing them with the highest quality preserved organs he could.” – Jim Southard, PhD



Southard empties a bag of UW Solution into the Belzer portable kidney perfusion machine.



Patents | Edmund L. Andrews

Preserving Organs for Transplant

WASHINGTON

A SURGEON and a biochemist at the University of Wisconsin Medical School in Madison won patent approval this week for a chemical solution that preserves human organs several times longer than present compounds, improving the chances of successful transplants.

The gain is still measured in hours, but the differences can be crucial because of the time it takes to match donor organs with recipients and ship them long distances.

The new chemicals are being used

James H. Southard, left, and Dr. Folkert O. Belzer, whose i chemical solution improves chances of successful transplan

the mixture help stim

A GROUNDBREAKING DISCOVERY

UW Solution opens new doors in organ preservation

It was 1985, and liver and pancreas transplantation had increased dramatically due to the discovery of new immunosuppressive drugs that prevented rejection of these organs.

Folkert Belzer, MD, who was chief of surgery at University Hospital and a prominent transplant surgeon, wanted to find a method for preserving pancreata and livers longer than the current limit of about four hours. Ideally, he would extend the time of preservation to about two days. If he could accomplish this, donor organs could be transported longer distances – the operations scheduled instead of performed as an emergency procedure in the middle of the night. Ultimately, he would save more lives.

He enlisted the help of colleague Jim Southard, PhD – a biochemist who worked in his lab – to find a cold storage solution that would work for organs other than kidneys (see page 9). Continuous machine perfusion was successful for kidneys but caused fatal cell swelling in pancreata and livers.

"One day Belzer and I were having our late afternoon chat in the laboratory and both enjoying our pipes," says Southard. "He told me he wanted to abandon machine perfusion as the way to preserve these organs and use a simpler method: cold storage, which involved flushing out the organ with a cold solution and storing it in a cooler until needed. But what solution could we use? The kidney perfusion solution that we developed was a starting point. He was thumbing his way through a book that listed most of the chemicals available and told me, 'Jim, the chemical is in here, if only we could find it.'"

He was right. Belzer came across lactobionic acid, a sugar acid formed from gluconic acid and galactose that could be used to prevent cell swelling in a cold storage solution. The two men modified the perfusion solution and came up with one containing lactobionic acid, hydroxyethyl starch and other additives. They first tried to preserve dog pancreata for three days before transplantation and it worked well, with all the transplanted animals surviving. Belzer was thrilled with the laboratory results and moved on to test the solution in dog livers. Again, it was wildly successful, extending liver preservation time to 48 hours.

Belzer and his staff began to use this solution for human liver and pancreas transplantation, with excellent results. "Belzer was a man of courage," says Southard. "His central goal in research was to improve the lives of his patients by providing them with the highest quality preserved organs he could."

The two reported their results to the American Society of Transplant Surgeons in May 1986. They knew they had conceived a groundbreaking solution, but had never thought about patenting and commercializing it until after they took it to the Wisconsin Alumni Research Foundation in September. "The folks at WARF couldn't believe we had disclosed this solution months ago and hadn't done anything about patenting it," says Jim. Immediately WARF began the patenting process and worked closely with DuPont to market the solution. In 1987, the solution became commercially available and produced excellent results in human liver and pancreas preservation.

The UW Health Transplant Program had just established a lasting legacy as one of the foremost organ preservation research laboratories in the world. Today, UW Solution remains among the gold standards for preservation of all organs.

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Belzer and Southard, featured in this 1989 New York Times article, became instant celebrities when they made their new organ preservation solution public.

The Patient Family Advisory Council
Bottom row: Herbert Heneman III, Walter G. Goodman, Mary Baliker, Steven R. Fillnow.
Top row: Rebecca Hays, transplant social worker; Nancy Jones, transplant clinic manager; Jill Ellefson, director, organ donation and transplant; Erica Bouska, senior transplant coordinator; Susan Little, senior transplant coordinator
Not pictured: Connie and Joseph Burns, Gary Einerson, Margie Haslam, Brenda Juhlin

PATIENT FAMILY ADVISORY COUNCIL

The Patient Family Advisory Council (PFAC) is a group of transplant recipients who meet quarterly to advise the UW Health Transplant Program. "We really want to make the patient experience better in any possible way that we can," says Mary Baliker, who sits on the council. "Having had multiple transplants, I have a unique perspective on how the staff can support patients."

PFAC has helped UW Health staff prepare patient education materials and promote the Capital City 5K Run/Walk for Organ, Tissue and Eye Donation. It also has offered ideas for the program's quarterly "Living Well" learning sessions.

Above, Mary Baliker is now living an active life following four kidney transplants. Right, she recovers in her hospital room after receiving "Baby," her first kidney, in 1980. Far right, she celebrates Baby's first birthday party with her mother, Jean Fregin.

THREE DECADES OF GRATITUDE

At age 17, Mary Baliker was sure she was going to die. She had been suffering from kidney disease since she was nine years old. When she progressed to kidney failure in 1980, her mother took her to see Folkert Belzer, MD, a transplant surgeon at University Hospital.

Belzer pulled no punches. "He was a very smart but very blunt man," says Mary. "He told me, 'You have three choices: chronic dialysis, transplant or die.' I ran out of the room."

Mary's brother donated a kidney to her and she underwent the transplant during her senior year of high school. She stayed at University Hospital 21 days – the minimum number of days required for transplant patients at the time. She recovered quite well from the surgery, but was frustrated when she began to experience side effects such as weight gain from prednisone and imuran – the main medications used at the time.

"I literally would go up to the mirror and not be able to recognize myself because my face was so round," says Mary. "For those of us who had transplants in the early days, we were hopeful, but we knew a lot of people died from infections and sometimes the kidney never started. If yours worked you were pretty darned happy, because there were other people on the floor who weren't so lucky."

Since then, Mary has had three more kidney transplants – in 1984, 1988 and 1999. By the last transplant, she had the process down to a science. "Now, you just don't see as many people having problems upfront," says Mary. "The doctors don't have to prescribe such high doses of medication. I was back to work two weeks after my last transplant."

"With four consecutive transplants, Mary has lived through the history of kidney transplantation in the past 30 years," says Arjang Djamali, MD, MS, FASN, division head of nephrology and transplant physician at the UW Health Transplant Program and Mary's nephrologist. "The progress in the fields of immunosuppression, immune monitoring and patient-centered care has evolved such that we can define the minimum effective dose of anti-rejection therapy with more confidence for each patient."

Mary credits a UW Health social worker, Annette Ellstrom, with pushing her during her first transplant to make plans for the future. She finished high school, attended college and became a transplant procurement coordinator and educator. Now 53 and living in Middleton, she refers to each of her kidneys affectionately by name: "Baby," "Sidney the Kidney," "Tres" and "Millie." "My transplants have made me realize that each day is a gift," says Mary. "I am so grateful to the donors who gave me that gift."

NEW TRANSPLANT DRUG HELPS POLICE OFFICER STAY ON THE JOB

Todd Stetzer doesn't feel ill, he doesn't look ill, and he doesn't need to take a cocktail of pills every day to stay that way. The only way you would ever know the Fitchburg, Wisconsin police lieutenant had a kidney transplant in 2013 is if you watched him undergo his monthly, hour-long infusion of belatacept, a new drug that has eliminated the need for some of the more side effect laden anti-rejection medications.

"The fact that I have had a transplant has no effect on my ability to do anything in my life," says Todd, 52, a married father of four and grandfather of two.

Eighteen years ago, doctors suspected Todd had a condition called IgA nephropathy, which can hinder the kidneys' ability to filter waste, excess water and electrolytes from the blood. It wasn't until 2010 that Todd, who lives in Pardeeville, Wisconsin, noticed that he was retaining water and had fluctuating blood pressure. He was able to put off a kidney transplant by drastically changing his diet, but by 2013 it was time for the inevitable. His brother-in-law, Michael Martin, volunteered to donate a kidney to him, and the two underwent their surgeries on February 28, 2013 at University Hospital.

As Todd was preparing for his transplant, Dixon Kaufman, MD, PhD, his transplant surgeon and chief of the transplant division, told him about a trial he was conducting for a new drug. Belatacept, an anti-rejection medication, already had been approved by the Food and Drug Administration (FDA), but Kaufman was involved in a trial that would allow patients to substitute belatacept for calcineurin inhibitors (CNIs) and the need for chronic use of steroids.

Todd had taken prednisone (a type of steroid) earlier in the treatment process and had experienced extreme mood swings and insomnia, so he was happy for the opportunity to avoid that drug. "All I could think of was the person who was the first living donor," Todd says of his decision to participate in the trial. "If that person had never donated, how many others would be lying on tables for the rest of their lives undergoing dialysis? I had been given a gift that prevented me from living a very limited life. How could I not participate in this trial to help someone in the future?"

Belatacept is a glimpse into the future of transplant medicine, Kaufman says. "Transplant is always in the process of becoming better and better," he says, "and as a result, our program is always evolving. Steroids can cause side effects including diabetes, hypertension, cataracts, hip disease and weight gain. CNIs are hard on the kidneys and can limit how long the kidney can last. If we can eliminate the need for those drugs, the future is very bright for transplant patients."

"It is very common for patients to leave the hospital with 12 to 14 medications they must take every day," says David Hager, Pharm.D., pharmacy manager for transplant services at UW Health. "Belatacept provides a greater level of convenience for patients because it decreases that number."

In 2015, Todd's participation in the trial came to an end. He had the option to stop taking belatacept, but he chose to continue with it indefinitely. "I've been doing so well, I can envision nothing but success," he says.

He now takes just one medication twice a day, plus a multi-vitamin. He undergoes his belatacept infusion once a month, then continues with the rest of his workday. "A lot of people asked me, 'Can you work as a cop after a transplant?'" he says. "I can – 100 percent."

Todd Stetzer, left, received a kidney from his brother-in-law Michael Martin, right, in 2013. He has experienced no side effects after participating in a clinical trial for belatacept, a new anti-rejection drug.

“The fact that I have had a transplant has no effect on my ability to do anything in my life.” – Todd Stetzer

The Next 50 Years

Preventing Organ Rejection

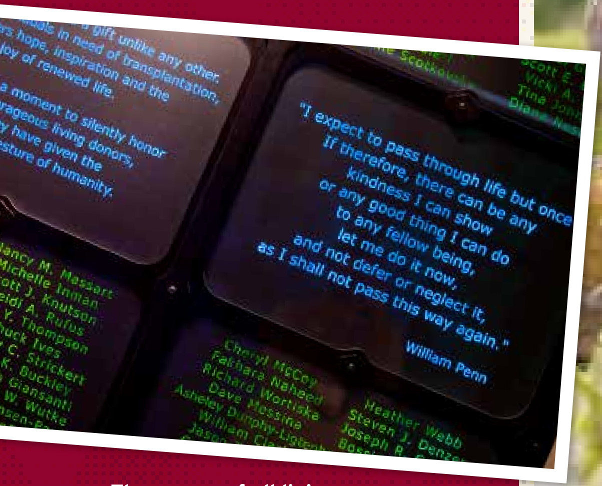
For transplant physicians, the ultimate goal is to eliminate organ rejection. To that end, Arjang Djamali, MD, MS, FASN, division head of nephrology and transplant physician at the UW Health Transplant Program, has dedicated his research to address the prevention and treatment of rejection and renal injury in kidney transplant recipients. This research, which is sponsored by the National Institutes of Health (NIH), has included evaluating imaging tools that can monitor kidney function.

Arjang Djamali, MD, MS, FASN, division head of nephrology and transplant physician at the UW Health Transplant Program

BELLY-BUTTON NEPHRECTOMY

Kidneys from living donors have been proven to last longer than kidneys from deceased donors. Because of this, UW Health transplant surgeons have been working to make the transplant process as easy and safe as possible for living donors. They offer four surgical options for living donation: open, laparoscopic, robotic and single-port, also known as the belly-button nephrectomy.

"The main benefit of the single-port surgery is cosmetic," says Josh Mezrich, MD, transplant surgeon at UW Health. "We make a 4- to 6-centimeter incision straight through the middle of the belly button, unfold it and put a port behind it. We insert all our instruments through the port and pull the kidney out. Recovery time is similar to a laparoscopic procedure, but there is little to no scarring."



The names of all living organ donors are featured on a special wall at University Hospital.

Marcia Booker, left, received a kidney from her daughter, Toril Booker-Fisher, right.

A DAUGHTER'S GIFT

Up until the day Toril Booker-Fisher donated her kidney to her mother, she and her father weren't sure the donation was going to happen. That's because her mother, Marcia Booker, was terrified her daughter would be harmed in the process. But Toril reassured her: "I told her our roles had been reversed, and that it was my chance to give her life now. She said, 'I didn't know anyone could love me that much.'"

On October 22, 2014, Toril donated her kidney to her mother at University Hospital. That gift of life gave Marcia another chance to play with her grandchildren and feel well for the first time in more than 15 years.

Toril, 48, an organic farmer in LaFarge, Wisconsin, initially was competing with her father, John, for the opportunity to donate a kidney to her mother. "We were kind of having a 'kidney beauty contest' at our house," she says. "But my father really wanted to be able to do this for her, and something told me I should let him go through the screening process."

It was a good thing he did: Josh Mezrich, MD, transplant surgeon at UW Health, found a $2\frac{1}{2}$-pound cancerous tumor growing in John's stomach. Just a few weeks later, John underwent surgery and started on the road to recovery. Meanwhile, Marcia was still sick. She finally consented to let Toril go through the screening process, and it turned out her daughter was a good match. Toril was also a candidate for a single-port nephrectomy, a minimally invasive procedure that causes little to no scarring (see box, left). Mezrich performed Toril's surgery. "When you look at the rest of my belly, you can't tell there was an organ removed from my body," she says. "It's really incredible he was able to do that."

After the surgery, Toril was bleary-eyed and recovering in her room when she saw a red-cheeked, smiley woman walk past her door and call out hello. She turned to her husband, Drew, and asked who that was. He told her it was her mother. "I had never seen her with red cheeks before," she says.

"When there is a living donor, the kidney typically works right away, and the patient often feels as if a dark cloud has been lifted," says Robert Redfield III, MD, transplant surgeon at UW Health.

Though her new kidney worked well, Marcia succumbed to leukemia in May 2016. "When I was considering becoming a donor," Toril says, "I told my friends and family that if my donation could help my mother remember who she was and rekindle her confidence and love for herself – even if it was just for a couple of weeks – it would be worth it. My mother lived 18 months with her transplanted kidney. In that time we celebrated her 50th wedding anniversary surrounded by family and friends. She was beautiful and so in love with my father and her life. I'm grateful she fell in love with herself and her life again during that time. Looking back, I would do it again and again!"

Creating Hope

Jill Dillon, a living kidney donor, and Sara Solinsky, the recipient of Jill's kidney, created a new Donate Life volunteer group in Wisconsin Rapids in 2015. The group raises awareness and funds for Restoring Hope Transplant House and UW Organ and Tissue Donation's Donor Education Fund. Front row: Sara Solinsky, Jill Dillon. Middle row: Patti Nelles, Tina Loeper, Kathy Gehrke. Back row: Janet Hoff, Bob Hoff, Paul Anacker.

KIDNEY TRANSPLANT

CHAIN OF LIFE

It is an understatement to say that putting a paired kidney transplant chain together is a highly complicated process. Like a game of dominos, when one part of the chain falls apart, the others often follow. Mitzi Neyens, 77, of Wausau, had been part of two chains that did not work, and she had asked UW Health Transplant Program paired kidney exchange coordinator Karen Miller, RN, not to call her again until she was sure Mitzi would be receiving a kidney. So Karen worked with Mitzi's husband, Bill, both of them taking extra care to spare her the emotional roller coaster.

Mitzi and Bill were at a doctor's appointment in March 2015 when he mysteriously left the room to take a phone call. Just as Mitzi's doctor was saying he believed many of her medical issues would be resolved once she received a kidney, Bill came back in with a big smile on his face. It was time.

High-tech kidney exchange

Since 2011, the UW Health Transplant Program has participated in the National Kidney Registry's paired exchange program, which works to match living donors with recipients using a computerized system. In a paired transplant chain, a humanitarian donor sets off a series of transplants in which family or friends of recipients give a kidney to another person in need – essentially paying donations forward on behalf of a loved one. "The program is wonderful," says Karen. "Five years ago, if I had a donor who wasn't the right blood type, that donor's loved one might have stayed on the wait list for three to five years. Now, the average wait time in the program is eight months."

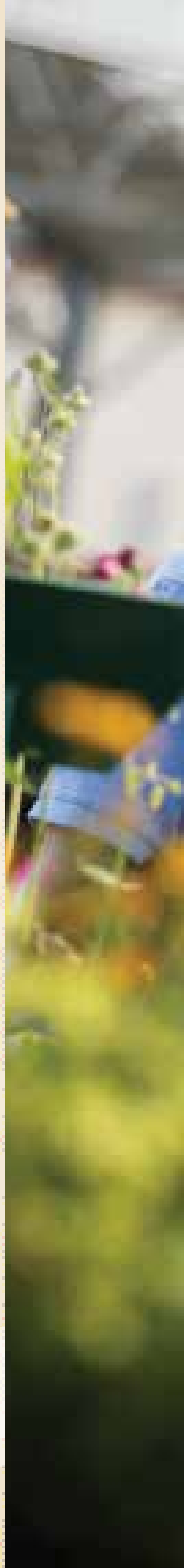
In Mitzi's case, she had many friends and relatives who wanted to donate a kidney to her, but she is highly sensitized (meaning she has high antibody levels), so it was difficult to locate the right match for her. Then, a family friend said she would donate a kidney to the National Kidney Registry to help Mitzi find a compatible donor. The friend became part of a different chain and donated a kidney in August 2014. Seven months later, Mitzi made history as the last link in a 34-way kidney exchange – the largest exchange at the time.

Mitzi's transplant surgeon, Jon Odorico, MD, completed the surgery on March 26 – nearly three months after the first recipient in the chain received her new kidney at University Hospital from a humanitarian donor from Minneapolis. "There are all kinds of reasons for chains to break down, and for this one to hold was nothing short of a miracle," says Mitzi.

Not only was the exchange a milestone for the National Kidney Registry, but the publicity it received may ultimately save lives: Living kidney donation became a national headline after "Nightline" aired a story about the exchange, which included 68 people from across the country.

As for Mitzi, who was quite active before her kidney disease slowed her down, life has been improving every day. "I feel so much better," she says. "I'm not so tired anymore."

> **"There are all kinds of reasons for chains to break down, and for this one to hold was nothing short of a miracle." - Mitzi Neyens**



LIVING DONOR TRENDS

There are more people waiting for a kidney transplant than for any other organ, which is why transplant centers across the country have placed a strong emphasis on living kidney donation. The UW Health Transplant Program recently designated a nurse coordinator to care for only kidney donors, rather than both donors and recipients. "By having a nurse coordinator who is dedicated to caring for donors, we ensure that our donors receive the attention they need," says Didier Mandelbrot, MD, medical director of kidney and pancreas transplantation at University Hospital. "We want to make the donation experience as comfortable as possible."

Mitzi and her husband, Bill, found themselves at the center of a media frenzy after participating in the nation's longest kidney chain.

Months after the landmark kidney chain, *Wisconsin State Journal* printed an in-depth story on UW Health's part in it. The map at right shows all the transplant centers that participated in the chain.

UW SURGEON DEVELOPS GROUNDBREAKING DRUG

The human body is hard-wired to protect itself against foreign substances and objects. One of the main challenges transplant surgeons and physicians have faced, then, is making sure a patient's body does not reject a transplanted organ.

By the late 1980s, the primary immunosuppressant (anti-rejection) medications were prednisone, cyclosporine and imuran. Imuran was not only an ineffective immunosuppressant, but it also had unpleasant and even dangerous life-long side effects: It caused breaks in the DNA, which created skin lesions such as unsightly warts and skin cancers. (Even today, patients who stopped imuran more than 20 years ago still require frequent skin tumor surgeries.) The market was ripe for a new drug to prevent rejection of transplanted organs.

In 1988, a senior scientist from a mid-sized pharmaceutical company called Syntex asked Hans Sollinger, MD, PhD, if he would be interested in testing a new immunosuppressant he was developing. Sollinger began testing the medication in dogs, which was unsuccessful at first. Then, he combined the new drug with lower doses of prednisone and cyclosporin. The combination worked so well the Food and Drug Administration (FDA) almost immediately agreed to Phase 1 trials at University Hospital. These trials paved the way for an international trial spearheaded by Sollinger.

In June 1995, the FDA approved the drug now known as CellCept (mycophenolate mofetil). Sollinger received a letter from the CEO of pharmaceutical company Roche – which had bought the drug for $5.1 billion dollars from Syntex – congratulating him as the "father" of CellCept.

In 2014 CellCept became the most commercially successful drug in the history of transplantation, with sales exceeding $30 billion. It has benefitted more than 600,000 patients worldwide.

Anti-rejection drug tested at UW is hailed

By JOE MANNING
Sentinel staff writer

A University of Wisconsin — Madison surgeon is experimenting with a new anti-rejection drug that could lead to "dramatically improved" success in organ transplants and, someday, could allow the use of animal organs in human beings, he said Tuesday.

"I am very, very excited about this drug. It is only once or twice in a lifetime that a researcher gets to work with a drug like this," said Hans Sollinger, director of pancreas transplantation at the UW Hospital and Clinics.

He said he is the only researcher in the world doing clinical trials with the drug on human patients.

So far, Sollinger's investigation has involved six kidney transplant patients. Human trials including other transplanted organs will be expanded in the fall.

Sollinger said the drug, called RS-61443, reduces rejection and has ex tended the survival of transplanted kidneys in animals dramatically. His research on kidney transplants in dogs shows few side effects

Sollinger, a professor the UW Medical S drug, derived from specific white bloo mune system, ca that attack a pati

Cyclosporin plants since sue cell in t

Even before it had a name, CellCept sparked excitement in the transplant world, as shown in this 1990 article from the *Milwaukee Sentinel.*

A NEW TECHNIQUE FOR PANCREAS TRANSPLANTATION

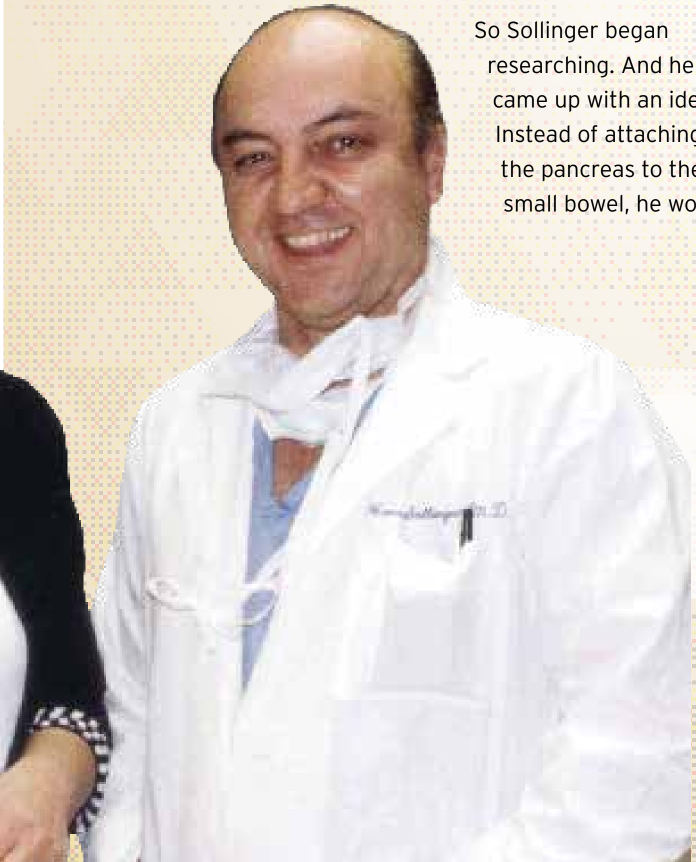
By the early 1980s, kidney transplants were becoming more commonplace, but pancreas transplants were rare. That wasn't because they weren't necessary – there were many type I diabetics who desperately needed a new pancreas to make the insulin their body required.

Yet a pancreas transplant was incredibly dangerous. At the time, surgeons attached the transplanted pancreas to the small bowel – a practice that didn't work very well because digestive juices leaked out, causing the patient to become very sick.

When he began at UW Health as a transplant surgeon, Hans Sollinger, MD, PhD, wanted to begin transplanting pancreata. But, because it was so problematic, Folkert Belzer, MD, chairman of the Department of Surgery, told him he would only allow it if Sollinger could find a way to make it work.

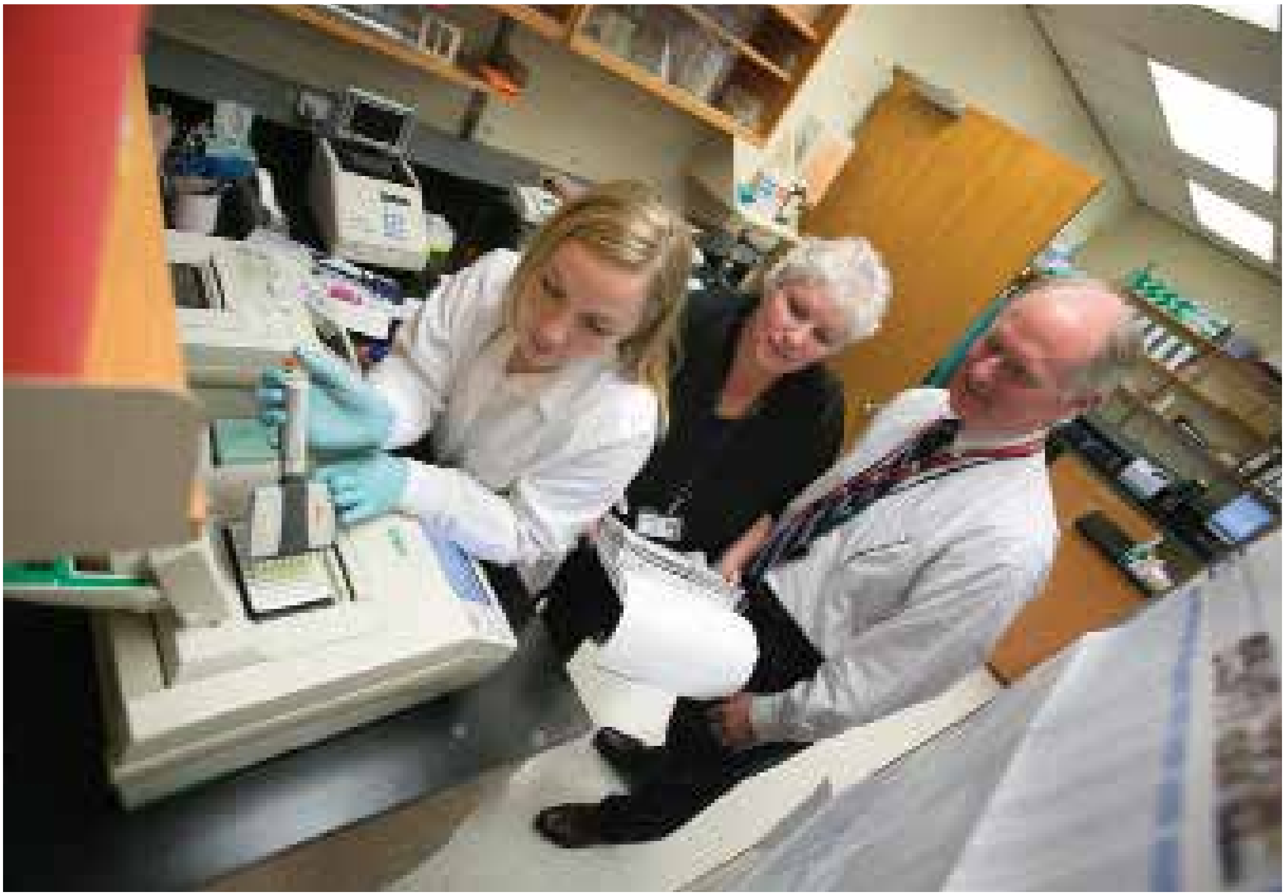
So Sollinger began researching. And he came up with an idea: Instead of attaching the pancreas to the small bowel, he would connect it to the bladder. "It was safer because when we put a catheter in the bladder, it took the pressure off and prevented most digestive juice leaks," says Sollinger. "The bladder does not have bacteria in it like the bowel does, so even if there was a leak, it didn't cause the patient to become sick." Sollinger first published his new technique in 1982. Surgeons throughout the world laughed at his idea – until they tried it. By 1987, most other institutions had adopted Sollinger's bladder drainage technique, dubbed the "Wisconsin technique." "The world had a 20 percent success rate using conventional techniques," says Sollinger. "We had a 75 percent success rate – it was a team effort."

Years later, Sollinger concluded that the problems with connecting the pancreas to the small bowel were actually because the small bowel was rejecting the new organ. After he developed his anti-rejection drug CellCept (see article on page 20) in 1995, he abandoned his bladder drainage technique and resumed connecting the pancreas to the small bowel – with much better results. By the year 2000, most other institutions had followed suit. Today, the Wisconsin technique is used in very few transplant centers, but it is credited with saving thousands of lives by making pancreas transplantation feasible.



> **"The world had a 20 percent success rate using conventional techniques. We had a 75 percent success rate – it was a team effort."**
> **- Hans Sollinger, MD, PhD**

Elaine Snyder, RN, nurse manager in the UW Health Transplant Program, worked side by side with Hans Sollinger, MD, PhD, as he tested his innovations in patients.



The human leukocyte antigen (HLA) system is the group of genes related to immune system regulation. UW Health's HLA laboratory tests organ donor/recipient compatibility to ensure an organ will be a good match. This lab utilizes UW Health's new virtual cross-matching system to perform that evaluation before an organ is transported from another facility. Here, lab technician Kelley Viney performs a test on a patient who is being evaluated for transplant while lab manager Kathleen Meuer, CHT, and lab director Thomas Ellis, PhD, D(ABHI) look on.

The Next 50 Years ★★★

Virtual Cross-Matching Helps Kidney and Pancreas Transplantation

When an organ donor and recipient are being matched, staff members need to test the patient-donor compatibility to ensure the organ will be the right fit for the recipient. Traditionally, this happens after the organ is brought to the transplant center and before it is transplanted, which can take an additional four hours to complete. When an organ is being transported to a recipient in another region, the transport time plus the compatibility testing time can be so long that the organ cannot be safely transplanted. UW Health recently developed a virtual cross-matching system that evaluates the patient-donor compatibility before the organ is transported so staff do not have to waste precious time performing those tests upon arrival. "We can optimize importation of organs from across the United States," says Jon Odorico, MD, transplant surgeon and surgical director of pancreas transplant. "This is an example of how we are always thinking about how to get more organs to more patients."

TAKING A RISK ON A NEW PROCEDURE

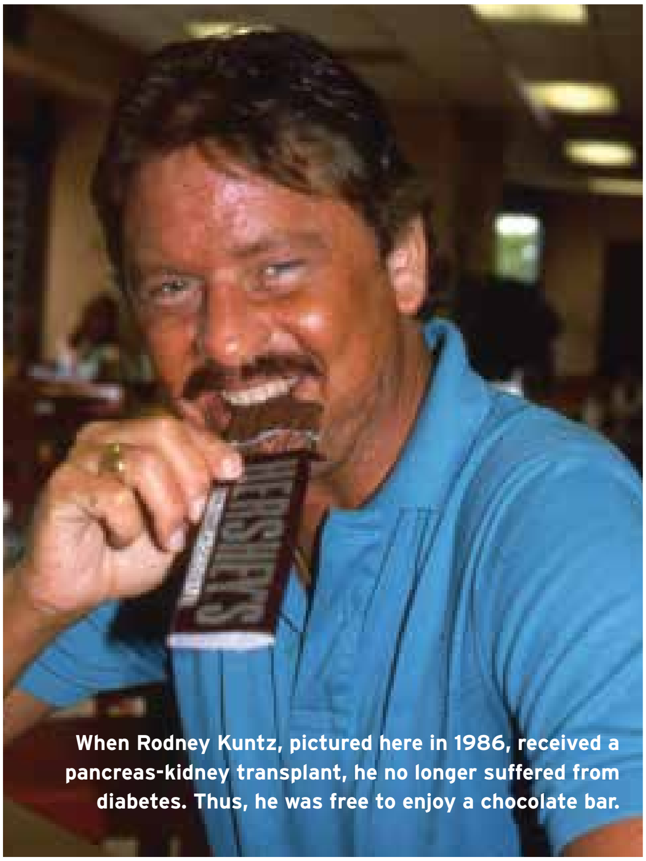
The night before his pancreas/kidney transplant in 1986, Rodney Kuntz called his parents to thank them for always being there for him. Then, he dialed the numbers of a few ex-girlfriends to tell them exactly what he thought of them. He wanted to make sure he had tied up all the loose ends in his life before he went under the knife in a procedure that was anything but tried-and-true.

In those days, a pancreas transplant was an extremely dangerous procedure. It was less risky because UW Health transplant surgeon Hans Sollinger, MD, PhD, was performing a study on a new technique that was saving patients' lives (see page 21), but it still was a leap of faith. Rodney, who was 32 at the time and had type 1 diabetes, had visited all three U.S. transplant centers that performed pancreas transplants and chose UW Health because he trusted Sollinger, who thought Rodney was an ideal candidate for his study.

Rodney lived in Norfolk, Virginia but moved to Wisconsin in March 1986 to wait for a suitable pancreas and kidney. The organs became available in May, and he underwent surgery. Afterward, he stayed in the hospital for five months, during which time his body rejected the new organs three different times. "The doctors were quite obviously feeling their way through the recovery as much as I was," he says. "It was a challenge for everybody."

Despite the arduous recovery process, Rodney has been able to live a full life. While he had been legally blind because of eye problems due to his diabetes, his retinas healed eight months after the transplant, and he can now drive a car without glasses.

"I often say I had really good surgeons, but it's by the grace of God that I'm here today," says Rodney.



When Rodney Kuntz, pictured here in 1986, received a pancreas-kidney transplant, he no longer suffered from diabetes. Thus, he was free to enjoy a chocolate bar.

> **"The doctors were quite obviously feeling their way through the recovery as much as I was. It was a challenge for everybody." – Rodney Kuntz**

BIOPSY CATCHES PANCREAS REJECTION IN TIME TO SAVE ORGAN

When it comes to health issues, Sean Govan has endured more than most other American 41-year-olds. He was diagnosed with type I diabetes when he was 20. Over the years, he experienced multiple complications from his disease, including foot pain, and he was on dialysis for about a year after discovering his kidneys were only at five percent capacity.

So when Sean, a Milwaukee resident, received the gift of life and underwent a combined pancreas/kidney transplant at University Hospital in 2012, he hoped that would be the solution to his health problems. And it was … until he returned in 2014 for routine bloodwork and the transplant team discovered his body was rejecting the new pancreas. Fortunately, the team caught the rejection in time and was able to successfully treat it.

"UW Health is one of the few transplant centers that is as vigilant as possible about pancreas rejection," says Jon Odorico, MD, Sean's transplant surgeon and the physician who caught and treated his rejection. "We keep a close watch on our patients to make sure their bodies are reacting well to the new organ. When we suspect something may be amiss, we take immediate action."

Jennifer Torino, MT (ASCP), medical technologist at UW Health, examines a patient's plasma sample before loading it onto a chemistry analyzer. It was after a routine blood test such as this one that staff discovered Sean Govan was experiencing acute rejection of his new pancreas and were able to treat it in time.

After a pancreas transplant at UW Health, patients must return to the hospital monthly to check the levels of certain pancreatic enzymes in their blood. When these levels are too high, that is a sign something may be wrong. After a second blood test showed Sean did, indeed, have abnormal levels, Odorico used ultrasound guidance to perform a needle biopsy of his pancreas and obtain a tissue sample. Testing confirmed that Sean's body was rejecting the new pancreas, even though he wasn't experiencing any symptoms.

Odorico used the results of the biopsy to determine which drugs he needed to use to treat the rejection, and he admitted him to University Hospital. "All the nursing staff here have the expertise to handle unforeseen complications," says Jessica Weber, MSN, RN, CCTN, clinical nurse specialist on the abdominal transplant unit at University Hospital. Four days later, Sean was once again in good condition and ready to return to his life.

"The sooner we treat pancreas rejection, the more likely it is that we can reverse the damage," says Odorico. "That is why we urge patients to return regularly for their blood tests. If they wait too long, the organ could stop functioning completely."

UW Health is nationally known for its steadfast commitment to following up with its pancreas transplant recipients. In fact, other centers have begun following in its footsteps — and have been able to save many other patients' organs.

"When they first told me I was experiencing rejection, I had that fear that I was going to have to go and find another organ," says Sean.

But, because the biopsy caught the rejection in time, the problem was easily treatable. Now, Sean spends his days working as a computer analyst for American Airlines and playing with his 6-year-old niece as much as he can.

"I was very happy with Dr. Odorico and his whole staff," says Sean. "They were always checking on me and making sure they answered all my questions. I'm feeling great now."

Though Sean Govan experienced pancreas rejection shortly after undergoing a pancreas/kidney transplant, his doctors' quick response enabled him to keep his organ.

The Next 50 Years ★★★

Stem Cell Research May Cure Diabetes

People with type 1 and type 2 diabetes suffer from a lack of working beta cells — the insulin-producing cells of the pancreas. While pancreas and islet cell transplants can give diabetics the beta cells they need, there are not enough organ donors to supply the demand. Researchers at UW Health are working on curing diabetes by creating a large supply of beta cells using stem cells. One type of stem cell can be produced from a diabetic patient's skin or blood cells and reprogrammed so it becomes a "blank slate" stem cell. "We add a mixture of protein growth factors and small molecules to the cells to make them turn into working beta cells," says Jon Odorico, MD, transplant surgeon at UW Health.

Odorico and other researchers are working on combining their stem cell research with tissue engineering strategies to rebuild the human pancreas from its components. "If this is achieved," says Odorico, "it might be possible to replace a patient's damaged pancreas with a new one that is less likely to be destroyed by the patient's immune system.

FINALLY PAIN FREE

Ever since she was in third grade, Stephanie McGuire – an Eagle, Colorado resident and Wisconsin native – had experienced intermittent stomach problems. In 2013, a doctor in Denver determined she had chronic pancreatitis, an inflammation of the pancreas that becomes worse over time and can lead to permanent damage. He recommended she undergo a total pancreatectomy with islet auto-transplantation (TP-IAT) to relieve the pain.

"It turned out there were only a few places in the United States that perform this type of procedure, and University Hospital was one of them," says Stephanie, 25. "So my parents flew me home to meet with the transplant team."

Islet cells are sugar-sensing cells in the pancreas that release insulin. During a TP-IAT, the surgeon takes out the pancreas, removes the islet cells from the pancreas, and then infuses the islet cells back into the same recipient. "We can remove the inflamed pancreas and return the insulin-producing cells back into the liver, where they lodge themselves and find a new home," says Luis Fernandez, MD, transplant surgeon and co-director of the islet transplant program at UW Health. "Eighty to 90 percent of the patients who undergo this procedure eliminate their dependence on narcotics."

Stephanie underwent her surgery on December 1, 2014. During the procedure, Fernandez and his colleague, transplant surgeon Hans Sollinger, MD, PhD, removed her pancreas, gall bladder, duodenum and spleen.

Life has become much easier for the girl who complained of stomach pain throughout elementary school."I'm living a normal life now, just without all these organs," she says. "I'm pretty lucky that I was able to participate in this program."

Stephanie McGuire was able to resume an active life after her islet cell transplant.

NO MORE ER VISITS

Nancy Williams and her husband, Bob, no longer have to worry about dangerously low blood sugar levels.

For Nancy Williams, being a diabetic meant sitting at home constantly monitoring her blood sugar. While she had received a new kidney from her husband, Bob, in 1996 at University Hospital, it wasn't filtering out all the insulin she took in, causing her blood sugar to dip dangerously low.

At least once a week for about six years, Nancy needed to be transported to the emergency room. When her husband was at work, her mother called every hour to make sure she was okay.

It was a hard life, but Nancy – who had had Type I diabetes since she was 7 – didn't know of any other options.

Then, she spoke with Nancy Radke, a transplant coordinator at University Hospital, who told her of a revolutionary new type of transplant that could cure her diabetes. Pancreatic islet allo-transplantation involves removing islet cells from a donor pancreas and transplanting them into the body of the recipient. "The goal is to inject enough islet cells into the patient so they begin to produce enough insulin to maintain a normal blood sugar without the need for extra insulin injections," says Luis Fernandez, MD, transplant surgeon and co-director of the islet transplant program at UW Health.

Nancy Williams was all for the procedure: It meant she would reap the benefits of a pancreas transplant without undergoing such a complicated surgery. "Islet transplant appealed to me because it was a non-invasive surgery," she says.

She underwent a first islet cell transplant in April 2007, and a second procedure a year later to ensure she would have enough islet cells. Since then, Nancy, now 51, has been free of her diabetes. "I go to the lab once a month for blood testing, and that's all," she says. "I don't have to give myself insulin shots anymore. It's just wonderful."

Nancy and Bob now live on a hobby farm in Iron Mountain, Michigan. "I've had horses and chickens and ducks, and I'm busy with them all the time," she says. "I can take long walks with my dog. I can even go without eating sometimes and still not worry."

UW Health is one of only six transplant centers that isolates islet cells to be distributed to researchers in the United States and Europe. "That is a very prestigious position to be in," says Fernandez. "At UW Health, we are able to isolate and purify the islet cells, then characterize their quality and potency to aid further research."

"I don't have to give myself insulin shots anymore. It's just wonderful." – Nancy Williams

The Next 50 Years
★★★

Warm Preservation for Livers

The UW Health Transplant Program is internationally known for its groundbreaking work in organ preservation. First, there was Folkert Belzer, MD's kidney perfusion preservation machine – an apparatus that pumps warm solution through the human kidney to keep it healthy for up to five days. Then, there was the "UW solution," a cold storage solution which was used to preserve other organs for up to 48 hours.

UW Health is now part of an international trial that seeks to develop normalthermic – or warm – perfusion preservation of the liver to expand the donor pool by extending its preservation time. "Research has shown that warm preservation can repair a liver," says Tony D'Alessandro, MD, transplant surgeon at UW Health. "The warm solution has nutrients that help preserve it better so the damage doesn't occur while it is on the machine."

Wisconsin State Journal

Wednes

August 22,
Madison, W

Johnson Creek athlete receives liver transplan

By William R. Wineke
Medical reporter

A 17-year old girl from Johnson Creek who was a member of the 1984 WIAA Class C championship girls' basketball team received a liver transplant Tuesday at University Hospital.

Darcy Weber, daughter of Mr. and Mrs. Joseph Weber, Route 4, Watertown, received the liver in a 12-hour operation conducted by a surgical team led by Drs. Munci Kalayoglu and Folkert Belzer.

She was listed in "critical" condition at the hospital Tuesday night but her surgeons said the operation appeared to be "very successful."

Miss Weber suffered from Wilson's disease, a rare inherited disorder that affects one in 200,000 persons.

People with Wilson's disease can-

Kalayoglu said that without the transplant Miss Weber would have had less than a week to live. He said UW staff members started looking for a new liver Sunday and learned Monday that a liver was available in New Jersey.

What followed was one of the dramatic stories that attend many transplant operations.

"We learned of the availability of a liver in New Jersey, but it had been promised to a hospital in Boston," Kalayoglu said. "Our transplant coordinator called Boston and convinced them that our patient was in desperate need of a transplant immediately, so Boston kindly agreed to wait."

Kalayoglu boarded a Lear Jet at the Dane Country Regional Airport at 6 p.m., flew to Newark, N.J., and prepared to "harvest" the donor liver, which came from a 19-year-old acci-

1:50 p.m. Kalayoglu returne
son at 4:30 p.m. with the d
and the operation contin
about noon Tuesday.

Kalayoglu said Miss We
good spirits preceding her o

"She was so happy whe
we had found a liver. She
let's go,'" he said.

Miss Weber has suffere
son's disease since birth
of her affliction only a few
Belzer said.

She was admitted to
Wednesday. Belzer said t
day her liver had deterio
point that it could not
body's waste products a
near death.

Miss Weber, who wil
at Johnson Creek High
fall, was a member of th
ketball team that wo
Class C state champi

BASKETBALL PLAYER MAKES HISTORY

The year was 1984, and star basketball player Darcy (Weber) Zietlow should have been on top of the world: Her team, the Johnson Creek High School Lady Bluejays, had just won the state championship. Instead, she was exhausted all the time and suffering from a mysterious belly pain. She was also gaining weight – 45 pounds in just three months.

Darcy saw doctor after doctor and underwent a host of tests, to no avail. No one could figure out what was wrong with her. Finally, that August, her family took her to see doctors at University Hospital. "I laid in the back of our van, vomiting the whole way," says Darcy. "I was so weak I could hardly stand up."

Two days after she arrived at the hospital, she received a diagnosis: She had Wilson's disease, an inherited disorder that causes too much copper to accumulate in the liver, brain and other vital organs. By that point, her liver was so damaged that she needed a liver transplant immediately. She was put on the waiting list on a Saturday. By Sunday, a liver had already become available and she was transplanted by Munci Kalayoglu, MD, the newest transplant surgeon on staff at University Hospital and a specialist in liver transplant.

After her surgery, the transplant team at University Hospital began to help Darcy heal. There was only one small challenge: They had never done it before. While Kalayoglu had performed one liver transplant at University Hospital, that patient was a veteran and had recovered at the William S. Middleton Memorial Veterans Hospital.

Darcy stayed in the hospital for six weeks following her surgery, but she doesn't remember much of it because she was so sick. She does, however, remember there was a man who came into her room seven or eight times a day and kissed her head. She found out later that man was Kalayoglu, who was keeping an ever-watchful eye on his star patient.

"I was the only doctor in town who had liver transplant experience," says Kalayoglu. "Any little complication could have resulted in a bigger problem. Therefore, I was following her very closely."

While Darcy wasn't able to talk much to Kalayoglu in the hospital, she became close to him during her thrice-weekly post-discharge blood tests. Nearly a year after her transplant, he became her confidant after her father died. "I call him Dad," says Darcy. "He has always given me fatherly advice and taught me so many things in life."

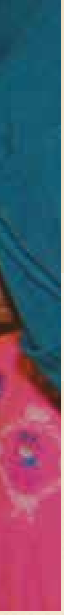
Every year, Kalayoglu, who now lives in Istanbul, Turkey, calls Darcy on August 20 – her transplant anniversary. Most years, he also sends her a bouquet of roses. For him, she was a true miracle and the beginning of a remarkable liver program at UW Health.

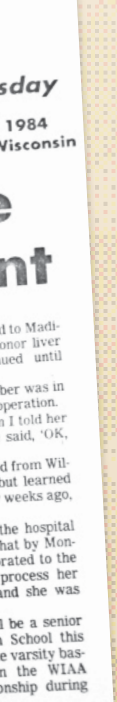
Over the years, physicians and staff have continued to refine and improve the process of liver transplantation. "The care of the patient has a much longer span today than it did 30 years ago," says Michael Lucey, MD, chief of the division of gastroenterology and hepatology and transplant hepatologist at UW Health. "The idea that we are working together as a team is much more pronounced now."

Darcy, now 48, lives in Watertown, Wisconsin with her husband, Mark, and sons Jackson, 12, and Jonathan, 11. "When I was leaving the hospital, I gave a press conference and reporters asked the doctors how long I would live," she says. "They said maybe five years. Well, five years came and went, so I continued living each day as though it was my last."

Darcy is the first of thousands of liver transplant success stories at UW Health. "I have always been proud to be a member of the UW Health Transplant Program, which is among the finest in the world," says Alexandru Musat, MD, who retired as medical director of the liver transplant program in 2015. "The transplant team is committed to providing the highest quality patient-centered care."

"My health now is amazing," adds Darcy. "The transplant truly changed my life."





Once considered a "pioneer" when she received her liver transplant, Darcy Zietlow has beaten all odds and created a full life for herself. At top, she and husband Mark introduce baby Jonathan (now 11) to big brother Jackson (now 12) in 2005. At middle, she and Mark, celebrate their wedding with her mother, Erma. At bottom, there was a media frenzy surrounding her successful transplant.

Did You Know?

The UW Health Transplant Program is one of only a few centers in the nation approved by the Veterans Administration to perform heart, lung and liver transplants for veterans.

Leonard Stringfellow now is able to devote his time to finishing the basement of his new house after recovering from his liver transplant.

THE RIGHT PLACE AT THE RIGHT TIME

When Leonard Stringfellow started feeling sick in the fall of 2014, he tried to ignore it. The Crown Point, Indiana man's life was already in turmoil – his brother had just experienced brain injury due to carbon monoxide poisoning, and he and his wife were trying to sell the apartment building they owned and build a new house.

However, when he began losing weight and feeling short of breath all the time, he couldn't ignore it any longer. In November, Leonard found out he had liver disease and his health was deteriorating rapidly. As he had been a military police officer in the Air Force for 28 years, he was taken to Jesse Brown VA Medical Center in Chicago. But, he needed a liver transplant, and that facility was not approved by the Veterans Administration to perform transplants on veterans, so Leonard came to Madison.

University Hospital, in conjunction with the William S. Middleton Memorial Veterans Hospital, is one of just six transplant centers in the United States approved to treat veterans. "It is a badge of honor that experts in the federal government recognize the outstanding liver care University Hospital and the VA Hospital provide," says Adnan Said, MD, chief of gastroenterology and hepatology and medical director of liver transplant at the VA Hospital.

The transplant physicians at University Hospital and the VA Hospital are the same. While transplant patients undergo their surgery at University Hospital, they receive their pre-operation and follow-up care at the VA Hospital.

Leonard came to the VA Hospital in December and received his new liver on March 10 under the care of transplant surgeon Josh Mezrich, MD. "I was blessed to be transferred to the VA Hospital in Madison and be put on the list there," Leonard says. "Because the Chicago VA Hospital is not an approved transplant center, I probably would have been on the list for a long time, waiting for a transplant at another facility."

Indeed, the UW Health Transplant Program is nationally known for having a short waiting list. Since the program was approved for liver transplants in 2013, veterans from across the country have traveled here for transplants.

Just a few months after his surgery, Leonard was back at his job, conducting national security investigations as a special agent with the federal government. He also has been able to work on his new pet project: finishing the basement of his new house.

"My wife, Cynthia, had to do so much around the house when I was sick," says Leonard. "Cynthia took care of me and her elderly mother who resides with us. She is truly a blessing, and I am so happy to have her in my life."

"The medical team at both hospitals were really great," says Leonard. "I appreciated everything they did for me. I thank God and the medical team for giving me a second chance at life. If you are ever in need of a liver transplant, you definitely want to have Drs. Mezrich and Said on your medical team."

Creating Hope

Donna Frett received a liver transplant at University Hospital in 2005. She founded the Donna Frett Organ Donation Foundation to raise awareness and funds for organ donation. Here, she and her husband, Buzz, left, pose with Mary Jo and Danny Rozmenoski, the parents of her organ donor, Dustin.

A GRATEFUL FAMILY

Aviva Gellman did not want her family to notice the whites of her eyes were turning yellow. The then-14-year-old from Madison thought she was dehydrated and blamed herself for not drinking more water. But when she was at a hockey game with her grandparents and opened her eyes wide in excitement, they saw just how sick she was.

Her pediatrician diagnosed her with liver disease, which led her to Tony D'Alessandro, MD, a transplant surgeon at UW Health. He determined she needed a liver transplant. "I can't tell you how horrified we were to hear the word 'transplant,'" says Sam Gellman, Aviva's father.

Less than a week after that hockey game, Aviva's parents took her to American Family Children's Hospital, where she became delirious – the effect of toxins entering her bloodstream. She needed a liver right away, but none were available. That's when D'Alessandro suggested living liver donation to Sam and Aviva's mother, Julie.

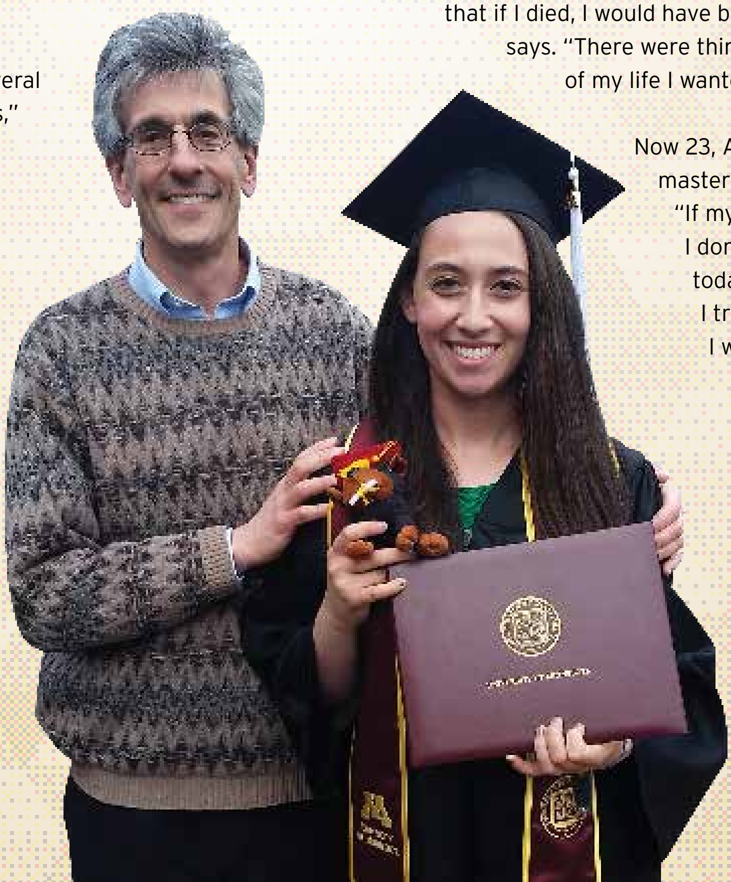
"Live donation typically is a multi-step process involving several weeks of testing and clinic visits," says John Rice, MD, transplant hepatologist at UW Health. "It usually is not done urgently. But, sometimes there are exceptional circumstances where we have to make an evaluation much more quickly."

Sam's blood type matched his daughter's, and over the course of a weekend, he underwent the required testing to make sure his liver was the right match. "When you see your kid leaving you right before your eyes, you don't care about anything else other than doing what you can to save her," he says. "My only thought was, thank God I'm a blood match, and how soon can we do it?"

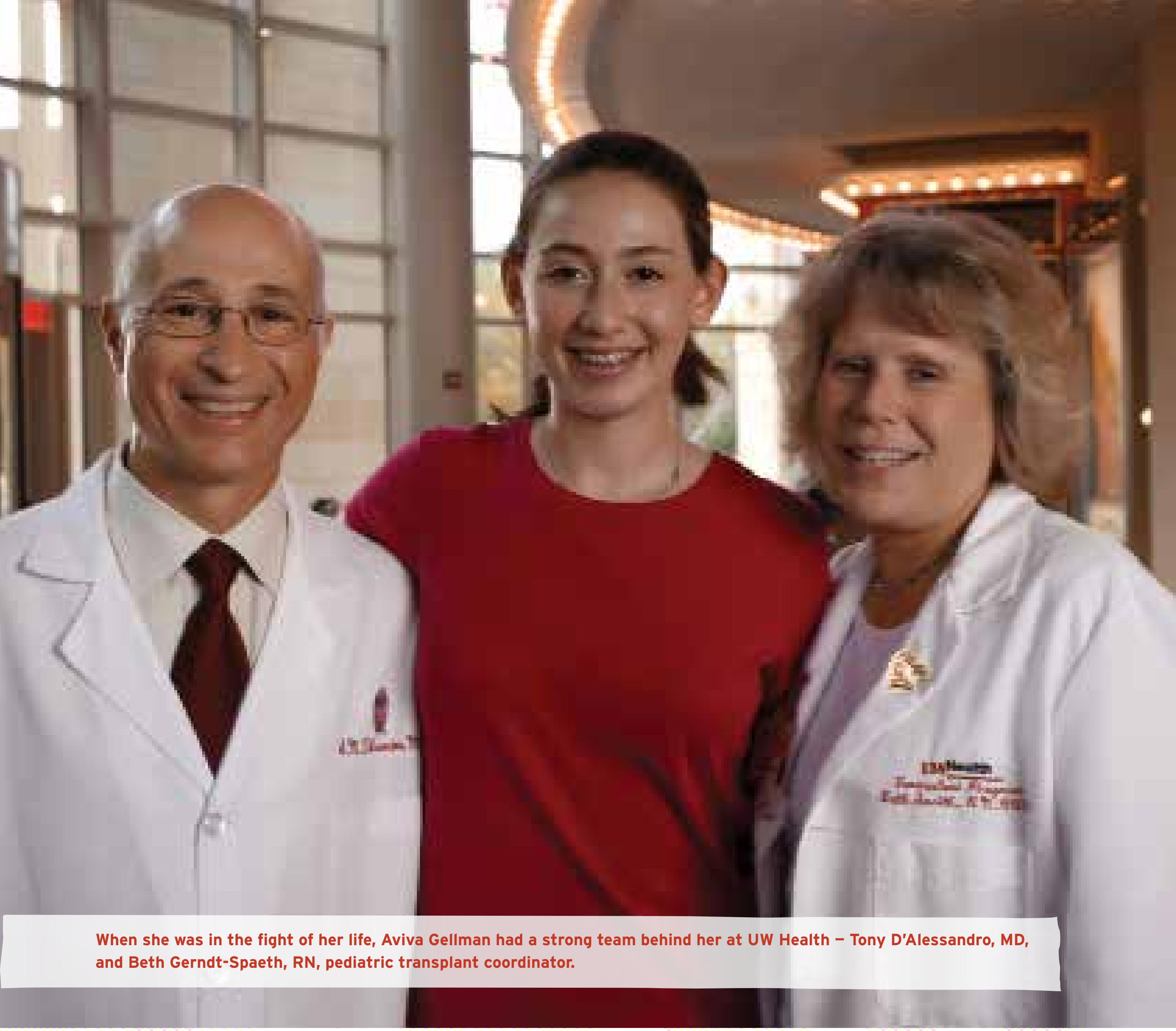
Aviva and Sam had their surgeries on Monday morning – just nine days after their first trip to the emergency room. Sam was out of University Hospital in 10 days, and Aviva stayed at American Family 24 days. A few days after her surgery, she experienced acute rejection, but staff caught it quickly and were able to treat it. "Even when there were hiccups," she says, "everyone did such a good job of preparing me and making sure I understood what I needed to do to move forward."

Since receiving the gift of life from her father, Aviva has become a different person. Once shy and quiet, she has grown to love performing – acting, singing and playing cello. Last year, she graduated from the University of Minnesota with a double major in political science and theater. "When I was in the hospital and having trouble sleeping, I remember thinking that if I died, I would have been so mad at myself," she says. "There were things I still wanted to do, parts of my life I wanted to explore."

Now 23, Aviva plans to pursue a master's degree in public health. "If my dad hadn't been a match, I don't know if I would be here today," she says. "Time is short. I try to push myself to do things I wouldn't ordinarily do."



"I feel so gratified that I could do this," says Sam, pictured here with Aviva at her college graduation in 2015.



When she was in the fight of her life, Aviva Gellman had a strong team behind her at UW Health – Tony D'Alessandro, MD, and Beth Gerndt-Spaeth, RN, pediatric transplant coordinator.

INTESTINAL TRANSPLANT

Intestinal – or small bowel – transplants are not very common. But for those who need them, they can be life-saving. The UW Health Transplant Program is the only program in the state of Wisconsin approved to perform liver-intestinal transplants. Since 1988, UW Health has performed 20 liver-intestinal transplants – all in pediatric patients. "Most of these patients are children who were born with conditions such as gastroschisis or small bowel disease," says Tony D'Alessandro, MD, transplant surgeon at UW Health. "They have received their nutrition intravenously, which causes cirrhosis of the liver. That is why they need both a liver and intestinal transplant."

The Next 50 Years

New potential for heart donation

The UW Health Transplant Program is well known for its research into the use of donation after circulatory death (DCD) organs. It would seem counterintuitive that DCD hearts would be deemed suitable for transplant – but that is exactly what researchers at UW Health are trying to do. A team that includes heart surgeons Satoru Osaki, MD, and Takushi Kohmoto, MD, is working on resuscitating DCD hearts, with the hopes of someday being able to transplant these organs into patients.

"We are hoping we will be able to transplant a DCD heart within two to three years," says Kohmoto.

MEMORIES WITH MADISON

Every summer, Jack and Lisa Palosaari of Lake Linden, Michigan take their daughter Madison to Madison, Wisconsin for their annual family vacation. They stay at a hotel with a pool and waterslide and take a trip down memory lane as they visit all their favorite haunts and restaurants.

It's not a coincidence that Madison, now 15, bears the same name as the city. Wisconsin's capital is home to University Hospital, where Jack received a heart transplant in June 1990 at age 29. Now, nearly 26 years later, his not-so-new heart is still beating strongly, and he makes an annual visit for a check-up to the hospital that has given him the chance to make so many memories with his daughter.

"Only half of the patients who receive a heart transplant are alive at 10 years," says Lucian Lozonschi, MD, surgical director of heart transplant and cardiothoracic surgeon at UW Health. "Jack is in a very unique class. But when a patient has a heart transplant at an early age, it is likely he will enjoy many quality years from this gift of a new heart."

"Over the years, we have watched the hospital grow," says Jack, now 55. "When they built American Family Children's Hospital, we got free bike helmets. We take pictures every year after I come out of my heart catheterization."

Jack and Lisa had only been married three years in April 1990 when Jack developed flu-like symptoms and began having difficulties climbing stairs. He wasn't a smoker or drinker, so he and Lisa were shocked when he was diagnosed with an enlarged heart. A doctor at a local hospital had heard raves about University Hospital's new heart transplant program, so the couple drove to Madison for testing that took a full week to complete.

Transplant physicians at University Hospital told Jack he would live only two to six months without a new heart. Fortunately for him, a donor gave the gift of life in June, and he was airlifted to Madison for his surgery.

"At the time, we didn't know anyone who had a heart transplant," says Lisa. "It was unfathomable. Before Jack got sick, we had a meeting at work where we learned about our insurance benefits, including heart transplants. I remember thinking, wow, that's extreme. What are the chances of that?"

When Lisa visited Jack in the intensive care unit following his surgery, the first thing she noticed was his chest: he didn't have an enlarged heart anymore. Even before they left the hospital, she told him that if they had a daughter, she wanted to name her Madison. "It's the place where he was given a second chance at life," she says.

For Madison the teenager, Madison the city is now the site of many fond memories. Judging from her father's energy level, they will be continuing their pilgrimage for many years to come.

"The staff at UW Health have been very good to us," says Jack.

Over the past 26 years, Jack and Lisa Palosaari have regularly traveled more than 300 miles to University Hospital. From left, Jack is all smiles after his transplant in 1990; Madison takes her first trip to her namesake in 2001; a 6-year-old Madison visits her father after his annual heart catheterization in 2007; Jack and Madison take a quick photo break after his check-up in 2015; and center, Jack, Madison and Lisa stop for a family photo in 2015.

A FATHER'S SECOND CHANCE

In February 2013, Jeff Merkes had reached the low point of his battle with congestive heart failure: The Brooklyn, Wisconsin man couldn't lie down because so much fluid had accumulated in his body. So he sat at the kitchen table, chin in his hands, and tried to sleep – usually jerking awake after about a minute. The 45-year-old needed a heart transplant, but the wait for a heart often can be long.

Then, the next month, Jeff received the Thoratec HeartMate II left ventricular assist device (LVAD) at University Hospital, and his world suddenly turned around. "By the time I got my LVAD, I was in really bad shape," he says. "I went from being bedridden in the hospital to actually being able to live my life again."

An LVAD is an implantable mechanical pump that assists the heart when it is unable to pump enough blood through the body. UW Health is one of a number of transplant centers approved to implant this device as an alternative to transplantation.

Many patients who receive an LVAD are awaiting a heart transplant, like Jeff was. However, for some patients who are in end-stage heart failure and ineligible for transplant, the HeartMate II can be used to extend their life.

"Patients do have limitations with LVADs," says Maryl Johnson, MD, FACC, one of the cardiologists at UW Health who treated Jeff. "But most people feel their quality of life improves tremendously with the LVAD. In recent years, the biggest area of growth has been with the 'destination therapy' population who would likely die without an LVAD."

Jeff had suffered from congestive heart failure since he was 39. In 2010, he nearly died after going into cardiac arrest while driving with his wife Lori, and he had two defibrillators implanted in his heart to manage his arrhythmia. As the years went on, his heart problems became worse, and he struggled to find the energy needed to manage his car repair shop and devote time to his young family. Shortly before receiving the LVAD, Jeff had to close his business.

Finally, on April 16, 2014, Jeff received his long-awaited gift of life: a heart transplant. "We got the call, and I was there in less than 30 minutes," he says.

Jeff's new heart has been just what he needed to get his life back. Now, he is able to spend time with his wife and three children, ages 26, 11 and 6, and he started a full-time job at a repair shop in July 2015.

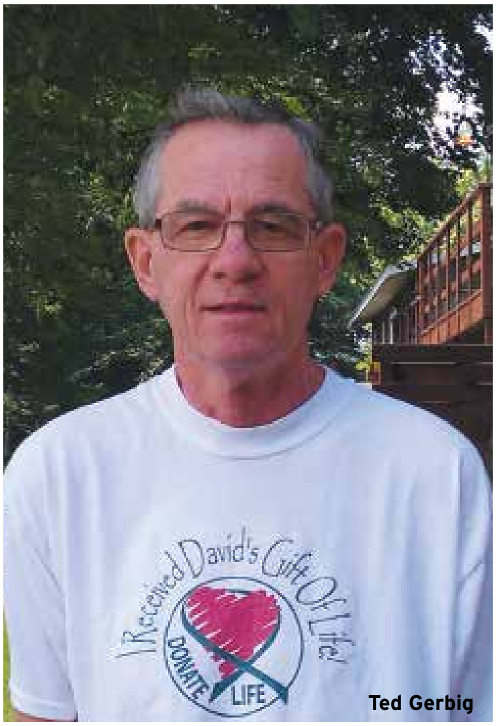
"Helping a patient go from being completely bed-ridden to going back to work and being involved in his family's lives is a great example of why I love doing my job," says Jennifer Brennan, RN, BSN, CCTC, clinical transplant coordinator for the UW Health Transplant Program who has worked with Jeff since before he received his transplant.

Instead of spending his weekends trying to rest at the kitchen table, Jeff participates in archery tournaments with his son Seth. "After my transplant, I can walk the circuit and do better than most people do at these tournaments," says Jeff. "I always believed that it would all work out, and it did."

> **"Helping a patient go from being completely bed-ridden to going back to work and being involved in his family's lives is a great example of why I love doing my job."**
> **– Jennifer Brennan, RN, BSN, CCTC**

Since receiving the gift of a new heart, Jeff — pictured here with sons Seth, 11, and Luke, 6, — has been able to go back to work and return to hobbies such as archery.

Creating Hope



Ted Gerbig

North Central Wisconsin Donate Life (NCWDL) was formed in 2007 by a group of volunteers comprised of organ recipients and donor families, including Ted Gerbig and his wife, Shelby Gerbig-Fehlhaber. Ted received the gift of a new lung in 2003 from organ donor David Duranceau (see story on page 57). Ted became a great voice for the organ and tissue donation mission, appearing in magazines, newspaper and on TV. Before he died in 2013, he received a Jefferson Award in recognition of his efforts promoting organ donation.

The members of NCWDL travel to many area events to promote organ and tissue donation, and raise money to support UW Organ and Tissue Donation's Donor Education Fund and Restoring Hope Transplant House.

The Next 50 Years ★★★

Modifying Donor Lungs

One of the biggest dangers for lung transplant patients is the body's potential immune reaction to an antigen called collagen 5. In many cases, this antigen provokes an inflammatory response that causes the lung to stop working. William Burlingham, PhD, lead researcher in the UW Health Transplant Program, is directing a team that seeks to avoid this problem by modifying donor lungs so the recipients will be less reactive toward collagen 5. "Fifty percent of lung transplant patients lose their lung by year five because of this reaction, and 90 percent lose it by year 10," says Burlingham. "If we can modify donor lungs, we can save lives."

FROM OXYGEN TANK TO BREATHING FREE

Margie Haslam thinks often about the family of the person whose lungs are now in her chest. She can only imagine the pain they suffered when their loved one became an organ donor.

What she does know is how much her own life has improved in the 12 years since her transplant. "I'm 52, and I feel like I'm 30," says Margie. "I just hope people realize the good they do when they choose to give the gift of life."

A short wait

Margie, who lives in Mequon, Wisconsin, was born prematurely and always had lung problems. But it wasn't until she turned 40 that she found out she had pulmonary hypertension, a rare lung disorder that causes the arteries that carry blood from the heart to the lungs to narrow, restricting the flow of blood. She was put on the wait list at University Hospital for a new set of lungs and only had to wait two and a half months before receiving her transplant on December 22, 2003. "I was told to prepare for a two-year wait," says Margie. "It was our Christmas miracle."

Margie's lungs were donation after circulatory death (DCD) lungs, which means the organ procurement team recovered the organs after the donor's heart stopped, rather than after brain death. Most lungs used for transplant are recovered from patients who are brain dead, but whose heart is still beating. "There are not enough organs for every patient," says Nilto De Oliveira, MD, director of lung transplantation at UW Health. "When we identify a suitable DCD donor, that is a good opportunity to proceed with a transplant that would not otherwise happen." (For more about how UW Health is nationally known for its DCD protocols, see page 48.)

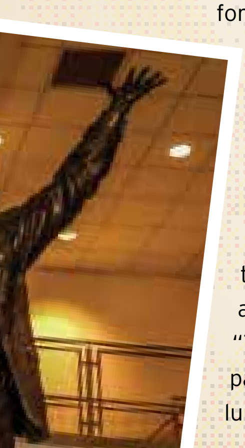
After Margie's surgery, it was like someone had flipped a switch for her. "The minute I woke up, I didn't have any shortness of breath," she says. "I went from needing oxygen all the time to needing nothing at all. Life changed – and it changed for the better."

Margie went back to her job working in a dentist's office just three months after her surgery. Now, she works in a periodontist's office and stays focused on her passions – her nieces, the Green Bay Packers and Marquette University men's basketball.

"I am so blessed that I went to Madison for my transplant," she says. "They are the most amazing people there. Between the doctors, nurses and the support I had from my family and friends, I had a wonderful network of people who were looking out for me."

"The five-year survival rate for a lung transplant recipient is 55 percent, and the 10-year rate is 30 percent," says Richard Cornwell, MD, pulmonologist and medical director of the UW Health Lung Transplant Program. "Margie has done so well because she has been very attentive to her therapies and has kept on top of medical issues as they arise."

"Organ donation is the most amazing gift anyone can give another human being," Margie adds." You look at life totally different. I was always active, but now I try to be even more active, because I don't take even one day for granted."



Margie Haslam is a lifelong Marquette University men's basketball fan. Thanks to her lung transplant, she is cheering loudly in the stands at nearly every game. At far left, she playfully mimics a statue of Al McGuire, a famous Marquette coach. At left, she poses with her group of friends during a 2013 vacation to Florida.

IN SICKNESS AND IN HEALTH

In December 2008, Chris Housley was flying high: His girlfriend, Lauren, had accepted his marriage proposal three months earlier, and they were escaping the Midwest's winter chill on a vacation to the Bahamas. Once they returned, they would begin planning their wedding for the third week of March in 2010.

Instead of tasting wedding cakes, however, Chris found himself in the fight of his life. He had always suffered from cystic fibrosis (CF), an inherited disorder that causes severe damage to the lungs and digestive system. Up until the end of 2008, however, his health had remained fairly stable; he had even been able to participate in sports throughout grade school and high school.

"Even when my health took a big turn for the worse after high school, I still reached a plateau where I was on the borderline of being listed," adds Chris, an architect who lives in Oak Park, Illinois.

"CF is always different for every patient," says James Maloney, MD, the section chief of thoracic surgery at UW Health and one of Chris's surgeons. "A lot of CF kids grow up watching all the other kids do the things they can't. Or they start out doing those things, and gradually those privileges are taken away."

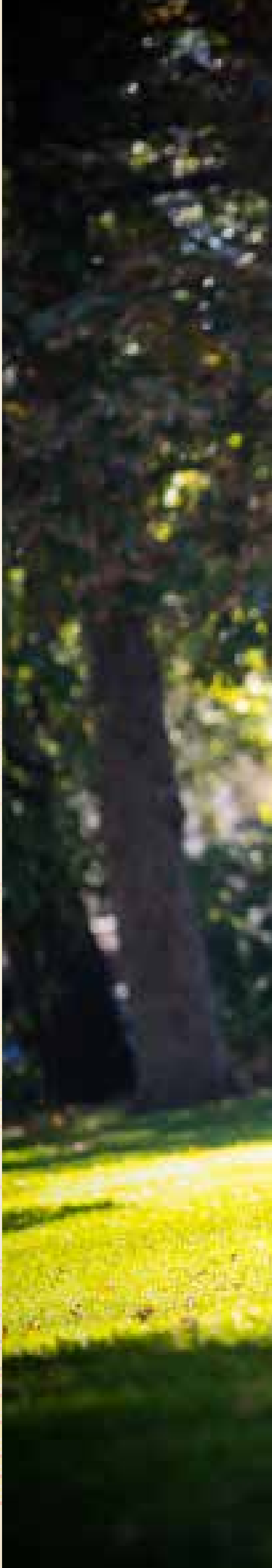
Chris's doctor had recommended the UW Health Transplant Program to him because it had some of the best outcomes in the country. "We have a very experienced group of people who work together," says Nilto De Oliveira, MD, director of aortic surgery and lung transplantation at UW Health and one of Chris's surgeons. "We have a passion for lung transplantation, which carries the highest risk of all organ transplants." Chris had been seeing doctors at UW Health, so when his health declined, he underwent the appropriate tests and was put on the wait list for a new set of lungs.

While he waited, Chris set to work raising funds to cover the cost of his surgery. He also reached out to Trey Schwab, outreach coordinator at UW Organ and Tissue Donation and a lung recipient, for advice and support. (See An Ambassador for Life, page 59.) He and Lauren delayed their wedding. Instead of getting married on their intended date, Chris received the gift of life with a new set of lungs on March 18, 2010.

The surgery went well, but starting life as a transplant recipient was a difficult adjustment for him. "Even after the transplant, when you're going through the recovery process, there are still a lot of unknowns," says Chris. "You take it step by step, trying to check all these steps off, resume doing all these things you're not supposed to do after this major surgery."

Months after his transplant, Chris finally felt comfortable enough to begin looking ahead. He and Lauren, a wedding planner, set their new wedding date for September 3, 2011.

"It's amazing how thankful, and appreciative, and stunned you can be after receiving a transplant," says Chris. "The idea that this is my new normal takes a while to set in. But when it does, it feels so good to plan for a future. My lungs are doing as good as the day I got them."



Nearly six years after his lung transplant, Chris Housley's lungs have continued to improve in function. He and Lauren revel in their new normal – trying new restaurants, going out with friends and seeing movies together.

CYSTIC FIBROSIS LUNG TRANSPLANT PROGRAM

UW Health's Lung Transplant Program provides comprehensive, research-based care for a wide variety of patients, including those who suffer from cystic fibrosis (CF). The surgeons, pulmonologists, transplant coordinators, nurses, social workers and other staff work together as a team to ensure patients experience the best possible outcomes.

At UW Health, CF lung transplant patients have a one-year survival rate of 93 percent and a three-year survival rate of 82 percent – outcomes that have attracted attention from many other centers.

"We have had great success because we have an experienced, harmonious team working together to give our CF patients the best outcome possible," says Richard Cornwell, MD, pulmonologist and medical director of the UW Health Lung Transplant Program. "We serve as a referral center for CF patients across the region, primarily because of our great depth of experience."

From left, Jenna, her father, Jim, her mother, Pat, and her sister, Alissa, pose for a family photo in 2011.

Creating Hope

Dottie Donor Dot, a donation mascot that mimics the orange donor dot on Wisconsin drivers' licenses, was created in 2008 at UW Health. Dottie travels the state promoting organ, tissue and eye donation and the Wisconsin Donor Registry. Dottie creates a unique opportunity for people to discuss their donation decision.

THE GIFT OF LIFE TIMES THREE

Jenna Lulich's life has been full of hospital stays, but throughout it all, she kept smiling. At left, the 4-year-old Jenna cuddles a bear two weeks after her first transplant. At center, she and her mom Pat, celebrate her second transplant with her classmates. At right, she shares her story as a Donate Life volunteer after her third transplant.

In the summer of 1993, Pat and Jim Lulich's world turned upside down. Their daughter, Jenna, was gravely ill with liver disease, and they had a bad experience with another transplant center before finally ending up at University Hospital, fighting for Jenna's life. Jenna underwent a successful liver transplant at age 4, but five years later, she had a potentially fatal blockage to her bowel. She was in the hospital for six months before receiving the gift of life again with a liver, intestine, pancreas and kidney transplant in January 1999.

The Luliches' life was in turmoil, but along the way, they found something they weren't expecting: a community. "I lived at the hospital with her," says Pat. "I would ask them, "So what are you doing this weekend?" because I wasn't doing much. I still exchange Christmas cards with many of them."

Over the years, Jenna's surgeon, Munci Kalayoglu, MD, became one of the family's most trusted medical advisers. The nurses in the transplant program were valuable resources for her continued medical needs. "I remember sitting with the nurses after her first transplant, saying, 'I'll never be able to go home because I'll never understand what they're talking about,' says Pat. "But I was amazed at what they helped me take responsibility for."

"During the child's hospitalization, the parents have intensive educational sessions to reinforce all that we've been teaching them," says Sharon Bartosh, MD, division head of pediatric nephrology at UW Health and Jenna's transplant nephrologist. "When the child becomes older, we prepare her for the transition to self-care."

Even after Jenna's multi-organ transplant, her ordeal wasn't over. The kidney from the 1999 transplant never fully worked, and while Jenna's own kidney began working again temporarily, by 2002 she needed another kidney. This time, Pat donated her own kidney.

While Jenna was hospitalized before her multi-organ transplant, she developed a seizure disorder that would affect her eight to 10 times a month. In 2014, surgeons at University Hospital removed her hippocampus, which has helped her live a normal life again. "It's been so nice to be more independent since the surgery," says Jenna, who lives in Hartford, Wisconsin with her family. "I'm not just waiting for the ball to drop like I was for most of my life."

She earned two associate degrees – the first from the University of Wisconsin-Washington County, and the second from Moraine Park Technical School in health information technology. Jenna has always been interested in health care, she and her mom say, because she has spent so much time in the hospital. "She would just sit in her hospital room and listen to the nurses and me," says Pat.

Despite all the medical challenges Jenna has endured, Pat believes their family are the lucky ones. "UW Health was wonderful," she says. "I can't even tell you how it's changed our lives. She was so close to death so many times. I wonder how we got so blessed to still have her in our lives."

"LIKE OUR SECOND HOME"

Dancing is a requirement in Bella Peterson's presence. When the 2-year-old is getting her groove on and points to you, you are obligated to join in. And the doctors, nurses and staff at American Family Children's Hospital did just that, creating a hospital room dance party that made the prospect of a toddler receiving a liver transplant just a little less stressful for Bella and her parents.

The Pittsville, Wisconsin youngster has received not one but two livers at American Family Children's Hospital. The first, which she received on November 2, 2014, failed just days later when she developed a clot in her hepatic artery. She underwent another liver transplant exactly two weeks after the first one.

"Like our second home"

Bella experienced liver failure when she was just three months old. Chris and Kari Peterson – who became her foster parents when she was five weeks old and adopted her in April 2015 – found out soon after taking her home that she had a host of problems, including familial interhepatic choleostasis, an inherited liver disease, and neonatal large cell hepatitis, an inflammation of the liver.

While Bella has gone through more than any child her age should have to endure, she has adapted remarkably well – largely due to her relationships with the caregivers at American Family Children's Hospital. "We joke that American Family Children's Hospital is like our second home," says Kari. "We could be gone for months and come back and pick up where we left off. Bella is comfortable, so it makes it a lot easier."

Early on, Chris and Kari named the equipment Bella uses, calling her perfusion pump "Joey" and her IV pole "Toodles." "The last time we were in the hospital, as soon as the nurse brought the IV pole in, she just started smiling," says Kari. "It was kind of like a toy."

Caring for pediatric transplant patients requires a special kind of patience and a gift for working with children. Lindsay Aschliman, RN, has been caring for Bella since she was a baby and has learned exactly what the toddler needs to feel comfortable. "It was important for me to take time to engage her in being a kid before I did anything I needed to do," says Lindsay. "I could connect with her more if I got on her level before I started to poke and prod at her."

Since her transplant, Bella has continued to improve. She is now a happy 2-year-old who loves blowing bubbles, playing with her siblings and, of course, dancing.

"We think that Bella is probably going to be a doctor," says Kari. "She is so interested in medical equipment. Now that she's healthy, she can do whatever she wants."

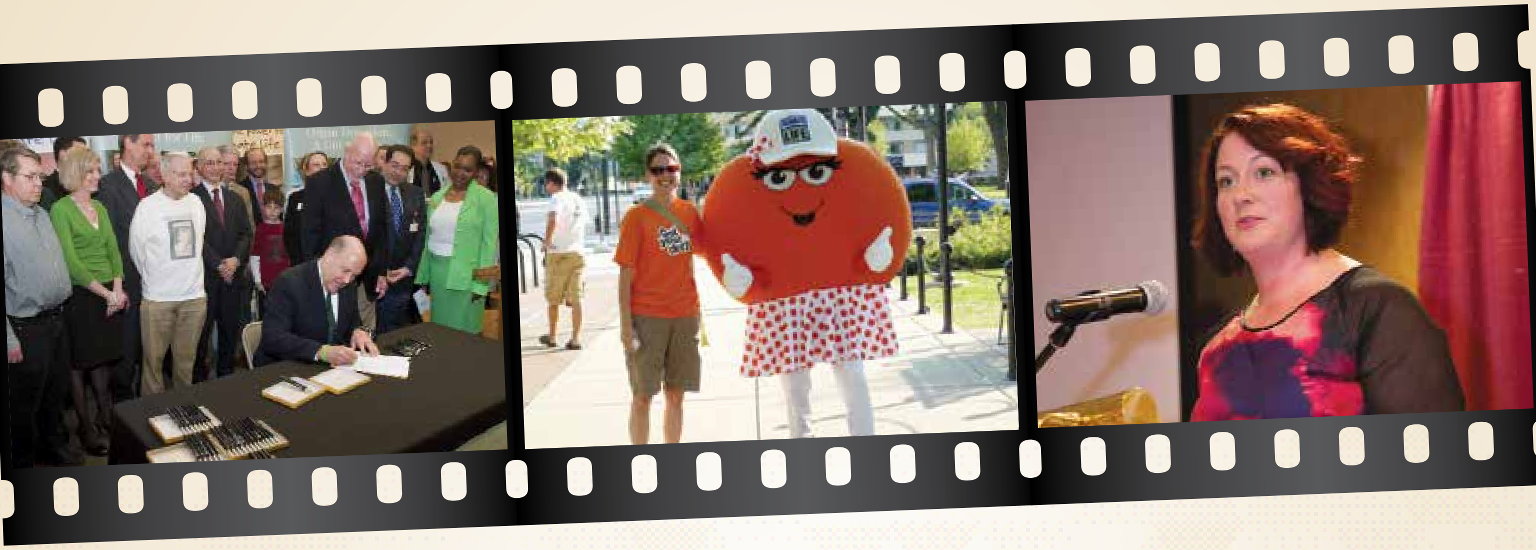
Bella's parents and siblings have doted on her since she first joined their family. Here, she visits a park with, clockwise from front: dad Chris Peterson, Chase Peterson, Kara Peterson, Jon Bannerman, Brennen Peterson, and mom Kari Peterson.

> “It was important for me to take time to engage her in being a kid before I did anything I needed to do.” – Lindsay Aschliman, RN

Jeff Ethington, UW Organ and Tissue Donation (UW OTD) surgical recovery coordinator, left; and Emre Arpali, MD, UW Transplant Program fellow, center; prepare to load a donor liver into a vehicle after it arrives by plane at the Dane County Regional Airport. With them is Terry Cullen, a driver with the Nationwide Organ Recovery Transplant Alliance.

Creating Hope

- In 2000, Wisconsin was the first state to pass a law – Kelly's Law – requiring driver's education teachers to devote 30 minutes of class time to organ donation education.
- In 1993, the state of Wisconsin began formally recognizing the lives of those who unselfishly gave the gift of life to others by donating their organs upon their death. An event is held annually at the Executive Residence to honor the organ donors and families of organ donors from the previous year.
- On March 29, 2010, the state of Wisconsin launched a registry that allows for anyone older than 15 ½ to legally authorize organ, tissue and eye donation.
- Every other year, UW Organ and Tissue Donation presents the Douglas T. Miller Symposium, a two-day educational program for donor hospital physicians and staff. A kidney recipient himself, Doug Miller was the first transplant coordinator at University Hospital.
- Currently, almost 60 percent of Wisconsin citizens ages 15 ½ or older are registered as an organ, tissue and eye donor.



At left, Gov. Jim Doyle signs Wisconsin's Uniform Anatomical Gift Act into law. UW OTD has a long history of backing new laws that support organ and tissue donation. At center, Dina Steinberger, program director, escorts Dottie Donor Dot, Wisconsin's donation mascot. At right, Jill Ellefson speaks at an event to honor living organ donors. She began as an outreach coordinator for UW OTD in 2000 and advanced to executive director in 2008. Jill has made significant contributions on the HRSA Organ Donation Breakthrough Collaborative and developed the UW OTD Forward Focus Collaborative. These contributions significantly increased organ, tissue and eye donation in the UW OTD service area. In 2013, she became service line director for organ donation and transplantation at UW Health.

A MISSION TO SAVE LIVES

While there has always been an organ recovery component to the UW Health Transplant Program, it wasn't until 1984 that UW Hospital and Clinics officially created an organ procurement organization (OPO). In that year, the federal government passed the National Organ Transplant Act, which called for the creation of an Organ Procurement Transplant Network (OPTN). The act also made it illegal for organizations or individuals to buy and sell organs.

UW's OPO, now called UW Organ and Tissue Donation (UW OTD), is federally designated to support 108 hospitals in Wisconsin, Michigan and Illinois. It accomplishes this by providing five main services:
- Supporting donor families
- Maintaining collaborative relationships with hospitals in the service area and supporting hospital staff
- Allocating organs
- Recovering and preserving organs for transplant
- Providing community outreach that promotes, and educates people about, organ, tissue and eye donation

Before 2000 the organization was relatively small, with a handful of people working together to provide all these services. Now, there are more than 40 people on the UW OTD team, all working together to serve and support donor families, hospitals and the community.

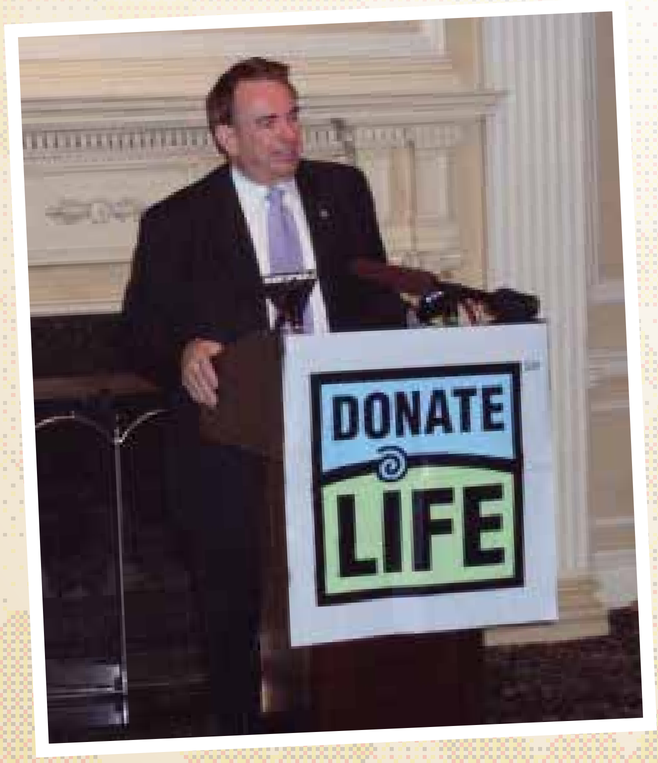
The UW OTD team is widely recognized as one of the nation's most important and successful programs.

Former Wisconsin Gov. Tommy Thompson was U.S. Health and Human Services Secretary when he launched the Organ Donation Breakthrough Collaborative in 2003. He listed the UW OPO as a Best Practice site and encouraged other OPOs to learn from it. Since that time, UW OTD staff members have served in multiple state and national leadership roles – creating, leading and directing other OPOs in practices that increase donor registrations, serve donor families and increase the number of organs available for transplant.

UW OTD HELPS OTHER PROGRAMS INCREASE ORGAN DONATION

In the early days of transplant, physicians would wait to remove a donor's organs until after his or her heart stopped. This practice remained the standard until about 1976, when most state legislatures accepted brain death as an indication of death. While most transplant centers across the United States began using only kidneys donated after brain death, the UW Health Transplant Program never stopped accepting donation after circulatory death (DCD) kidney donors.

"(Department of Surgery Chairman) Dr. Belzer was a great transplant pioneer and visionary," says Tony D'Alessandro, MD, transplant surgeon and medical director at UW Organ and Tissue Donation (UW OTD) who has led much of UW Health's DCD research. "He realized that kidneys worked just as well from DCD donors as from brain death donors. When we look at the outcomes long term, there's absolutely no difference in the recipient's survival rate."



As UW Health began its pancreas, liver and lung transplant programs, physicians continued to use only kidneys from DCD patients, but they were researching the feasibility of recovering the other organs. In 1993, UW OTD formalized its DCD protocols for those three organs, becoming a national leader in that area. "The question is, how much lack of blood flow can each organ tolerate?" says D'Alessandro. "We honed our methods for making that determination."

In 2003, when former Wisconsin Gov. Tommy Thompson was U.S. Health and Human Services (HHS) secretary, he launched the Organ Donation Breakthrough Collaborative to increase donations. UW OTD was thrust into the spotlight, because while 8 to 10 percent of its donors were DCD, the national average was only 2 percent. Armed with HHS grants, UW Health and UW OTD set out to educate other programs about how they could expand their donor pool. "One of the things that is unique about UW Health is how closely the transplant program works with the OTD," says D'Alessandro. "When you have that combination, you recover and transplant more organs."

The collaborative's goal was to increase the national DCD rate to 10 percent of all organ donations. It succeeded – and then some. The national rate is now 14 percent, while the UW Health rate is 33 percent.

D'Alessandro served as the UW OTD executive director from 1999 to 2009. Under his leadership, organ donation in UW OTD's service area grew by more than 30 percent, and DCD donation increased from 8 percent to more than 30 percent. He now serves as medical director of UW OTD. Over the past decade, he has traveled to both England and Canada to help OPOs establish DCD policies. "Hospitals across the world are seeing that we have the ability to expand the donor pool and provide life-saving transplants for people who are waiting," says D'Alessandro.

Then-Wisconsin Gov. Tommy Thompson was a frequent visitor to UW OTD. Here, he helps launch a new statewide donation collaborative with Wisconsin business leaders.

Kiley Hackl

Gary and Terry Flugaur (left) remember their daughter, Kiley Hackl, as a faithful Catholic woman who loved her job as a nurse because it allowed her to help others. She was able to give the gift of life when she became a donation after circulatory death (DCD) organ donor at age 32 after suffering a stroke. "Her life was her children, her friends and God," says Terry, right, pictured here with her husband Gary at Our Lady Queen of Heaven Church in Wisconsin Rapids, where Kiley attended school.

UW DCD TOOL

How do physicians know whether a patient's organs will be viable after his or her heart stops? UW Health researchers have created protocols based on the "warm time" — the amount of time between removal of the breathing tube and when the heart stops. Physicians will wait up to 30 minutes for the liver, 45 minutes for the pancreas and two hours for the kidneys.

Hospitals across the country are now using our process – the University of Wisconsin Donation After Circulatory Death Tool. The tool allows physicians to counsel family members about the likelihood of a dying patient becoming an organ donor. It assesses the patient's respiratory function using a variety of factors, including the patient's ability to breathe deeply and the volume of air he or she is receiving. The physician assigns a score based on these factors, which indicates whether the "warm time" will be short enough to allow organ donation.

A LEGACY OF LIFE

Before Alan Zinda was born, his mother Bev suffered three miscarriages while trying for a third child. Then, finally, she gave birth to a healthy baby boy. After Alan grew old enough to understand how miraculous his birth was, he liked to remind her that he was "meant to be" – a man with a purpose.

Neither he nor his family members realized that purpose ultimately would be to give life to others. In August 2010, Alan died in a tragic car accident at age 22 and became an organ donor. Three people received his heart, liver, pancreas and kidneys – and his parents received an opportunity to ensure his legacy would touch thousands of others' lives.

Heartbreak

Alan was driving home from a close friend's house when his car veered out of control and hit a tree just down the road from the home he shared with his parents in Rosholt, Wisconsin. Neighbors saw the accident and ran to the Zindas' house to tell them.

The next few days were a blur for Bev, Alan's father, John, and his two older brothers as doctors at Aspirus Wausau Hospital tried to save his life. "I was at the hospital practically the whole time," says Bev. "I just told him over and over, 'I love you.' They made us go home for one night so we could sleep, but we didn't sleep at all."

On the morning of August 11, doctors told the Zindas their son was brain dead. Bev informed Alan's nurse that her son had signed up to be an organ donor on his driver's license. "His exact words were, 'What good are my organs going to do me when I'm gone? Somebody else could use them,'" says Bev.

Hospital staff took Alan off life support and his family said their final goodbyes to the man who loved to hunt, dance and listen to music.

New life

Over the next two years, the Zindas tried to piece their lives back together and slowly began to heal from their loss. They knew that three people had received Alan's organs, but that was the only information they had.

Laura Braund, who handles donor family and recipient correspondence at UW Organ and Tissue Donation (UW OTD) had helped Bev write letters to the recipients. "The correspondence is what helps families heal," says Christine Monahan, social worker with UW OTD. "It guides them and gives them purpose, memories and a legacy for their loved one."

In June 2012, the Zindas received a letter from a man in Israel, Yitzahk Wolf, who said he had received Alan's heart and one of his kidneys while in the United States and was doing well. He wrote that he hoped the two families could meet, but the Zindas knew that was unlikely because he lived so far away.

Many months later, Bev received a phone call from a television producer in Tel Aviv, Israel, who said she was making a documentary about organ donation and transplant and wanted to fly Yitzahk to the U.S. to meet the Zindas. Bev thought it was a hoax and called Laura for help, but UW Health staff investigated the request and discovered it was the real deal. So on Halloween 2013, Yitzahk, his wife and a film crew came to the Zindas' house. "I just grabbed him immediately and started crying," says Bev.

continued on page 52

> **"The correspondence is what helps families heal. It guides them and gives them purpose, memories and a legacy for their loved one." – Christine Monahan, social worker with UW OTD**

The Zinda family plants a fern in Alan's memory during Aspirus Wausau Hospital's annual remembrance ceremony at R.W. Monk Botanical Gardens in Wausau.

continued from page 50

A media specialist from UW Health was present for the interview and had brought along a stethoscope so Bev could hear her son's heart. "It was one of the best things that could have ever happened," she says. "We all said Alan was home again for a while."

Never forgotten

In the years since Alan died, his family has had multiple opportunities to tell the world about his gift of life. In January 2015, Alan's face was featured as a floragraph on the Donate Life float in the Rose Parade in Pasadena, California. UW OTD provided support so the Zindas could travel to California, participate in special events and see the parade. Later the same year, Bev was a featured speaker at Aspirus Wausau Hospital's annual remembrance ceremony at R.W. Monk Botanical Gardens in Wausau.

The Zindas have now connected with the other two recipients of Alan's organs. In spring 2015, UW OTD staff arranged for the family to meet one of the transplant recipients during a special breakout session at the Doug Miller Symposium, an organ transplantation and donation workshop for health care workers.

"We've gotten so close with the UW OTD people in Madison after all this," says Bev. "They are so sweet to us."

"With all the things we have been able to do since we lost Alan," she continues, "I tell people it's all for him. He deserved this. He's never going to be forgotten."

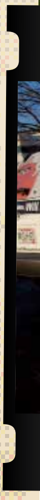
> **"We've gotten so close with the UW OTD people in Madison after all this. They are so sweet to us."**
> **– Bev Zinda**

Creating Hope

Al Wright (pictured here with UW Organ and Tissue Donation social worker Christine Monahan) lost his wife Charlene in 2008. Charlene was an organ donor. For the past several years, Al has paid for a band to play at a church in his hometown of Barneveld, Wisconsin to promote organ, tissue and eye donation. He collects a freewill offering at the concert for UW OTD's Donor Education Fund.

Photo top right: When Eric Gutierrez died in July 2014 at age 11, Mercy Hospital and Trauma Center raised the Donate Life flag in the presence of his family members to honor his gift of life, and bring closure to the family's experience at the hospital.

Photos to right: Dottie's image turns the vehicles used by the UW OTD staff into mobile billboards as they travel across Wisconsin. The UW OTD's Donor Family Services team helps connect recipients who wish to share their gratitude with their donor's family. Staff from hospitals across the state host donation education booths to help people from their community better understand organ and tissue donation and register their decision to be a donor.




ONATE
LIFE
Donation Saves Lives


DONATE LIFE
Will you save lives by being an organ donor?
Yes I Wi
ORG N DONOR
VED MY LIFE
Yes, I Will DONATE

CREATING THE FUTURE OF TRANSPLANTATION

The research performed at the UW Health Transplant Program has saved and improved thousands of lives across the world. The physicians and researchers here continue to make innovations and discoveries that will benefit generations to come. National Institutes of Health (NIH) is the nation's medical research agency. It is considered the "gold standard" for researchers who are trying to make advances in the field – if a researcher's study is NIH-funded, he or she garners support and respect from peers.

Over the past 50 years, dozens of UW Health Transplant Program studies have had NIH funding – including the current study on pre-treatment of organ donors before procurement, detailed on this page. This speaks to the program's emphasis on research that advances the field of transplantation.

Dixon Kaufman, MD, PhD, chief of the transplant division, and Will Burlingham, PhD, professor of surgery, are the team leaders of new research that aims to allow complete elimination of immunosuppression to create tolerance induction in patients receiving a kidney transplant. Large animal pre-clinical studies and human pilot studies are underway that may redefine how future patients are treated following their transplants.

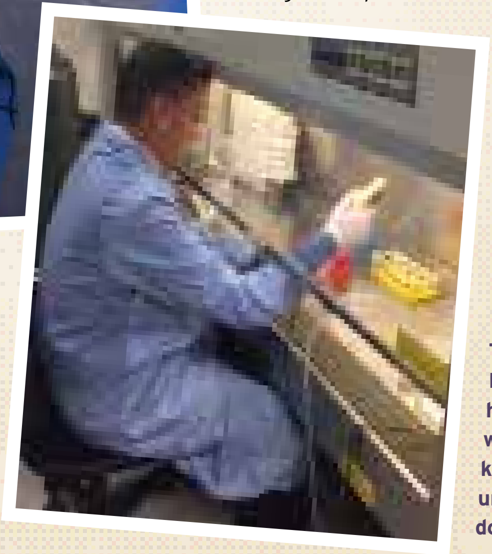
ORGAN DONOR TREATMENT

While organ transplantation has come a long way in 50 years, transplant physicians still are limited by the quality of the organs procured. In the UW Health Transplant Program, researchers are in the early stages of discovering how they can improve the quality of organs before transplantation.

People who experience brain death undergo an inflammatory response in their bodies that can damage their organs. UW Health researchers are working to understand all the changes that occur in a person's body after brain death. "We want to identify how we can treat these donors before the damage occurs," says transplant surgeon Luis Fernandez, MD.

Kidneys taken from a living donor typically last about twice as long as those taken from a deceased donor. "We strongly believe that a lot of that discrepancy comes from changes that occur right after brain death in those donors," says Fernandez. "If we can create a mix of medications that will minimize that inflammation, we can make a difference for organ recipients across the world."

The study, which is funded by the National Institutes of Health (NIH), is currently in the midst of a Phase I clinical trial.



Transplant surgeon David Foley, MD, pictured here in his lab, has been studying ways to decrease injury to kidneys and livers as they undergo the transition from donor to recipient.

RESEARCHERS STUDY ENVIRONMENTAL FACTORS IN REJECTION

Transplant rejection continues to be one of the main challenges facing physicians and surgeons. Transplant surgeon Josh Mezrich, MD, and other researchers are working to identify factors that can increase a person's risk of rejection and other complications. They are examining a cell receptor called aryl hydrocarbon receptor (AHR) that responds to pollution, diet and other environmental factors. "We believe that these environmental exposures – as well as antibiotics and dietary issues – can cause problems in patients," Mezrich says.

Mezrich and his team also have been studying how these factors can impact Clostridium dicicile (C. diff), a bacterial infection that can cause severe problems for transplant patients right after surgery. They have found an oral supplement that, when given to mice, eliminates the infection.

"I think we are within five years of being able to study these factors in human patients," Mezrich says.

Josh Mezrich, MD, surgical director of the living kidney donor program, right, and John Fechner, a researcher in his lab, study the medical and surgical outcomes of kidney transplant patients to help direct current and future research studies.

Lucian Lozonschi, MD, surgical director of heart transplantation at UW Health, leads work that directs the use of LVADS as destination therapy or a bridge to heart transplant.

ADVANCES IN LVADS

UW Health is one of a select group of centers involved in a clinical trial for the Heartmate III – a left ventricular assist device that has been designed to continue to improve upon the excellent results of the Heartmate II. The new device is not only smaller, which may allow for less invasive implantation, but also has an improved design aiming for an even better safety profile.

UW Health also is involved in a National Institutes of Health (NIH)-funded trial that involves injecting stem cells into the left ventricle at the same time an LVAD is installed. "Our goal is to see if the heart can achieve recovery significant enough to allow removal of the LVAD," says Lucian Lozonschi, MD, surgical director of heart transplantation at UW Health and one of the physicians involved with the trial. "We are on the leading edge of a therapy that may be able to expand our approach to treating heart failure."

DONATING TO RESEARCH THAT WILL SAVE LIVES

Peter and Sharlee Eising are not newbies to the world of transplant medicine. When their daughter, Lauren, (called "Muff" by everyone who knows her), went into kidney failure at age 29, the Seattle couple did extensive research at the University of Washington Health Sciences Library to learn about possible treatments.

When it became clear that she would need a kidney transplant, they visited transplant centers across the country and settled on the UW Health Transplant Program and transplant surgeon Hans Sollinger, MD, PhD. "He was our first choice," says Peter. "We liked his protocol of replacing both the kidney and pancreas as well as the results that he was attaining."

Muff underwent her transplant on Oct. 12, 1989 – just four months after she married Mark Jacox. Since then, Sollinger has become her trusted advisor for all medical decisions. "He's bailed me out of so many situations medically," says Muff, who is now 56. "He'll tell me, 'Don't worry.' And that's all it takes to make my blood pressure go down."

Peter, a retired commercial real estate owner and manager, and his wife, Sharlee, have taken a special interest in Sollinger's ongoing research to cure diabetes. They have made several donations to the Sollinger Fund for Cure and Prevention of Diabetic Complications through the UW Foundation.

"When we learned what Hans was doing and what his needs were, we absolutely wanted to support it," says Peter. "He has already done so much to save lives through transplantation. We want to do what we can to help him continue his research."

Since her 1989 transplant, Muff has undergone a second kidney transplant (with her husband as her donor) and other medical challenges. Through the years, she has remained deeply grateful for all that Sollinger and his colleagues have done. Her daughter, Madison, 21, was named for the city in which the transplant took place to honor the doctors, nurses and staff who cared for her. "The UW Health Transplant Program is an amazing program," Muff says. "It's a magical place."

At left, Peter and Sharlee Eising of Seattle, Washington have become faithful supporters of the UW Health Transplant Program after their daughter received two kidneys and a pancreas there.

At center, Muff and Mark named their daughter, Madison, (pictured here in 2010), after the city where her mom received life-saving transplants.

Madison's dress relays mother's story:
"I'm here to tell you . . . Transplants work!"

Many happy 'rebirthdays'

"It's a wonderful feeling to be able to come, to share your story and hear others."

Herb Parsons

SPREADING THE WORD IN DAVID'S NAME

At the time, the situation was unprecedented in the UW Health Transplant Program: Just three months after receiving the gift of life through a kidney and pancreas transplant, David Duranceau donated that same kidney to another person following a brain hemorrhage that took his life.

Since then, other organs have been "retransplanted" after the recipient died – a process that is essentially paying forward the gift of life. David's family have become among the most active organ donation advocates in the state of Wisconsin, creating the David Duranceau Foundation and sponsoring an annual golf outing to raise money for organ donation awareness. "We desperately need people to understand what a beautiful thing organ donation is," says Conni Duranceau, David's mother.

The Duranceaus, who live in DePere, Wisconsin, hosted their first golf outing on August 12, 2003 – just a month after David died. Every year he had thrown himself a birthday party, and since the invitations had already gone out before he died, they chose to golf with family and close friends in his memory. "When we were in the waiting room at the hospital, we decided we needed to celebrate his life by golfing every year on his birthday," says Conni.

Funds from the outing are donated to the Donor Education Fund at UW Organ and Tissue Donation (UW OTD). To date, the David Duranceau Foundation has raised more than $300,000 that works to promote organ and tissue donation education across the state.

"The impact they have had is incredible," says Mary Nachreiner, community development specialist at UW OTD. "The money they raise helps us afford many outreach efforts, such as sponsorships with the Milwaukee Brewers and UW Badgers, television advertising and detailed organ and tissue donation curriculum kits for driver's education programs throughout the state."

After he died, David was able to donate his lungs and liver in addition to his kidney, and his family became quite close to one of the lung recipients and his wife. When that recipient died in 2013, the Duranceaus were by his wife's side during her husband's last moments of life (see Creating Hope box, page 38).

From left, David's brother, Billy, his mother, Conni, and his father, Mike, pose with former UW OTD outreach coordinator, Trey Schwab. (See An Ambassador for Life, page 59.)

David Duranceau with his dog, Bunker

"I believe that 90 percent of people will come in contact with someone who has been on one side or another of transplant," says Conni. "It was a no-brainer for us to choose to support UW OTD."

"I think a lot of people have listened to our story," she continues, "and we have made a difference."

Creating Hope

In the world of organ donation and transplant, hope comes in many forms. These pages highlight the ways a few very special people are creating hope for others. There are hundreds more just like them. Our transplant and donation family is large, and includes people from every state and 10 other countries. We're grateful for their dedication, and for joining us to create more hope and save more lives.

Jackie Pische's son, Joshua Richards, became an organ donor in 2013. She and a group of family and friends created the Joshua J. Richards Charitable Foundation to increase awareness of – and raise funds for – organ and tissue donation. Here, Jackie is wearing Josh's football jersey.

When Ben Ketterhagen, 26, became an organ donor after losing his life in a motorcycle accident, the Ketterhagen family began organizing a golf outing in Ben's name. They chose to use proceeds from the outing to benefit transplant patients and their families by defraying the cost of accommodations, travel and other unexpected expenses. Clockwise from bottom left, the Ketterhagen family includes: Marlene Daniels, Gary Ketterhagen, Valerie Ketterhagen, and Chantry Kerkman. Ben is pictured in the center.

Steve Parsons' daughter, Kim, became an organ donor at age 21 after suffering injuries from an accident. A racing announcer, Steve now travels to dozens of race tracks each summer to lead activities that work to promote organ and tissue donation.

Kay Anderson is a volunteer who has logged hundreds of hours promoting organ and tissue donation. Here, she shares her story at the National Kidney Foundation of Wisconsin's 2014 "Legacy of Life," a celebration of organ, tissue and eye donation.

Restoring Hope Transplant House in Middleton, Wisconsin was founded in 2012. It offers a home-like setting for patients undergoing pre-transplant testing, families whose loved ones are undergoing a transplant and recipients who have follow-up appointments and treatments.

AN AMBASSADOR FOR LIFE

For 11 years, Trey Schwab served as the Community Outreach Specialist with UW Organ and Tissue Donation (UW OTD). Trey joined UW OTD as a way to express his deep gratitude for his donor and the second chance at life he received through a double-lung transplant. He worked tirelessly to ensure more people could receive their gift of life. His knowledge of teamwork and commitment, finely honed during his time as an NBA and collegiate basketball coach, were expressed through his passionate ambassadorship to the mission of increasing organ, tissue and eye donation.

Trey was instrumental in creating the Wisconsin Donor Registry, and was on the leadership team for the 2010 Transplant Games held in Madison, Wisconsin. He mentored patients and donor families, and was a guiding force behind many donation improvement initiatives. Trey served on several state and national boards and received awards for his work to improve organ, tissue and eye donation. Trey died March 20, 2016. His passion for life continues to inspire all who knew him, most especially his family, friends, teammates and the thousands of donor families and transplant recipients whose lives he touched.

FOCUS ON THE FUTURE

Heart recipient Gary Robb supports donor mom Pattie Duerkop as she listens to the sound of her son Patrick's heart.

★ ★ ★

For the last 50 years, the people featured in this book have worked to change the face of transplant surgery and organ and tissue donation. The result has been tremendous: a program that is known worldwide for its innovations and compassionate care.

But the work is not nearly finished.

On any given day, there are dozens of research projects underway in the UW Health Transplant Program – not just those featured in this book, but others as well. Many people work tirelessly to make sure transplant patients have a place to stay, transportation and food to eat. And UW OTD staff members and volunteers travel the state, determined to increase the number of registered organ donors.

The next 50 years are full of promise. And the possibilities are endless.

This book was made possible by hundreds of donors and their families, our transplant recipients, the dedicated and passionate UW Health Transplant and UW Organ and Tissue Donation team, our hospital partners, our volunteers and everyone who has registered as an organ, tissue and eye donor. It was produced, written and edited by Kathy Schultz and Beth Earnest, and designed by Lisa Koehler. New photos were taken by Chris Paskus, John Maniaci, Matt Kryger, Jeff Phelps, and Gretchen Hansen. Historical photos were courtesy of patients, donor families, UW Health staff and the University of Wisconsin-Madison.

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