

DEMAND AND SUPPLY

WITH PATIENT NEED FAR SURPASSING
ORGANS AVAILABLE FOR TRANSPLANT,
HOW CAN THE GAP BE NARROWED —
AND MORE LIVES SAVED?

Robert Merion (M.D. 1979, Residency 1986) worked in a meat-packing plant in the 1970s while he was an undergraduate at the University of Michigan, trying to make ends meet. He worked the halls of Congress in 2007 as an eminent transplant surgeon, trying to make it easier for patients who need kidneys to get them.

“As the saying goes, two things you don’t want to know in detail are how sausage is made and how laws are made,” he says. “I already knew a little about how sausage is made, and I found out a lot about how laws are made. They actually are remarkably similar.”



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he law that Merion, a professor of surgery in the Division of Transplantation, wanted to see made was an amendment to the National Organ Transplant Act (NOTA) of 1984, which established a national network for organ procurement and transplantation, made it mandatory that all transplants were part of it, and set up a registry to keep track of all organ recipients for life. It also outlawed the buying and selling of organs or their exchange for “valuable consideration.”

That last phrase, a relic of the early days of the Republic, was the rub. The U-M Health System had recently launched its Kidney Paired Donation (KPD) Transplant Program, which makes it possible for donors who are incompatible with an intended transplant recipient to donate to a different patient in need. In exchange, the original intended recipient receives a kidney from another living donor in the program.

Some surgeons feared that the kidney a patient received could be deemed “valuable consideration” for the one their friend or family member had donated. The Department of Justice had issued a finding that it would not make such an interpretation, but that wasn’t enough for Merion and his colleagues.

“Justice could make such a finding today and change their minds tomorrow,” he says. “The transplant community felt that it was important to see this through and have it codified into law.”

As a leader in that community — he’s now president of the American Society of Transplant Surgeons — Merion became the expert point man: writing letters, briefing Senate staffers, and winning a powerful ally in Michigan Senator Carl Levin, to whom he gives most of the credit for getting the legislation passed.

“It ended up taking a couple years,” Merion says. “There were a variety of political land mines that we frankly were not very sophisticated about and did not anticipate, including those who opposed the amendment on the basis of bringing in what we thought were extraneous and unrelated issues, like late-term abortion.”

By the time the amendment was signed

into law on December 31, 2007, “We understood how challenging it is to get laws passed in the U.S. Congress,” says Merion. They were also visionary enough to word the amendment to include livers, lungs and other organs, even though, at present, they rarely come from living donors.

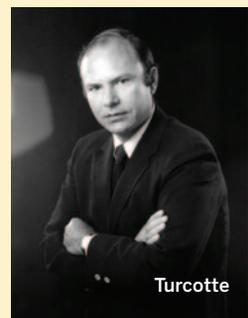
Such activism, a kind of patient care at the macro level, is a hallmark of the transplant community at the U-M. One reason is that Michigan is generally acknowledged as the world leader in transplantation outcomes research, and the unique relationship between the federal government and kidney disease — Americans who suffer from it qualify for Medicare, making it the only illness with a federal entitlement — means that translating that research into better care requires participation in policy-making.

Transplant surgery is the only kind of medicine where the practitioner has no control over whether and when it’s done; it depends entirely on the availability of organs, and that depends on an educated public that’s willing to provide them. “We can’t simply send for another organ through purchasing,” says Merion. “We need a donor.”

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n many ways, transplantation has been victimized by its own success. When the first organ transplant at the U-M was performed in 1964 by Jeremiah Turcotte (M.D. 1957, Residency 1963), the donor and recipient were identical twins. “At the time, it was pretty brave to take a kidney from a healthy person and give it to someone else,” says Jeffrey Punch (M.D. 1986, Residency 1992), who now holds the Jeremiah and Claire Turcotte Professorship in Transplantation Surgery and serves as chief of the Division of Transplantation in the Section of General Surgery.

When the first organ transplant at the U-M was performed in 1964 by Jeremiah Turcotte, the donor and recipient were identical twins. “At the time, it was pretty brave to take a kidney from a healthy person and give it to someone else,” says Jeffrey Punch.



For a couple of decades thereafter, it was believed that only transplants between closely related individuals were likely to be successful. Even then, highly toxic drugs were necessary to keep the recipient's immune system from destroying the "invader." A major breakthrough came in the early 1980s, when a paper by Merion, who had trained and done research with the legendary British transplant surgeon Sir Roy Calne, showed that a drug called cyclosporine, which targeted the part of the immune system that caused kidney grafts to fail, effected a dramatic increase in success rates with markedly reduced toxicity.

"Almost overnight, we went from a success rate of 30-40 percent for kidneys from unrelated people and 70 percent from closely matched siblings, to 70 percent for unrelated and 85 percent for related," Punch says.

When further research revealed that success rates for kidneys from unrelated donors were as good as those for kidneys from spouses, "We started accepting in-laws and then best friends and then bowling buddies," he adds. "As time went by, we got even farther away. People would donate to someone they hardly knew. Success rates improved to 90 percent for unrelated and 95 percent for related. When that happened, everyone was suddenly a candidate for transplantation."

Waiting lists for organs spiked, reaching nine years in some areas. More than 100,000 Americans are currently awaiting transplants; roughly 80 percent of them need kidneys, and the rest wait for livers, lungs, hearts, pancreases or intestines. Thirty or so patients receive transplants every day, but another 12 die waiting.

"Much of my own research has to do with maximizing donor availability," says Alan Leichtman, M.D., professor of internal medicine and medical director of the Transplantation Program, "like whether programs are maximizing the potential for living donation and living unrelated donors, do they make rational decisions when they discard organs, what constitutes a transplantable organ, and are programs using all the potential sources of organs."

Leichtman and his transplantation colleagues at the U-M extend their efforts well beyond the clinical setting to lead-



ership positions in professional societies and public institutions. For example, Merion and Punch both have served as president of Gift of Life Michigan, the federally recognized organ procurement organization for virtually all of the state, and Leichtman has been its treasurer.

Leichtman is also the medical director of the U-M Kidney Paired Donation Transplant Program, the largest such center in the country and one with a uniquely designed mission. "We set out with two specific goals to differentiate ourselves from other programs," he says, "to find organs for the most difficult to transplant patients, and to make sure that type O donors are preserved for type O recipients. We're also unique in that we run our list to look for matches every week, whereas the other systems run theirs every two or three months."

The U-M program is one of 83 in the country that comprise the Alliance for Paired Donation, which has 120-140

people active on its match list at any given time. U-M accounts for about 100 of them. “We’re really good at organizing care and really committed to finding organs for hard-to-transplant people,” Leichtman says. “We did 15 transplants in the last 15 months that wouldn’t have been done otherwise.”

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he U-M is the mecca of transplantation data. It’s currently deeply involved in two massive national studies of living organ donors: as the data coordinating center for the Adult to Adult Living Donor Liver Transplantation Study, and as the home of the Renal and Lung Living Donors Evaluation Study, a joint project of the Medical School and the School of Public Health.

But first and foremost is the NOTA-mandated Scientific Registry of Transplant Recipients, located in Ann Arbor since its inception. Administered jointly by the U-M and the Arbor Research Collaborative for Health (which Merion also serves as president), it tracks every aspect of transplant activity from organ donation and

waiting list candidates to transplant recipients and survival statistics.

“It’s the only thing like it in history, where everyone in a particular area with a particular disease is followed in detail for life,” says Punch. “You can look up the percentage of chil-

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dren ages 2-10 they transplanted in North Dakota last year. Transplants make baseball statisticians look like amateurs.”

And while baseball fans argue about their statistics, transplant doctors actually do something with theirs.

“I realized,” says Leichtman, “that if we didn’t change the donor pool at all, and only changed the way we allocate organs, we could generate in each decade of allocation significantly more than 100,000 additional years of life than the current system will allow. That’s why I’ve been working since 2003 to try to improve the way organs are allocated in the U.S. by matching the potential longevity of the organ with the potential longevity of the recipient.

“That’s what I muse about: saving more years of life,” he adds. “That’s what the Kidney Paired Donation Program does, that’s what better medications do, that’s what better post-transplant and pre-transplant care do.”

Better management of waiting lists would save even more years of life, in Leichtman’s view. “Many people of all disciplines view waiting in line as fair,” he says, “even though waiting in line is not fair because sicker people and older people who have limited potential often don’t live long enough to receive organs or are too ill for transplant when the opportunity comes to them. It would only be fair if everyone in line had the same potential to survive, which they don’t. It’s not the grocery store. It has a superficial fairness to it but the social costs are horrific.”

When it comes to the financial costs of kidney disease, which are also pretty horrific, transplantation is an easy winner. It costs about \$10,000 a year for the medications needed to suppress the immune system of a stable post-transplant



Alan Leichtman

patient, compared to \$70,000 annually for dialysis. Moreover, a study led by Akinlolu Ojo, M.D., the Florence E. Bingham Research Professor of Nephrology and professor of internal medicine, showed that life expectancy after a kidney transplant is doubled compared to being on dialysis, creating a veritable trifecta of lower cost, a dramatically improved lifestyle, and more years in which to enjoy it.

“A high-efficiency furnace takes 15 years to pay for itself,” says Merion. “A kidney transplant takes two, so from the federal government’s standpoint, transplantation is not only the best medical option for patients with kidney failure but far and away the most cost-effective. Both arrows point in the same direction, and you don’t often see that in medicine.”

The federal government can’t quite seem to see one of those arrows at all. Medicare’s reimbursement for immunosuppressants expires three years after surgery.

“The government will happily pay \$70,000 a year to put you back on dialysis rather than \$10,000 per year for medications,” says Merion. “There’s nothing worse than hearing patients reluctantly confess that they’ve been paying the rent or putting food on the table rather than paying for their immunosuppression pills.”

The transplant community has been fighting that legislative battle even longer than it campaigned for the “valuable consideration” amendment, without success.

“We’ve been trying for 10 years,” says Merion. “Every year we get close. But when the Congressional Budget Office scores it as costing money because it doesn’t count savings on persons spared a return to dialysis, they say you have to find something else to cut under pay-as-you-go. And if it’s counted as saving money, there’s a fight over what other programs to spend it on. The amendment was almost in the health care reform bill, but it got tossed at the last minute.”

Someday, perhaps, the specialty’s legislative triumphs will rival its clinical ones, which enhance the lives of the doctors as well as their patients.

“I think I have the best damn job in the world,” says Leichtman, “because patients that receive kidney transplants do really well for a really, really long time. Most of the patients that I inherited when I came here in 1989 are still with me. And patients that are very ill tend to be on their best behavior. They’re honest, don’t whine, and endure hardships and challenges that would knock most of us off our feet with dignity and humor and intelligence. I get to see people at their best.”

That includes donors. “I’ve been doing this for over 25 years,” says Merion, “and I can count on the fingers of one hand the



Jeffrey Punch

number of donors who have shown up for their evaluation appointment and changed their mind, even though I tell them I am the only surgeon who will ever say to you, ‘Let’s do a completely unnecessary operation on you that cannot improve your health and can only potentially do you harm.’ Donors that are ruled out on the basis of our evaluation are the most disappointed patients that you’ll ever find.”



Jeffrey Punch recalls a scene from the movie “Star Trek IV: The Voyage Home.” The Enterprise has traveled back to present-day earth, where Dr. McCoy encounters a patient who tells him she is on dialysis. He mutters something about being in the dark ages, gives her a pill from his fanny pack, and she grows a new kidney.

“Someone once said that medicine is the only industry that seeks to eliminate itself,” Punch says. “Transplantation is a miracle, but we all hope that someday it will not be needed.” [M]