Experts Recommend Single Registry to Oversee Kidney Transplant Donations

By KEVIN SACK

HERNDON, Va. — Leaders in the field of kidney transplantation recommended last week that a single nationwide registry should oversee the complex matching process needed to expand the use of transplant chains and other forms of paired donation.

But after a two-day conference that ended here on Friday, there was little consensus on how, when, or even whether the fragmented young field should unify.

Kidney paired donation, which was first attempted in the United States in 2000, makes transplants possible for renal patients who have a willing donor but who do not match that donor’s blood type or antibodies. Instead of giving a kidney directly to a loved one, the donor essentially swaps an organ with a stranger who also has a willing but incompatible donor.

In another iteration, called a domino chain, a good Samaritan donor gives to a stranger, whose paired donor then gives to another stranger, and so on.

In December, the National Kidney Registry, one of the several nonprofit groups that arrange such swaps, completed a record chain of 30 successful transplants, performed over four months at 17 hospitals.

Nephrologists and transplant experts are hopeful that paired donation might chip away at the waiting list for kidneys from deceased donors, which on Friday stood at 91,681. But of 16,812 kidney transplants in 2011, only 429 were through paired exchanges with living donors.

Researchers believe that several thousand transplants might be possible if paired donation were better understood, if more hospitals participated, if practices for evaluating donors and allocating kidneys were standardized and if all pairs of recipients and donors were listed in a single registry.

The current system includes several national and regional registries that are largely unregulated, as well as a pilot program sponsored by the federal government. Some hospitals also make substantial numbers of matches among their own patients.

The conference, attended by about 70 people, was organized by several medical societies to seek consensus on ways to increase the number of transplants made possible by paired donation and address ethical issues.

One committee, which was charged with examining how kidneys are allocated through paired donation, advised that a single national pool would increase opportunities to make matches among incompatible pairs and to find kidneys for patients who are the hardest to match.

“We should eliminate the barriers to a national registry,” said one of the committee’s leaders, Sommer Gentry, a mathematician at the Naval Academy who studies organ-matching algorithms. “With two pools of 100, you get fewer opportunities than with one pool of 200.”

The committee also concluded that listing pairs of donors and recipients in multiple registries could be counterproductive. Registries with the resources to make the most frequent computer match runs would end up with the best candidates, and others might waste time constructing chains with pairs they later discover are no longer available.

“It causes cherry-picking that undermines optimization,” Dr. Gentry said. “It kind of creates this race to the bottom.”
But Dr. Gentry’s mathematical observations do not take into account the politics of kidney transplants, where competing registries are invested in their own methods and successes and see little advantage in unification.

Garet Hil, the founder of the National Kidney Registry, which has arranged more transplants than any other group, said he did not agree that there needed to be a single system.

“So long as all the transplant centers enter all the pairs into the systems out there, you’re not disadvantaging patients and you are engendering competition,” said Mr. Hil, whose registry is based on Long Island. “I don’t see the need to try to reinvent the wheel.”

Even the conference’s lead organizer, Dr. Sandy Feng, a transplant surgeon at the University of California, San Francisco, worried that unification might stifle the innovation of successful registries like Mr. Hil’s.

“Maybe we can have different operations with common allocation methods and principles,” she said after the conference. “A national registry may be where we need to be when the field is more mature, but maybe we don’t need to do that right now.”

A number of people at the conference said the federal government should oversee a unified system for living donor exchanges in the way that it currently manages the deceased donor waiting list. The Department of Health and Human Services has long contracted that task to a single nonprofit group, the United Network for Organ Sharing.

Dr. Gentry’s committee recommended that biological traits and medical need should take precedence in determining which transplant candidates are first in line for paired exchange matches. Priority should be given to the patients who are hardest to match, to children and to those who have been waiting for long periods, the committee said.

It cautioned against building long chains because they bear a greater risk of falling apart.

Those attending the conference, including representatives of several major health insurers, agreed that it was important to establish a single reimbursement rate for paired exchanges. The rate must take into account the staff time and technology resources needed to make matches and to arrange the logistics of moving organs across the country. Insurers should compensate living kidney donors for travel and lodging costs, the group said.