

Grassroots "networks" succeed in recruiting kidney donors, Hopkins program shows

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Johns Hopkins researchers say a program they developed that uses personal advocates and community networks to find organ donors for friends and loved ones who need kidney transplants resulted in success for nearly half of the participants in its trial run.

Previous research had shown that 25 percent of people surveyed would be willing to donate a kidney if they personally knew someone who might die without one. But studies also found that [transplant candidates](#) are reluctant to talk publicly about their illnesses and the hardships associated with the [kidney dialysis](#) that keeps them alive as they wait from three to 10 years for an organ.

To address the disconnect, the Johns Hopkins researchers created a program that has transplant candidates designate an advocate, someone besides themselves to tell members of their family, office or place of worship about their plight and to spread the word about becoming a living kidney donor.

The 15 transplant candidates in the researchers' initial study all chose a "Live Donor Champion," usually a friend or a relative, who shared each patient's story. Of the 15 who participated, four have already received a kidney this way, and three more have identified promising donors who are undergoing [medical evaluation](#) in order to donate. Meanwhile, the transplant team says it has fielded "serious inquiries" from 25 people interested in donating and who said they learned about the option directly or indirectly from one of the champions. Details of the study

are published online in the journal Transplantation.

"Before this effort, there was no live donor in sight for these patients. Being part of this program made it happen," says study leader Dorry L. Segev, M.D., Ph.D., an associate professor of surgery at the Johns Hopkins University School of Medicine. "Approaching and recruiting live donors is a daunting and overwhelming experience for a transplant candidate, and this program takes away that burden from the patients."

Segev's team matched each of the 15 patients who chose a champion with 15 patients without champions. All 30 were also on a waiting list for a kidney from a deceased donor.

"None of the 15 without an advocate got live donors and we got no phone calls from people asking to donate on their behalf," he says.

"If this result turns out to be generalizable, I would estimate that thousands of people could find donors in their own networks, among people who would be willing to donate if only they were aware that they knew someone with kidney failure."

Most of the champions were the patients' spouses (67 percent), while the others were family members (20 percent) or friends (13 percent).

The Johns Hopkins team provided six months of training to the champions, giving them information on kidney failure and live donation, teaching them how to dispel myths about the process and offering different techniques for starting the conversation about their loved one's need. For the next nine months, the champions distributed business cards to potential doors, spoke at churches, started websites, reached out to local media or found other means of both drawing attention to the patient's need and inspiring as many potential donors as possible.

"Hundreds of people a year donate their kidneys to strangers, so there is clearly a desire out there among people who are healthy to help people who are not as lucky," says Segev, a transplant surgeon and director of clinical research in Johns Hopkins' Division of Transplant Surgery.

"There are probably a lot more people who would be willing to donate to someone they know. It's just a matter of getting word to them that someone they know is sick and needs their help."

Not only were the champions successful in finding willing [organ donors](#), but they also became much more comfortable over the course of the study period with approaching friends, neighbors and even strangers to discuss their family member's or friend's need for a kidney.

Says Jacqueline M. Garonzik-Wang, M.D., Ph.D., who conducted the training sessions: "Nobody wants to stand up at work or at church or at the family reunion and say, 'I want your kidney.' It's much easier for someone else to say, 'Uncle Joe is on dialysis three times a week and it is very hard for him, and we're trying to find him a new kidney.'"

The success rate of the pilot program could have something to do with the fact that those who participated all volunteered, Segev says. In July, Johns Hopkins will begin a large, randomized trial of the champion program to test whether this concept would work for all types of transplant candidates, which researchers hope could potentially result in hundreds of transplants.

There are more than 90,000 people on the [kidney transplant](#) waiting list in the United States, and many die before a donor is found. With a live kidney donor -- people can safely live a normal life span with just one healthy kidney -- transplants can occur much more quickly, sometimes within weeks or months. Studies show that a [kidney](#) from a live donor lasts twice as long, on average, as one from a deceased donor.

Over the course of the pilot study, four of the participants with champions and five of those who did not have champions received kidneys from deceased donors.

More information: livedonorchampion.com/

Provided by Johns Hopkins University

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