

Putting 'Care' in Health Care

'Donor WIn' program follows living donors — for life

BY ELLEN BROWN

An innovative new program at Cleveland Clinic — designed to monitor and foster wellness in living kidney donors — is receiving rave reviews from patients. The Donor WIn (short for Donor Wellness Initiative) program was launched in November 2009 and is currently monitoring the health of about 100 living kidney donors.

Titte Srinivas, M.D., a Cleveland Clinic transplant nephrologist, started the program, which begins when patients are first evaluated as potential donors and then provides them with support, testing, counseling and care for the rest of their lives, if they so choose.

REGULAR CHECK-UPS, COUNSELING

The program includes scheduled follow-up appointments for the living donors at three, six and 12 months after surgery, and then annually thereafter. In the future, Dr. Srinivas hopes to offer patients in the program an even more comprehensive wellness program and potentially expand to include living liver donors.

During their follow-up appointments at Cleveland Clinic, donors receive a complete physical exam, as well as extensive lab testing, blood pressure monitoring (including ambulatory blood pressure monitoring) and other cardiovascular physiologic testing that measures their vascular health.

Donors are also counseled by their nephrologists on how to maintain the health of their remaining kidney and stay well, in general, through diet and exercise. Their physicians, who are specially trained to understand the risks and needs of living donors, also counsel patients on how to deal with any health-related issues that may arise.

BEYOND THE BASICS

Since UNOS began mandating transplant centers to obtain follow-up information on living donors (such as kidney function, blood pressure and survivorship), some institutions have chosen to obtain the bare minimum data and submit it to UNOS, while others have launched programs that actually monitor the health of living donors.

But Donor WIn is different from most programs, Dr. Srinivas explained. For one thing, the program is more comprehensive than others, offering living donors support, education and testing throughout their lives. It doesn't restrict follow-up to the required two years.

Cleveland Clinic's transplant center chose to offer living donors a comprehensive program because it wanted to reward and honor those people who are, essentially, saving and improving the lives of people with end-stage renal disease.



"If it were not for their gift of life," Dr. Srinivas said, "a lot of transplants would not happen."

Donor WIn is also unique in that it focuses on maintaining the wellness of patients throughout their lifetime, instead of treating donors as though they have a disease.

"Living donors start out as healthy people, and our goal is to make sure they maintain their health for life," Dr. Srinivas said. "If we notice someone's weight is creeping up or we find an abnormality in their lipids," he added, "it allows us to address those things early rather than letting things slip by for years."

APPRECIATIVE LIVING DONORS

While living donors are welcome to visit their primary-care doctors for their follow-up and lab work, many of them are choosing to participate in the program even if they live out of town.

"I think what really makes donors happy is that fact that somebody really cares," Dr. Srinivas said. "Sometimes they feel like all the emphasis is on the recipient and that they get left out.

"But through this program," he said, "we are able to show them that we really do care."

Nan Robison, who donated her kidney to her husband, Don, in 2008, has heard the message loud and clear.

"At Cleveland Clinic, they gave me the royal treatment. It's good public relations, of course, but it also makes good sense in terms of health care," Robison said. She travels to her follow-up appointments from her home in North Canton.

"I love this program because once you've donated, it's not just 'Oh you've given a kidney, goodbye.' You still feel special because they're taking good care of you." Robison also has a certain peace of mind, knowing she is being followed by experts who treat living donors and understand the nuances of their health.

That understanding came in handy during one of her visits, when her creatinine levels were elevated. She told the nurse that she was surprised, since she was feeling well and was exercising



Living kidney donor Elaine Damo, who lives in Columbus, travels to the Cleveland Clinic for her follow-up care as part of the clinic's Donor WIn program. She said the comprehensive care she receives is more than worth the drive. In photo with her is Titte Srinivas, M.D., transplant nephrologist, who started the program. Photo/The Cleveland Clinic Center for Medical Art and Photography © 2011.

regularly, as instructed by her doctor. The nurse asked if she was drinking enough water to compensate for fluid she may be losing through exercise.

Robison, who admits that she probably wasn't, said that if she had gone to her primary-care physician for follow-up care, the staff there may not have made that connection.

A MORE THOROUGH APPROACH

Donor WIn participant Elaine Damo also appreciates the thorough care. Damo, who donated a kidney to her cousin in 2010, explained that she could stay in Columbus and receive the minimum follow-up care from her primary-care physician, "but by traveling to Cleveland Clinic, I receive so much more."

Staff perform more extensive blood pressure testing and even sent her home with a 24-hour blood pressure monitor that records her vitals when she's active, at rest and asleep. They also run a special test to measure her mean arterial blood pressure.

"I just feel like it's a more thorough look at my health," she said, "and I walk away from the appointments feeling like my health is just as important to my doctor as the recipient's health," she said. Damo has appreciated the support she's received throughout, even in the beginning when she was being evaluated as a potential donor.

"The donor coordinators did an excellent job of answering all my questions and getting me through the process of the testing and arranging the surgery.

"I also appreciate," she said, "that there's a lot of face-to-face contact with health-care professionals throughout the program."

Ellen Brown is a freelance writer, based in Cleveland, who specializes in health and wellness.

Open Forum Held on Patient Safety

Focus was on preventing infectious-disease transmission from living donors

On July 28, UNOS co-sponsored a daylong consensus conference in Baltimore — held as an open forum — to discuss ways to help prevent infectious-disease transmission from living donors to recipients. Other co-sponsors included the American Society of Transplantation, the American Society of Transplant Surgeons and NATCO—The Organization for Transplant Professionals.

The objective of the conference was to determine the optimal strategy for evaluating living donors to prevent transmission of infectious diseases to their recipients, focusing on HIV and the hepatitis B and C viruses. In the weeks before the conference, four working groups met to draft recommendations on the following key issues (chair's name in parentheses):

- **defining the risk groups** (Dorry Segev, M.D., Ph.D., Johns Hopkins Medicine, Baltimore)
- **optimal testing strategies** (Michael G. Ison, M.D., M.S., Northwestern University, Chicago)
- **developing a uniform consent** (Emily Blumberg, M.D., University of Pennsylvania, Philadelphia)
- **strategies for implementation** (Timothy L. Pruett, M.D., University of Minnesota Medical Center, Minneapolis).

The working group chairs presented their recommendations to the participants — surgeons, transplant physicians, transplant coordinators, infectious disease physicians and others from the transplant community, including a living donor and a living donor recipient. Also sending representatives were the Food and Drug Administration, Centers for Disease Control and Prevention, Department of Health and Human Services as well as the Association of Organ Procurement Organizations and the Canadian Society of Transplantation.

Participants discussed the presentations, as well as recommendations applicable for paired exchange and living donor chains, and then voted on potential recommendations for the living donor guidance or policy.

As of this writing, the working group chairs are developing a manuscript of the consensus conference findings with plans to submit it for publication in the *American Journal of Transplantation*. [U](#)