

# A Critical Link

*Follow-up data on living donors helps assure present and future safety*

BY KAREN SOKOHL

**O**PTN policy requires that transplant centers submit follow-up forms on all living donors after transplant at six months, one year and two years. Those requirements don't specifically state, however, that the forms must be filled out completely and—unfortunately—often they're not.

These forms, though, deserve respect—they represent a healthy person who volunteered for elective surgery to help someone else.

Having comprehensive and accurate follow-up data on living donors is a critical part of ensuring their safety as well the safety of living donors to follow. We can't just assume that everything's OK if we don't know the facts.

That said, last year the OPTN/UNOS board of directors directed the living donor committee to develop a resource to help centers fill out their forms more completely.

"We decided to talk with programs with excellent donor follow-up and find out not only what worked well but also what hadn't worked so well," said Mary Amanda Dew, Ph.D., professor of psychiatry, psychology, epidemiology and biostatistics at the University of Pittsburgh and a member of the committee. Dr. Dew led the living donor follow-up workgroup.

In November, the workgroup began interviews of eight transplant centers that demonstrated a commitment to their living donors by submitting accurate and complete follow-up forms. The workgroup then analyzed the centers' responses and drafted a useful "best practices" resource.

"We hope that, after reading what works for some centers, staff at other centers will look at the follow-up forms in a new way.

Three of the centers who contributed to the resource share some of their effective strategies below.

## EMPHASIZING FOLLOW-UP FROM THE BEGINNING

Three years ago, the living donation transplant program at the University of Virginia in Charlottesville changed its process for submitting required living donor follow-up forms. Information had been submitted by a data collection coordinator, who based the information on chart reviews. Later, the form was made the direct responsibility of the living donation clinical transplant coordinator, Anita Sites, RN, B.S.N., CCTC.

"I think it should be a clinician who is responsible for collecting the follow-up information and submitting the form," Sites said. "As the living donor coordinator, I'm the one who

regularly interacts with the patients. I'm the first person they speak with when they inquire about being a donor, and I'm the one who continues to follow them for the next two years.

"If the donors know me," Sites continued, "they are much more likely to return my call or respond to my letter than to someone they've never heard of before."

Sites receives roughly 450 calls a year from potential kidney and liver donors, and she emphasizes to all of them that follow-up medical appointments are critical.

"I stress from the beginning that, if they end up being a living donor, we are going to continue to follow them for a minimum of two years," she added. "It's a commitment we make to them, and one that they need to make to us."

Site supplements her verbal emphasis on follow-up with written materials, including what U.Va. calls an "agreement of understanding."

"Our potential donors hear about follow-up repeatedly from the very first interaction—on the phone, at their evaluation, from their surgeon and at their postoperative visit."

"Often the recipient's insurance will pay for the donor's six-month follow-up tests. If necessary, U.Va. will pay for the donor's follow-up testing, but we cover costs for the one- and two-year follow-up. I also do whatever I can to make it easier. I'll fax test orders to a lab of their choice. I'll call their primary care physician—whatever it takes."

Sites emphasizes the need for organization.

"I usually pick one day a week to print out my required living donor forms list from TIEDI," she said. Then she enters the deadlines in her Outlook calendar and makes her calls accordingly.

"It's actually enjoyable," Sites said, "because I get to communicate with the patients, and they look forward to hearing from me. I just have to plan.

"This isn't just about crossing your t's and dotting your i's," she said. "The transplant community realizes that donor follow-up is critically important, and we need to submit accurate data to benefit living donors and the transplant community at large."

## COMMITTED TO DONOR FOLLOW-UP FROM THE TOP DOWN

In a typical year, Lahey Medical Center in Burlington, Mass., will perform about 100 living donor liver and kidney transplants. The staff on the living donor teams are committed to excellent and consistent follow-up.

Like U.Va., Lahey emphasizes follow-up from the donor's evaluation to post-op and beyond. They spell everything out in a PowerPoint presentation that every potential living donor sees at the very beginning.

"We have to be realistic," said living donor nurse coordinator Denise Morin, RN, M.S.N. "You have to be flexible for donors who come from a distance." You also may need get follow-up information by phone or by e-mail, she said, and have their testing performed at a local lab.

Morin added that follow-up appointments can be turned into a kind of celebration if the donor's and the recipient's appointments are made for the same time. Sometimes, the donor and recipient that aren't that well connected. Often, though, there is a connection, Morin said, "so use it to your advantage."

Critical to Lahey's success is the global philosophy regarding follow-up shared by the kidney and liver programs as well as buy-in from the top down. Lahey's administration is committed to hearing from its donors every year.

"We have our own internal donor survey," Morin said. On that form, she added, we ask about their job, their weight and blood pressure, new medications or health issues. We also ask if they've had any health challenges they didn't expect.

"We just want to know how they are," Morin emphasized. The information is critical, she added, because we're looking at "the longer-term outcomes for donors, the consequences, for example, of living with one kidney." If there are long-term issues, she said, we need to know so we can change what we're doing now.

"We need to modify our practice to make sure that living donation is ultimately as safe as it can be," Morin said.

#### **'WE'RE RESPONSIBLE FOR TRACKING THEIR SAFETY'**


"I'm fortunate to have a group of people on my staff that value donor follow-up," said transplant administrator Kelli Jantz, RN, at Presbyterian St. Luke's Medical Center in Denver. "Making sure that donors are taken care of, and that we have their complete and accurate follow-up data, is important to all of us."


At the center of their collective dedication to donor follow-up is a letter created by Presbyterian's living donor advocate. The letter is sent to the donor's primary care physician, along with the donor's test results and information about hospitalization and discharge. At the same time, the donor is given a complete outline of his/her required follow-up responsibilities.

"We make sure our patients are educated regarding the importance of follow-up, have a personal physician and the information they need to get that follow-up," Jantz said.

"Sometimes my clinical coordinator has to make multiple phone calls to track down the donor," she admitted. "It can be quite an investigative process. Sometimes we call the recipient because the donor and recipient often stay in touch. We just don't let it go...It's a group effort!"

"Follow-up is always a challenge," Jantz said, "and the busier we get, the more of a challenge follow-up becomes. But these donors have done an amazing thing, and we're the ones responsible for tracking their safety.

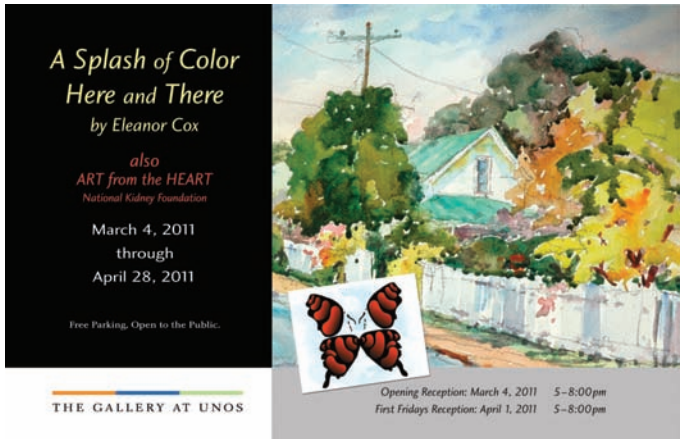
"It's more than just meeting a requirement to us," Jantz emphasized. "We're committed to the safety of the donor." 

 The best-practices resource is available on the OPTN website <http://optn.transplant.hrsa.gov> (resources > professional resources). A policy proposal (7) on living donor reporting practices is open for public comment until June 10. See page 5 or visit <http://optn.transplant.hrsa.gov> (policy management > public comment).

The transplant centers that participated in the interviews are listed on the communication archive, <http://communication.unos.org> (resources and training materials).

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### A SPLASH OF COLOR

The Gallery at UNOS launched its latest exhibit, "A Splash of Color Here and There" at the March 4 "First Friday" art walk, held across various locations in downtown Richmond. Artist Eleanor Cox's watercolors are on display, which focus on landscapes in Virginia and in Italy.

The exhibit also included the first showing of the National Kidney Foundation's (NKF's) 60th anniversary collection of artwork by 15 kidney patients. In addition to recognizing the NKF's six decades, the exhibit is a tribute to kidney patients, transplant recipients and donors.