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Successful follow-up of living organ donors: strategies to make it happen

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Living organ donation is a mainstay of transplantation in the United States. Donors provide an incomparable gift, and the protection of living donors' well-being is among the foremost priorities in transplantation. In particular, follow-up information on living organ donors' health status is crucial for understanding the risks and consequences of donation. We in the transplant community have much more than an academic interest in obtaining such follow-up data: the general public and the media seek current data on the safety of living donation, and prospective donors justifiably request such information. Without accurate and complete follow-up data, it is not possible to answer questions about safety, risks, and any health impact of donation. In short, without such data, we cannot ensure that we are doing all that we can to protect living donors from harm and fully inform them about donation.

Unfortunately, despite modest improvements in recent years, rates of national follow-up data collection from our living donors remain poor—too poor to allow meaningful analysis of any trends in donors' health status. Currently, the Organ Procurement and Transplantation Network (OPTN) requires that transplant programs in the United States submit living donor follow-up (LDF) information forms on donors at hospital discharge (or 6 weeks after donation, whichever is earlier) and 6 months, 1 year, and 2 years after donation. Compliance with reporting requirements is very high: almost 100% of forms are submitted by transplant programs. However, the forms are often submitted with missing or incomplete data. Living

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donors may be reported as permanently lost to follow-up, or transplant centers may have obtained only partial information on their donors. In addition, they may report information that was not collected in a timely way, that is, the information was collected either many months before or after the specific time point to be addressed by the LDF form.

As illustrations of the extent of these problems, consider some recent OPTN data on the rates of complete and timely information reported on 1-year postdonation LDF forms for 2 characteristics: (1) donor status (alive or deceased) and (2) a key donor laboratory value (numerical serum level of creatinine for kidney donors and bilirubin level for liver donors).¹ Among individuals who donated from July 1, 2008, through June 30, 2009, only 63.5% of living kidney donors and 66.8% of living liver donors had 1-year LDF forms submitted by their transplant centers with a known status (either alive or deceased) dated within 2 months before or 2 months after their 1-year anniversary. Even fewer—38.2% and 50.0% of kidney and liver donors' LDF forms, respectively—had laboratory values. These percentages are aggregated across all transplant programs (ie, they are percentages of the entire living donor population in 2008-2009 for whom this information was reported).

It is also noteworthy that transplant programs differ dramatically in their rates of complete and timely data reporting, with some programs providing such data on 100% of their donors, and others failing to provide complete and timely data on any of their donors. The median rate of reporting complete information on donor status at 1-year follow-up for 2008 to 2009 donors is 71.4% for kidney transplant programs and 66.7% for liver transplant programs. The median across programs for reporting complete laboratory values is 42.9% for kidney and 40.0% for liver programs. Interestingly, little to no relationship exists between the number of transplants performed at a center and the center's rate of reporting complete data.

For the past several years, the United Network for Organ Sharing (UNOS) has been working with transplant programs to facilitate improved donor follow-up. For example, since 2009, OPTN/UNOS has provided annual summary information to each transplant program on the program's own rates of follow-up, and programs have been encouraged to request more details on their performance in order to identify potential areas of improvement. In addition, to ensure that donors will expect to be contacted for follow-up, OPTN bylaws approved in September 2007 state that living donors must be informed before donation that centers are required to submit LDF forms supplying donor health information to UNOS at multiple specific time points during the first 2 years after donation. Moreover, a new OPTN policy proposal currently open for public comment, if adopted by the OPTN board of directors, will require that transplant programs report complete and timely donor status (alive or deceased) for at least 90% of their living donors at each of the required reporting time points. It is likely that additional policy proposals will be developed in the future that specify levels of completeness for other items requested on the LDF forms.

How will transplant programs achieve increasingly stringent standards for donor follow-up reporting, given the generally poor rates of such follow-up to date? Or are programs being expected to do the impossible? Anecdotally, the requirement to provide LDF data has been described as an "unfunded mandate." We have heard more than once and in both formal and informal discussions that "donors do not want follow-up," that follow-up cannot reasonably

be accomplished because transplant programs are not reimbursed for any care provided, and that donors prefer care from their own local physician rather than their transplant program. Yet, if these factors—individually or in combination—universally precluded the collection of complete and timely follow-up data, why are some programs (both large and small) in fact able to achieve 90% to 100% follow-up with their donors? Clearly, some centers have identified methods to achieve successful follow-up with their donors despite the obstacles, demonstrating that this goal is not impossible.

On behalf of the OPTN/UNOS Living Donor Committee, a work group (chaired by M.A.D.) recently developed a guidance document that outlines a range of strategies for maintaining contact with and collecting follow-up data from living donors.² This document is now publicly available on the OPTN Web site (http://optn.transplant.hrsa.gov/ContentDocuments/Guidance_Post_Donation_Donor_Follow-Up.pdf). We believe that it will serve as a vital resource for programs seeking to develop and improve their procedures for following their donors. It contains more than 60 discrete recommendations for programs to consider. We realize that every program operates within the context of a specific institutional setting, and the guidance document does not represent an effort to specify clinical practice. Instead, we hope that it will serve as a springboard for discussion within individual transplant programs on how they might work to overcome any difficulties they face in following their living donors.

The approach we took to preparing the guidance document is, we believe, one of its greatest strengths. Namely, we decided against the typical “expert consensus” approach, in which leaders in the fields of transplantation or follow-up research might have been asked for their views on how best to achieve complete and timely donor follow-up data collection. Instead, we consulted directly with transplant programs that have the highest success rates in reporting complete and timely donor follow-up data. Our methods and approach are described fully in the guidance document itself but, in brief, we conducted qualitative interviews with 8 programs in order to learn in detail about all aspects of their follow-up activities. The programs’ staff members listed in the Table generously offered their time and insights, and their enthusiasm for following up on their living donors was evident. We talked with them about, for example, their specific procedures for donor follow-up, what strategies they found to be most and least effective for maintaining contact with donors, and what barriers they faced in following living donors.

Our work group’s decision to interview representatives from 8 programs (rather than fewer or more programs) was based on principles of qualitative methodology. Thus, we continued conducting interviews with additional programs until no new themes or major strategies emerged that had not been discussed in earlier interviews. We also interviewed UNOS transplant program auditors about their general observations (not specific to any single program) about factors contributing to transplant programs’ ability to maintain contact with donors and obtain donor follow-up.

Three categories of program activities emerged from our interviews. Although the specific strategies that the programs used for follow-up varied, high-performing programs each have developed core activities reflecting

1. the conviction that donor follow-up is essential for donors' safety and well-being,
2. the importance of building and maintaining a relationship with each donor, and
3. the use of a systematic approach to follow-up, with ongoing quality assurance activities.

Within each of these categories, the guidance document lists a wide variety of recommendations for improving donor follow-up, based on the strategies that the programs used for maintaining contact and collecting complete and accurate follow-up data. For example, recommendations for activities supporting a program “culture” that promotes donor follow-up in order to ensure donor safety and well-being include specific steps to consider when educating donors about postdonation health issues, steps for developing staff commitment to donor follow-up, strategies to minimize any burden of follow-up data collection on the living donor (including any cost burdens for medical care or laboratory work), and strategies to work effectively with donors' primary care physicians. Recommendations for relationship-building with donors include ideas for identifying transplant program members who will maintain connections with the donor both before and after donation, strategies for contacting donors and scheduling follow-up visits, and strategies to ensure that donor issues and concerns are addressed in a timely manner. Finally, recommendations for the use of a systematic, methodical approach to donor follow-up include activities for finding and recontacting donors, methods for tracking and generating reminders about donor follow-up data collection activities, the development of systems for recording data collected during donor follow-up care, and strategies for quality assurance and quality improvement activities.

No single program used all of the strategies included in the guidance document. However, it is noteworthy that no recommendation was included unless it was used by at least 1 program. We were struck by the great variety of strategies that programs used to build and maintain their follow-up practices. We were encouraged by the dedication of program members in monitoring their donor follow-up activities—not solely because they are required to complete LDF forms, but because of programs' commitment to ensuring their donors' long-term well-being. We hope that members of the transplant community will take a look at the new guidance document with the goal of generating their own ideas about ways to increase their programs' success at donor follow-up. Living donors deserve no less!

Acknowledgments

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Living donor transplant programs participating in interviews about donor follow-up practices at their centers

Table

Transplant program	Program members participating in interviews
<u>Living donor liver programs</u>	Denise Morin, RN, MSN
Lahey Clinic Medical Center, Burlington, MA	Anita Sites, RN, BSN, CCTC
University of Virginia Health Sciences Center, Charlottesville, VA	Barbara Groene, RN, BSN
<u>Living donor kidney programs</u>	Sharon White, RN, BSN, CCTC
The Christ Hospital, Cincinnati, OH	James Pittman, RN, BSN
Mayo Clinic, Jacksonville, FL	Laura Murdock, MHA, Robin Petersen-Webster, LPN, CCTC
North Austin Medical Center, Austin, TX	Kelli Jantz, RN, Marita Dougherty, MSW
Ohio State University Medical Center, Columbus, OH	Lauren Kearns, MSN, RN-BC, Ann Litts, RN, BSN, CCTC, Deborah Erickson, RN, BSN, MS, PhD
Presbyterian–St Luke’s Medical Center, Denver, CO	
University of North Carolina Hospitals, Chapel Hill, NC	