



# Considering Living Donation

Potential donors have many questions

*Editor's note: In the Nov.-Dec. Update (p. 26), you heard from kidney transplant candidate Kathe LeBeau, who told how receiving the transplant center's patient notification and UNOS' patient information letters has allowed her to "live with hope." In the Jan.-Feb. Update (p. 26), Isabel Stenzel Byrnes said the letters represented her "passport to life."*

*In the following article—the final in our three-part series—two living donors describe the difference information made in their donation journey. Although transplant centers aren't required to send a notification letter to potential living donors (many do), centers have been required since August 2008 to give potential living donors UNOS' patient services line phone number so that they will have access to current, accurate information on the donation process.*

*Last year, the patient services line received about 1,000 calls from individuals who identified themselves as living donors, living donor candidates or interested in living donation. In other words, information is critical for living donors who have made, or are making, that life-changing decision.*

## KEITH DIAZ

My name is Keith Diaz and I am a living donor from New Hampshire.

In 2002, my good friend, Bonnie, confided over coffee that she had been sick with kidney disease for a long time. She needed a kidney, and her relatives were not viable donors. I privately thought about her predicament, and a few days later told Bonnie that I would give it a shot.

The transplant coordinator at Bonnie's hospital guided me through the process of being a living donor. The work-up began only a month and half prior to the transplant surgery. Being a full-time law student and working 20 hours a week at a local law firm, I was easily distracted from the anxiety attendant to the potential risks of surgery and of living with only one kidney.

The medical testing was quick. I continued to struggle over the risks of donation, but was able to temper my anxiety through faith.

When I received the phone call telling me that I had been accepted as a donor, I found myself doubting the rationality of

my decision to donate. I recall that once I awoke in the middle of the night, wracked with intense fear, feeling empty and alone.

At that moment, I wanted out. But I began reacquainting myself on my faith in the decision to donate, and on Dec. 12, 2002, I went into surgery.

When I decided to give my kidney, though, I wish I had known there was a place to call for more information and to help answer my questions. I first heard about UNOS five years after my surgery.

In view of my experience, I believe that it is critically important for transplant centers to give potential living donors the number to the UNOS patient services line. [Editor's note: The policy went into effect in 2008, after Diaz' donation.] Having access to that information can help to orient and educate the potential living donor on the reality of donation.

Timely provision of the UNOS patient services line phone number is essential in giving potential donors the time they need to make an informed decision.

Keith F. Diaz, J.D., is an attorney at Bussiere & Bussiere, PA, in Manchester, N.H., and a member of the OPTN/UNOS patient affairs committee.





FAR LEFT: Keith Diaz on a walk in New Boston, N.H., with his three children (from left) Andrew, Ava and Greyson.

LEFT: Living kidney donor Kristie Lemmon with her son and recipient, Tyler, at a Seattle Seahawks game. Tyler's transplant was performed in 1994.

### KRISTIE LEMMON

My name is Kristie Lemmon, and I am from Alaska. I believe living donors need to know about UNOS and what UNOS can offer them.

I donated a kidney to my son Tyler in 1994 after an accident destroyed his kidneys. Right after the accident, a pediatric nephrologist explained to me that Tyler would need to go on dialysis or would need a transplant.

Tyler was placed on hemodialysis and then spent another six months on peritoneal dialysis. He did not tolerate dialysis well. It was hard as a mom to see my son hooked up to a machine for 14 hours each day.


He couldn't attend school, and there constantly were logistics to deal with when traveling. It was during that time that I first heard about UNOS.

When it became clear Tyler would need a transplant, I did a massive amount of research. I learned about what UNOS does and about the waiting list and living donation. I learned that, with a transplant, my son would be able to have a "normal" life! There was tremendous hope after all.


The nephrologist encouraged me to consider donating a kidney to Tyler. My biggest concern during my transplant work-up was that I wouldn't be able to donate. I was afraid that they'd find something wrong with me. I was afraid we couldn't find anyone else to donate if I wasn't a match.

The doctors did so many tests, all of which were stressful and scary to me. Waiting is never easy, especially when it involves a loved one—and it seemed like the process took forever. Fortunately, my work-up showed nothing abnormal.

When I was notified in a phone call that I could be Tyler's donor, I felt a huge sense of JOY and EXCITEMENT. I also felt a huge sense of relief. And, when I received the notification letter later—which I now call a "very treasured" letter—the impact of being able to donate to my son became even more real.

I now work in kidney education, and I strongly believe that all potential donors should know that UNOS offers education specifically for them. I now give the UNOS number all the time to help empower kidney patients and their families. 

Kristie Lemmon is program manager of KEEP [Kidney Early Evaluation Program] for the National Kidney Foundation Serving Alaska.

 The UNOS patient information letter is available for download and distribution at <http://optn.transplant.hrsa.gov> (resources > professional resources > patient information letter). If you missed UNOS' March 9 webinar on staying in compliance with patient notification, send an e-mail to [patientnotify@unos.org](mailto:patientnotify@unos.org) and request a link to a recording of the webinar.

### QUICK REFERENCE GUIDE AVAILABLE

The OPTN/UNOS transplant coordinators and transplant administrators committees have developed and made available a "patient notification quick reference guide."

The guide is a one-page summary (and checklist) of the requirements\* for notifying patients about their placement on, or removal from, the transplant waiting list and is intended to aid in compliance with those requirements.

Included are a list of situations that require centers to notify patients, a list of what the notification letters must include as well as a checklist to help centers make sure they're in compliance.

If you missed UNOS' webinar on staying in compliance with patient notification, you can access a recording of the session by sending an e-mail to [patientnotify@unos.org](mailto:patientnotify@unos.org) and requesting a link to a recording of the webinar.

\*OPTN Bylaws Section II: Transplant Hospitals, B.11.F; and Appendix B, Attachment I, XIII—Transplant Programs Patient Notification, Section 13.