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In Pursuit of a Living Kidney Transplant:

## It's About Your Donor Finding You!

Malifing the Most of Your Time & Energy

Washington Update: AAKP Responds to the CMS Proposed Dialysis Payment System

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#### In Pursuit of a Living Kidney Transplant;

# It's About Your Donor Finding You!

By Harvey Mysel

When someone in need of a kidney transplant is instructed to "find a living donor," one of their first thoughts is, "How am I going to ask someone to donate a kidney to me?"

In reality, most living donors say they volunteered to donate once they heard about their family member or friend's need. Health care professionals need to advise their patients: rather than "ask" someone to donate, just let them know about your situation. Although it's a subtle difference, it could have a significant impact on a patient's willingness and state of mind about pursuing living donation.

How do you start the quest to have the donor find you? It's very important to start by learning as much as you can about living kidney donation. The more you know, the more confident you'll be when discussing the subject and informing others. You will likely be the person to educate your donor about the process. Therefore the more accurate information you provide, the more you will dispel some of the myths and misconceptions surrounding living donation.

There are many resources you can seek to gain information about living kidney donation. Start with your transplant hospital and meet with the coordinator of their living donation program to learn how they can help you. For additional information about pursuing living kidney donation, visit the Living Kidney Donor Network Web site at www.lkdn.org.

Once armed with knowledge about living kidney donation, you'll then need to effectively communicate your need and the information

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you've learned. If you have initial unease discussing the subject, practice and rehearse what you want to say with someone who is willing to share your story with others, such as a family member or friend who can also become an advocate on your behalf. Advocates are often the ones to educate the person who ends up being your donor.

When letting others know about your need, speak from your heart, make it personal, and tell your story. You and your advocates need to be positive. Tell others how you envision your life improving after the transplant. And remember, you are not asking outright for anyone to donate.

Technology has changed the way we communicate. Some people use less personal

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channels such as the Internet to reach out and let others know about their need. A word of caution, some transplant hospitals are not receptive to these less personal outlets, so you should speak to your transplant hospital about their living donor policies. There's no substitute for "high touch" personal channels, "high tech" electronic channels come with risks and many people have been disappointed after months of email contact when communication stops, so pursue these cautiously.

"High touch" and personal channels abound. There are many success stories of donors coming from places of worship, schools, reunions or local media feature stories. The only limit in reaching out is your comfort level of letting others know about your need. There are myths and misconceptions about living donation that you may confront and need to dispel. One of the most common myths is that only a close relative can be a match and be able to donate. Medical advances have enabled a much easier matching process of donor and recipient. The need of a "perfect match" no longer exists. New anti-rejections drugs have allowed a much wider range of people to become donors.

For example, in 1998, 77 percent of the living kidney donors were from close blood relatives. By 2008, only 57 percent of the living kidney transplants came from close blood relatives and this trend should continue. Also important is the fact that medical procedures have advanced dramatically. Today, donor surgery often uses the minimally invasive laparoscopic procedure, or a minimal open approach, both of which allow many donors to return home within 1 to 3 days after surgery.

The emergence of paired kidney exchange programs has also had an impact in facilitating transplants between incompatible pairs. A paired kidney exchange occurs when two or more incompatible pairs of recipients and donors donate or swap between each other. More information on pair exchanged kidney donations can be found in the November issue of aakpRENALIFE located at www.aakp.org/aakp-library/Big-Swap. The laparoscopic procedure is still considered major surgery and as such, the surgical risk, emotional and psychological implications need to be taken into consideration. When properly screened, the surgical risks for the donor are not high, and trained social workers speak with the recipient and donor to make sure the donor is donating for the right reason and is not under any pressure to donate.

Letting people know about your need for a kidney transplant may at first seem overwhelming. However, once you get started it's often not as difficult as you might imagine. Develop a plan and start slowly. The more people you speak to, the easier it will get and the greater your chances will become of a donor finding you. Donors often come from the most unlikely connections, and as such, reach out to everyone you know. As a final word of encouragement, in the U.S. there are more than 16 successful living kidney transplants performed every day. Perhaps the next happy ending will be yours!

Harvey Mysel is a kidney transplant recipient and Founder of the Living Kidney Donors Network, a nonprofit 501(c)(3) organization that offers workshops to educate people in need of a kidney transplant about living kidney donation and helps prepare them to effectively communicate their need to family members and friends. The Living Kidney Donors Network Web site is: www.lkdn.org and Harvey could be reached at: harvey@lkdn.org

### Kidney Facts Types of Living Donation

- Living related donation: the living donor directs the donation to a specific recipient who is a blood relative (such as a parent, child, or sibling). Looking at United Network for Organ Sharing (UNOS) data for living kidney donations made since 1988, about 75 percent were living related donations.
- Living unrelated donation: the living donor directs the donation to a specific recipient who is not a blood relative (such as a spouse, a friend or coworker). About 24 percent of living kidney donations since 1988 were living unrelated donations.
- Living non-directed donation: the living donor does not direct the donation. Instead, the recipient is selected from a list of compatible people on a kidney waiting list. This form of donation is also sometimes called "anonymous" donation because the donor and recipient do not necessarily ever meet. Only about 1 percent of living kidney donations are of this type.