Are There Living Kidney Donor Registries?

By Harvey Mysel

I’ve often been asked: “Where can I register to get a living donor?” Unlike deceased donation where there’s one national list, (although you can multi-list because some areas have a shorter wait time) there’s no such list for someone looking for a living donor. You must find your own living donor. When you do have someone that is able to be a living donor, many are not compatible with their recipient. Thirty to 50 percent of donor/recipient pairs are not compatible with each other.

In such a situation the incompatible donor could still help the person in need by getting involved in a paired exchange. What this incompatible pair needs to know is that there are many paired exchange options. A paired exchange occurs, when two or more incompatible donor/recipient pairs swap their incompatible donors as is shown here. In this example there are two pairs, but there could be three, four or an unlimited number of pairs.

Paired exchanges have already increased the number of living kidney transplants by more than 1,000 a year, and since so many donors are not compatible with their recipient, this number is likely to continue to grow. To maximize your chances of being paired with another (or more than one) incompatible pair, you should be aware of all the paired exchange options. One of the barriers to increasing the number of paired exchanges is that a centralized national program of ALL incompatible pairs does not exist. The likelihood of being matched with another incompatible pair is increased when there is a large pool of incompatible pairs.

Here are the different types of paired exchange programs that have been developed:
1. If your transplant hospital has a paired exchange program, then they will try to match you with the other incompatible pairs that are registered at their hospital.
2. Some hospitals share some or all of their incompatible pairs with other local hospitals or ones in different parts of the US.
3. Hospitals have transplant centers in different markets, and they share their information within those hospitals.
4. There are three national paired exchange organizations—Alliance for Paired Donation, National Kidney Registry and the UNOS Paired Exchange Program. These organizations have developed a “co-op” type relationship with many transplant centers. These centers list their incompatible pairs with one or more “co-op.” To register with one of the paired exchange programs, an incompatible pair needs to register with one of their affiliates.
5. You can register with multiple centers for a paired exchange and with multiple “co-op” organizations. With private health insurance, you need to check to makes sure you are covered at other hospitals. Those with Medicare are covered at all transplant hospitals.

Here is the information about the 3 “co-op” type of organizations:

Alliance for Paired Donation
www.paireddonation.org

Alliance affiliated centers
www.paireddonation.org/transplant-center/
By Michael Ramirez

The worst day of my life became the best day of my life. “Your kidneys are failing,” my physician said to me. My first thought, “What does that mean?” My doctor confirmed, “You need to see a specialist.” I learned that a nephrologist is a kidney doctor, and that was the type of specialist I needed. I trusted my doctor so I asked, “Who should I see? Who do you trust?” My doctor referred me to his choice of nephrologist—and so I made an appointment right away.

If your doctor says you need to see a nephrologist, don’t wait months to make the appointment. Some people will research the different nephrologists in the area, look at patient reviews, look at the distance to their office and identify the types of treatment they do. And then make an appointment. That is a good way to do it too; just don’t wait too long.

During our first appointment, the nephrologist explained what could happen and that my kidney function was deteriorating. I asked questions so that I would understand clearly what he told me. Make sure you ask questions while you are at the appointment—it is much harder to call the office after you are back home to try to talk to your doctor. Barrering a miracle, I was told my kidneys would fail within a matter of time. That was hard to hear, and I had to force myself to listen closely. It is easy to zone out when given serious news and then to miss much of what was being said. Take someone with you to your appointment if you can or at least take notes. The nephrologist laid it on the line for me, and I took it to heart and knew I would follow his instructions! People forget a lot of what they hear, so always ask your doctor and health care team to give you written instructions.

I believe your health depends on establishing a trusting, respectful and knowledgeable relationship with your medical professionals. This includes your general practitioner, nephrologist, dietitian, social worker, behavioral health provider, nurses, technicians and the end-stage renal disease community. They assisted me in my next phase of well-being. It is important to accept and provide yourself the time to face the shock and disbelief that your life, as you knew it, is changing. You may be sad and angry at what you cannot do or what you need to change in your daily life. You will become a new person, and your old way of life will be over. You must change, you must adapt and you need to retrain yourself to have a good life—the quality life you deserve.

The result of your efforts will be that you are still ALIVE! And that, my fellow patient, says it all!

National Kidney Registry
www.kidneyregistry.org

NKR affiliated centers
www.kidneytransplantcenters.org

UNOS
www.transplantpro.org

UNOS affiliated centers

You should ask if your hospital is involved with one or more of the “co-op” programs. Some hospitals will keep the pairs that are easy to match and offer the more difficult pairs to their exchange member(s). This is not an efficient way of maximizing paired exchanges.

Here’s what you could do to maximize your chances of being matched with another incompatible pair:
1. Register with your original transplant center’s paired exchange program.
2. If your center is not affiliated with one of the “co-op” organizations, find transplant centers that are affiliated.
3. The National Kidney Registry is completing 70 percent of all paired exchanges. Since they are the major player, you should try to first get registered at a transplant center that is affiliated with National Kidney Registry, then look at other options. Registering with many transplant programs may not be easy, but it will increase the odds of being matched with another incompatible pair.

Harvey Mysel is a 2-time kidney transplant recipient and Founder of the Living Kidney Donors Network, a 501(c)3 non-profit organization that offers workshops, webcasts and private consultation educating people in need so they could be successful at finding a living donor.