

From the Committee Chair **Maggie Carey, Chair, Consumer Committee**

Welcome to another issue of *Common Concerns*. We are finishing up our series on treatment options by focusing this issue on kidney transplant. This is near and dear to my heart because I have had a transplant since 1992. There are two thoughts I need to express about this subject. The decision to go forward with a transplant is not always an easy one. I hesitated for over a year before I signed up. I was doing well on dialysis and didn't know if I wanted to rock the boat or not. My second thought is this: a transplant does not mean you are *cured* of chronic kidney disease. It is only a treatment option. In my case, it was the right option and the right decision. It has made my life much easier to live in the manner that I choose. I have much more freedom and flexibility in my schedule, but it does not come without certain risks and drawbacks. My advice to you if you are faced with this decision is to gather all of the information you can and talk to as many people as possible. Read these articles and see how their stories compare with your life. As I have said before: Knowledge is Power.

I would also like to remind you of the resources available through Network 11. They have released a new Disaster Preparedness brochure and it has been sent to all of the dialysis units. Check it out. We all know that disasters happen quickly, whether man-made or natural. As renal patients, we have some special needs that require special precautions. Also, don't forget to get your Stop Signs! These are still available either through your dialysis unit or the Network office. They would make a wonderful addition to your Disaster Kit.

Kidney Transplant

Barbara Danielson, RN, Transplant

Transplantation is the preferred treatment for many patients with chronic kidney disease (CKD) because it replaces the filtering and hormonal functions that have been lost and returns patients to a more normal life style. There are two basic types of kidney transplant—living donation and deceased donation. Transplant requires that a normal kidney with a matching blood type be transplanted into the lower abdomen of the recipient. The blood vessels of the kidney are attached to the receiving patient's blood vessels and then attached to the bladder.

Patients who receive a kidney transplant must take medications as prescribed to prevent the body from rejecting the kidney. These anti-rejection medications curb the immune system in order to prevent rejection. These

medications can cause side effects and other problems. In an effort to lower this risk, all patients who seek a kidney transplant must have a full medical evaluation to identify and treat any health problems prior to transplantation. Some patients are excellent transplant candidates because they have few or no other health problems, and others have multiple health problems that place them at high risk if transplanted. Each case is carefully considered, and the benefits and risks are discussed with the patient so the best decision regarding treatment can be made.

There are frequent follow-up visits early after transplant to help identify any complications as soon as possible. The earlier that problems are discovered, the more likely they can be resolved. The frequency of follow-up visits decreases over time, however taking daily anti-rejection medications is critical for as long as the transplanted kidney is functioning.

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There is a widening gap between people who need a kidney transplant and organs available for transplantation. Nationally, there are close to 85,000 people who are on the waiting list for a deceased donor kidney transplant. Nearly half of the patients transplanted receive a living donor kidney. Transplantation is very successful with the first-year success rates above 90%.

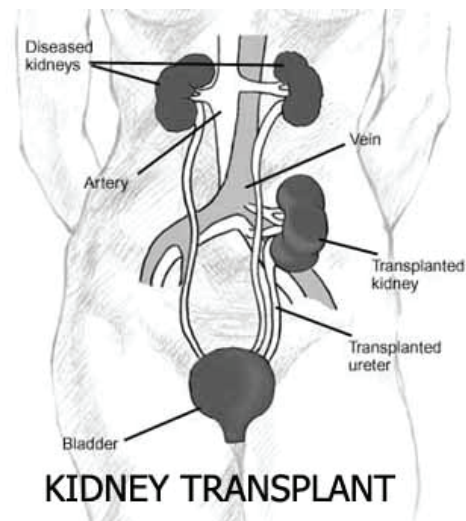
Living Donor Paired Exchange

Some of the transplant centers in the Upper Midwest have been working together to form a *paired exchange* cooperative in an attempt to provide more patients with transplants than would otherwise be possible. It is called the North Central Donor Exchange Cooperative (NCDEC). This allows non-matching living donors the potential to give a kidney to their loved one through an exchange program. Non-matching recipient and donor pairs can participate by allowing their information to be entered into a database that searches for another pair in the same situation that match. If a match is found among pairs, the exchange or "swap" of organs can take place with the collaboration of the transplant centers involved. Two transplants have taken place so far this year as a result of the NCDEC.

There are paired exchange initiatives taking place across the country similar to the NCDEC. The United Network for Organ Sharing (UNOS) will be conducting a national paired exchange pilot project in the near future, and the NCDEC will be participating in this pilot project with Johns Hopkins Hospital. The more pairs in an exchange program, the more likely matches can be found, thus, helping more people.

Occasionally a non-directed living donor will come forward. A non-directed living donor is a person who wishes to donate a kidney to anyone needing it. If this type of donor successfully completes a physical and psychological evaluation, and their information is entered into a paired exchange program, it is possible to have a chain response with multiple transplants occurring. Entering non-directed donors helps to optimize the gift, benefiting as many people as possible.

You can find more information on the NCDEC at www.ncdec.org



My Choice --Mitzi

I love my life after the kidney transplant. I am more mobile. I am able to do a lot more activities than when I was on dialysis. I was on both hemodialysis and peritoneal dialysis. While on dialysis, I was often sick and spent a lot of time in and out of the hospital. I had many physical problems while I was on dialysis, including skin problems and heart problems. It was difficult for me to get through each day.

After the transplant surgery, I had several complications that required additional surgeries, but after the surgeries, I began to feel better each day. I am able to do so much more than I was while on dialysis. I have had my transplant for almost 11 years and in spite of all I have been through, the transplant was worth it. At the end of the day, I am thankful for the transplant and a much healthier life.

My Choice --Ruth

When I went on hemodialysis, I was working full-time as an elementary school teacher in Milwaukee. It was very difficult to work all day and then go to dialysis after work. I would usually get home around 10:00 p.m., fall into bed and then get up the next day to go back to work feeling tired even before the day began. I really could not see myself doing this for a long period of time. I got seriously ill during the time I was on dialysis with pneumonia and that took a long time for me to recover. Fortunately for me, my sister turned out to be a great match and she was willing to be my donor. I had to wait for my sister to arrange for someone to take her

place at work for the time that she was going to be off of work after the surgery, and so I ended up being on dialysis for 22 months before my transplant.

I was told by the medical team all of the possible risks and side effects of the transplant anti-rejection drugs that I would need to take for the rest of my life. After much thought and prayer, I decided that the benefits out-weighed the risks. It has been more than 20 years since I had the transplant. Even though I have had to be hospitalized several times during that time for a variety of things, I still feel that my decision was a good one. I was able to teach for 35 years, get a Masters Degree, was able to travel abroad and live a productive life with my family and friends. I have also been able to serve on the Consumer Committee of Renal Network 11, and I learn more from other dialysis and transplant patients in our part of the country than I can give. I am very thankful that my transplant has lasted this long and am still convinced that it was the right decision for me. I encourage anyone to discuss this option with his/her medical team to see if it is possible to have a good life with a transplant. My best wishes and prayers go to everyone making this important decision.

My Choice --Christine

Someone once said to me, "We're all on the same journey, on the same bus. We're just in different seats."

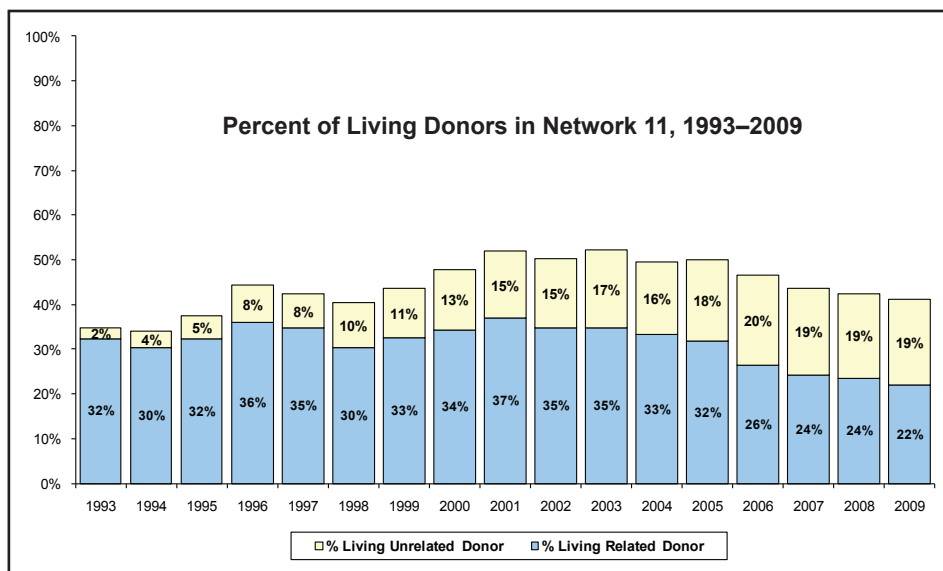
My name is Christine, and I was diagnosed with Type I Diabetes at the age of seven. I lived most of my life coping with this disease and the many complications that sometimes develop. I was very brittle. My blood sugar yo-yoed up and down, and it was extremely difficult for even the doctors to control. After 30 years, I developed kidney disease, and eventually I had to start dialysis. In spite of an overwhelming sense of sadness, loss and failure, I went on dialysis and learned new ways to take care of myself. I was on dialysis for a total of 18 months. When I began to explore the possibility of receiving a combined kidney/pancreas transplant, I realized this could open up new doors for me. I hoped that the new kidney would do all the things that my own kidneys were no longer able to do, and a new pancreas could mean normal blood sugars. For what would be the first time since I was a very little girl, I could finally be free of the need to take multiple insulin shots daily! I was very blessed, and after a relatively short time of being on the waiting list, my transplant occurred in 1988. I had

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Highest Number of Kidney Transplants in the Nation

Network 11's five states lead all other Network regions for number of transplants performed. In 2009, 1,621 kidney transplants were performed in Network 11 transplant centers. This chart shows an increasing trend in the percent of unrelated living donors such as paired donation and non-directed donation, as well as donation from friends and non-related family members.

(Source: Network 11 2009 Annual Report)



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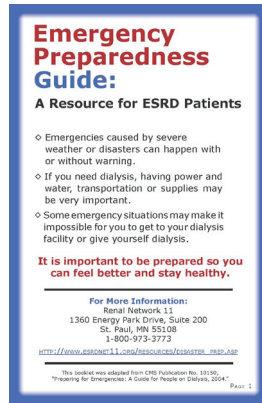
to work very hard to overcome extreme challenges and recover. That part of my journey was the most difficult thing that I've ever had to endure, but perhaps I appreciate my health all the more now because it was so hard won!

I now have hope for a future that includes a fairly normal life. Although the complications that existed prior to the transplant remain with me, I now have a sense of completeness that is beyond belief. While other recipients are just as grateful as I am, the difference for me is that I've had health problems almost all my life, so I feel new in a way that many others cannot possibly understand. It's like being well and whole for what seems to be the first time in my life!

Emergency Preparedness Brochure

Network 11 has developed a brochure on what to do in case on an emergency or natural disaster. These Emergency Preparedness Guides should be available on your unit.

If you haven't received one yet, please ask your unit for a copy or call Network 11 at (800) 973-3773 for your free copy.



Stop Sign Wallet Card

Be sure to ask your dialysis and/or transplant provider for your copy of the Stop Sign wallet cards. There are cards for hemodialysis, peritoneal dialysis, and kidney transplant patients.

You may also obtain a full page copy of any of the wallet cards by contacting Network 11. Please:

- Call 1-800-973-3773
- Download a copy at www.esrdnet11.org/consumer/consumer_committee.asp

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