



Focus on Transplant

The Right Treatment, for the Right Person, at the Right Time ...

Kidney transplantation is accepted as the preferred treatment for many people with kidney failure. Transplantation has many advantages such as a lifestyle free from dialysis and fewer fluid and dietary restrictions. Kidney transplant, when successful, usually provides a better quality of life for most people and is less expensive than dialysis in the long run.

Over time, researchers have found ways to make transplants more successful. As a result, more people can be helped by transplantation. However, the number of organ donors has not grown as fast as the number of people who need organs. As of May 2006, there are over 66,000 people waiting in the United States for a kidney transplant.

There are many things to consider before deciding to get a kidney
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Note from the Editor ~

When we decided to make the focus of this newsletter on Kidney transplant, the Network invited a few individuals to write about their own experience with the overall transplant process. These personal accounts describe the emotional aspect of kidney transplant and dialysis.

Getting the Call: A Personal Account

Hello, My name is David Moskovitz, and I am an employee of ESRD Network 4, Inc. I am also a kidney transplant recipient (twice). I am a registered nurse by profession and have worked in the field of dialysis for the past 19 years. I worked as a dialysis nurse for 13 years prior to my current employment with ESRD Network 4.

I received my first kidney in 1975 as a gift from my father, which I had for 22 years. My second transplant was on May 5, 1999 as

a gift from a donor family. My first kidney transplant began to fail in 1996; and I took the initiative to be re-evaluated for another kidney transplant that same year. Unfortunately, in the summer of 1998, I had to return as a patient to hemodialysis.

I did very well with my treatments and continued to work at the outpatient dialysis unit part-time on the days I wasn't scheduled to have dialysis. I remember having to carry a pager to work and
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Getting the Call: A Personal Account

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everywhere that I traveled. My pager did “beep” a couple of times, but they were false alarms. That really gets your heart and mind racing.

Late one evening, I received a call from a transplant coordinator. It was May 4, 1999 at approximately 10:30 PM. I recollect that I was getting ready for bed in order to go to work the next morning. I called my wife into the room



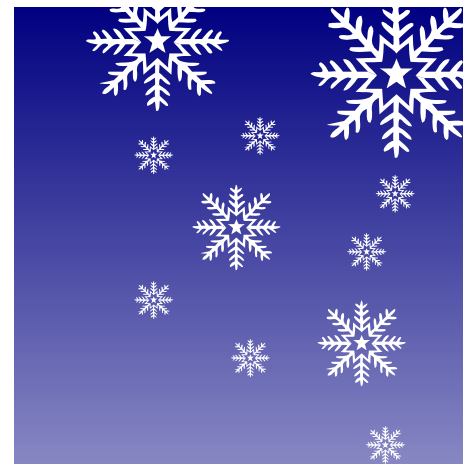
and told her what the call was about. My body started to tremble inside; and I tried to compose myself to the best of my ability. My wife and I had a couple of questions for the transplant coordinator before we decided to say “YES” to receiving the donor kidney.

Of course, many different thoughts go through your mind before you actually get

to the hospital. My wife and I tried to think of anything necessary to bring to the hospital besides my insurance cards and us. Of course the transplant staff at the hospital wanted us to arrive there as soon as possible. I am fortunate that I only lived 30 miles (1 hour) from the transplant center.

Once we got to the hospital and were registered for admission, we were taken to a room where a couple of tests (chest x-ray, EKG, blood work) had to be performed as a safety check to make sure that everything was clear for transplant. I remember my wife and I being in that room for a few hours until a person from the kidney transplant staff came in at approximately 4:30 AM and said that they were ready for me. My wife

and I looked at each other and let the grip loose of each other’s hands, hopeful that everything would turn out positive with the surgery. I am pleased to say that 7 years and 3 months after the transplant, the kidney is still functioning. Believe me when I say that I am grateful to the donor family for this “Gift of Life”. ■



Happy Holidays
and
Seasons Greetings!

From the Staff of ESRD Network 4, Inc.

How Are We Doing?

The Network is interested in your feed back about our educational newsletter. Please be sure to complete and return the evaluation page insert in this newsletter. We value your opinions!

Focus on Transplant

(Continued from page 1)

transplant. Your transplant center will discuss these issues at the time of your evaluation. Some of these include: the risks and benefits of transplant, medications and their side effects, financial coverage and your ability to continue necessary follow-up care and to follow treatment instructions. The final decision is up to you so you will need to ask questions at your evaluation in order to be comfortable with your final decision.

Patients who want a kidney from a deceased donor must wait for a transplant. It is important to remember the following:

- There is no way to know exactly how long you will have to wait for a kidney since many factors determine how long an individual must wait.
- Your transplant team can talk with you about the waiting period.
- You will need to have annual testing to remain ready for your transplant.
- And most importantly, let your transplant team know of any change in your phone number, address or insurance coverage.

After you are medically cleared for the kidney transplant, the transplant center will add your medical profile to the national patient waiting list through a computerized system. This information is held at the United Network of Organ Sharing (UNOS) in Richland, Virginia where they store and access the information for organ donor matching. When you are

placed on UNOS, your name is added to the “pool of people waiting.” When an organ is donated, a list of potential recipients who match that organ is produced by the computerized database at UNOS.

Waiting times vary because each patient’s situation is unique. The major factors that influences the waiting time are blood type, tissue type and antibody sensitization (whether your immune system makes antibodies against potential donors). Talk with your transplant center to assist you in understanding how long your wait might be based on your situation.

In general, a kidney is given to a recipient who is local first, then regionally and then nationally, based on waiting time. However, a kidney is offered nationally first if there is a perfect antigen match between the donor and recipient.

When your transplant center calls you with the good news that a kidney may be available to you, you will be asked a series of questions to determine your current health (cough, fever, any sign of infection, etc.). If you meet the criteria, you will be told to go to your transplant center for surgery. This could be an emotional time and it is suggested that someone drive you to the hospital. Your transplant center will provide information about the specific process for reporting to your surgery. ■

...United Network of Organ Sharing (UNOS) in Richland, Virginia stores and accesses the information for organ donor matching.

Preparing For A Kidney Transplant: Frequently Asked Questions

Question: How do I find out if I am a candidate for a kidney transplant?

Answer: Express your interest in exploring the option of transplant with your nephrologist (kidney doctor). There may be slight variations among dialysis centers and physician practice; however, most nephrologists will refer you to a transplant center for an evaluation.

Question: What is involved in the transplant evaluation process?

Answer: Your initial meeting with the transplant team may take four to seven hours depending on differences between transplant center protocols:

- blood work to determine your blood and tissue type (5 or more tubes of blood)
- a meeting with the pre-transplant coordinator (generally a nurse)
- a meeting with the social worker and financial counselor to make sure you are emotionally able to deal with the transplant process and to make certain that financial resources are available.
- a detailed review of your medical history
- an examination by the transplant surgeon

Question: When will I find out if I am accepted as a transplant candidate?

Answer: Soon after your initial evaluation you and your nephrologist will receive a letter that will let you know if you are a potential candidate for transplant. In some cases, based on your medical history, having a transplant might not be an option for you.

Question: What if I am told that I am a transplant candidate and should proceed with the transplant work up?

Answer: Further tests will be ordered and may be listed on your preliminary acceptance letter. They may include:

- chest X-ray and EKG
- additional blood work
- gallbladder ultrasound
- mammogram (females)
- test for prostate cancer (males)
- dental examination

Question: How long does it take to complete the transplant workup process?

Answer: These tests are extremely important and generally take three to six months to complete. The transplant center might request that all testing be done at their center, or they might allow you to have them done at an alternative site (which may be closer to your home).

Preparing For A Kidney Transplant: Frequently Asked Questions

When all of the results are reviewed by the transplant team, you will then get the final acceptance letter and your name will be added to the waiting list. In some health situations, transplantation might be considered to be a risk and denied by the transplant team.

Question: Where do kidneys for transplant come from?

Answer: There are three sources:

1. Living donors = a relative, spouse or friend
2. Non-Living donor = a person who has recently been determined brain dead and permission has been given to use his/her organs for transplant
3. Non-designated donation = with no specific recipient in mind, a person donates his/her kidney to help someone on the general kidney transplant waiting list

Question: How long will I have to wait for a transplant?

Answer: It is not possible to predict waiting time. Waiting time varies between regions of the country. The general average waiting time for a non-living donor kidney is two to five years. In some cases a perfect match may become available and the waiting time would be less. If a living donor is

available, the transplant would occur as soon as the donor completes a series of tests to assure good health and when the actual surgery date is coordinated.

Question: Where will the new kidney be placed in my body?

Answer: The kidney will be placed in your lower abdomen and connected up to the main artery that supplies blood to your bladder and your leg. It is placed in the front so that it is an easier surgery and to make the kidney easily accessible if further testing (biopsy) is required.

Question: How long will surgery take?

Answer: The operation generally takes between two to four hours.

Question: How long will I have to stay in the hospital?

Answer: Admission time varies with a range from three to seven days depending on the center's policy and the person's readiness for discharge.

Question: What types of medication will I have to take after the transplant?

Answer: Again, transplant centers vary. Most use a combination of three anti-rejection medications (to prevent rejection of the foreign organ), other medications are used initially and reduced

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Preparing For A Kidney Transplant: Frequently Asked Questions

(Continued from page 5)

gradually. Discuss the specifics of medications with your transplant team, as this will be an extremely important part of your long-term care.

Question: How can I learn more about transplantation?

Answer: The **National Kidney Foundation (NKF)** has a toll free number with free information available. The number is 800/622-9010. You may go to their web pages at www.kidney.org.

Question: How successful are transplanted kidneys?

Answer: Living donation is usually preferred because the success rate is higher (better than 90% for the first year), the recipient requires less anti-rejection medication, and it is possible to plan when the transplant will take place. The success rate for non-living donor transplantation is about 80% for the first year.

Question: Which individuals are candidates for transplant?

Answer: Many people with kidney failure are suitable candidates for transplant. To get a kidney transplant, you must be healthy enough to have the surgery and be free from cancer and infection. You must also be able to

comply with the medications and follow-up treatments.

Question: What is involved in being evaluated for a transplant?

Answer: Anyone interested in transplantation needs to meet with a transplant surgeon to learn more about risks and benefits of transplantation. They will also meet with a transplant coordinator at the transplant center to discuss pre-transplant preparation and follow-up care after the transplant. A tour of the transplant unit is provided and often you will have an opportunity to talk to a recent transplant recipient. The initial interview takes about an hour but can be longer if necessary. If there are specific insurance concerns, a meeting with the transplant social worker can be arranged.

The material for this article was provided by the National Kidney Foundation's Kidney and Urology Facts. The article was contributed by both Rhonda Locket, Data Manager for ESRD Network 4, and Cate Lewis, RN with the Moses Taylor Hospital System. Cate is also a member of the ESRD Network 4's Patient Advisory Committee and Organ Procurement/Transplantation Committee. ■

Second Time Around



“It’s Not Any Easier The Second Time Around”

Written By:
Roger
Chapman of
Clarks
Summit, PA

Roger
returned to
dialysis in
2005 after
14 years
success
with a
transplant.

He is
pictured
above with
his grand-
daughter on
his motor-
cycle.

Here I go again, kidney failure, dialysis, renal diet, transplant work-up – hasn’t this happened before in this life or am I dreaming?

Nope – reality check – it’s really happening and so I prepare myself for the long journey ahead. “Hindsight is 20/20”, and “experience adds wisdom” are expressions I hope are true in my situation, as I begin this journey I’ve been on before. There are some changes on this second time around. I am 14 years older from my first transplant and 17 years past my last dialysis experience. I opted for hemodialysis instead of peritoneal dialysis this time because I believe I have become lazier with age (so much for wisdom).

I must say at this age I made the right choice. The staff at my dialysis center have done all things possible to help me feel comfortable and to re-educate me in all areas of this illness. I thank them for their kindness. Then, there is still the wait. All the pre-testing and vaccinations are done and I am awaiting that call. Has my patience become better over these years? That remains to be seen.

Here I go again, the second time around. ■

Paired Kidney Donation

Kidney failure affects one in 9 Americans, and oftentimes a kidney transplant is the only hope to end their suffering and prevent premature death. The critical need for organs has extended the national kidney waiting list to more than 66,000 individuals, and less than 20 percent will receive a kidney transplant from a deceased donor this year. However, a new program Paired Kidney Donation, allows a living donor to save someone else’s life, and in return, the donor’s loved one will be saved as well.

Brothers want to help sisters; wives want to help husbands; friends want to help friends. Unfortunately, they are not always a match. The program uses a computer database to match donor/recipient pairs. One pair consists of Recipient A (a patient who needs a new kidney) and Donor A (a family member or friend who wants to give their gift but isn’t compatible). The other pair consists of Donor B and Recipient B who are in the same situation. However, the computer generates that Donor A is compatible with Recipient B, and Donor B is compatible with Recipient A. Both people who need a transplant will receive one at the exact same time if all four participants agree.

The more pairs that are willing to participate in this program, the better the chances are for loved ones to receive the gift of life. For more information on the Paired Kidney Donation Program, or if you and a friend or family member would like to be added to the list, please contact the following organizations:

[Center for Organ Recovery and Education \(CORE\)](#) at 1-800-DONORS-7
[Gift of Live](#) at 1-800-DONORS-1. ■

The Hardest Part

“The Wait”

Written By:
Maria Zaccone
of Carbon
Dale, PA

It seems like an eternity waiting for that special call!

Time goes on each day while you wait to have a better quality of life. A

time when you can do what you want, when you want to, without having to work dialysis around your schedule!

When you receive that call you have many emotions of what you are about to do with your life. You are nervous, happy and scared all at the same time. You probably will cry happy tears because you have a better chance for a better life and sad tears, especially for the family that had lost someone very dear to them.



The ride to the hospital is very stressful because you have to travel the highway at any given time of the day or night. You need to get to the hospital as soon as possible. When you get there you have more tests to go through! At that time, the doctors will determine if you are a good match for the transplant. You may be the lucky person to receive the organ or not. You may have to go home without that special gift. But if all goes well you may be the person to receive a very special gift – THE GIFT OF LIFE!!! ■

Answers to the ESRD Crossword Puzzle from page 8 —
DOWN: 1=transplant, 2=kidney, 3=rejection.
ACROSS: 4=xray, 5=donor, 6=sunos.

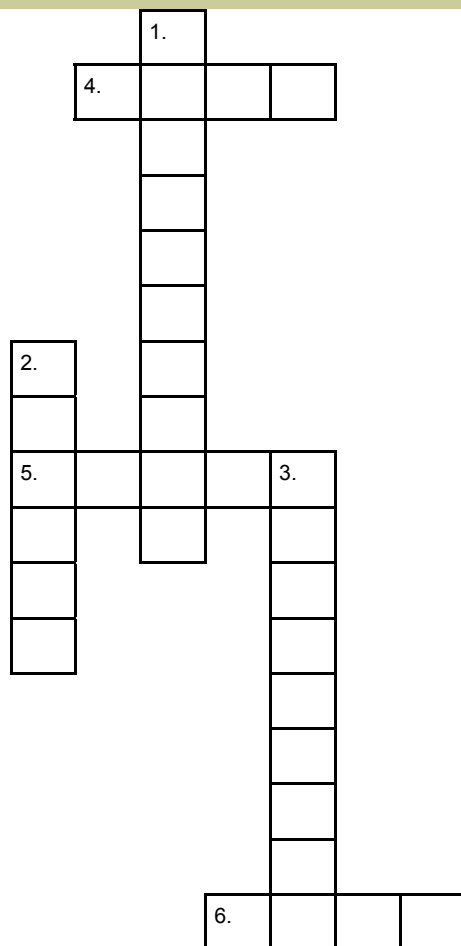
Puzzle Fun

Down:

1. The process of placing an organ from one person to another.
2. Bean shaped organ.
3. ___ occurs when the body’s immune system attacks the transplanted organ.

Across:

4. Radiation text to evaluate disease or injuries.
5. An organ ___ gives the “gift of life” to another.
6. United Network for Organ Sharing



This Newsletter was brought to you by:

ESRD Network 4, Inc.



: Working for you

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WE’RE ON THE WEB!

WWW.ESRDNETWORK4.ORG

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Tell us what you think

We want to know what you think about our patient newsletter. We will use what you tell us to make it better.

Please take a moment to fill out this form.




A. I am ...

(please place an "x" in the most appropriate box)

- a patient
- a family member
- other (please specify _____)

B. Tell us how you feel about this newsletter.

(select the most appropriate response for each of the following statements by placing an "x" in box that matches how you feel. Please select only one box for each statement.)

				Does Not Apply
	Agree	Neutral	Disagree	Apply
1. I learned new things.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
2. What I read helped me.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
3. I understood what I read.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
4. I would tell my family or other patients to read this newsletter.	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

C. Please share anything else you want to tell us about this newsletter, or share topics of news stories you would be interested in reading for future newsletters:

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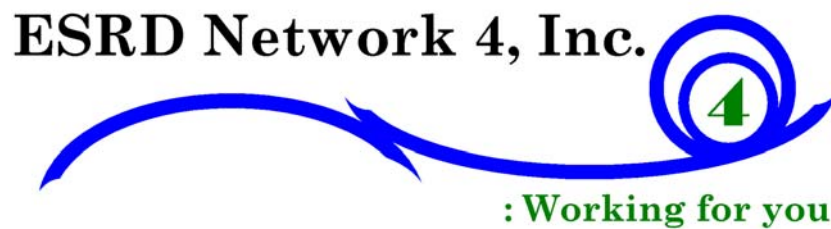
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Return to the Network office by March 1, 2007!



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