



**National Kidney  
Foundation®**

*Making Lives Better*

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A near stranger donates a kidney and saves a life.

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**PATIENT ADVOCACY**

# Family FOCUS

A publication of the  
National Kidney  
Foundation

Vol 13, No 4  
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**WHAT YOU NEED TO KNOW ABOUT TRANSPLANTATION**

## Taking Control: One Man's Choice

By Dale A. Ester



**I** BEGAN HEMODIALYSIS ON JUNE 7, 1990, as a life-sustaining solution for what was my “less-than-perfect” management of juvenile onset diabetes.

Many kidney doctors (nephrologists) had advised me that some form of dialysis was the only option to keep me alive as I required treatment immediately. Once stabilized on dialysis, I was told that a kidney transplant might be another treatment option, as it would allow me to “survive” chronic kidney disease (CKD) too. The list of choices I was offered was:

- (1) peritoneal dialysis
- (2) hemodialysis
- (3) kidney transplant or
- (4) no treatment at all!

I also want to state with certainty that any form of kidney replacement therapy that helps keep someone alive with a quality of life that is acceptable to them is nothing less than wonderful news! Choices allow people with kidney failure to have some control over their treatment and select the modality (treatment choice) that best suits their individual needs and lifestyles.

I selected hemodialysis to sustain my life during the wait for a transplant. After much medical pre-transplant testing,

I was finally placed on the kidney waiting list about two months after starting hemodialysis. The hemodialysis helped me become medically stable and capable of receiving a transplant if/when I should decide to seek one.

During the days when I was going through the kidney pre-transplant evaluation, I had ample time to think about everything I was doing and where I was headed. That included learning more about all forms of effective and life-saving treatments for CKD. My choice to pursue a kidney transplant was made knowing that it is simply another form

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Transplantation is often seen as a cure for chronic kidney disease (CKD). In reality, however, it is actually not a cure and should be considered one of many treatment options for CKD. When someone faces the need for a form of kidney replacement therapy to sustain life, the treatment options of center and home hemodialysis, the various forms of peritoneal dialysis and kidney transplantation should always be offered to all who are medically eligible for these treatments. Individuals should also be told of their right to refuse any of these treatments while being educated about the consequences of such a decision.

Transplantation is the closest that those with CKD can come, however, to achieving the level of kidney function they had prior to developing CKD. Successful transplantation can also lead to a higher overall quality of life for many. It is for these reasons that all who are candidates for transplantation should seriously consider whether it is a viable treatment option for them. It is the hope of our Editorial Board that this issue of *Family Focus* will assist you in making such a decision.



**Karren King**

I began working in the field of dialysis and kidney transplantation in 1979. Since then, the kidney community has come a long way in many areas, including transplantation. It was not uncommon at that time not to consider those with diabetes or those over age 55 for a kidney transplant. The donor options were also much more limited. A transplant using kidneys from a non-living donor was the most common type of kidney transplant, and the only other option commonly used was donation from a blood relative. I can still recall the excitement and awe when the transplant center where I worked performed a transplant on an adolescent

with a kidney donated by his adoptive father. Next came a transplant with the spouse of the recipient as the donor. Both of these were rarities. At that time, in the 1980s, none of these transplants could have occurred without the donor and recipient being a good "match" or having compatible blood cells. As you read the articles in this issue I think you will be amazed at just how far we have come in a relatively short period of time.

This issue is the last for our 2004 Editorial Board. As Editor, I want to acknowledge each of them for their expertise and dedication. Their work has contributed to maintaining *Family Focus*' excellent reputation of providing objective, reliable information to those with CKD and their family and friends. I especially want to acknowledge Dale Ester, the Patient Editor, and Linda Harte, the Transplant Editor, who are leaving the Board this year. I would also like to welcome two new members, David Jones, as Patient Editor, and Nancy Swick, as Transplant Editor.

We believe the themes planned for the four issues of *Family Focus* in 2005 are very relevant for everyone affected by CKD. The first issue will focus on Patient Advocacy and will highlight a new National Kidney Foundation (NKF) program on empowering those with CKD. That issue will be followed by one on Home Dialysis, exploring the variety of home treatment options with both hemodialysis and peritoneal dialysis. The third issue will be devoted to Mental Health, and the last issue of the year will summarize the upcoming NKF Kidney Disease Outcomes Quality Initiative (K/DOQI) on cardiovascular disease and its implications for people on dialysis. As always, you are encouraged to send letters, articles, poems or pictures to *Family Focus*, and we would be especially interested in those that relate to any of the 2005 themes.

We hope you enjoy and learn from this issue on kidney transplantation! 

*Karren King, MSW, ACSW, LCSW  
For the Editorial Board*

# Family Focus

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## Taking Control: One Man's Choice

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of kidney replacement treatment; even after a successful kidney transplant, I would not be considered “cured” of kidney failure. Yet, I was conscious of my own feelings—they told me that a kidney transplant would help me regain a sense of “preferred” normalcy in my own life. I thought a successful transplant would not place as much of a demand on my time, which was often taken up by hemodialysis. Things like treatment time, schedules and traffic delays would not seem to matter as much to me. My time would seem more free.

Although many individuals still remain employed after beginning some type of CKD treatment, I was hopeful that a transplant would make employment a whole lot easier—again, my time would not be so restricted. I also hoped to rid my feelings of tiredness so much of the time, although this issue has been largely resolved since the increase in hematocrit levels. During my 1990 hemodialysis

treatments, target ranges for hematocrit were 27-30 percent, instead of the current 33-36 percent level. The increase helps individuals to have more energy and stamina to do the things they enjoy, including working! Most importantly, I believed that after a transplant I would be better able to complete college, which I had been striving to do prior to the CKD diagnosis. Even though graduating from college is a possibility for all people with CKD, I was longing for the ability to use my current treatment days (Monday, Wednesday and Friday) to study at the library. Time would not be the limiting factor for achieving my educational goals.

Personal ambition plays an important role in any CKD treatment: thus, whatever one chooses, the world of opportunity still exists as long as “adapt and compromise” are a part of the overall plan to reach success.

*“For now, I am successful at overcoming the hurdles, with special thanks to many great doctors and nurses who helped me along the journey!”*

I was 31 years old and on dialysis for one month when I chose to pursue a non-living kidney transplant. I waited just seven months for the call, and when it came, I did not hesitate to rush to the hospital and begin my new life as a kidney transplant recipient. I knew the medications I would be taking for a kidney transplant could have unpleasant side effects, but I also believed I could overcome setbacks and come out a winner through it all!

As I write this today, I am a post-kidney transplant survivor of almost 14 years. I suffer few ill effects from the twice-daily routine of immunosuppressant (anti-rejection) medications that I must swallow for the remainder of my life. For now, I am successful at overcoming the hurdles,

with special thanks to many great doctors and nurses who helped me along the journey!

Would I recommend that others with kidney failure consider a kidney transplant? Certainly! However, individuals must consider all of the positives and negatives each treatment might bring and how these effects would impact their lives, eventually arriving at a decision that is best for them.

Life—and living it well—continues to be an awesome adventure, no matter what treatment you choose to survive CKD! 

Editor's Note:

*Dale received a pancreas transplant from a non-living donor in July 2004 and is doing great! He had been a diabetic for over 41 years.*

### FROM ILLNESS TO WELLNESS: *Life After Transplantation*

*From Illness to Wellness: Life After Transplantation* is a new booklet written by organ transplant recipients for organ transplant recipients, with input from professionals. It discusses the emotional impact and practical realities of the change in one's life as a result of chronic kidney disease, including the time after transplantation. An emphasis is placed on living life to the fullest and finding joy in the new freedom of transplantation, while not ignoring the challenges and complexities that can come with transplantation. Resources and recommended readings are included. Individual review copies are free to individuals with chronic kidney disease and their family and friends, as well as to professionals by calling the National Kidney Foundation Information Specialists at 800-622-9010.

From Illness to  
**WELLNESS:**

*Life After Transplantation*

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Regardless of where a kidney for transplantation comes from, it is because of the generosity of another person. The timing of your kidney transplant depends on the availability of a suitable donor. Kidneys can come from either a deceased (non-living) donor or a living donor. We will briefly discuss each of these options.

Transplantation from a deceased donor (formerly called a cadaveric donor) happens when someone dies suddenly from an illness or accident that causes brain death. This can be a severe head injury, stroke or one of many other causes. Since this happens very suddenly, the next of kin is asked for permission to donate the loved one's organs. These donors are screened very carefully with blood tests, x-rays and interviews with the family. Family members are asked questions about the donors' previous illnesses, medicines they may have been taking and lifestyle behaviors such as eating practices, drinking or drug habits.

Kidneys from deceased donors can become available at any time. It is important that if you are on the waiting list, you are available and not currently sick with any infections or conditions besides your kidney failure, such as uncontrolled blood pressure.



**There are only a few programs that work with anonymous donors, so ask your transplant coordinator if there is such a program in your area.**

## DONOR OPTIONS: More Choices Today

By Linda Harte, RN, BSN, MA, CNN, CCTC

*Through kidney transplantation, the definition of "family" has expanded.*

The wait for a kidney from a deceased donor can take two to three years, depending on your blood type. One reason for this delay is because there are not enough people who agree to donation. Also, there are more people added to the list every day and there are not enough kidneys to help everyone.

Because of this shortage of deceased organs, there has been an increased interest in living donor transplants in the last few years. The advantages of a living donor are:

- 1 The waiting time to receive a kidney is shorter
- 2 Surgery can be scheduled at a time that is convenient for the donor and the recipient
- 3 The kidney usually works quicker if the time between taking it from the donor and placing it into the recipient is shorter.

A living donor can be a blood relative (parent, child, brother, sister), someone related to you by marriage or a close friend, or even someone you do not know (an anonymous donor). Living related donors are often preferable if they have the right blood type and are healthy. When family members share a close relationship, they may be very eager to help a loved one. Also, living relatives may be a better match since the donor and the recipient may have similar blood cells. Keep in mind that

matching is not as important as it used to be. Poorer matches can have the same good results as perfect matches because anti-rejection medicines are so much better than in the past.

*"A newer source of donors includes individuals who want to donate a kidney but do not know anyone who needs one."*

Someone who is a close friend or someone related to you by marriage might offer to be a donor. This "emotionally related" donor is typically someone you have a close relationship with.

A newer source of donors includes individuals who want to donate a kidney but do not know anyone who needs one. This "anonymous" donor goes through preliminary testing to be sure he or she is healthy. This usually includes an interview with a transplant coordinator. The possible donor will also meet with a social worker or psychologist to be sure he or she is emotionally ready to undergo the donation process for someone the donor may never meet. The donor is then matched with someone on the transplant list the same way a deceased donor would be. The anonymous donor completes a donor evaluation, just as a related donor would. Because the donation is anonymous, the donor and recipient do not meet unless they both agree to

the meeting about six to 12 months after the surgery. In the meantime, before they actually meet, they can correspond through letters, much the same way that recipients of deceased donor kidneys can correspond with their donor families.

There are only a few programs that work with anonymous donors, so ask your transplant coordinator to check for you if there is such a program in your area. Some of these programs are run by

transplant centers and others are run by organ procurement organizations.

All living donors go through extensive testing to be sure they are healthy, both physically and emotionally. The transplant team assists donors in understanding the donation process and throughout the evaluation and surgery. It is important that the donor not feel pressured by anyone to donate, nor expect any kind of payment for donating. The transplant team needs to be assured that he or she is donating out of the goodness of his or her heart to help someone.

Other donor sources that are becoming more common in some areas are:

**1. Deceased Swap Donation:** Suppose a relative or friend of yours wants to give you a kidney, but does not match you. They would

*Continued on next page*

## Hear Their Story

*“How many times in life do you have an opportunity to make an impact... on someone else’s life?”*

At Hadassah, the Women’s Zionist Organization of America, medical miracles do not just happen. Recently in New York, however, a medical saga that began three years ago came to a wonderful conclusion when a living donor kidney transplant occurred between members of this women’s organization.

In March 2001, Belle Simon, who was a 63-year-old member of Hadassah’s National Board, started to experience chronic fatigue. She was unprepared for her diagnosis: glomerulonephritis, a form of kidney disease that would eventually

“This was almost like it was meant to be,” Katie recalled. “I had always thought this was something I would do when I was no longer alive. I was not really aware you could be a living donor. So I went to Belle and said I’m really interested in finding out more information. Belle was speechless. She probably thought that June

would mention it and that would be the end of it. Later she passed me a note and thanked me profusely for even initiating the conversation.”

Belle gave Katie the contact information for a transplant coordinator at a hospital in New York and left it up to her to make the contact. Katie did, and within days she had started the first of many medical exams and tests to learn if she was a compatible match. Soon she learned that her kidney was a match for Belle.

Katie gave Belle her left kidney in May 2004. “I was not scared at all,” she recalled. “I was so excited. I probably would have been just as upset as Belle if this couldn’t have happened.”

The highlight of the surgery for Katie happened in the recovery room, where, placed in a bed next to Belle, she heard the doctors declare, “It’s working!” referring to Belle’s new kidney.

Since the surgery, the two have talked every day and each is elated by the other’s progress.

“What Katie did for me was over, above and beyond the call of duty,” says Belle. “She’s such a unique, selfless individual. I keep calling her ‘my angel.’ Now I can live a full life and watch my grandchildren grow up.”

As for Katie, though her family was hesitant, she claims she never gave her decision a second thought.

“How many times in life do you have an opportunity to make an impact like this on

someone else’s life? But this is not for everybody. If you can’t do this with a full heart then it’s not something that you should do. I’m happy I did it and even happier that it’s working!”

Asked if she’s concerned about her one remaining kidney, Katie said, “Anything can happen at any moment in life. I don’t lead my life that way!”

Both women want as many people as possible to hear their story so the public realizes that it is possible to be a living donor—and to save a life. 

### Founded in 1912

Hadassah, the Women’s Zionist Organization of America, promotes health education, social action and advocacy, volunteerism, Jewish education and research.



lead to dialysis and a possible need for a transplant. By mid-2003, she had begun dialysis three times a week and had added her name to the New York State kidney transplant list. She anticipated a five-year wait for surgery.

At Hadassah’s semi-annual board meeting in January, their President, June Walker, opened the meetings with the words, “Dear friends, as many of you know, one of our fellow board members is in need of a kidney transplant.”

Katie Edelstein, the President of the Pacific Northwest Region of Hadassah, was sitting in the room. In a split second she decided that she wanted to donate a kidney to Belle.

### Donor Options: More Choices Today

*Continued from page 4*

donate a kidney to another person on the waiting list. Then you would have priority on the waiting list for the next kidney that matches you. This allows you to be transplanted sooner and shortens the waiting time for others who may match your relative or friend.

**2. Living Donor Paired Exchange:** You may have a friend or relative who does not match you, and the transplant center may have another donor and recipient pair who also do not match each other. It may be that your friend or relative could donate to the other recipient and the other donor could donate to you.

These types of programs are new and not available everywhere. Check with your transplant center to see if they would participate in this type of donation.

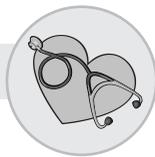
Kidney transplantation has gone through many positive changes through the years. It is encouraging that these changes include more donor options compared with the days when the only choices were deceased donors or blood relatives. These new options will help many of those who are on the waiting list for a kidney transplant receive the “gift of life.” 

Recently, several kidney transplant recipients were asked what they thought the best thing was about being transplanted (besides no longer needing dialysis, of course) and the answer was unanimous: “The diet.” One was thrilled to be able to eat all the potatoes he wanted, and another was happy to once again drink milk and eat ice cream every day.

The group was also asked if there were any surprises in how their lives changed after the transplant. There were few, if any: This group of kidney transplant recipients knew that after their surgery their anti-rejection medications could increase the risk for heart problems, gaining weight, bone problems and possibly developing diabetes.

Are you as prepared for your transplant? Let’s take a look at some of the dietary issues you should know about:

**EAT HEART HEALTHY:**



It is always a good idea to exercise and follow a heart healthy diet. Sadly, many people will die of heart problems before their transplanted kidney wears out. The increased risk of heart disease is one of the major concerns after a kidney transplant. Anti-rejection medicines can cause increases in cholesterol and other lipid levels, both of which can be harmful to your heart. Get into the habit of eating a heart healthy diet while you are waiting for your kidney.

**OBESITY:**



Just about everyone gains weight after a transplant. You feel well, and want to eat! Plus, it is likely you will be given anti-rejection medication. One side effect of this

# Paving the Road for a Successful Kidney Transplant

By Lois Tobin, RD, CSR, LD

*Making wise nutritional choices will help now and after transplant.*

medication is hunger. The weight gain is dose dependent, meaning the more medicine you need to take, the more weight you are likely to gain. Since the weight gain is mostly fat, this will cause problems with body lipids—and as stated above, increased lipid levels mean increased risk of heart problems. Weight gain is also a risk factor for diabetes.

**DIABETES:**



Some anti-rejection drugs may cause an increase in your blood sugar. If you have diabetes, knowing how to control the diabetes before surgery will help to ensure that you have the skills to gain control after your transplant surgery. If you have Type 2 diabetes and are controlling it with diet and/or oral medication, you might require insulin to control your blood sugars after a transplant. Even if you do not have diabetes before your transplant, you may be at higher risk of developing Type 2 diabetes after the transplant due to some of the anti-rejection drugs.

Uncontrolled diabetes puts you at risk for the complications of diabetes, including increased chance of infections. (Anti-rejection medications alter your immune system and many also make you more susceptible to infection.) Closely monitoring your blood sugars, eating a healthy diet, controlling your weight and exercising before and after the transplant are the best ways for everyone to keep blood sugars in control.

**BONE HEALTH:**



The anti-rejection medications needed after a transplant may cause weakening of the bones, which means a higher risk of osteoporosis, a kind of bone disease that causes bones to break easily. You might already have weak, brittle bones from your kidney disease. Your new kidney will try to replace the lost calcium and restore bone density. You



**If you are currently on dialysis your renal dietitian can help with a diet plan specific to your needs.**

payments and is familiar with the nutritional needs of individuals with kidney disease.

*“The increased risk of heart disease is one of the major concerns after a kidney transplant.”*

will need to help the process by taking calcium supplements and eating more dairy foods. Surprisingly, after years of avoiding phosphorus, you might also need a phosphorus supplement to help strengthen your bones. Your doctor and dietitian will instruct you on what you need to do.

Forming good dietary habits is not something you should do alone. If you are currently on dialysis, your renal dietitian can help with a diet plan specific to your needs. If you are not on dialysis, but have Medicare Part B, then Medicare will pay for limited visits with a registered dietitian up to three years after a transplant. Your doctor should be able to refer you to a dietitian who accepts Medicare

Remember, you have no control over the side effects of the anti-rejection medications but you do have control over lowering the risks and/or severity of problems. If you are thinking about a kidney transplant, this information can put you on the right track for making lifestyle changes toward a successful transplant. If you have a transplanted kidney, then hopefully you are like the individuals above, doing well and enjoying all those foods you missed!



**About the Author**  
Lois Tobin has 19 years of experience working with those with chronic kidney disease. She currently works as a renal dietitian in Portland, Oregon.

Receiving a kidney transplant gives many people a chance to live a life without the limits and time demands of a dialysis center. Although many recipients of a kidney transplant may have been inactive before the transplant, there is no reason why an active lifestyle cannot be added into your life once you have a transplant. As seen with results from both the U.S. and World Transplant Games, organ transplant recipients are able to push their bodies to amazing levels during practice and competitions.



**Pedro Recalde, MS, ACSM**

## Will a Transplant Affect My Energy?

By Pedro Recalde, MS, ACSM

*Adding exercise to your post-transplant health plan is beneficial.*

and has been associated with high weight gain and storage of fat in the stomach area. Although the sound of these side effects may make a person cringe, these are all perfect reasons why an exercise program should become a part of your life.

The exercise training should begin soon after transplant, as soon as you feel stable on your feet and are aware that your blood pressure and heart rate responses are within normal ranges. As always, check with your doctor before you begin an exercise program.

Some low-level exercise (walking and light weight training) can be continued even during transplant rejection episodes to keep up the good habits of activity and counteract the muscle wasting effects of prednisone.

Setting goals is an important part of developing an exercise routine—even if it is not specific training for a sport but instead the training involved in recuperating from transplant surgery. Some of your goals should be to:

- Tolerate an increased intensity of exercise from the point where you begin
- Increase the amount of exercise you can tolerate before needing a rest
- Increase your ability to function within your lifestyle demands
- Improve your resting blood pressure
- Maintain or lose weight, as needed
- Lower your overall risk of cardiovascular (heart) disease
- Most importantly, find an exercise routine that makes your life more enjoyable. Exercise is not a punishment!

Lastly, remember to get out there and make life fun and more pleasant through exercise with your friends and family.

*“The exercise training should begin soon after transplant, as soon as you feel stable on your feet and are aware that your blood pressure and heart rate response are within normal ranges.”*

After organ transplant, almost all recipients are treated with medications that aid in the body’s acceptance of the new organ. Most people are also concerned about potential side effects of these medications (immunosuppressants) that are prescribed to keep the new organ healthy. One of the medications prescribed may be prednisone. Prednisone may cause muscle weakness and wasting (the breakdown of muscle fibers) and joint discomfort

Gradual progression of exercise is vital and aerobic exercises are often recommended. Remember, aerobic activities are exercises that can be done for 30 to 60 minutes at a time, where your heart rate stays at a high level during the exercise. Non-weight bearing exercise (swimming, bicycling or row machines) are tolerated well, while many recipients will be able to progress to jogging and other sporting activities without any problem.

For more information, please see “ACSM’s exercise management for persons with chronic diseases and disabilities” from the *American College of Sports Medicine*, Chapter 24: Organ Transplant by Patricia L. Painter, PhD, FACSM, 1997. 



To find out about the many services and activities offered in your community or to join the Patient and Family Council at no cost, contact us at

**800-622-9010**

or visit us at

**[www.kidney.org](http://www.kidney.org)**

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**DIRECTLY TO**

**THEIR HOMES**

CONSIDERING TRANSPLANT AS A TREATMENT CHOICE IS A BIG DECISION. FINDING OUT AS MUCH AS YOU CAN ABOUT WHAT HAPPENS AFTER TRANSPLANT WILL HELP YOU PREPARE FOR THE CHANGES TO COME.

Will you consider all the changes good? Probably not. Is there a chance that you will have a better quality of life? Yes. However, you will want to think carefully about some of the possible changes that might come before taking the step to have a transplant. Issues to consider include:

1. **LOSING MEDICARE** three years after a transplant unless you are disabled due to another illness, or are over 65 years of age
2. **COST OF MEDICATIONS** and long-term insurance coverage for health care
3. **SOCIAL SECURITY** Disability is usually reviewed about 12 to 18 months after transplant. You will no longer be considered disabled based on kidney failure
4. **IF YOU HAVE STOPPED WORKING** while on dialysis, beginning to plan your return to work after your surgery and recovery period
5. **SHORT-TERM AND LONG-TERM** side effects of medications
6. **EXPECTATIONS THAT OTHERS** may have of you and that you may have of yourself.

## Preparing for Transplant: So Many Things to Consider

By Mary Beth Callahan, ACSW, LMSW-ACP

*Do you have all the facts about kidney transplant?*

Regardless of how well your transplant goes, it is usually a stressful event. Someone—YOU—will be going through major surgery; after surgery you will most likely start taking numerous new medications. Some of these are very costly and some have unpleasant side effects. The first three to four months following a transplant can be a big adjustment period—not only for you emotionally, but for your body. Some people experience a “rejection episode” during this time, when your body adjusts to having a new organ. This is not unusual and can usually be successfully treated. Even though you may get through the rejection episode and keep your transplant for many years, going through this period can leave you feeling uncertain or anxious about the future. One of the side effects of medications called steroids can be mood swings. The emotional and physical changes combined can make you feel like you are on quite a roller coaster ride.

If you decide to be tested for a transplant, you may talk to a transplant social worker as part of the evaluation process. The social worker will



Mary Beth Callahan, ACSW, LMSW-ACP

help you understand the psychological and physical changes that can occur after a transplant and help you plan for your future with a transplanted kidney. The social worker will also help you look at transplantation as a treatment choice and decide if it is the best choice for you regarding your emotional and financial situation and support systems. Right now, about 59,000 people are on the kidney transplant waiting list in the United States. If you do not have a living donor, you may wait five years or more, depending on your blood type, for a non-living donor kidney. Waiting

can be difficult. You can make the most of this time by staying in the best shape possible while you wait. After checking with your doctor, this would include increasing your physical activity and sticking to an exercise plan.

There are many resources available for information on living donation. If you have a living donor, he or she will go through the same basic assessment as you did to get on the transplant waiting list. A transplant social worker will also meet with your potential donor. Usually this will not be the same social worker who met with you during your preparation for transplant. A different social worker is used so your donor can have a separate advocate (or supporter) through his or her evaluation process. The social worker will be looking to see that the donor has insurance in case a health problem comes up in the future. They will also discuss how the normal living expenses of the donor (such as rent or food) will be covered during time off from work, as well as assess if the donor is psychologically ready to donate.

Be an active part of your care. Know everything you can about your current treatment and issues related to a kidney transplant. Information about transplantation can be very confusing. Keep asking questions until you feel comfortable that you understand what you need to know to consider if transplant is a part of your future. 

# Karla's Story

WHEN I WAS YOUNG, ILLNESS ENVELOPED MY LIFE LIKE A FOG. MY OUTLOOK ON LIFE WAS LIMITED TO THE PRESENT. MY CONCERNS WERE GETTING THROUGH MY NEXT TREATMENT, REMEMBERING MY MEDICATION AND, IF I HAD THE ENERGY, DOING MY HOMEWORK. I COULD NOT EVEN IMAGINE A FUTURE CAREER OR FAMILY OF MY OWN BECAUSE GETTING TO TOMORROW WAS ENOUGH OF A CHALLENGE.

When I received my kidney transplant, the fog lifted, and I could see I had a bright future. No longer tied to a



Karla Ogradnik Boresi

machine, I had the freedom to pursue opportunities and make choices I never allowed myself to imagine. I went to college, became a lawyer and was appointed a judge. I got married, endured a divorce and bought a home. I moved to a different state, vacationed abroad, learned how to play golf (sort of) and competed in the National Kidney Foundation's U.S. Transplant Games. But my greatest accomplishment by far was giving birth to my daughter, Alison Marie—the true light of my life. Without my transplant, I would not have become a mother, my most prized role.

With the transplant, however, comes great responsibility. My freedom came at great personal sacrifice from

my donors. To this day, I am in awe of the amazing, selfless courage shown by all organ donors and donor families. Since I am living because of another's sacrifice, I feel a tremendous obligation to maintain my health. I take my medicine religiously. I exercise regularly, even when it means telling my friends at work to go to lunch without me. I try to limit the stress in my life. Most importantly, I keep a positive outlook on life. In the fight against illness, I have found that optimism can be the most powerful weapon of all.

So what has my transplant given me? I have hope for the future, which is brighter and broader than I thought it could ever be. I have the freedom to consider all of life's opportunities and the energy to follow my choices. I carry a heavy responsibility to stay healthy, live my life to the fullest and to make a positive

impact on the world. I found an Arabian Proverb that sums it all up: "He who has health, has hope; and he who has hope, has everything." My transplant is everything to me.

*Karla Ogradnik Boresi was in junior high school when her kidneys failed. She was on dialysis until she received a kidney transplant from her father in 1981. She completed high school, graduated from Saint Louis University and earned her law degree. After 18 years, her dad's kidney fell victim to slow rejection, but before she had to return to dialysis, Karla's sister donated her kidney. Karla is now an Administrative Law Judge for the State of Missouri.*

### Editor's Note:

If you have received a transplant and are considering pregnancy, talk with your doctor first. 

Four years ago, 42 year-old Alec Chenault of Los Angeles could barely drag himself out of bed to go to work. A lifelong athlete, he began to wonder why he was constantly fatigued. A routine physical soon found that kidney damage was the cause of his exhaustion. His wife, Monique, stepped forward to donate one of her kidneys and his life slowly returned to normal. An avid runner, Alec's post-transplant dream was to compete in track events at the U.S. Transplant Games, and so he did!

Alec returned home from Minneapolis triumphant with four gold medals around his neck. But the Games offered more than just the thrill of winning. "During the opening ceremonies I looked into the faces of all of the athletes and their

enthusiasm made me feel proud. After all that we organ transplant survivors have been through, we can join together and celebrate our new life in one of the best competitions in the world," says Chenault. He secured the gold in the 100, 200 and 400 meters and the 4x100 meter relay.

Bound by a common thread, 1,500 enthusiastic transplant athletes of all ages competed for gold, silver and bronze

## Games and Glory

medals in 12 sports at the National Kidney Foundation's 2004 U.S. Transplant Games.



Alec displays some of his Track and Field medals.

This spectacular event attracted such well-known people as actors Larry Hagman and Ken Howard, Olympians Carl Lewis and Chris Klug, former National Basketball Association great Sean Elliot and Secretary of Health and Human Services

Tommy Thompson.

"Right now, more than 86,000 Americans are on the

transplant waiting list and 17 people die each day while waiting," says John Davis, CEO of the NKF. "The Games draw attention to the critical need for organ donors in this country and inspire the public to take action by signing a donor card."

In addition to offering sports for every level of athlete, ceremonies and educational programs were presented for donor families, living donors, transplant recipients and transplant professionals. The Games also celebrated the 50th anniversary of transplantation in an event commemorating five decades of medical breakthroughs.

For more information about the U.S. Transplant Games, visit [www.transplantgames.org](http://www.transplantgames.org)

The time between finding out that a kidney transplant is needed and the time a suitable kidney is found varies from child to child. Whether the wait for a kidney is less than six months or more than six years, it is very important to spend time preparing to be able to take good care of this very special gift.

One of the most important aspects of helping to prepare your child for a kidney transplant involves making sure that he or she can take medication on a strict schedule. After transplant, your child will be on multiple medications that will need to be taken exactly as recommended. Unfortunately, even missing a few days of medication can damage your child's new kidney beyond repair. Therefore it is vital that problems with taking medications are identified before the transplant so that a workable after-transplant medication routine can be set up.

The main feature of a medication routine includes deciding who is going to do what. For example, you will need to plan who can supervise and help your child take medication, who will obtain medication refills, who will take your child for medication and transplant-monitoring blood work and who will communicate with the health care team if problems arise about taking medication.

Also, it will be important to figure out where medications can be stored conveniently and where you will be giving the medication. Many parents keep their child's after-transplant medications in an open-topped plastic box in a kitchen cabinet.

Even though it may seem that caring for a new kidney is much easier than helping your child with dialysis treatment,

## Getting Ready for a Precious Gift

By Arlene Gerson, PhD

*Your child's good health pre- and post-transplant is a group effort.*

establishing a routine for taking many medications and monitoring the medications' effects on your child's kidney function takes careful planning.

Another important aspect of preparation involves your relationship with your child.

*“Even if your child does not have any problems taking medication before transplant, it is very important to watch your child's medication-taking behavior very carefully after transplant.”*

Conflict can occur between parents and children at medication time. Therefore, while all parents and children argue and disagree about some rules, it is important that the taking of medication become a cooperative effort. If conflicts arise, they should be discussed and solutions should be found.

Even if your child does not have any problems taking medication before transplant, it is very important to watch your child's medication-taking behavior very carefully after transplant. Because of their drive for independence, adolescents might rebel against taking medications. They may need closer supervision than they are willing to admit to support a medication-taking routine.

Your child's health care team should be notified immediately if you notice that he or she is having trouble taking medication after transplant. Although difficult and sometimes embarrassing, being honest with your medical team about your concerns is

necessary for them to help your child's special gift remain healthy for many years.

Preparing for the physical changes that your child will experience after transplant is also important. Many of these changes will be positive. For

example, your child will likely have more energy to play with friends and do schoolwork. Your child's appetite may improve and he or she might be able to concentrate better or have more interest in participating in family activities.

Unfortunately, there are some side effects of transplant medications that many parents and children view as negative. For example, it is likely that your child's weight will increase after transplant because immunosuppressant steroid medications often cause an increase in appetite. Also, many children develop acne or grow more body hair after transplant due to the steroid medications.

Parents can help their child lessen the impact of physical changes caused by transplant medications by working with a nutritionist and a dermatologist to establish new eating and hygiene routines. Letting friends, family and school staff know about the common physical changes can also be

helpful in reducing the chance that someone will say something to embarrass your child. Finally, reminding your child that transplant medications will usually be adjusted, and thus their side effects reduced as time passes may also help him or her adjust. Teenagers, in particular, may benefit from counseling aimed at highlighting their positive skills and attributes.

In summary, here are some tips for children's caregivers to improve medication adherence after transplant:

- 1) Identify the person who will supervise and help your child take his or her medication.
- 2) Identify the person who will be responsible for checking when medication refills are needed.
- 3) Identify the person who will take your child for medication-monitoring and kidney function blood work.
- 4) Keep your child's medications together and in a convenient location.
- 5) Make medication time pleasant and upbeat.
- 6) Give your child his or her medication in the same place each day.
- 7) Identify the person who will discuss adherence concerns with the health care provider.
- 8) Prepare your child, family and school staff for body changes that might occur.

### About the author

Arlene Gerson, PhD, is a pediatric behavioral psychologist at the Johns Hopkins Hospital in Baltimore, Maryland. She has been a licensed psychologist for 12 years and has been with the Division of Pediatric Nephrology for the past five years.



## Laparoscopic Donor Nephrectomy

By David B. Leeser, MD

The 1990s were a time of much progress in the field of transplant surgery and medicine. The development of new medicines which stop rejection enabled organ survival rates to surpass 90 to 95 percent at one year, over 75 percent at three years and over 65 percent at five years. The success following kidney transplant, along with a growing waiting list (over 80 thousand patients are waiting for kidneys), that has increased waiting times for organs from donors that have died, has made living donor kidney transplants more appealing to people waiting for kidneys. However, the long, often painful recovery times from traditional operations to remove the kidney discourage many family members and friends from becoming donors.

As the success of kidney transplants improved, doctors and kidney donors became more enthusiastic about using kidneys from live donors. At the same time, most gallbladder surgery was performed using several small cuts instead of a large surgical opening. This minimally invasive technique is called laparoscopic cholecystectomy (removal of the gallbladder). The development of improved laparoscopic techniques allowed the development of a technique to also remove kidneys laparoscopically. The first laparoscopic removal of a kidney from a live donor (live donor nephrectomy) was performed in February 1995 at Johns Hopkins Bayview Medical Center and was a success. Since that time, laparoscopic donor nephrectomy has been found to be as good as the standard way to remove the kidney. Donor recovery has also improved among donors undergoing the laparoscopic operation. Most

donors leave the hospital within one to two days of the operation and can return to work within two weeks. This is compared to hospital stays of three to five days following the standard kidney removal operation and six to eight weeks of recovery before returning to work. The excellent results of laparoscopic donor nephrectomy and

Currently, two different ways for removing the kidney with small cuts are used. One way uses all small cuts to free the kidney from the surrounding tissues in the body and then uses a three inch cut in the middle of the lower part of the belly to remove the kidney. In the second operation to remove the kidney with small

*“As the success of kidney transplants improved, doctors and kidney donors became more enthusiastic about using kidneys from live donors.”*

the shortened recovery time have made the operation the standard of care for the new millennium.

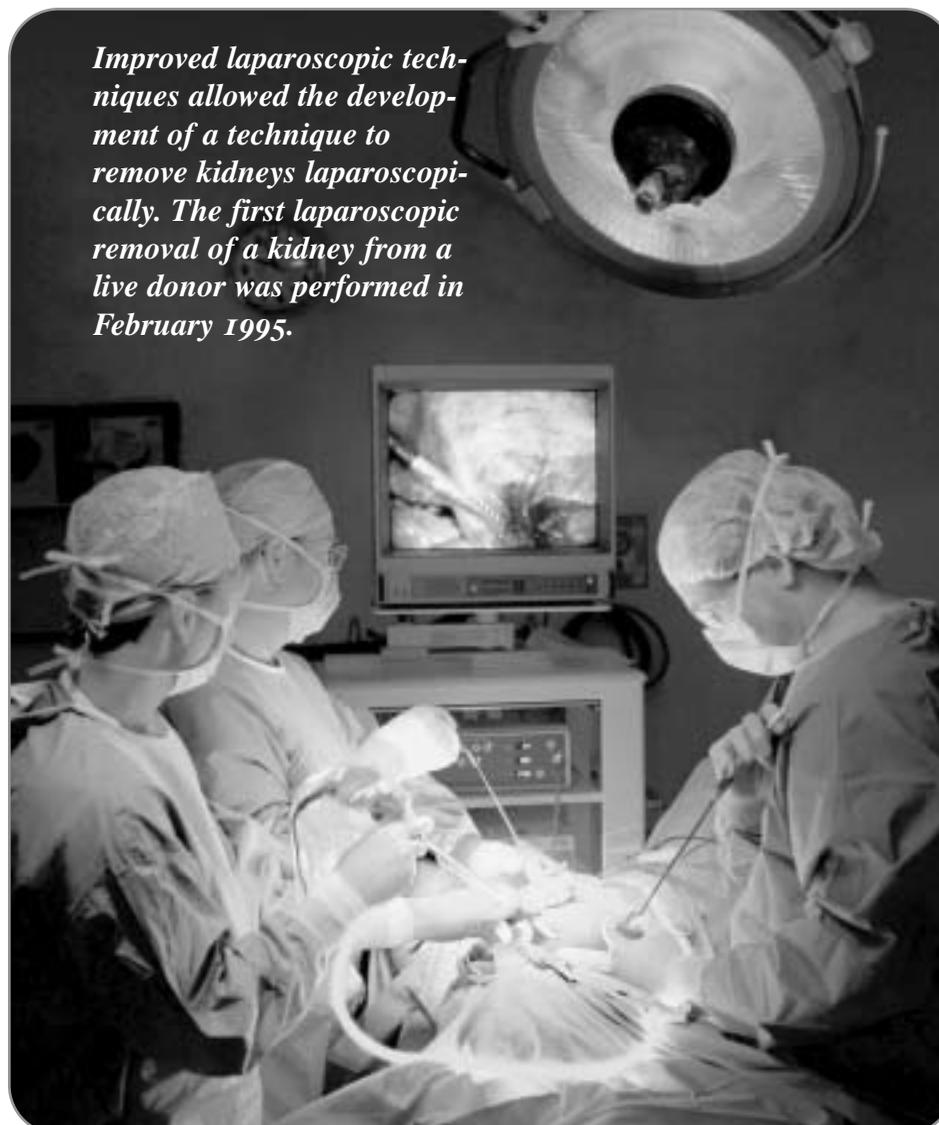
cuts, the surgeon puts a hand into the belly through the cut to remove the kidney and to help separate the kidney from

the surrounding tissues. Once it is free, the kidney is removed through the incision created for the surgeon’s hand. This second way is called the hand assisted laparoscopic donor nephrectomy and often uses a cut in the upper part of the belly.

Today, most transplant centers perform as many living donor transplants as deceased donor transplants. In addition, many people with kidney failure receive kidneys before they need dialysis and can avoid dialysis altogether. Kidney transplants from living donors can last 15 to 25 years. As for donors, surgeons continue to improve the operations to remove the kidney that will make living kidney donation safer and allow them to return to their lives more quickly. For most donors, laparoscopic donor nephrectomy is the preferred method to remove the kidney. However, each individual case should be discussed with the transplant surgeons to decide which method is best.

Information on kidney transplantation can be obtained from the National Kidney Foundation ([www.kidney.org](http://www.kidney.org)), The United Network for Organ Sharing ([www.unos.org](http://www.unos.org)) or from your local transplant hospital center. 

**About the Author**  
*David B. Leeser, MD, is the Director of Kidney Transplantation at Walter Reed Army Medical Center in Washington, DC.*



*Improved laparoscopic techniques allowed the development of a technique to remove kidneys laparoscopically. The first laparoscopic removal of a kidney from a live donor was performed in February 1995.*

The Organ Donation and Recovery Improvement Act ("ODRI," or Public Law 108-216) was signed by President George Bush on April 5, 2004. It is the first comprehensive transplant and organ donation legislation since the National Organ Transplant Act of 1984. This major milestone was made possible by the dedication of Senators Frist, Dodd, Gregg and Kennedy, as well as Representatives Bilirakis, Dingell and Tauzin. However, it is only a first step. Before ODRI can have an impact on transplantation in this country, it will be necessary to get Congress to give funding to the programs outlined in the statute, and the appropriate Federal agencies will have to map out the details for how the programs will work.

The National Kidney Foundation (NKF) has long advocated a way to repay living donors for travel and living expenses that are related to organ donation. Therefore, it is gratifying that such a program is at the top of the list of new initiatives authorized by ODRI. That priority, however, does not mean that every living donor will be reimbursed.



*"Public Law 108-216 also has provisions concerning donor registries, which are lists of those individuals who have made a positive decision concerning organ donation should they die under circumstances when they could serve as organ donors."*

When this provision is eventually put into practice, the law requires the Secretary of Health to give preference to those individuals who would be unable to cover such expenses in allocating the limited funds that will be available. Reimbursement can be

## First Major Transplant and Organ Donation Law Enacted in 20 Years

By Dolph Chianchiano, JD, MPH

*Another step toward the awareness of organ donation.*

given to individuals who have nonmedical expenses related to living donation evaluation even though they were ultimately unable to serve as living donors. The legislation does not specify how these payments will be processed. The statutory language simply reads: The Secretary of Health "may award grants to States, transplant centers, qualified organ procurement organizations...or other public or private entities" for this purpose.

The legislation recognizes the growth of living organ donation since the enactment of the National Organ Transplant Act of 1984 in other ways as well. For example, the Secretary of Health is required to submit a report to Congress by December 31, 2005, including an evaluation of living donation practices and procedures.

According to the legislation, this evaluation must include a review of issues relating to informed consent and any possible health risks associated with living donation. Another section provides the Secretary of Health with the opportunity

to "establish and maintain mechanisms to evaluate the long-term effects associated with living organ donations by individuals who have served as living donors."

A second new program authorized by ODRI will give grants to organ procurement organizations and hospitals that will put organ donation coordinators in medical centers that provide significant trauma care. However, the Secretary of Health can award such a grant only if the organization or hospital contributes at least 30 percent of the amount of the grant, in cash or "in kind" from non-Federal sources. Public Law 108-216 also has provisions concerning donor registries, which are lists of those individuals who have made a positive decision concerning organ donation should they die under circumstances when they could serve as organ donors. The Secretary's December 2005 report to Congress must include an evaluation of the costs and benefits of State donor registries, including the number and characteristics of existing State donor registries, the effect of State donor registries on organ donation rates, issues relating to raising informed consent for donation and recommendations to improve the use of State donor registries in overall organ donation rates.

The enactment of this legislation was made possible by the ability of the transplant community, motivated by the need to make more organs available for transplantation in this country, to join together to support common legislative objectives. It will be important for the community to pull together for a similar concerted effort to make the promise of ODRI a reality.



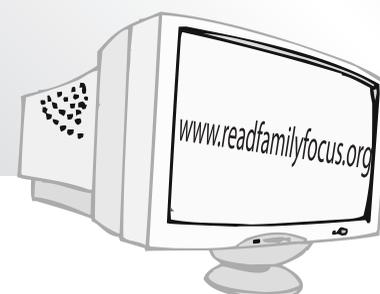
**Dolph Chianchiano, JD, MPH**

UPDATE: On May 17, 2004, the Supreme Court decided the case of Tennessee v. Lane. The court ruled that individuals with disabilities could sue a state for violation of the Americans with Disabilities Act. The plaintiffs, paraplegics confined to wheelchairs, sued the State of Tennessee for damages because they were unable to use Tennessee courthouses that were not equipped with elevators. 

*Family Focus is available on the Web.*

To find this issue or back issues of the newspaper go to

[www.readfamilyfocus.org](http://www.readfamilyfocus.org)



# End Stage Renal Disease Medicare Benefits For Kidney Transplant: The Basics

By Roberta Bachelder, MA

*What is covered by Medicare?  
How long am I covered?*

Getting a kidney transplant is a complex process, clinically and financially. Medicare does not pay for the actual kidney organs used in transplant procedures, and the buying and selling of human organs is against the law in this country! Here is a very brief summary of what Medicare pays for if someone qualifies for End Stage Renal Disease (ESRD) Medicare Part A and B benefits. This summary was taken in part from the Medicare booklet entitled “Medicare Coverage of Kidney Dialysis and Transplant Services”, which can be obtained at [www.medicare.gov/Publications/Pubs/pdf/10128.pdf](http://www.medicare.gov/Publications/Pubs/pdf/10128.pdf)

some of the costs of kidney transplant are covered, including the following: inpatient hospital stay and service, in- and outpatient laboratory tests, screening, or finding the proper kidney for transplant, full medical expenses of a kidney donor (deceased or living), doctors’ visits and immunosuppressive drugs.

Immunosuppressive drugs are transplant drugs pre-

check before you lose Medicare coverage. If you have no other resources for the drugs, review Medicaid eligibility guidelines and ask about Medicaid “spend down” if you have too much income to qualify for full coverage.

The transplant social worker and/or transplant coordinator at the hospital where you had your transplant may be

*“If you are on dialysis, you have the right to be evaluated for transplant potential, or to know the reason you are not a candidate for transplant.”*

scribed following transplant to reduce the risk of rejection of the new organ. A person who gets a transplant will need these drugs for the rest of his or her life. However, ESRD Medicare benefits, including those for immunosuppressive drugs, end after three years (36 months) after a transplant unless a person has Medicare because of age or disability.

There are a number of ways to pay for anti-rejection drugs when Medicare coverage ends. If you are a member of an HMO or if you have other types of insurance, your drugs may be covered under those plans—be sure to

able to guide you to other local sources of assistance or to large drug companies, some of which have medicine assistance programs.

For more information on the National Kidney Foundation’s efforts to eliminate the 36-month limit for Medicare ESRD beneficiaries, visit [www.kidney.org](http://www.kidney.org) and click on “Government Relations.”

If you are on dialysis, you have the right to be evaluated for transplant potential, or to know the reason you are not a candidate for transplant. Talk to your nephrologist about your options for a transplant.

## Our Pillar of Strength

By Billie Gora

There’s a beautiful day lying just over the hill,

Full of sunshine and hope for the future, yet, still,

Just out of sight, but not out of mind,

The light for our path, when the way’s hard to find.

When things don’t go right, the light at the tunnel’s end starts to wane,

Get down and crawl if need be, but on that light you must gain.

It’s a miracle you know, even at our slow pace,

Through faith and “God’s” help, we can all win the race.

Start each new day with excitement, dedication and zest,

You know that “God” is with you, so you’ll pass the test.

“He” gave all “His” children a choice of their own,

Then “He” walks right beside us so we’re never alone.

And there’s a beautiful day lying just over the hill,

We will reach it soon, if it be in “God’s” will.

Open your soul to the sunshine that’s in “His” every day,

Magnify it and spread it as you go on your way.

With a dream full of hope and a heart full of love,

We can be thankful to “God”, for “He” guides from above.

And there is a beautiful day lying just over the hill,

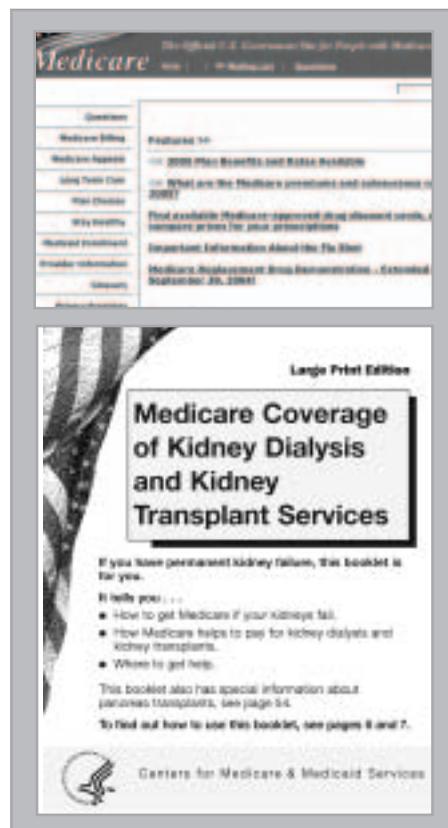
Full of sunshine and hope and “God” is with us still,

Just out of sight, but not out of mind,

“He” is our pillar of strength, when the way’s hard to find.

About the Author

Billie Gora is a dialysis patient at the Rose Quarter Dialysis Unit in Portland, OR.



If you qualify for ESRD Medicare Parts A and B,

Family Focus

a letter to  
*the editor*



*Dear Editor,*

When I was diagnosed with kidney failure, I didn't know anything about it. I had heard of it, but it was always happening to someone else, not me. I could have been prepared, because I had diabetes and high blood pressure. I knew they would lead to kidney failure, but I just would not believe that this was in my future.

But it happened, and I knew that the symptoms were pointing to just what I feared. I was shocked and afraid. I was not prepared when my feet and ankles started to swell. Nor was I prepared when the fluid continued to travel up my body, into my stomach and chest and up around my heart and lungs. I could hardly breathe and I was so weak that I could barely take a few steps at a time. My turning point came one day when someone rang the doorbell downstairs at my home. I pulled myself out of bed to answer it but was so weak that when I got to the door, the person had gone. I had to crawl back up the stairs just to lie back down. I then dialed 911. God has a way of making you listen and maybe he sent that person to the door to give me my wake-up call.

They admitted me to the hospital right away. I was put on dialysis and that day was really bad for me. I had tubes in my neck, tubes in my chest and tubes in my nose. When I was told how my blood would be pumped from my body into this machine and, after being cleaned, returned back into my body, I was very afraid. But after a few sessions, I began to feel better. I could breathe better and my body began to lose the swelling and puffiness. My eyes were not swollen shut, and I was beginning to look normal again.

I have been on dialysis for four years, going for treatments three times a week. The kidney machine has become my friend and it is always there waiting for me. I make the choice to keep my appointments.

I am not saying that I don't still have problems, because sometimes I do. Some days go well, and some days don't. Sometimes I am weak after treatment and when I start to feel like myself, it is time to repeat the process. But it's my life now, and I am very thankful for this life.

I always try to have a positive attitude and a smile on my face even when I want to frown. I see so many of our patients look so sad when they come in for treatments. I ask myself what I can do to put a smile on their faces, if just for a little while.

My nurses are great, and the techs and doctors treat me well. They seem to always be concerned and ready to help if they can. If I need to talk, there is always someone to listen and try to give me the best solutions to solve my concerns.

Now I look forward to seeing all my friends at dialysis, each and every one. Their faces are what I look for when I enter the center, and if I miss one, I'm always asking about them. The doctors, nurses, techs, social workers, dietitians, the staff at the esk and all the rest have become my family and I love them.

## MILESTONEMILESTONEMILESTONE

Vernon Johnson is on CAPD. He lives in southeast Nebraska in Bruning, population 130. Vernon started CAPD in August 2001 at the age of 84. He recently celebrated his 87th birthday. He has enjoyed working in his wood shop over the past 20 years of his retirement. Vernon is shown here with a pair of wood cutout reindeer he created in his shop. This pair could be spotted in a number of medical clinics in the area during the holiday season. They found a permanent home at the Hastings Dialysis Center for Christmas 2003.

The staff at Vernon's dialysis unit describe him as "sweet and lovable like a teddy bear."



Although he has recently been hospitalized for the amputation of a lower limb, the staff believe Vernon will be home and back in his wood shop in no time.

# JUMP START

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\*Consult your tax advisor for details.

As you may recall, there is a question that relates to the particular theme of each *Family Focus* issue posted on the National Kidney Foundation Web site. We encourage our readers to share their thoughts with us so that we can, in turn, share them with you.

The question for this issue was “How did you make the treatment decision about whether or not to pursue a kidney transplant?” Although the responses were few in number, they were heartfelt.

Two of the five individuals who contacted us stated they would not opt for a transplant. One of them began hemodialysis in 1986 and has not pursued a transplant. Her major concern was how she would react to the oftentimes potent medications those with a transplant must take to keep their body from rejecting the transplanted kidney. She shared that she felt healthy on dialysis. The other person actually had a kidney transplant several years ago, and although the kidney continues to function, she regrets pursuing a transplant. She has had multiple medical problems and lengthy hospital admissions she attributed to the anti-rejection medications. This woman resides alone, making recovery after each hospital stay all the more difficult. Also, due to one of these medical

## Dialysis or Kidney Transplantation: Is There a Right Choice for You?

By Karren King

problems, she has been forced to alter her diet, and the prospect of having a less restricted diet may be one of the reasons people elect to pursue a transplant. This person also pointed out that three years after a successful kidney transplant, unless one has

*“Most who wrote stressed that everyone must realize a kidney transplantation is not a cure; rather, it should be viewed as one of several treatment options.”*

Medicare due to Social Security disability or age, Medicare will be terminated. As a result, medical insurance coverage for such things as immunosuppressive medications and hospital and doctor visits may be problematic. Also, people who were receiving disability income prior to a transplant often find that they are no longer considered disabled after a transplant. It is no surprise that after experiencing these various disappointments and problems, depression can be a factor.

Those who elected to pursue transplant seemed to do so because it was viewed as a chance at a more “normal” life—a way to enhance quality

of life and expand the opportunities available to them. One person shared that often feeling poorly after dialysis motivated her to pursue a transplant. The importance of educating oneself prior to making the decision about any treatment option, including transplantation, was

stressed. They pointed out that those considering transplantation must take a critical look at themselves. Factors to consider are your desire to take control of your life and take care of yourself, which includes exercising and following dietary and medication requirements. One person pointed out that if someone does not stick to a medication regimen while on dialysis, this could be a “red flag” that it will continue to be a problem after a transplant, when the functioning of the kidney depends on following a strict medication schedule. It was also pointed out that individuals must be prepared for potential unexpected side effects of the anti-rejection medications, as well as less contact with the health care team; that, in turn, requires even greater personal responsibility for health and well-being. One individual shared that receiving a transplant resulted in a deeper appreciation for life, as well as a re-evaluation of life goals. Another person told us a transplant offered more freedom and greater opportunities for travel.

As one person put it, “Transplants that work are awesome!” The key here is a functioning transplant. This person has had her current transplant for 12 years but had two unsuccessful transplants prior, which resulted in a great deal of medical complications and the decision, at least for seven years, not to pursue another transplant. She is now faced with a rejection of the current transplanted organ, but is planning on having a fourth transplant with a kidney that will be donated by a relative. It is important that those considering a transplant realize that while most transplants are successful, not every one will be successful.

Most who wrote stressed that everyone must realize a kidney transplantation is not a cure; rather, it should be viewed as one of several treatment options, with its own set of responsibilities, and recipients must do all they can to take care of their gift.

Ultimately, there is no right or wrong answer for all of those with chronic kidney disease. Only you can know what is best for you. Educate yourself thoroughly about each treatment option, be it transplant, hemodialysis or peritoneal dialysis, and the advantages and disadvantages of each. Then evaluate the impact each of these would have on your life and which would be the best “fit” for you. Also, remember that the decision you make today does not have to be the one that you live with forever. People and their situations change. What works for you today may not be the best for you tomorrow. Unlike the early days of chronic kidney disease treatment, you now have a variety of options. Make one of them work for you!



### Family Focus VOICES

WE LOVE TO HEAR FROM OUR READERS, so every issue of *Family Focus* includes a special question.

Read the question below, also posted online at [www.familyfocusvoices.org](http://www.familyfocusvoices.org), and let us know what you think.

*What have you done to advocate for people with chronic kidney disease in your community, state or nationally?*

You may visit the Web site above to share your thoughts, or send your response in writing to:

Family Focus Voices

30 East 33<sup>rd</sup> Street, New York, NY 10016



# Check It Out! Kidney Transplantation Web Sites

By Bobbie Knotek, RN, BSN

Organization	Web site	Organization	Web site
<b>National Kidney Foundation (NKF)</b>	<a href="http://www.kidney.org">www.kidney.org</a> A-Z index makes it easy for you to find specific educational topics related to kidney disease and treatments. Read or print online pamphlets and fact sheets about chronic kidney disease and kidney transplantation. Find out how to join the NKF Patient and Family Council at no cost.	<b>National Kidney Foundation Donor Family Council</b>	<a href="http://www.kidney.org/recips/donor">www.kidney.org/recips/donor</a> Information about organ donation and support for organ donors and their families. Updates on the latest news and events, information on the Donor Quilt, links to message boards and more.
<b>transAction Council</b>	<a href="http://www.transplantrecipients.org">www.transplantrecipients.org</a> Patients' perspectives on transplantation for people waiting for a transplant and people who have already received a transplant. Find out how to join the transAction Council and receive the patient newsletter, <i>Transplant Chronicles</i> , at no cost.	<b>American Association of Kidney Patients (AAKP)</b>	<a href="http://www.aakp.org">www.aakp.org</a> Information about kidney failure often written by people who have kidney failure. Read or print out the AAKP Patient Plan booklets (a four part education series) to learn more about the pre-transplant workup, transplant medicines and the pros and cons of transplant.
<b>Coalition on Donation</b>	<a href="http://www.shareyourlife.org">www.shareyourlife.org</a> Education about organ donation, including what a person needs to do to become a donor, facts about organ donation and common questions about living donation. Section written in Spanish about how the organ shortage affects the Hispanic population.	<b>American Society for Transplantation</b>	<a href="http://www.a-s-t.org">www.a-s-t.org</a> Resource for education, public policy and legislation that relates to transplantation.
<b>Life Options</b>	<a href="http://www.lifeoptions.org">www.lifeoptions.org</a> Interactive Web site with "tips" on feeling better and living longer with kidney disease. Includes stories from people with chronic kidney disease who have received a kidney transplant. Includes sections on exercise, working and insurance.	<b>Kidney School</b>	<a href="http://www.kidneyschool.org">www.kidneyschool.org</a> Education and advice about how to live with kidney disease is presented in a chapter format by the Life Options Rehabilitation Program. Includes an excellent chapter on kidney transplant.
<b>Organ Procurement and Transplantation Network</b>	<a href="http://www.optn.org/resources/brochures.asp">www.optn.org/resources/brochures.asp</a> View or order brochures about kidney transplantation and kidney donation. Look for the new 106-page booklet, "Partnering With Your Transplant Team", which discusses waiting for a transplant, sources of financial support and more.	<b>National Kidney and Urologic Disease Information Clearinghouse (NKUDIC)</b>	<a href="http://kidney.niddk.nih.gov">http://kidney.niddk.nih.gov</a> Site sponsored by the U.S. government. Offers information and easy to read online brochures about kidney transplantation. Brochures can also be ordered through this site.
<b>Transplant Recipients International Organization (TRIO)</b>	<a href="http://www.trioweb.org">www.trioweb.org</a> TRIO's aim is to improve the quality of life of transplant candidates, recipients, donors and their families through donor awareness, support and education.	<b>United Network for Organ Sharing (UNOS)</b>	<a href="http://www.unos.org">www.unos.org</a> Detailed information about kidney transplantation and national transplant statistics and data. View or print their kidney transplantation education booklet.
<b>University Renal Research and Education Association (URREA)</b>	<a href="http://www.ustransplant.org">www.ustransplant.org</a> The place to look for data and statistics about kidney transplantation in the United States. On this site you can select a specific transplant program and review a report that describes the program's transplant activity and outcomes.	<b>Keep yourself informed: Review these helpful resources periodically.</b>	

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For example, many people with chronic kidney disease on dialysis develop **anemia**, a shortage of red blood cells. Anemia can make you very tired and unable to complete routine daily tasks. Anemia may also lead to more serious problems like heart disease.

An important gland called the **parathyroid** can also be affected by kidney disease, leading to a condition called **secondary hyperparathyroidism (secondary HPT, for short)**—which can cause serious problems in your bones and blood vessels.

Amgen offers an entire family of products and services to help support people on dialysis and the people who love them. Because we're not just dedicated to improving the lives of people with kidney failure, we're dedicated to protecting them.

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