The Evaluation and Process of a Kidney Transplant
by Jacqueline Harris, RN, BSN, CCTC

Anyone who has kidney failure is a potential candidate for a renal transplant. Yet, it’s important to know that the procedure comes with both advantages and disadvantages, and it may not be a good choice for everyone.

Although a transplant is not a cure for kidney disease, many people seek this procedure in the hope of no longer having to rely on dialysis. The only method of determining who is a good candidate for receiving a new kidney is to establish contact with a transplant hospital and to obtain an evaluation by a transplant physician. Evaluations are based on an individual’s medical history, current health status, and other determining factors. Only then can a prospective recipient hope to get on the hospital’s list for possible transplantation.

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Tips to Remember

Advocating for a Family Member
by Karol Franks

When our daughter Jenna was diagnosed with kidney disease, it was a huge shock to our family. The doctor said, “In 1 to 5 years, she will need dialysis or transplant.” That was the worst news ever. She was 15 years old and in (what we thought) good health, besides having what they called a “non-neurogenic, neurogenic bladder.” After the initial angst and mourning, I got busy trying to find answers and solutions to help her.

We took her to numerous appointments the month following her diagnosis. We had her examined by 3 different urologists, 2 nephrologists, 2 neurologists, and all the information came back the same. She was facing a life-long illness with no cure.

I began to research on the internet. It took a while to find help, but when I came across message forums with other patients and caregivers sharing their experiences, it was great support. So many people had been down this path before, and their knowledge was invaluable. Good sites are ihatedialysis.com and kidneyspace.com.

When it came time to begin dialysis, Jenna was a senior in high school and very sick. Life inside a dialysis unit was a foreign and frightening experience. Even though we had tried to prepare for it, I don’t think we really knew what to expect. We were fortunate to

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I have always been fascinated by the history of dialysis. A historic breakthrough in modern medicine, the dialysis machine is now in common use and has saved millions of lives. In the 1960s, access to the life-sustaining dialysis machines that we now take for granted used to be strictly rationed.

The Renal Support Network’s production of Who Lives? is a powerful and illuminating stage play that chronicles the agonizing moral decisions that were made by citizen’s committees in the 1960’s. These committees determined the lucky few who whose lives would be saved by dialysis. We are all thankful that dialysis or kidney transplantation now extends the lives of the vast majority, and not just a lucky few.

During the past four decades, I have witnessed many incredible advancements in the treatment of patients with kidney disease. I will be forever grateful for all of the people who worked tirelessly to preserve my life and the lives of the millions of others who have lived with this disease. Unfortunately, there is a widely held public perception that kidney disease is still a death sentence like it was in the 1960s, and that individuals with kidney disease are bed-ridden and cannot live a satisfying life. Nothing is further from the truth.

My personal journey may help to illustrate the humbling and rewarding paths that many with kidney disease have experienced. I was diagnosed with kidney failure as a child in 1968 and, after a few dialysis treatments, my kidneys miraculously started working again. For the next 10 years I struggled to keep my own kidneys, but at the age of twelve I suffered complete kidney failure and both kidneys were removed. For the next 12 years I relied on dialysis to survive. Although I had two kidney transplants during that time, neither was successful. One day in 1990 I headed out the door for a memorable camping trip. Amidst the mountainous beauty and fresh air I received some life-changing news—my transplant coordinator called to offer me yet another transplant! Though haunted by past disappointments and discouraging medical statistics, I decided to go for it.

My new kidney has now been working for over 18 years and I am forever grateful to my donor who gave me the gift of life. During that time I have gone to school, held several jobs, married the love of my life, wrote a book, trained a menagerie of pets, and started the Renal Support Network. Trust me when I say that I am not bed-ridden!

I encourage everyone to live their life to the fullest. We are so lucky to have options for a second chance, we need to embrace them. Take your meds, follow your health regimen, get involved and volunteer, take time to play, learn all you can about your illness and don’t ever give up on your dreams. Hope is all around us.

Chronically Yours,

Lori Hartwell
President & Founder of the Renal Support Network
Giving Away Life
by Tom Falsey

I understand that it seems like a heroic gesture to give away a kidney—especially if you have no idea who will receive it. On the surface, it may seem like heroism, but for me (and other donors I have talked with) it is not. My donation was not heroic; it was simply the right thing for me to do.

My sister-in-law donated a kidney to her son in 1990 without hesitation. This left a huge impression on me. Eight years later, live close to a well-regarded unit and she got good care. But we had to stay on top of what was going on, always reviewing her lab slips, double checking her dry weight so they would not remove too much fluid, asking questions and again, getting help from other patients.

Jenna was evaluated and accepted on the wait list for a kidney. Sadly, there are thousands of other people waiting as well. The wait time in our area was 5 to 7 years at the time, with the list growing every day. During her three years on dialysis, Jenna had about nine people offer to donate a kidney, but for various reasons they were found to be unsuitable donors. I had hoped I could donate a kidney to Jenna, but sadly was the wrong blood type. We changed transplant centers because the local one did not accept strangers as donors. We began to look for an altruistic donor willing to give a kidney to Jenna.

We went through a rollercoaster of feelings with each donor who turned out to be unsuitable. And each time I would think “What if no one else comes forward?” But then I would hear from another kind soul. It really gives you faith in mankind when strangers offer to help. You want your transplant team to be thorough in their evaluation of a potential donor. Protecting the donor while giving the recipient a new start is the goal!

Jenna is now two years post-transplant and doing great. Her donor is also healthy and back to her normal activities. There is a lot of support and hope, whether you’re the patient, caregiver, family member, or friend. The whole process can be daunting, but it’s worth it. 

To find a living donor, here is what worked for us:

1.) Set up a FREE Caringbridge site and post your story and some photos and start your journal. www.caringbridge.com

2.) Let your story be known. Email all your friends, relatives, co-workers, alumni association, fraternity/sorority, neighbors, and church that you have the Caringbridge site and ask that they get the message out that you’re hoping to find a kidney donor.

3.) Be sure to check to see if your hospital will accept an altruistic donor, not all hospitals do. If yours does, go to www.livingdonorsonline.org and read the section for transplant recipients about searching for a kidney. You can also post a “Looking for” message on the forum. NOTE: set up a separate free email account specifically for responses so you will not get spammed or give out your primary email address. It is illegal to buy organs. Use common sense when dealing with strangers on the internet.

4.) Post a plea for a donor on www.Matchingdonors.com. There is a fee, but it will be adjusted or waived for those people who cannot afford it.

5.) If you have a friend or family member who is willing to donate but is the wrong blood type, you could possibly arrange a swap through John Hopkins Hospital or consider PDN, www.paireddonationnetwork.org.

6.) If you are the patient and are too sick or overwhelmed to explore options, or don’t have access to a computer, ask someone to help do this for you.

7.) DON’T GIVE UP.

Advocating
Continued from page 1

To find a living donor, here is what worked for us:

Karol Franks lives in Southern California. She is married and a mother of 4. Her 22 year old daughter received a kidney from an altruistic donor in Jan. 2007, and as a result

Karol became an advocate for patients and living donors. She serves as an administrator for livingdonorsonline.org and ihatedialysis.com.
No one skates through life without an occasional bruise, whether it’s a learning-to-walk toddler bumping into a coffee table, a harried worker inadvertently walking into the corner of a desk, or an amateur home handyman hitting a finger with a hammer. Such occurrences are seldom a cause for concern. For those with chronic kidney disease, however, frequent and easy bruising presents problems and challenges.

A bruise occurs when small blood vessels close to the skin’s surface break. Blood then leaks into the surrounding area causing discoloration. As the body breaks down and reabsorbs the blood, the color of the bruise changes from red and blue to green and yellow. Eventually the bruise disappears.

Normal bruising is usually caused by direct trauma to the skin with resultant injury to the blood vessels. The injury sets in motion a complex domino-like series of reactions called the coagulation cascade, resulting in the clotting of blood. This chain reaction involves a host of factors including platelet activation, clotting factors that are produced in the liver and bone marrow, and even inadequate nutrition. When something goes awry with this system, abnormal bruising can occur.

The CKD population is getting older and kidney disease compounds the normal effects of aging. Capillaries become more fragile and tissue surrounding the blood vessels weakens. Skin thins and loses the fatty tissue that helps protect vessels. Changes in sweat glands lead to itchy, dry skin.

Various medications can also contribute to easy bruising.

Drugs such as Plavix and Aspirin inhibit platelet function. Surprisingly, the effects of Aspirin can last for up to two weeks after stopping the drug. Other medications like Coumadin and Heparin interfere with the coagulation cascade. Corticosteroids, of which Prednisone is one, causes skin to thin and therefore predispose to easy bruising. Don’t forget about topical and inhaled steroids either, such as those used to treat asthma. Supplements like fish oil and ginkgo can have an anticoagulant effect, too. A class of antidepressants, known as SSRIs, changes the serotonin receptors on platelets which could stimulate increased bruising. Never start, change, or stop a medication without checking with a health care professional.

In addition, good nutrition is necessary to counteract easy bruising. Vitamin C keeps blood vessels healthy, Vitamin B2 helps maintain healthy skin and Vitamin K is a vital part of the clotting process. Diarrhea, as a side effect of medication or illness, can deplete vitamins. Likewise, illness and lack of appetite prevent adequate intake of vitamins. In older persons, ill-fitting dentures, difficulty chewing, and trouble swallowing all contribute to nutritional deficiencies.

So what can kidney patients do to curtail or minimize bruising?

Meticulous skin care is paramount. Avoiding sun exposure is important. United Network of Organ Sharing (UNOS)

UNOS coordinates the nation’s organ transplant system, providing vital services to meet the needs of men, women and children awaiting lifesaving organ transplants.

Based in Richmond, Va., UNOS is a private, nonprofit membership organization. The UNOS website www.unos.org and www.transplantliving.org contain a great deal of resources and information on transplantation.

If you don’t have access to the internet you can call toll free (888) 894-6361 to receive information.
You must undergo an evaluation before you will be considered for a transplant. This process includes:

- A physical evaluation
- A psychosocial evaluation
- Financial counseling
- Laboratory tests
- Dental checkup

During the first transplant clinic visit, the transplant team will review your past medical and surgical history. After this phase is completed, the transplant coordinator will discuss with you other required tests and the transplantation process.

After examining all the information, the evaluation committee makes one of the following choices:

- A transplant is a good choice for you;
- More tests are needed, and your case will be discussed again; or
- A transplant is not a good choice for you

You will need to have several vaccinations before you get a transplant. These are:

- Diphtheria and tetanus (every 10 years);
- Pneumonia (every five years);
- Influenza (annually); and
- Hepatitis B series vaccine (recommended).

The average waiting time on the transplant list varies, but it can be two years or longer. It is important to keep in touch with the transplant center.

When a deceased donor kidney and/or pancreas becomes available, the transplant coordinator will call you. You will need to go to the hospital immediately. The transplant will take place within hours of the telephone call, so do not eat or drink anything. If you are on peritoneal dialysis, bring enough supplies to the hospital for five exchanges.

You should also know that transplant centers will often call several people on its waiting list when an organ becomes available. A call does not automatically guarantee the recipient the organ. Patients often refer to this procedure as a “fire-alarm drill.”

Before surgery, you will be admitted to the hospital. Certain criteria must be met to determine your readiness for surgery. These include a chest X-ray, an EKG, urine and blood tests, and a history/physical performed by a nephrologist, surgeon, and anesthesiologist.

Your family and friends can stay with you until you go into surgery and then wait in the surgical waiting area. The transplant surgeon will meet with them when the surgery is over.

The transplant surgery usually lasts about 2-3 hours. The new kidney will be placed in the left or right groin area of your abdomen. Your hospital stay will depend on your medical condition.

Remember that you play an important role as a member of your transplant team. The success of your transplant depends on everyone working well together. You need to learn about your new organ, your prescribed medications, and what procedures to follow after the transplant. All these factors will play a part in the longevity of your transplant.

For more information on this subject, check with your local transplant center to determine if they have a procedure manual that will help you learn if transplantation is right for you.

The Advantages
- You will not need dialysis once the new kidney begins working;
- There will be very few diet and no fluid restrictions;
- You will enjoy a more active lifestyle.

The Disadvantages
- For the first three months following a transplant, you will need to see a doctor frequently (often several times a week) and have your blood drawn for analysis. Additional frequent doctor visits will continue for as long as your kidney or kidney/pancreas is functioning.
- You will have to take immunosuppressive medications daily for as long as the organ is working, which may prompt long-term side effects, including infections and/or different types of cancers.

Read the full article Evaluation and Process of a Kidney Transplant and other articles about transplantation on www.KidneyTimes.com

Kidney Transplantation

EasyLink #197
How Can You Care For Your New Kidney Transplant? EasyLink #124
A Roundup of Anti-Rejection Medications for the Kidney Transplant Patient EasyLink #109
Kidney Transplant
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I was given the chance to question doctors one last time before surgery. Two and a half hours after my operation began, I was taken to the recovery area. Shortly after, I returned to the 11th floor, which was my home until I transferred to Northwestern’s Galter/Carriage Outpatient Pavilion on Monday, April 3, where I stayed until April 10.

Kidney Transplant

My father and I both went through physicals on Wednesday, March 29, to ensure we were still in good health. We both checked out.

The time finally came to see my dad off. Needless to say it was really hard. The real breakdown didn’t come until I returned to my room.

I finally realized what was happening. For months we both couldn’t wait for the day to arrive. We just saw it as something that had to be done—almost like a business transaction. I think my dad and I were both pretty oblivious to the feelings involved. From that moment on, I knew my relationship with my father would never be the same.

I’d been told I would be up and walking the day after surgery; what I didn’t realize was how painful that task would be. Within hours after my father’s surgery, he was walking around the hospital floor. Nurses had me sitting in a chair that night, also. By Saturday, we were told it was imperative for us to sit up and walk around in order to heal.

I was watching the Michael Douglas film, The Game, recently. At the end, his brother, played by Sean Penn presents him with a t-shirt emblazoned with “I was drugged and left for dead in Mexico and all I got was this t-shirt.” Of course, besides the t-shirt, he also earned a little more of my love and appreciation.

More photos can be seen at www.johnfmartin.net
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Dr. Alan Koffron and Dr. Leventhal use four
laparoscopic instruments to define and dissect
the blood vessels of my father’s left kidney.

My heavily medicated father entertains my stepmother,
Patty, just moments after regaining consciousness.

The easiest time I’ve ever
had falling asleep. After I
“dozed” off, a tube was
placed down my throat so my
breathing could be controlled
throughout the 2.5-hour
operation. Thankfully it was
pulled back out before I
regained consciousness.

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around the hospital floor. Nurses had me sitting in a chair
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John F Martin was 7 years old when
he was diagnosed with Alport’s Syn-
drome. It wasn’t until 1998 that his
kidneys began to fail. In 2000 John
received a kidney transplant from
his father. In April John celebrated
his 9th anniversary of his trans-
pant. John lives in Michigan with
his wife, Sara and their 1-year child.
Donors do not have to be biologically related to their recipients. In fact, more than 40% of living donors are not related biologically. Friends, church members, acquaintances and yes, even total strangers are stepping forward and giving the gift of life. The first step in becoming a donor is the knowledge that a problem exists. How can someone offer you a kidney if they don’t know you need one?

Tom Falsey lives in Shawnee, Kansas. He is the author of “Giving Life, Inspirational Stories of Hope for Organ Donors and Recipients.” He has served on the Boards of Directors of the United Network of Organ Sharing and the National Kidney Foundation serving Kansas and Missouri.

Chronicly Happy
Joyful Living in Spite of Chronic Illness
by Lori Hartwell

If you’ve recently been diagnosed with a chronic illness, the life you previously knew has been turned upside down. Chronicly Happy acknowledges the frustrations, concerns and fears that you face and provides you with insight on how to overcome these obstacles.

Visit Amazon.com to purchase Chronicly Happy: Joyful Living in Spite of Chronic Illness.
Or call 866-903-1728
$12.95 plus shipping & handling
The Surprise Gift of Life
by Julie Gentile

For those of us suffering from kidney disease and in need of a kidney, we know what the gift of life is. We hear it from every organization regarding living donation and know firsthand what an impact it would make on us as a group, us as individuals, and our families who suffer right alongside of us. But, what if our kidney disease gave the gift of life?

I am a 35 year-old female from South Hadley, Massachusetts. I have been on dialysis for 18 months. At the beginning of January, I was scheduled to receive a kidney from a lifelong friend of mine. Instead, he received the gift of life from me in a way.

Gift of Friendship

Kurt and I have been friends forever. Our families were close when we were growing up so we saw each other a lot. Back in September, 2008, he called me from his home in San Diego, California and told me he would like to get tested to see if he could give me his kidney. He said he and his wife, Kendra, had researched the procedure and they wanted to see if he would be a match. So, the testing began in San Diego. Kurt and I were a match and he proceeded to undergo all of the required tests sent to California by my transplant team here in Massachusetts. Everything came out fine and the transplant was scheduled for December 3, 2008. One final test, a CT angiogram, was scheduled for Kurt when he came home to Massachusetts for the surgery.

Out of Sight/Out of Mind

On November 25, 2008, the CT angiogram detected a small cyst, about a millimeter wide, on the underside of Kurt’s left kidney. We both met with the surgeon who didn’t seem alarmed by the cyst, but did say it would have to be biopsied once it was removed to be certain it wasn’t anything to be concerned about. He said there was less than 1% chance that it was an abnormality. Both Kurt and I felt it would be nothing and put it out of our minds for the next week.

Not to Be

On December 3, 2008, we checked into BayState Medical Center in Springfield, Massachusetts to have the transplant. Kurt went in and they successfully removed his left kidney and biopsied the cyst. After 3 renal pathologists reviewed the tissue, it was determined that the cyst was actually the beginning stages of renal cell carcinoma, or renal cell cancer. The transplant was off.

A Happy Ending

From what we have been told, renal cell cancer is rarely detected so early. Had the kidney not been removed or been transplanted, one of us would have likely died in 7 to 10 years. Thankfully the cancer originated in the kidney and has now been removed, leaving Kurt cancer-free and me happy to have helped my friend.

The gift expected that day was for my friend to give me the gift of life and for me to be able to receive it. However, as happens in life, it didn’t turn out the way we expected it or planned it. The package may have been shaped differently and the wrapping a little bit off, but the gift was far more precious between us as friends. I never expected to be helping my friend save his life by my having kidney failure. How wonderful a surprise for the both of us and our families!

2009 KidneyTimes Essay Contest

“What Helps You Live a Joyful Life In Spite of Kidney Disease?”

Announcing the 2009 KidneyTimes Essay Contest.

Accepting submissions March 1st - August 31st 2009. To submit an essay you must have been diagnosed with chronic kidney disease (CKD). Essay length should be between 400-750 words. Please include your full name, mailing address, phone number and e-mail address at the top of the essay. Essays must be typed and may be submitted via e-mail MS Word document attachment (preferred), mail, or fax—see addresses below. Submissions will be judged on their relationship to the contest theme, originality, creativity, and technical expertise. Essays may be submitted in English or Spanish. All essays become the property of the Renal Support Network. For more information and contest rules visit RSNhope.org or KidneyTimes.com.

Send essays to:
essay@RSNhope.org
KidneyTimes Essay Contest
c/o Renal Support Network
1311 N Maryland Ave
Glendale, CA 91207
Fax: 818-244-9540
For questions call (toll free): 866-903-1728

Julie’s renal story began at 24 weeks pregnant with her son, Anthony in October 2001. She delivered a healthy baby in February 2002 but was officially diagnosed with kidney disease in March 2002. Julie began dialysis in June 2007. On February 4, 2009 Julie received a kidney from a close friend. She is doing well at her home in South Hadley, Massachusetts.
Bruising
Continued from page 4

lessens damage and drying. Bath water should be warm, not hot. Use unscented soaps and pat skin dry. To seal in moisture, apply moisturizer while the skin is still damp. Never use alcohol-based products or abrasive body scrubs. Wearing long-sleeved clothing can offer good protection, too. Keep nails short, clean, and smooth to forestall scratching injuries.

Use common sense to head off accidents that could result in bruising. Be alert to hazards in the environment. For those prone to falls, use assistive devices such as walkers or canes. In health care facilities, be careful to avoid bumping bed rails. Keep elbows and hands tucked when being transported by wheelchair. Both diabetics and non-diabetic kidney patients may suffer from neuropathy which may lessen the sensation of painful injuries.

Check skin regularly and, most importantly, report frequent and easy bruising to the physician. Although bruising is a frustrating problem for kidney patients, understanding some of the causes and preventative measures can help minimize the risks and complications.

Reference

Denise Eilers is both a healthcare professional and family member. Her husband Jerry was on traditional home hemodialysis (three days per week) from 1980 until his death in October 2004. Denise is a volunteer with Genesis VNA Hospice in Davenport, IA, where she resides. She also teaches nursing fundamentals at United Township Area Career Center in East Moline, IL.
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Book Review

The Gift that Heals
Reviewed by Julie Glennon

The Gift that Heals: Stories of hope, renewal and transformation through organ and tissue donation
By Reg Green
184 pages

Lives consumed with illness and suffering can be miraculously restored by the gift of organ donation. The Gift that Heals by Reg Green is a compilation of stories about ordinary people who live day to day waiting and hoping for improved health. Throughout the book we meet heroic folks in life and most times in death who transform the lives of others—most times a stranger, by being an organ donor. Such is the case of this author who lost his son, Nicolas, in a tragic event while vacationing in Italy. This accident resulted in 7 Italian recipients receiving organs and tissue from his son.

Another such story took place on September 11, 2001. A young 13 year old boy, Will Dean, was unfortunately brain dead after shooting himself. His family decided to donate his organs. While 4 recipients had been prepped for surgery, the FAA grounded all civilian flights because of the events of 9/11. Through a series of dramatic events, a special exemption was granted and Will’s organs were flown by helicopter to downtown Seattle.

A fireman trying to save lives is burned terribly. Through tissue donation he received skin grafts that helped ward off infection. He now speaks on behalf of an organization for burn survivors—sharing the miracle of organ and tissue donation.

As a person with kidney disease waiting for a transplant, I knew that someone had to die for me to get a second shot at life. The generosity of one person, one family, is why I feel good today. I am forever grateful for the gift I received December 15th 1999. I frequently think of the courageous families that have to make this extremely difficult decision during such a tumultuous time in their life. Many families explain that they do feel some peace knowing that their loved one is living on by improving the lives of others; organ donation really can revive marriages, careers and passions.

I think the note Reg Green received from a lady in Rome sums it up best—“Since your son died, my heart is beating faster. I think that people, common persons, can change the world. When you go to the little graveyard place please say this to him, ‘they closed your eyes, but you opened mine.’”

Julie Glennon received a successful kidney transplant in 1999 after being diagnosed with both lupus and chronic kidney disease in 1988. She keeps active by volunteering with The Kidney Association of South Florida. She is also a weKAN patient activist and HOPE-line operator with the Renal Support Network. Julie and her husband live in Florida.
In this issue of Live & Give...
Stories of Kidney Transplantation

Spotlight On You

A Kidney Transplant in Pictures
A Photojournalist Chronicles his Surgery
by John F Martin

My dad and I woke up around 3 a.m. Friday, March 31, and we made the short walk to Northwestern’s emergency room, where we waited to be admitted. Accompanying us were Erik and Miranda, two of my best friends and photographers of the story. My dad’s surgery didn’t begin until around 9 a.m. Hours passed before we heard his operation was taking a little longer than expected, simply because his adrenal gland was more tightly stuck to his kidney than most people’s.

A little before 2 p.m., I was wheeled from my room on the 11th floor to the operating room on the seventh, where

Continued on page 6