30 YEARS & Counting

By Pat Koppa

I COULDN'T WAIT TO OPEN THE MAILBOX. I reached in and grabbed the unique birthday card. It was neatly addressed to my kidney and was from my father, Cy Koppa, of Mosinee, Wisconsin.

My 79-year-old father has done this every year in commemoration of the day he donated his kidney to me. This year's card was special because it's been 30 years since my transplant. From 1975 on, the cards have been accompanied with amounts of money corresponding to the number of years since the transplant. Each card from 1975 on had money enclosed for the number of years since the transplant. I received $30.00 this year, and I intend to get richer!

I remember my surgery as clearly as if it had happened yesterday. When I returned from the recovery room at Methodist Hospital in Rochester, Minnesota, I saw my Dad slowly circling the nursing station. He came into my room holding something more than his catheter bag behind his back. He walked up to the bed and he handed me a replica of a doll I played with as a toddler. He looked me in the eye and said, “Fathers are the luckiest people in the world because they have daughters.” Then he added, “I'm the luckiest father in the whole world because I gave birth to you—twice.”

My dad retired from his job as a letter carrier 11 years after the transplant. Now he enjoys daily walks, bowling twice a week, and spending time with his companion, Betty, traveling, going to concerts and attending community events together. I've often joked with my friends that Dad's social life is more active than mine!

An inspiration to family and friends, Dad's positive attitude is infectious and I'm convinced that laughter really is the best medicine. I was “incarcerated” in Methodist Hospital for six months after my transplant because I needed three operations to repair bladder fistulas. My parents, three siblings, friends, health care providers and many kind strangers helped me break out of the hospital.

My professors at the University of Wisconsin Madison even allowed me to finish classes and final exams over the telephone. I completed my senior year in journalism while I was still in the hospital.

Continued on page 12
THE EDITORIAL BOARD of the NKF Transplant Chronicles wishes you and your families the happiest of holidays! What an exciting time of year this is. It is a time often spent with friends and family to celebrate new beginnings and possibilities. It is a time to reflect upon the things that have happened during the past year, to learn from them and to move forward. It is a time where many of us make resolutions to improve. No matter where you are on your walk through life, I would like to leave you with two thoughts. The first is from author Margaret Lee Runbeck: “Happiness is not a state to arrive at, but a manner of traveling.” No matter what happens during the next days, months and years we can choose the attitude we carry with us. I challenge you to do it with happiness and see what a difference it will make in your life and the lives of others. The second thought comes from Mother Teresa: “Let no one ever come to you without leaving happier.” Wouldn’t that make this New Year a year to remember?

Best Regards,
Laurel
on behalf of the editorial board

transplantchronicles@kidney.org

let your VOICE be HEARD

What advice would you give others about handling natural disasters and other types of emergencies?

Log onto www.recipientvoices.org and let us know!

A Few of the Recipient Voices Responses to:
What Are Your Best Tips for Remembering to Take Your Meds?

- “I bought a cheap watch at Target, for about $20, which has two settings for a timer to go off at the times I take my meds. They are pretty quiet and pretty unobtrusive. It works great for me.” — Kathie Hild

- “I have a picture of my granddaughter on my mirror, and in her smiling face I see the constant reminder to take my medicine.” — Charles Dawson

- “On Sunday morning, I fill my med container for the whole week and leave out Sunday’s container. Then, on Sunday night when I take my evening pills, I take out Monday’s for the next day. Before my transplant I did not even take vitamins, so this was a challenge for me. Now I am religious about taking my meds.” — Kathie Wing

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Editor’s Note

The last issue of Transplant Chronicles included an article entitled “What About the Kids? A Heart Transplant’s Challenge.” We failed to include a short bio about the author Jim O’Donnell! Jim O’Donnell is a published author. His works include “Letters for Lizzie,” the story of a family’s heart transplant odyssey. For more information on this publication contact the NKF.
SARA IS FINALLY ADMITTED for her liver transplant. Of course, she's very frightened at the thought of such a major operation. She wonders, “Will it work?” “Will I make it to recovery?” “What about my family and friends?” Thankfully, everything goes smoothly and she has a second chance at life with a new liver. Having gotten this far, she now faces the daunting challenge of taking immunosuppressive medications that will hopefully prevent rejection. The risks involved are nearly as great as they are in the operating room. Is this the best medication? Is this the best dose? How will this medicine make her feel? The choice and dosage of medications in Sara's blood must be precise. Too little medicine, and her new transplant could be lost to rejection. Too much medicine, and unwanted side effects, including headaches, heart or kidney disease and infections, could occur.

How do Sara's doctors know what choices to make? They rely on the experience they have had with other patients or have read about in medical journals to help make these tough decisions. Sara's doctors will start with medicines that are potent enough to make sure her liver is working well and to be certain that the amount of medicine in her blood is within a desired range. But, because so many things can influence Sara's medicinal needs, this process involves a large amount of trial and error.

What if the medicines and doses could be specifically designed for Sara and not for most cases? This may be a part of the future of transplant medicine. Research is currently being done to look at how individuals differ from one another in their needs for and reactions to specific immunosuppressive medications, based on their genetic makeup or DNA. This new field of research is called pharmacogenomics.

The concept of pharmacogenomics recently made news in other fields of medicine. Earlier this year, the U.S. Food and Drug Administration (FDA) approved a new drug called BiDil. BiDil is a medicine specifically designed to treat heart failure in people with African American ancestry. Clinical studies suggested it reduces the risk of death among African Americans by 43 percent. This drug, however, was not as effective with other groups. Why did the drug work better for persons of this particular ancestry? Researchers have noted differences in DNA. Based on this information, heart doctors can make selections among heart failure medicines based more closely on the individual rather than most cases.

Pharmacogenomics is not limited to ancestry. It goes further. In other research, oncologists have discovered that some types of breast cancer have large amounts of a unique protein (Her-2/neu) on the surface of the cancerous cells. The presence and amount of this protein is determined by the genetic makeup of the tumor. If a patient has this protein on her cancer cells, doctors will choose medications that will work better for her cancer. If she doesn’t have this protein, they will select a completely different drug. Again, this is an example of choosing medicine more for the individual, as opposed to a choice made based on most cases.

Transplants like Sara's will be treated differently with pharmacogenomics in the future. Upon being listed for transplant, and possibly months before being admitted, the transplant team will draw blood and submit it for DNA testing. Immunosuppressive drugs compatible with the patient's genetic makeup will be selected. To select the best drugs, they will look at many genes, including those that affect how a body metabolizes drugs. The patient may metabolize drugs quickly and would therefore require higher doses to get the best effect. This may be compared to the person who can eat more, but always remains thin. Nevertheless, there are those who metabolize drugs slowly and don't need quite as much to get the desired results. Such people...
BK VIRUS and TRANSPLANTATION

By Debra Tarara, RN, CCTC

The BK virus belongs to the human polyoma virus family. It was discovered in 1971, and can be found in all geographical areas.

The virus was named “BK” after the initials of the kidney transplant recipient in whom it was first identified. Initial contact with BK virus usually happens in early childhood. The majority of the population in the United States has developed an antibody to it by the time they are adults. The mode of transmission of the virus remains uncertain. There is some evidence, however, that it may be passed through bodily fluids, including donor organs.

AFTER A PRIMARY INFECTION, the BK virus settles into the cells of the renal system where it lies dormant and usually does not cause a complication. The virus may be, however, awakened when the immune system has been compromised. Numerous studies have pointed to the newer and more potent immunosuppression medications as a possible explanation for the increased incidence. Although BK virus can be seen in a variety of immunosuppressed states, it is most common in kidney and bone marrow transplantation. BK virus activity can be detected by checking a urine sample for “decoy cells” or taking a blood sample that requires special testing. A kidney biopsy must be done to make the final diagnosis to determine if the virus has affected the transplanted kidney.

PRIMARY INFECTION OR REACTIVATION of dormant BK virus in the kidney transplant population usually occurs within the first 3–14 months following transplantation, but cases have been reported in people who have had their transplanted kidney for many years. Approximately five percent of kidney recipients will have BK virus in their transplanted kidney. There is no specific treatment that has been proven effective in all cases. Nevertheless, lowering the doses of immunosuppressive medications allows the body to use its natural defense system to try and control the viral load. Unfortunately, this strategy may also increase the risk of graft rejection. Some studies have shown that using an intravenous antiviral medication such as Cidofovir, or human immune globulins (IVIG), may have an impact on BK virus activity.

EXAMINING BLOOD AND URINE tests for BK virus at scheduled intervals in the post-transplant period may result in early detection. Many transplant centers have now incorporated routine screening for BK virus, in an attempt to detect its presence before the creatinine level is affected. Current treatments aim to carefully balance control of the virus while preventing rejection of the graft. If a kidney is lost due to damage from BK virus, re-transplantation is generally successful, providing the viral counts in the blood are negative at the time of the surgery. Research is ongoing to learn more about this disease, identify those at risk, and improve treatment options.

Katrina and Rita Relief

THOUSANDS OF VICTIMS OF HURRICANES KATRINA AND RITA face homelessness and devastation, but kidney patients without access to dialysis treatment face life-threatening danger in addition to loss of property.

To help patients in the affected areas get the services they need, the NKF has created a relief resource network posted on www.kidney.org, offering dialysis locations and treatment information, other direct patient assistance and information for health care professionals interested in volunteering for the effort.

“We are very gratified by the terrific cooperation we have seen by everyone involved in helping our patients deal with this disaster. National Kidney Foundation Affiliates, other kidney organizations, the large dialysis organizations and the kidney-related industries have all worked hard and closely together on behalf of the people who are suffering,” stated John Davis, CEO of the NKF.

To contribute to the Foundation’s Patients Hurricane Relief Fund, visit www.kidney.org or mail checks to the National Kidney Foundation Patients’ Hurricane Relief Fund, 30 E. 33rd Street, New York, NY 10016. One hundred percent of funds contributed to the Relief Fund will go directly towards patient assistance.
AFTER GETTING A DIAGNOSIS of diabetes–related kidney failure at the age of 37, I hoped for a kidney transplant. When my insurance approved an evaluation, we were very excited.

That excitement didn’t last long. The first thing they had me do was step on the scale. My weight at that time was around 350 pounds. At 6’4” tall, that gave me a BMI of 42. The University of Arizona transplant team said that I needed to lose about 70 pounds before they would even consider a transplant. They ended the evaluation at that point, shook our hands and sent us on our way. That had to be one of the biggest disappointments of my life.

Back home, I went back to dialysis and tried to diet enough to lose the weight. Life went on and I didn’t progress with my weight loss very well. At the beginning of 2003, I was informed that Banner Good Samaritan in Phoenix had become the transplant center that my insurance used. I was encouraged to have them evaluate me, and this led me to believe they might have had different requirements. Again, I was told that my weight was too high.

At that point, I still weighed 350-360 pounds. Due to the kidney failure and dialysis, I had no energy. I had two artificial legs, and exercising was a difficult chore. There weren’t many things that I could do. We began reading up on gastric bypass surgery and attended a seminar on it. After speaking to all of my doctors about it, everyone thought it would be my best bet for losing weight. They all wrote letters on my behalf to the insurance company, and they agreed to cover the surgery. We scheduled the surgery for May 29, 2003.

The day of surgery finally came. My top weight before the surgery was 385 pounds! I had done the usual fasting before surgery and reported to the hospital that morning. About halfway through the surgery, the doctor was concerned because I continued to belch. He decided to insert a scope down my throat to take a look in my stomach. It should have been completely empty, but it was not. Apparently I had yet another complication of diabetes, gastropareises! This condition causes the stomach to empty at a much slower pace than normal.

Dr. Newhoff decided that if he had gone ahead and completed the gastric bypass surgery, my condition of gastropareises would have caused me to be constantly sick, throwing up all the time. He removed the gall bladder, but he left my stomach alone, and sewed me back up again. I was devastated and ready to give up. My wife, Kathy, helped me get through this time. We decided that since we were all psyched up for the new bypass diet, we would just pretend that I had the surgery and I would eat tiny, protein-filled meals spread out through the day.

We came up with an eating plan that was high in protein and vegetables, and low in simple carbohydrates. We met with a dietitian to review the meal plan, and her only suggestion was that I add a piece or two of fruit a day. I have stayed on that meal plan since June of 2003 and have lost a total of 110 pounds! I reached the plateau of around 275-280 pounds after about 12–15 months on this diet, but have managed to keep the weight off.

My stepdaughter, Veronica Philpot, decided she wanted to donate a kidney to me. Veronica met with the transplant team and they completed a full evaluation to see if she would be a good match, and to make sure that she was ready to make this lifelong commitment. I had mixed feelings about her offer. I was concerned that she was only 22 years old, and wondered if I was asking too much. She told me that she was so committed to donating a kidney and that if we weren’t a match, she wanted to donate anonymously to whoever needed a kidney. That was enough to convince me that we should go ahead.

The surgery took place on April 6, 2005. Veronica and I had a bet to see who would be able to visit the other’s room first. I lost that bet, but was relieved to see that Veronica was doing so well. She was released four days after surgery, and I was released the following day.

Now we are about four months post-transplant, and so far everything is going well. Veronica went back to work less than two weeks after surgery. I am settling in to my new routines and looking forward to spending the summer with my youngest daughter Jenna, who will be 16 in July. My message to anyone out there who is facing the weight-loss obstacle is that it can be done if you are dedicated and have the right kind of motivation. I thank God for my family and the support they have given me. I would not have been able to do it without them.

Patients should always check with their medical team prior to embarking on any change of diet (as high protein diets might not work for liver patients).
I finished my treatment, the devastating effects of this disease ever since.

AFTER THE FIRST YEAR, I became extremely ill. My doctor decided to give me infusions of a very strong medicine with side effects that caused my hair and eyelashes to fall out, and my fingernails and toenails to fall off. It was terrible. I only took this medicine for about nine months, but by the time my name is nancy robes

I'm 25 years old, and the mother of a beautiful five-year-old boy. Unfortunately, my doctors diagnosed lupus nephritis when I was 17, and I have been dealing with many complications of this illness ever since.

My Name is Nancy Robles

I felt so ugly and sick that all I wanted to do was to die. Then, five years ago, I started having problems with my kidneys. My doctor discovered that I had a very high level of creatinine in my urine. The months passed and kidney started shutting down. Now I am on dialysis. I go every other day for three and a half hours to keep my body clean from all the toxins. As all of us know, our kidneys are the filters of our body and, when they don't work properly, the solution is dialysis. It does the job of getting rid of the “dirt” for us.

THANK GOD FOR THE TECHNOLOGY and for all the people who make it possible for a person like me with kidney failure to continue living.

NOT EVERYTHING IN MY LIFE IS BAD. God gave me a beautiful gift when he gave me my son. He's the strength that I need to keep going and to stay positive, even in the worst situations. His little smile gives me the focus to keep fighting back against this terrible disease. My baby gives me energy to pursue a better life.

I recently started a jewelry business after achieving success selling “Mary Kay.” It's the best decision I ever made. This business gives me a chance to sell and earn a profit. Now I get to meet women from different situations and have gotten back the self-esteem that I lost after I became ill and my appearance changed so dramatically. Thanks to the interactions I have with other women of all ages, I now realize that all of us go through much heartbreak in life and sometimes we don't understand why or how.

THE MOST IMPORTANT THINGS I have learned are the importance of loving and accepting myself the way I am, and to try to enhance that potential we all have to look and feel better.

Nancy Robles lives in New York with her son and sister, and hopes to receive a kidney transplant one day.

Understanding Skin Cancer

By Ervin Epstein, MD

You may remember reading in the Summer 2004 Transplant Chronicles about our NIH-funded Study in which we are trying to understand exactly why organ transplant recipients develop so very many skin cancers. We will soon begin the third year of our research and now have new easier-to-remember contact information. Our new toll-free number is 888-NMSSCURE [for “Non-Melanoma Skin Cancer CURE”] (888-667-2287) and our new email address is nmsscure@derm.ucsf.edu. So far, nearly 400 persons have contacted us to find out more and to offer help. We greatly appreciate each and every response. Unfortunately, we need about 1000 participants with non-melanoma skin cancer as well as 1000 without non-melanoma skin cancers so we have a very long way to go to reach our goal.

Therefore, we are asking again for your help. All we need you to do is let us know your name and contact information. We will send you a short questionnaire and, if the information you provide indicates that you can help us help advance the research, we will have you ask your lab the next time you have blood drawn to take a bit extra and send it to us. There is no cost to the participants. We will pay the lab fees, handling and shipping.

Many participants have asked us how our study is coming along. Actually, as you see from the above plea, we are still in the collecting phase, and real answers are down the road. However, we hope that the work we do will serve as a building block for real progress in this area. We thought you might be interested in some facts about your fellow transplant recipients who have been good enough to participate in the study. The results of the study will be publicized.

Our youngest participant is 31 years old and is now eight years post-transplant; our oldest is 84 and 11 years post-transplant. The vast majority are aged 50–64; those 65 and older comprise the next largest group. We have 14 people who have had their transplants for 30–39 years. Most of our study participants have had kidney
UNOS won’t compete with donor matching Web sites; will provide information for people considering live donation

The United Network for Organ Sharing (UNOS) decided in late June 2005 that it will not develop its own Web site which would have included listing patients in need of a kidney transplant and individuals considering live kidney donation. The decision not to compete with existing Internet listing programs such as Matchingdonors.com and livingdonorsonline.com was arrived at after an intensive month of fact-gathering. Robert Metzger, MD, the outgoing OPTN/UNOS President, pointed out that it was UNOS/OPTN’s duty to oversee the entire system and act in the public interest. “We also need to maintain the public trust in the national transplant system, and to ensure that candidates are considered equitably,” he said. “Ultimately, it’s up to the individual transplant center to ensure that the donor is medically suitable, understands what’s involved and has a proper motivation to donate.”

The board adopted the following recommendations:

☑ Provide comprehensive resource information to support prospective live donors, including medical criteria for who can donate and individual transplant institutions’ protocols for live unrelated donation. The OPTN will not participate in efforts to solicit living donors for specific transplant candidates.

☑ Develop a nationwide mechanism to allocate organs from live non-directed donors (those wishing to be a living donor without naming a specific recipient).

☑ Encourage transplant institutions to inform prospective live donors about the principles of the organ allocation system.

“This is a complex and evolving issue,” Metzger said. “We want to do all we can to meet the needs of transplant candidates through living and deceased donation. But with live donation, we also want to ensure that the potential donor has valid, complete information and is not exploited in the process.”

Senator Frist breaks with President's stem cell funding policy; now favors expanding Federal funding

Returning to a position many in the medical and scientific community wished he’d never left, Senate Majority Leader and transplant surgeon Bill Frist, MD, (R-TN) announced on July 29 he is parting ways with President Bush, and now favors expanding federal research for embryonic stem cell lines that existed prior to August 9, 2001. The number available was believed to be 78, but recent reports say only 22 lines are eligible and they are becoming less stable.

“While human embryonic stem cell research is still at a very early stage, the limitations put in place in 2001 will, over time, slow our ability to bring potential new treatments for certain diseases,” Frist said. “Therefore, I believe the President’s policy should be modified. We should expand federal funding (and thus NIH oversight) and current guidelines governing stem cell research, carefully and thoughtfully, staying within ethical bounds.”

World Day for Organ Donation and Transplantation observed October 14, 2005

The first-ever World Day for Organ Donation and Transplantation was observed in Geneva, Switzerland on October 14, 2005. The day, which featured a series of lectures and special events, was organized under the patronage of the Council of Europe, in association with the ESOT (European Society of Transplantation)/ETCO European Transplant Coordinators Organization and the World Health Organization (WHO). Political, economical

Continued on next page
and medical issues were discussed by invited speakers and patient organizations from around the world. Some of the topics included quality of life after organ transplantation; sport, rehabilitation and organ donation; and access and regulation of organ transplantation, a global perspective.

At the end of the day, attendees participated in the launch of an international donor card, and a ceremony announcing that Argentina will be the host of the second World Day for Organ Donation and Transplantation in 2006.

**Breakthrough Collaborative's new goal is to end patient deaths on transplant waiting list**

The U.S. Federal government has set its sight on a large target—reducing the number of people who die while waiting for an organ from the current 17 every day to zero. To reach this ambitious goal, the Organ Donation Breakthrough Collaborative (ODBC), implemented in 2004 by the Department of Health and Human Services (HHS) Health Resources and Services Administration (HRSA), is turning its efforts to increasing the mean number of recipients transplanted per donor from 3.06 (the 2004 mean) to 3.75 or higher.

**Here are some of the increases projected by HRSA to occur in the next 10 years (2004–2013) as a result of the Collaborative:**

- An increase of annual deceased donor organs by 100 percent.
- An increase of annual non-cardiac death donors by 333 annually.
- An increase of annual cardiac death donors by 175 annually.
- An increase of average annual number of organs transplanted per non-cardiac death by 0.08 percent.

- An increase of average annual number of organs transplanted per cardiac death donor by 0.08 percent.

**Rodent virus responsible for the deaths of at least six organ transplant recipients in past two years, CDC says**

At least six organ transplant recipients in the U.S. died after being infected with lymphocytic choriomeningitis virus (LCMV), a virus rarely found in humans but transmitted by rodents, such as hamsters and mice. LCMV seldom causes problems for healthy people, but in immunosuppressed patients, infection can be serious, and even fatal.

Four people—two from Massachusetts and two from Rhode Island—received organs donated by a Rhode Island woman who died from an embolic stroke in early April. Within weeks, three of the recipients died. The fourth patient, who received a kidney, was treated with an anti-viral drug and is recovering. The donor's organs were tested for several infectious diseases, but not LCMV, a viral infection she got from an infected hamster she bought three weeks before her death, the *Boston Herald* reported. The woman's infected kidneys, lungs and liver were transplanted in four people and three died within three weeks. The transplants were performed at Massachusetts General Hospital, Brigham and Women's Hospital in Boston, and Rhode Island Hospital in Providence. The victims included a liver recipient and double-lung recipient from Massachusetts and a kidney recipient from Rhode Island. Two patients received corneas from the donor but have been asymptomatic.

Following the deaths of the New England recipients, health officials in Wisconsin revealed that four transplant recipients died in December 2003, the only previously known cases involving the virus, the Associated Press reported.

James Kazmierczak, an epidemiologist for the Wisconsin Department of Health and Family Services, told the AP the cases were not clear-cut—the donor and a woman who received one of his lungs both tested negative for LCMV; however, three other recipients who died tested positive for the virus. Kazmierczak said about five percent of mice, hamsters and other rodents carry LCMV and two percent of the general public has antibodies to it. The virus seldom causes illness in healthy people, but can be serious and even fatal in those with compromised immune systems.

Wisconsin officials said they made no public statements about the deaths in 2003 because of the tenuous evidence and the virus wasn't considered a public health risk, since it doesn't spread person-to-person.

**Bill providing a tax credit for living organ donors introduced in the House of Representatives**

Living organ donors would receive a one-time tax credit of up to $5,000 to help cover personal expenses under legislation introduced in the U.S. House of Representatives in late May 2005. Representative Joe Wilson (R-SC) introduced the Living Organ Donor Tax Credit Act of 2005 (H.R. 2474) which would “amend the Internal Revenue Code of 1986 to provide a non-refundable personal credit to individuals who donate certain life-saving organs. The bill specifies that eligible living donors would include: kidney, liver, lung, pancreas, intestine, bone marrow or any part thereof. It also emphasizes that payment is restricted to living donors only.
“Due to lost wages and increased medical expenses, the organ donation process is expensive, time consuming, and discouraging for many potential donors,” Wilson said in introducing the bill. “Since many Americans could benefit from the tremendous generosity of organ donors, I believe Congress should help make it easier for people to donate their organs.”

Co-sponsors of the bill include: Reps: Henry Brown (R-SC), Mark Foley (R-FL), Katherine Harris (R-FL), Jeff Miller (R-FL), Charles Norwood (R-GA), and Ileana Ros-Lehtinen (R-FL). The bill has been referred to the House Committee on Ways and Means, in addition to the Committee on Energy and Commerce.

**SPOTLIGHT ON TEXAS**

**Texas Donor Registry signed into law; Donor Council will coordinate efforts**

For the first time since 1997, Texas citizens will once again be able to indicate their willingness to be organ and tissue donors on their drivers' license. Governor Rick Perry signed a bill in early July creating a donor registry that includes a donor education program and allows the Department of Safety to let drivers indicate their willingness to donate on their license. Individuals will also be able to join the donor registry by phone, online or when they renew their license plates.

The bill also creates the Texas Organ, Tissue and Eye Donor Council, which is expected to be appointed in the fall, to coordinate the registry and education efforts. The contract to operate the registry must be awarded by September 2006.

Between the years of 1993 and 1997, the Texas Department of Transportation asked residents about organ donation when they renewed their driver's license. According to the Associated Press, however, a computer glitch led the state to replace the practice by making donor packets available at driver's license offices.

**Texan becomes world’s first heart assist device patient to get multi-organ transplants**

A 42-year-old Texan became the world's first heart-assist device patient to undergo a multi-organ transplant. The operation was performed at The Methodist Hospital in Houston.

Garry Davis, a 42-year-old oil-rig worker who suffered from a rare blood disease which damaged his organs, received a heart and liver transplant after being kept alive on a left ventricular assist device (LVAD) for two months. According to a hospital press release, he is in good condition and talking with family and friends. Davis was diagnosed in May with hemochromatosis, a rare blood condition that develops when too much iron builds up in a person's body, and can cause severe organ damage. When the disease is caught early, it is treated by periodically removing about a pint of blood from the body to deplete the excess iron. “Iron deposits in his heart muscle were causing the heart to stop working,” said Methodist Hospital heart transplant surgeon Matthias Loebe, MD. “It is very rare for this disease to lead to the need for a transplant. Without the LVAD, Mr. Davis would not have lived.”

The liver is the most common organ damaged by hemochromatosis, but Davis’ heart was in such poor condition due to the disease that doctors first implanted the LVAD before performing liver biopsy, which revealed he also needed a liver transplant.

The 12-hour operation for removing the LVAD, transplanting the heart, and finally transplanting the liver, was performed in four-hour shifts.

**Understanding Skin Cancer**

*Continued from page 6*

transplants, followed by heart, and a smaller number of liver, lung, pancreas, and bone marrow transplants. Men outnumber women by almost two to one. The largest group of participants—40%—has had both squamous cell and basal cell carcinomas. Most have suffered from sunburns and either did not tan or tanned only gradually. As a group, most now try to avoid the sun, and try to use sunscreen frequently.

Truly it has been pleasure getting to know everyone who has contacted us and we look forward to hearing from far more volunteers. Please contact us, for without you we really cannot make any progress. We promise to send you a pamphlet describing skin cancers and sun screens—avoidance of sunlight is not the whole answer but it is what we have today. Help us so that we might have more tools for preventing this problem in the future.

Dr. Epstein is Clinical Professor at the University of California San Francisco, Department of Dermatology.

Would you be willing to share your experience about coping with cancer with other recipients? If so, e-mail Cathy Paykin at cathyp@kidney.org or send a note to:

Cathy Paykin  
National Kidney Foundation  
30 East 33rd Street  
New York, NY 10016.
Letter to the Editor:

Hello:
I am a kidney transplant patient serving my country in Iraq.
I had my transplant in August 2000. My sister gave her kidney to me. Incidentally, 10 years before the transplant, I had given my bone marrow to her when she had leukemia! SO this was a perfect match.
Since then, I am leading normal life. I am a Civil Engineer with a focus on Construction Management of construction projects.
I always wanted to join U.S. Army Corps of Engineers. I got accepted for a one-year assignment to Iraq. Since February 2005, I am working in Gulf Region North (GRN) Mosul Headquarter Office. I am working on schools renovations, construction of primary health care clinics and renovation of hospitals. Recently, I switched to the electrical sector where I oversee improvements in electric substations and the nationwide automated monitoring and control system.
We are stationed at an Army base that is located in a Palace compound. The Army is taking good care of soldiers and civilians. The food, lodging, working facilities are good.
The workload is tremendous but we are making valuable contribution towards improving infrastructure of this country. On positive note, my health is excellent.
I hope my experience will motivate other patients not to place any limitations on what they can achieve in their career.
Thank you,

Pradip T. Patel
Program Manager, U.S. Army Corps of Engineers,
Gulf Region North - HQ Office, Mosul, Iraq

Medicare Part D

JOIN THE NKF ON TUESDAY, JANUARY 17, 2006 AT 12:00 NOON for “Medicare—How It’s Changing to Help More People: Helping to Fill the Coverage Gap”

This is the last of a series of teleconferences sponsored by the NKF.

A social worker will facilitate and speak. Experts will make presentations and answer questions. If you missed the earlier five programs, download, listen and view at www.kidney.org/transplantation/transAction/index.cfm/

The objective of this offering is to share key messages and factual information to help health care professionals answer questions they may have or their patients may ask. Any health care professional or person with kidney disease who is interested in learning more about Medicare prescription drug coverage may participate.

You can download a PowerPoint presentation for this and previous teleconferences from www.kidney.org/transplantation/transaction/index.cfm. The “Medicare” PowerPoint will be available the Monday before the event and indefinitely thereafter. Participants can access the teleconference by calling 877-707-9628 and using the code: 44919. Callers will then be asked to register. Hold music will play until the conference begins. You can e-mail us questions to info@kidneydrugcoverage.org Please type ‘question’ in the subject line. Questions about the teleconference and other issues will be answered and posted on the Web site FAQ page. For more information about the teleconference or the community initiative, visit www.kidneydrugcoverage.org If you do not have access to the Internet, visit your local library or ask someone to look up the information for you.

Pharmacogenomics...

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may experience unbearable side effects when exposed to higher doses. Finally, such testing could reveal that a particular drug that the transplant team uses for most cases actually won't work at all for this particular patient. This will obviate the necessity of trying to adjust the dosage of drugs that turn out not to work at all. Knowing in advance could prevent many complications.

It is hoped that pharmacogenomic testing will take more of the “guess work” out of how patients like Sara respond to medications. Unfortunately, there will probably always be a need for close monitoring of blood levels. As specific as the information obtained from genetic information may be with regard to tailoring medication to the individual, other influences, including environmental ones, will continue to exist as variables that effect how medications are metabolized on a daily basis. Pharmacogenomic research has a long way to go before transplant patients will see tremendous benefits from it. Nevertheless, it is an exciting new field that will hopefully result in fewer organs being lost to rejection and fewer side effects because it will change the way physicians select and monitor medications for patients.
If You Should Need HIP REPLACEMENT

By Chris L. Wells, PhD, PT, CCS, ATC

Transplant recipients are susceptible to weakened bones. For all transplant recipients, weak bones may be caused by the prednisone or other steroid immunosuppressives, or in the case of kidney patients, by kidney failure. This can lead to the need for hip replacement. The hip joint is the largest in the body. It is a ball-and-socket joint with the round head of the thigh bone (femur) fitting into the cup-like cavity of the pelvis (acetabulum). The shape of the joint provides great range of movement, along with good stability.

HIP REPLACEMENT surgery is indicated when the joint becomes painful, unstable, immobile, or limits function and quality of life because of injury or disease. Osteoarthritis (OA) or degenerative joint disease is associated with obesity, abnormal forces across the joint that result in abnormal wearing of the joint surfaces, and abnormalities in the development of the bones of the joint. It is the leading cause of hip dysfunction and hip replacement. Hip replacement may be also be indicated: after a fall in which a fracture occurs just below the ball, a decreased blood supply to the ball associated with long-term use of corticosteroids; and rheumatoid arthritis in people under the age of 40 years.

Although the majority of hip replacement surgeries are performed in people who are over age 60, it is common among younger people as well, with women undergoing the procedure almost twice as often as men. The timing for surgery is dependent on the level of pain, degree of disability, and general health and age of the individual. It is important that medical therapy and rehabilitation be trialed to manage the pain and improve mobility prior to undergoing surgery.

There are several things transplant recipients should address to improve their outcomes prior to undergoing hip surgery. One should hire a surgeon who routinely performs hip replacements and has experience performing surgeries on transplant recipients. Discuss the associated complications, including joint failure, infection, persistent pain, and disability with the doctor. Smokers should stop at least four to six weeks before the surgery to decrease the risk of complications and decrease the length of stay in the hospital. A post-discharge plan should be discussed with the family. Arrangements should also be made in advance for people to stay with the patient to assist with meals and some personal care activities like dressing, bathing and household chores. Additionally, de-cluttering, including the removal of small throw rugs to insure clean and safe passage through the home is necessary.

Patients can begin some gentle exercises to improve the strength of the muscles around the joint.

One can expect to see a physical therapist within the first 24 hours after surgery. At that time, the therapist will assist the patient in regaining motion, strength and mobility, while monitoring vital statistics. Patients are usually assisted out of bed on post-op day one and begin gait training with a walker. The therapist teaches how much weight one can place on the leg during walking. Patients need to follow hip precautions to prevent a dislocation of the joint. Generally, these hip precautions include not bending the hip more than 70–90 degrees (e.g., not bringing one’s knee toward the chest), no crossing the legs and no rotation. Weight bearing and hip precautions will vary depending on the type of procedure the surgeon used. One may also see an occupational therapist to learn how to use adaptive equipment to assist one in bathing, dressing and reaching.

The primary goals after a hip replacement are to regain range of motion and strength, and restoration of the ability to walk, climb stairs, and return to recreational and work activities.

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My career path was influenced by my transplant experience. I started out as a medical reporter for a large metropolitan newspaper, and then entered graduate school at the University of Minnesota for a Masters degree in Public Health. Why did I pursue Public Health? Although I didn't realize it at the time, it was related to the transplant. Much of what I've done has focused on health promotion, e.g., educating the public about not smoking, healthy diet, exercise, stress management, life balance and maintaining effective doctor-patient relationships.

I try to practice personally what I preach professionally. What have I done personally to maintain my health? In the first place, I never refer to myself as a ‘transplant patient.’ Instead, I always consider myself to be a regular person who was blessed to get a kidney from her Dad.

Currently, I'm president/owner of a company called Public Health Consultants, LLC, in Minneapolis, MN. We help our clients do strategic planning on cardiovascular health, cancer and other chronic diseases. The business mix also includes consulting on project management, health research and advocacy related to public health.

Over the years, I've had several health issues related to medications, including a hip replacement. Immediately after the surgery, I developed a DVT, a blood clot in a leg vein. With a small group of volunteers across the county, I built a national organization called The National Alliance on Thrombosis and Thrombophilia (NATT). I've dedicated my life to helping others cope with the problems blood clots can cause. It's also a way of giving back the tremendous gift that I received from my father.

Prior to my transplant, I'd become progressively worse physically and had become used to it. I thought it was normal. Well, it wasn't. When I received the kidney at age 21, I knew for the first time in my life what it felt like to feel good. In that moment, I discovered how precious life was and that I couldn't ever take it, or anyone, for granted.

Whenever my Dad introduces me to someone, he proudly says, “This is my oldest daughter, Patty, and I gave her my kidney 30 years ago.” I always add, “Yes, my Dad saved my life.”

I feel like I'm the luckiest daughter in the world.

activities. Physical therapy is generally progressed to an outpatient setting where more advanced training can be completed.

SOCIAL WORKERS or case managers will assist in discharge planning. Discharge planning usually begins on post-op day two. Depending upon the patient's living situation, amount of family assistance, insurance coverage, and progress with in-patient therapy, it will either be recommended that the patient be discharged home with family and home rehabilitation services, or be sent to a rehabilitation facility where one can receive more aggressive therapy in order to restore strength and mobility.

THE BEST OUTCOMES for hip replacements are related to several factors. A patient who is educated about the procedure and involved in the medical decisions is more likely to have better pain control and be better able to achieve their rehabilitation goals. Furthermore, the patients who are motivated, have established goals with the medical team, and are prepared with a discharge plan have more favorable functional outcomes and are more satisfied with the whole surgical experience.
Our daily activities could revolve around sitting in a dark room, eating a tub of ice cream, downing Oreos, or simply pulling down the shades on life.

Once we get over the initial shock (not like we ever do), at some point we have to decide to give up or get up. I’d like to believe that most of us mobilize the strength to push forward and accept life’s curve balls with determination and hope.

Here are a few tips that my mom, a kidney recipient, and I came up with, based on our experiences over the last 10 years, that we hope will help others.

❙ **FIND A DOCTOR** you feel comfortable with—a doctor who will answer your questions.

❙ **MAKE YOURSELF KNOWN** to the transplant team. That does not mean being demanding, but it does mean demanding good care. Making yourself known means that you are not just a number, but also a human being with very real human needs.

❙ **BE HONEST.** It’s okay to be scared and anxious. Try not to let those feelings cloud your judgment. Bring a list of questions with you. If your doctor presents you with something that you are unsure about, take some time. Once you’ve taken the time to mull things over, ask questions again. You might want to bring a tape recorder so you can review the conversation later. Bring someone along to help you remember.

❙ **BE INFORMED.** The Internet offers information that is informative and extensive. Just remember: one should review information found on the Internet with the doctor. Not all Internet information is up-to-date. The more facts you have about a medicine or procedure, the less anxious you might feel.

❙ **DOCTORS LIKE INTERESTED PATIENTS.** When a patient is an active participant in the treatment plan, everyone is on the same page. This is a very good thing.

❙ **BEING VIEWED IN “TOTALITY.”** The fact that you are a patient does not exclude the fact that you are someone’s parent, spouse and/or significant other. Decisions are not made in isolation, but in the context of your life needs. Your physician has to understand this. It is the patient’s job to help the transplant team understand the importance of this fact.

❙ **BE SENSITIVE** to the fact that, despite long office visits, your doctor is doing his/her best to find the most effective treatment program for you. They are people too. Don’t let your frustration cloud the way you approach the treatment team.

It’s been about 10 years now since my mother had a kidney transplant; I have sat on the sidelines and observed my mom and her doctor nurturing their relationship. What started out as two strangers coming together has evolved into a friendship of mutual support. My mom has learned to accept help, while her doctor has had to learn how to offer the assistance without receiving resistance. I often speak about a dance between people, because I think it serves as a great metaphor for relationships. My mom is my hero, but her doctor, Dr. Alan Wilkinson, shows heroism every day by the manner in which he practices medicine, treats his patients and conducts his life.

Josh’s mom had a kidney transplant 10 years ago. Josh is 13 years old.
“I offer you my solemn vow to be your faithful partner in sickness and in health, in good times and in bad, and in joy as well as in sorrow.”

While almost every married couple vows to stay together “in sickness and in health,” the constant strain of an extended illness can wear down even the strongest of marriages. On the other hand, surviving adversity together can also provide an opportunity for strengthening bonds.

The transplantation process can be an especially trying time. The primary caregiver, who is often a spouse, experiences the emotional rollercoaster of transplantation as much as the transplant recipient. Marriages are tested when chronic illness plays a role in the relationship. Looking at it another way, "chronic wellness"—as we like to call transplantation—can also change the existing dynamics of a partnership.

The Georgia Transplant Foundation, recognizing that the serious illness of a family member is a particularly challenging event, offered its first marriage enrichment weekend retreat in 2005.

Entitled "A Step Together," the retreat was open to 25 couples who had recently been affected by transplant. Being affected was defined as having either a spouse or child who received a transplant within the preceding three years. The retreat was designed for couples who value their marriages and want their relationships to be strong and enduring while dealing with the stress related to transplantation.

The goal of "A Step Together" was to enhance the couple's relationship, resulting in stronger communication, greater intimacy, and mutual support. The program provided an opportunity for couples to learn skills and to share experiences that help to increase their mutual understanding and commitment to each other. Workshop session topics included: effective communication, coping strategies, intimacy, conflict resolution and planning for the future. The program also allowed couples the opportunity to gain a better understanding of the special issues that arise following a transplant, and to develop skills to make a plan toward specific marital and family goals.

The weekend retreat was held at a beautiful, secluded conference site adjacent to the Chattahoochee River outside of Atlanta, GA. Couples were surprised to find there were no TVs on the property! Jackson P. Rainer, PhD, a nationally renowned psychologist specializing in couples dealing with chronic illness, facilitated the retreat.

The enrichment weekend began on a Friday evening with an opening icebreaker session. Following breakfast Saturday morning, we began the program, which covered the following topics:

- **Understanding and Respecting Your Relationship:** Changes brought on by transplant.
- **Communication—Just Because I Love You, Doesn't Mean I Understand You:** Effective communication.
- **Roles, Rules and Rituals:** Identifying roles that keep a family in balance.
- **For Myself and You:** Myths of sexuality; sex after transplant.
- **The Art of Relaxation:** Couples massage therapy.
- **Rediscovering Delight:** Compassion, desire, and vulnerability.

Couples were expertly guided through a lecture and discussion of each agenda topic, and were then provided with exercises to complete as a couple. The groups reconvened to discuss what they had learned through the exercise. It was a relaxed atmosphere, and group discussions focused on the process rather than the personal content.

The results were amazing. Many of the attendees expressed how much the conference had changed their outlook on their marriage, and on the future of the relationship. The response of one attendee was especially poignant:

“I have not worn my wedding ring in months due to issues and distance between me and [my husband]. But after this weekend we have [reconnected] and will continue to reconnect and grow together. I am wearing my wedding ring today!”

Evaluations like this reflected appreciation for the opportunity to discuss marital issues in a structured setting, and the positive tone contributed to the success of the enrichment weekend. If even one couple was inspired to create positive change in their relationship as a result of the marriage retreat, we will happily consider it a success.

Chris Goldman and Sandy McMath, MSW, are employees of the Georgia Transplant Foundation.
"I wake up at 6:00 am daily, so it's easy to take my meds then. I have a watch with an alarm set for 6:00 pm. I am at work five days a week, so it's easy to take them at 6:00 pm. When I'm home, the alarm reminds me. Hope this helps others."

—Rita Solimene

"I have used dual alarm watches and now use a cell phone that has two alarms to remind me to take my meds."

—Chuck Leggett

"Like most of the respondents, I have a set system that involves repetition. That is the key. Since I travel in my job, I always have a day's supply of my meds in one of those flat football-shaped coin holders. It's easy to carry in your pants, purse or vehicle, in case you get caught away from your regular daily container of meds."

—G. W. Herring

"I've had to take meds since I was little, so remembering to take them comes naturally to me. Anytime I get something new, though, I keep them next to my night stand so that they're one of the first things I see every morning when I wake up. Setting an alarm to go off at the times I should take them also helps."

—Terri

"I have dedicated a medicine cupboard just above the area where meals are served that holds color-coded containers for time of day. I never miss my meds. I use travel containers for meal times outside the home."

—Josephine Mahi

"I try to take my medications at the same time each day. This not only “glues” the idea in my memory, but it also helps to keep my blood levels constant. I don't use the plastic containers. I find it much easier to keep them in their original containers. Then, I follow with a full glass of water. Therefore, I take all my pills at one “gulp.” I also keep them in the original containers when I travel to avoid questions regarding the contents of each container. I must say that I do get looks from people when I take all my pills at one time. I just don't have the time to pick them up one at a time. I've got too much living to do yet."

—Kristina Elizabeth Johanssen Finch

"I preplan my meds in two-week intervals in the week-long “AM” and “PM” dividers. I have a list on my computer, and keep quite a few copies in my briefcase for the many requests that I often get. A plasticized copy in a wallet is a good idea, also. If you are traveling, take an extra week's dosage, as well as the telephone numbers of all pertinent doctors and pharmacies."

—Rich Salick

“Thank you to everyone for your ideas. I only had my first kidney transplant for two days, so I didn’t really get to know what the ‘after’ time was like. I'm getting ready to have another kidney transplant and I've had concerns on how to remember my meds. It's great to hear everyone's different ideas. Thanks!”

—Juli Temple

“Wear a watch with an alarm or set your cell phone alarm. What worked for me specifically is that I knew if I didn't take my meds on time, I'd get sick. What a motivation that was!”

—Cheryl Ross

“I've gotten into the habit of taking my meds every morning with a cup of tea. I make my tea and eat my breakfast while catching up on my e-mail—and I keep my meds right there by the computer. I keep a small bottle with a couple of each meds in my purse in case I have to dash out of the house early for work. It's been working pretty well for the past 15 years, but it took a while to get into the habit."

—Kathleen Madsen

“I keep all my meds, immunosuppressants as well as ones for hypertension, etc., in a basket on the counter. Every night after supper, I take a large glass of Kool-Aid™ and the basket to my den chair and fill two small medicine holders with the night’s meds for that night and the following day. I take the nightly ones right away, and leave myself a reminder about my morning meds on the “to do” list that I keep posted on my fridge. In the morning I take them with a glass of juice. I have been doing this for 11 years and I think I forgot twice in all that time—I was sick in bed and forgot the evening ones.”

—Ann Pepper

“I use the plastic containers with ‘Sunday’ through ‘Saturday’ marked on them. Since I take meds twice a day, I use two of them. One is marked ‘morning’ and the other ‘evening.’ They are also different colors. I keep them in a location where I must see them every day. If I go out for the evening, I just take what I need in a small container."

—Bill Evans

“I have been a kidney transplant recipient for 27 years. I could probably count the number of times I may have missed a dosage of meds on one hand. Many years ago, I started keeping a plastic daily dosage keeper. It's easier for me to make up four separate ones so everything’s all done and ready for the coming month. It's also much easier for me, when I have an unexpected medicine change, to change my meds with this system. Hope I may have helped.”

—Beverly Artemyak
What are the possible effects of solitary kidney?

If having a single kidney does affect your health, the changes are likely to be so small and happen so slowly that you won’t notice them. Over long periods of time, however, these gradual changes may require specific measures or treatments. Changes that may result from a single kidney include the following:

HIGH BLOOD PRESSURE. Kidneys help maintain a healthy blood pressure by regulating how much fluid flows through the bloodstream and by making a hormone called renin that works with other hormones to expand or contract blood vessels. Many people who lose or donate a kidney are found to have slightly higher blood pressure after several years.

PROTEINURIA. Excessive protein in the urine, a condition known as proteinuria, can be a sign of kidney damage. People are often found to have higher-than-normal levels of protein in their urine after they have lived with one kidney for several years.

REDUCED GFR. The glomerular filtration rate (GFR) shows how efficiently your kidneys are removing wastes from your bloodstream. People have a reduced GFR if they have only one kidney.

You can have high blood pressure, proteinuria, and reduced GFR and still feel fine. As long as these conditions are under control, they will probably not affect your health or longevity. Schedule regular checkups with your doctor to monitor these conditions.

As a transplant recipient, you may face many issues after receiving the Gift of Life. This booklet is a companion to the NKF telephone audioconferences “Making the Most of Your Life: Issues for Today’s transplant recipients.” (Spring 2005; transcripts available at www.transplantrecipients.org). Learn how you can get the most out of Medicare, how to identify and understand depression, and how to empower yourself.

Single copies available by calling NKF at 800-622-9010.