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(for web)

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You can now read the latest issue of Transplant Chronicles on-line at: www.kidney.org/recips/transaction/chronicles.cfm

I Endured the Storm of Chronic Kidney Failure

By Being Captain of My Ship

By Tamra Lewis

Monday my husband rushed me to the emergency room because I could not breathe. It was unbelievable. My blood pressure was so high, and at 43 I had no idea that I had high blood pressure. I realized that I had severe headaches and could hear my heart beating. The high blood pressure and stress had damaged my kidneys.

Wednesday, the doctors told me that I had kidney failure and was going to be on dialysis until I received a transplant. My destiny was up to me. I said the words, “I am captain of my ship.” I had delivered a motivational session called “I Am Captain of My Ship” hundreds of times to executives, salespeople and employees. I heard the words as I was saying them, and they were real for me. I was able to find my way in just a matter of a few hours. On the day of my diagnosis I got a grip and realized that I was alive. I am committed to my life and the lives of my family, and I will persevere and not give up. I will endure the storms of life.

I became joyful and at peace knowing that I was living during a time where technology was awesome. My blood would be cleansed and I could breathe and be happy again. I could do dialysis realizing that I was captain of my ship.

Each time my nephrologists spoke to me about the importance of managing my blood pressure, I listened. When the dietitian explained to me about the foods that were good and bad for me and how to enjoy tasty meals, I listened. My social worker showed great concern for my well being. She was constantly asking questions. When she talked to me, I listened. My dialysis team became my crew, and I was captain of my ship.

I knew the importance of packing for my life’s ship. When I went to dialysis, I had a large, camouflage army duffel bag. I packed all the comforts of home in that bag. I pulled the bag on wheels while patients and staff would laugh at me because I would often say, “This is war.” I packed the right attitude with all of my stuff. I packed my: sheet, pillow, blanket, audio tape player, audio tapes, books, pens, paper and prayers.

I use to get to the dialysis unit every morning at 4 a.m. to pray for other...

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Woodrow Wilson once wrote, “Without enthusiasm there is no progress in the world.” So it is with enthusiasm that we ring in this New Year and hope you all had happy holidays. As you may know, there have been some changes on the Transplant Chronicles editorial board. It was with gratitude that we said thank you to Beverly Kirkpatrick, the longtime Editor-in-Chief of Transplant Chronicles. Beverly continues to be a strong supporter and mentor to the members of the board.

We have added some new and willing volunteers who join with the “old” to enthusiastically bring exciting new information and resources to the readership. We welcome your ideas and suggestions and ask you to join with us to make this the best newsletter possible. From the editorial board and staff of the National Kidney Foundation, we wish you an exciting and enthusiastic year filled with good health, much happiness and good reading!

Laurel Williams
for the Editorial Board
transplantchronicles@kidney.org

Let Your Voice Be Heard!

Q: Do you have experiences and tips to share on how you overcome habits that affected your health? Respond online at www.recipientvoices.org

The following response was posted online in response to the last issue’s question: “If you received a live donor organ, has your relationship with your living donor changed over time?”

I received a kidney from my mom 11 years ago. At that time, we didn't have a great relationship. We always loved each other, but weren't the best of friends. I was very hesitant about having my mom give me a kidney, in case something were to happen to her. Since my mom gave me the kidney, we have matured into best friends. My mom felt really good about helping to improve the quality of my life. In turn, I was so grateful for the chance to go back to school and become a registered nurse, which I have been for the past six years. My mom and I have only had positive things happen in our relationship since the transplant. I know what my mom gave up for me took strength and love, and it is something I will never take for granted.

— Cindy Fernandez
Obesity in the United States has increased dramatically over the past two decades, and now represents one of the greatest risks to the health of Americans. Obesity is defined as a body mass index (BMI) greater than 30. The BMI is an estimate of a person’s body fat based on height and weight. Currently, 61 percent of adults and 14 percent of children are overweight or obese. These numbers have nearly tripled during the past 20 years and continue to increase at an alarming rate.

The epidemic of obesity in the U.S. is also beginning to be seen throughout the world. Many believe that the increase in obesity is related to inactive lifestyles and increased availability of food. Most Americans are not active, and modern conveniences such as elevators, riding lawn mowers and remote controls only serve to exacerbate the problem. While in the past energy was expended without thought at work or at home, the population is now more sedentary and is surrounded by calorie-dense foods offered in larger and larger portions.

The consequences of obesity are grave and include increased risk for diabetes, heart disease, stroke, cancer and premature death. The prevalence of diabetes, a leading cause of kidney failure, has increased from 9 million in 1991 to 15 million in 2001. In fact, it is estimated that obesity will soon eclipse smoking as the leading cause of preventable disease and death.

The proportion of patients with kidney failure who are overweight or obese mirrors that of the general population. In 1987, 10 percent of patients receiving kidney transplants were considered obese, while in 2001, obese patients represented almost 25 percent of recipients. Traditionally, many centers have refused kidney transplantation for obese patients, as early experiences demonstrated the outcomes to be poor compared to non-obese recipients. Many centers asked patients to lose weight prior to being considered for transplantation. However, studies have shown that most patients who are on dialysis are unable to lose weight. In addition, studies have demonstrated that increased time on dialysis leads to poorer outcomes for patients.

More recently, data have shown that with careful evaluation for heart disease, obese patients can receive kidney transplants safely with good outcomes, though they are at a higher risk for wound healing problems and other complications. Many centers (though not all) now treat obese patients like other higher risk groups, such as patients with diabetes or those who are elderly, and do not deny access to kidney transplantation based on obesity alone. Ideally, obese patients would undergo transplantation with a living donor after careful medical evaluation. Frequent re-evaluation with attention to heart disease should be performed if a patient has a prolonged wait for a deceased donor kidney transplant.

How does the epidemic of obesity affect potential kidney donors? Traditionally, only young, healthy, non-obese people have been considered for living donation. This insured the least potential harm to the donor, in addition to providing the best possible kidney for the recipient. The advent of laparoscopic surgery, which allows the kidney to be removed through a smaller incision, has made kidney donation possible for obese people. Short-term studies have shown this procedure is safe and feasible in obese donors, though there is an increased risk of wound complications. Long-term studies for obese kidney donors are not yet available. Some centers will accept an obese donor who is otherwise in perfect health, though outcomes over the long term will need to be closely followed.

Surgical treatment of obesity gastric bypass surgery emerged as a high-risk but successful approach to severe obesity. One procedure, called Jejunal-Ileal Bypass, is no longer performed because it caused many complications, including the risk of kidney failure. Today, obesity is sometimes treated with a Roux-en-Y Gastric Bypass, which makes the stomach into a very small pouch and bypasses a short segment of the intestine. This newer type of surgery is less risky, but the safety for patients who have had kidney transplants or donated kidneys is not known.

Ideally, overweight or obese patients would proceed to kidney transplant and then begin an intensive “kidney rehabilitation” program similar to cardiac rehabilitation programs; these have been shown to be successful. The goal would be to dramatically increase daily exercise and modify dietary intake. Overweight or obese donors could also be eligible to participate. Few transplant centers currently have such programs, but with the exploding epidemic of obesity, this difficult problem will need to be addressed as aggressively as possible.

About the Author
Julie Heimbach, MD, completed her residency training in general surgery at the University of Colorado. She is currently a transplant surgery fellow at the Mayo Clinic in Rochester, Minnesota.
**Live Longer, Live Better—Stop Smoking!**

By Shirley Schlessinger, MD, FACP

**IF I TOLD YOU THAT EVERY CIGARETTE YOU SMOKED MEANT ONE DAY LESS YOU LIVED, COULD YOU STOP?** If I told you that each cigarette you smoked meant one day sooner that you would return to dialysis, would you quit?

What if we talk about cancer? Not just lung, but throat and stomach and bladder? What about heart attacks, strokes, amputations and emphysema? What if I could promise you an extra few hundred dollars cash a year? Yes, I’m still talking about using tobacco—or rather NOT using tobacco! The evidence is solid that tobacco is always dangerous and ultimately expensive—not only in terms of dollars, but also in terms of health.

If you are a smoker who wants to quit, it is best to first develop a “game plan.” First, critically evaluate your smoking habit. Why did you start using tobacco? Was it a social activity you began at school, at work or with family members? Did smoking build self-esteem or just “give you something to do”?

Think about why you want to quit. Patients who have already experienced a heart attack or daily shortness of breath and coughing are often motivated because they want to feel better and live longer. For transplant patients who struggle to pay for medicines, cost of tobacco may be a key motivator. Many women don’t like the skin changes smoking may cause. Many patients are frustrated by their lack of control over their habit. And of course, no one wants to be back on dialysis any sooner than they absolutely have to.

Think about both the risks of smoking and the reward of stopping. It is important for each smoker to have a personally identified motive to stop!

Once you are sure you want to stop, identify how smoking (or chewing or dipping) fits into your daily routines.

It is important to recognize all the places and times that you may grow weak. Identify alternative activities to occupy the hands, the mind or the mouth at all key “trigger” places and times. If family members, co-workers and friends smoke, it is helpful if they will commit to quitting, too, or at least support your personal efforts. Many patients try to incorporate exercise into their routines as a substitute during times they usually smoke.

Some eat peppermints to reproduce the “mouth-tingling” associated with smoking. Some choose nicotine gum, a substitute that will decrease both the nicotine craving and occupy the mouth. Some chew toothpicks to occupy both mouth and hands. You must identify your “weakness” and plan a defense.

Weight gain with smoking cessation is often a concern. Remember, the health risks of smoking far outweigh any health risk associated with weight gain. You will also smell better and look younger. Diet and exercise changes can accompany smoking cessation to help minimize weight gain, although these should not be your focus. Working with your transplant or renal dietitian on an ongoing basis can be helpful, but to be successful, your focus should remain on smoking cessation.

Pharmacotherapy (medication) is now recognized as a safe and effective aid for patients who want to stop smoking. Unless you smoke fewer than 10 cigarettes per day, are pregnant or have specific medical contraindications, medication will enhance your likelihood of sustained success. There are five “first-line” agents now available. Four products provide substitute nicotine to limit the physical symptoms of withdrawal. Each of these products uses a different “delivery” method:

- **patches**, available over the counter, allow nicotine absorption through the skin throughout the day.
- **gum, inhalers or nasal sprays** provide “bursts” of nicotine absorption through the oral or nasal linings or lung air sacs, more closely mimicking the physical effect of cigarettes. They are also available without a prescription.
- **Buproprion SR** a fifth option, is also used as an antidepressant medication, but was introduced in 1997 as an aid for smoking cessation. It should be begun approximately two weeks before you plan to stop smoking, is available only by prescription and should not be used by patients with seizure disorders.

For most patients, it is safe to combine agents, but please discuss this with your physician. You may wish to use a patch for “all-day” nicotine release, but chew gum or use an inhaler to get instant relief of “cravings” at certain “trigger” times during the day. Two additional second line medications have also been identified, which may be helpful for some patients who fail smoking cessation.
with the first line choices. Clonidine, traditionally used for blood pressure control, and nortryptyline, an anti-depressant, are both available by prescription only, and should always be used with physician’s supervision. Once you are sure you want to quit tobacco, consider your options in pharmacotherapy and discuss them with your doctor.

The final step in smoking cessation is setting your “target date.” Tell your family and friends the day you’ve marked on your calendar to stop smoking. Remove all tobacco products from your home and work environment. Clean your car and home to remove the tobacco odors. Purchase your patches and gum. Review again your trigger times, and make sure you have gum or activities readily available to substitute for your cigarettes. If you have planned well, you WILL be successful!

Although the first few weeks without tobacco are the toughest, relapse remains a risk forever for the former nicotine addict. Encourage your smoking friends or family members to quit for your sake if they won’t quit for their own. Continue to avoid places or people that will tempt you to resume tobacco usage. “Just one” is enough to resurrect the addiction, and backsliding can occur after many nicotine-free years.

Giving up cigarettes is the hardest thing your physician may ask you to do, but it is ultimately more important than weight loss, lipid control, influenza vaccines or all the other health maintenance issues we spend so much time talking about. Heart disease accounts for most “death with a functioning graft,” and it is also the most common cause of death on dialysis. Tobacco usage dramatically increases heart disease risk. Tobacco use also contributes to chronic renal failure and hastens return to dialysis after transplant. Don’t be a statistic. Live longer, live better, stop smoking. And you’ll have some extra money to help pay for your medications for those extra years your transplant functions!

For more information: www.surgeongeneral.gov/tobacco

About the Author
Dr. Schlessinger is the Associate Dean for Graduate Medical Education and the Medical Director, Renal Transplantation at the University of Mississippi Medical Center in Jackson, Mississippi.

Even medical issues as severe as a heart transplant are not enough to stop some people from smoking.

According to an article by Carol Stilley, PhD, assistant professor of nursing and psychiatry at the University of Pittsburgh, 55 percent of heart transplant recipients began smoking again after the transplant. While this is lower than the return rate to smoking among the general population (90 percent), it is still “quite bad,” according to Mary Amanda Dew, PhD, principal investigator of the study. “These patients had much more severe heart disease than smokers in the general population, and the smoking contributed to the heart disease. In addition, smoking post-transplant greatly increases the risk of complications including cancer—much more so than in the general population, because heart recipients are on immunosuppressants and are already at heightened risk for cancer. Given these very life-threatening issues, it is striking that 55 percent would return to smoking and it certainly attests to the strength of the addictive powers of nicotine.”

The study found that the most common reasons for recipients to take up smoking again were:

- a return to cigarettes after a brief abstinence around the time of the transplant
- bouts of depression or anxiety within a few months of the transplant
- a caregiver who smokes.

Stilley and Dew’s article was published in a 2002 issue of Journal of Heart and Lung Transplantation, volume 21, issue 81.
I met Cathy in 1988 and 11 months later we were married. Cathy was diagnosed a few months later with Focal Glomerular Nephritis. She was able to keep it in check for seven years with diet control.

As her kidney function declined, we started to look for hospitals to get Cathy on a transplant list. I was tested to see if I was a match for her. The results came back that we matched in blood values and that our bloods were not allergic to each other. With all the new medicines available today, we did not have to be as closely matched as in the past. We then scheduled the transplant.

I was lucky, because our transplant center had just done its first laparoscopic kidney donation. I would be their sixth laparoscopic donation. Instead of having a 10-inch opening, I had a two-inch opening and four small holes, which only needed a bandage afterward.

The day before the transplant we did all the pre-testing and stayed close to the hospital. Cathy had a small complication—there was some fluid in her lungs. That night they were able to remove the fluid, so they did not have to postpone the operation.

I was taken to the operating room at 6 a.m., and surgery started at 7. Cathy was brought to the operating room a few hours later. Within a few hours of my surgery my kidney became Cathy’s. The surgery went great for both Cathy and me. It is amazing how many tubes are attached to you when you wake up.

Cathy, like all transplant patients, had to start taking medication immediately. Her brother, also a transplant recipient, had struggled with his many antirejection medications, but she was able to try a new medicine (mycophendate mofetol) in a clinical trial.

I was able to return home two days after the operation. Cathy came home the next day. Those next few weeks we visited the transplant clinic three times a week for blood tests to check on Cathy’s values and additional test medicines. Taking care of someone, especially when I myself was recovering is not easy, but fortunately her mother was able to help.

Cathy did have an episode of rejection, but it was caught very early. She was treated at home by a visiting nurse for two weeks. Since then, things have been very good.

In 2002 we had one of the greatest experiences since the transplant. We participated in the US Transplant Games in Orlando. We were members of Team Illinois, Cathy as an athlete and I as a living donor. The opening ceremonies were very emotional. We walked into the stadium holding hands, waving to family members and feeling great. Cathy ran over to shake hands with Chris Klug and Sean Elliott on the way in. The greatest part was watching the donor families and living donors enter the stadium knowing that they had made this celebration of life possible.

Cathy participated in bowling. She did great—she even bowled a 212 game. I was very proud of her. I kept thinking of all that we have been through, from that day in March 1997 and hemodialysis to Cathy bowling in the Transplant Games. We had come full circle. After she finished bowling, her family members who came to Orlando went out for lunch with us, and we had a great time the rest of the day.

It has been five and a half years since the transplant, and both of us are doing very well. The new medicines that are available today are even better than what Cathy is taking. They are truly amazing—living donors do not have to match as closely as was needed just a few years ago, and the surgical techniques are far better, with shorter hospital stays needed.

We are also very thankful for Cathy’s doctors and nurses, our families and Walt Disney World. Going there was a goal that Cathy strived for and reached just months after her transplant. Most of all, I am thankful for Cathy: I always knew that Cathy was a very strong person, but as every day goes by I am awestruck by how she gets stronger every day. She truly is my hero and I love her very much!  

Rich and Cathy Ostry went to Walt Disney World in Orlando a few months after her transplant, and again for the 2002 U.S. Transplant Games, when this picture was taken.  

Rich and Cathy Ostry live in Illinois.
Surprise! Senate passes first significant organ transplant legislation in more than a decade

The U.S. Senate’s Nov. 25 approval of a national transplant bill is almost certain to be followed by passage in the House of Representatives, which would make it the most important transplant-related bill to pass both houses since the Transplant Amendments Act of 1990.

The bill—the Donation and Recovery Improvement Act (S. 573)—was guided through the maze of pre-Thanksgiving legislative frenzy by Senate Majority Leader Bill Frist (R-TN), Senator Judd Gregg (R-NH), chairman of the Senate Health, Education, Labor and Pensions Committee, Senator Edward Kennedy (D-MA), ranking member of the committee, and Senator Christopher Dodd (D-CT).

The legislation authorizes $25 million to be appropriated for carrying out a variety of provisions including:
- $5 million for reimbursement of travel and subsistence expenses incurred by living donors;
- $3 million for funding to hospitals to hire in-house organ procurement coordinators;
- $15 million in grants for developing public awareness programs and demonstration projects to increase organ donation;
- $2 million in support for studies on increasing organ donation, and improve the recovery, preservation and transportation of organs.

The bill also calls for development of a means to evaluate long-term effects associated with living organ donation by individuals who become donors.

The one provision anticipated by many and dreaded by others—funding for a demonstration project on determining if offering financial incentives will increase the number of deceased donors—never made it out of committee.

According to insiders familiar with the committee’s deliberations, Senators Gregg and Kennedy were strongly opposed to allowing a trial, while Frist and Secretary of Health and Human Services (HHS) Tommy Thompson supported including a provision on seeking proposals to hold a demonstration project.

The bill contains a provision calling for the HHS Secretary to study the “ethical implications of proposals to increase cadaveric (sic) donation that may disproportionately affect certain populations” which might be construed by some to include holding an organ donation financial incentives trial in the future.

New CMS regulations governing OPOs, transplant centers expected this year

New regulations governing US organ procurement organizations (OPOs) and transplant centers are in the process of being reviewed by various governmental agencies and could finally be issued sometime in 2004, according to a government official.

“Both of the regulations are out for comment and when they come back we have to respond to all of them.” Marcia Newton, a staffer in the Centers for Medicare and Medicaid (CMS) told members of the Department of Health and Human Services (HHS) and Advisory Committee on Transplantation (ACOT) in November. “The OPO regulations will probably be finished first but it’s hard to predict.”

Newton observed that both regulations must be signed off on by the Health Resources and Services Administration (HRSA), the National Institutes of Health (NIH), and the Food and Drug Administration (FDA), before going back for review by intragovernmental agencies and HHS Secretary Tommy Thompson. Once that cumbersome process is complete, the regulation is sent to the Office of Management and Budget (OMB) who then has 90 days to comment.

Continued on next page
The two regulations will be “Proposed Rules” containing information in a preamble about the economic impact of the rule, who will be affected, what paper is needed, and, most importantly a rationale for what and why we (CMS) did, Newton explained.

Once a rule is published, the transplant community will have a 30 to 60 day period in which to comment. “We want to know what you think and new things that should be of interest to us,” Newton said.

Medicare to pay for LVAD in heart patients not eligible for a transplant

Medicare patients who are suffering from chronic end-stage heart failure but are not candidates for a heart transplant will soon be eligible to receive part of the cost of a left ventricular assist device (LVAD).

The Department of Health and Human Services (HHS) Centers for Medicare and Medicaid Services (CMS) announced on October 1 it intends to expand coverage for Medicare patients who have chronic end-stage heart failure, and meet inclusion criteria outlined in the Randomized Evaluation of Mechanical Assistance for the Treatment of Congestive Heart Failure trial (REMATCH). The effective date was not announced.

“This decision is based on the best available scientific evidence following a clinical trial that showed VADs can extend and improve the quality of life in patients with heart failure,” said CMS Administrator Tom Scully.

In a “decision memo” CMA says it has “determined that the evidence is adequate to conclude that implantation of a LVAD approved by the Food and Drug Administration (FDA) for destination therapy is reasonable and necessary as permanent mechanical cardiac support for Medicare beneficiaries who have chronic end-stage heart failure, i.e., New York Heart Association Class IV end-stage left ventricular failure for at least 90 days with a life expectancy of less than two years.

CMS noted it plans to develop accreditation standards for facilities that implant LVADs and, when implemented, LVAD implantation will be considered reasonable and necessary only at accredited facilities.

Major advance in immunosuppression on the horizon

New Pfizer pill reduces rejection in animals with fewer side effects

A novel form of immunosuppressant—patterned after an aspect of what is commonly called Bubble Boy Disease—is showing promise in preventing rejection of transplanted organs in animals without compromising the health of recipients. The drug also has exhibited positive results in treating autoimmune disease, according to a report in the Oct. 31 Science.

If the experimental agent developed by Pfizer, called CP-690,550, works in humans, it could provide a new anti-rejection strategy for the more than 200,000 US transplant recipients as well as a novel treatment for autoimmune diseases like lupus, rheumatoid arthritis, and eczema.

Taken by mouth, CP-690,550 specifically blocks janus kinase 3 (JAK3), an enzyme that regulates the activation and reproduction of white blood cells—immune cells that attack transplanted organs or, in autoimmune disease, the body’s own healthy tissue. In initial experiments in mice given heart transplants and subsequent studies in monkeys receiving kidney transplants, CP-690,550 extended graft survival with fewer side effects compared with traditional antirejection drugs.

“It’s a brand new concept,” said Dominic Borie, MD, PHD, director of transplantation immunology at Stanford University and senior author of the study. “We can say that it does as well if not better than the other immunosuppressive drugs we now have.”

Some side effects, such as kidney damage, were seen with high doses of the compound in early testing. “But we have found how to manage them by reducing the dosage,” Borie noted. “At lower doses, all the side effects disappear.”

“In spite of numerous treatment options for organ transplant and autoimmune disease patients, there remains a need for effective and safe immunosuppressive agents,” said Paul Changelian, PhD, principal research investigator at Pfizer.

Accumulating knowledge about severe combined immunodeficiency (SCID) or “bubble boy disease,” a lethal condition in which children are born without a functioning immune system, led to the development of the new compound. SCID is caused by mutations in the gene responsible for producing the JAK3 enzyme.

Pfizer scientists theorized it might be possible to harness some aspects of SCID—specifically JAK3 activity—to suppress but not completely incapacitate the immune system. The researchers prepared a pure version of JAK3 and began a long search for an inhibitor of this enzyme. After screening nearly half a million compounds, they identified a promising molecule and then chemically modified it to produce CP-690,550. This compound turned out to be extremely potent in block-
ing JAK3 with little effect on other immune system enzymes.

“The difference between previous immunosuppressive drugs and [CP-690,550] is that the previous ones were discovered randomly—for instance, they were antibiotics that turned out to also block the proliferation of immune cells,” said Borie. “This drug started from the knowledge of mutations that explain a human disease.”

CP-690,550 is being tested jointly by Pfizer, Stanford, and the National Institute of Arthritis and Musculoskeletal and Skin Diseases. The drug was well-tolerated in phase I safety studies in healthy human volunteers, and trials are underway in patients with psoriasis, an autoimmune condition in which skin cells grown more quickly than normal. “Their lesions are very accessible, and they can be treated for a short period of time,” Changelian explained. Eventually, the compound will be tested in kidney transplant recipients.

“It took about four years…to get something promising enough to go to animals tests, and it will be five years or so before [CP-690,550] might enter clinical practice,” said Changelian. “But we’re excited by it, and we will stay the course.”

Year in Review
The year 2003 in transplantation will be best remembered for two issues that are joined at the hip—the increasing disparity between people on the waiting list for a lifesaving organ and the number of people willing to donate and the increasing role money is going to play in the donor process.

The year began with a recommendation from a small transplant ethics meeting held in December in Germany that under certain circumstances commerce in organ donation is acceptable. It ended in December with the uncovering of an international organ trafficking scheme involving paid donors from Brazil, transplants performed in at least one South African hospital, and recipients including at least one Israeli.

In any other year the most significant event would have been the surprise passage of national transplant legislation in the US Senate. Under the guidance of Senate Majority Leader (and transplant surgeon) Bill Frist (R-TN), The Donation and Recovery Improvement Act (S. 573) passed the Senate in November. The centerpiece of the legislation is $5 million in funding for reimbursing expenses of living organ donors.

In March the Organ Procurement and Transplantation Network (OPTN) released data showing that for the third straight year the number of organ donors, deceased and living, increased, by a miniscule number (1.3%) over 2001. And, like 2001, living donors outnumbered deceased donors.

The tiny increase underscored what has been known for the past several years—public and professional education programs designed to increase donors simply do not work. The lack of new donors fueled interest in offering financial incentives to donor families to see if it will increase donation. In June, a House subcommittee chaired by Rep. James Greenwood (R-PA) held a hearing on the donor shortage which included testimony by groups and individuals who were for and against offering incentives. Greenwood had introduced legislation last year that would authorize a financial incentives trial.

In September the federal government released the results of a comprehensive study—the “Organ Donation Breakthrough Collaborative: Best Practices Final Report” which recommends that others emulate the success in increasing organ donation of the nation’s most successful organ procurement organizations and transplant centers. The report led to the launch of a nationwide effort in 200 of the largest hospitals in the US to increase the conversion rate of eligible donors from the current 43% to 75% in the next year.

Here’s a look at the major news developments in transplantation in 2003.

**JANUARY**
Bipartisan legislation introduced in the House and Senate which could ease financial strains on transplant recipients and living organ donors alike. Under these bills organ transplant recipients would receive lifetime Medicare coverage for their life-saving immunosuppressive drugs and health insurers would be prohibited from raising premiums or imposing preexisting condition exclusions on living organ donors.

**FEBRUARY**
A Mexican teenager brought to the US by her parents in search of a lifesaving heart-lung transplant died on February 22 because of a tragic mistake that resulted in her receiving organs with the wrong blood type. Despite heroic attempts to rectify the mistake with a second transplant, 17-year-Jesica Santillan died at the Duke University Medical School in Durham, NC.

**MARCH**
The number of Americans who consented to be organ and eye donors in 2002 remained virtually the same as 2001, according to preliminary data compiled by the Organ Procurement and
MARCH (cont’d)

Transplantation Network (OPTN)/United Network for Organ Sharing (UNOS). The number of organ donors—deceased and living—increased by only 164 (1.3%) in 2002 over 2001. Austrian man gets world’s first double forearm-hand transplant.

APRIL

In a legal opinion that carries implications for those in need of a kidney, an analyst ruled that it is legal and proper to give waiting-list priority to a recipient whose loved one or relative has donated a kidney anonymously to someone else. Such an arrangement is not in violation of the 1984 National Organ Transplant Act’s (NOTA) Section 301, which prohibits buying and selling of human organs, according to the legal analysis.

MAY

Deceased liver donor transplants have increased 9%, while patient deaths on the waiting list for a liver have decreased 23% since the inception of a new liver allocation policy in the US. The new policy, known as MELD, for Model for End-Stage Liver Disease and PELD, for Pediatric End-Stage Liver Disease—which was implemented in February 2002, directs that for all but the most severe and acute cases of liver failure, patients’ priority for a transplant is based primarily on a formula that calculates their short-term risk of death without transplantation.

JUNE

In Memoriam—The transplant community lost two pioneers in June. Belding Scribner, MD, the inventor of the shunt that allowed physicians to administer dialysis without having to tap into a new blood vessel for each treatment and Robert Good, MD, a pioneer in modern immunology who is credited with performing the world’s first successful human bone marrow transplant.

JULY

The OPTN/UNOS board of directors moved aggressively to begin addressing areas of concern to transplant professionals and potential live donors. The board overwhelmingly adopted a series of actions which will allow long term assessment of live donors, require certification of live donor programs, and create a national registry to follow live donors for at least nine years.

AUGUST

The largest study of donor potential in the US ever conducted finds if it ever hopes to provide organs to all patients who need them, the transplant community must look beyond getting organs from deceased donors and focus on increasing live donation and developing future technologies, such as xenotransplantation and tissue engineering. A 42-year-old man who had a malignant tumor on his tongue and jaw became the world’s first tongue transplant recipient. The 14-hour operation was performed July 22 at Vienna’s General Hospital.

SEPTEMBER

The Health Resources and Services Administration (HRSA), Office of Special Programs, issues an alert to organizations associated with organ transplantation as a reminder of the potential for transmission of West Nile virus (WNV) through organ transplantation. In August 2002, four organ transplant recipients became infected with WNV after receiving organs from the same donor.

James Burdick, MD, is first physician ever to be named director of the Division of Transplantation.

OCTOBER

Tissue banks are legally immune to liability claims if one of their transplanted tissue products is tainted by disease, a California appeals court ruled. Distribution of tissue transplantation is a “service,” not a sale of goods, thus tissue banks are not strictly responsible for product liability, according to the California Court of Appeal for the Sixth Appellate District.
Many physical complications can result from the long-term use of corticosteroids. Patients who must take these organ-saving drugs often face untoward side effects.

A partial list of the side effects of corticosteroids includes hypertension (high blood pressure), osteoporosis (reduced bone mass), hyperlipidemia (elevated concentrations of lipids in blood), weight gain, “moon face,” and mood changes. Fortunately, to limit such side effects, you now have other treatment options available.

Corticosteroids have been a big part of the anti-rejection “cocktail” since the beginning of kidney transplantation. Early combinations included two drugs, the corticosteroid prednisone and azathioprine. Even with this combination, rejection rates were still high.

In the early part of the 1980s, after cyclosporine was introduced, kidney transplantation entered a new era. Rejection rates were reduced significantly, resulting in longer survival of the kidney.

But with every advance came a price in terms of side effects. Some of the most common side effects were hypertension, hyperlipidemia, and gingival hyperplasia (non-inflammatory enlargement of the gums).

Then in the early 1990s, treatment options expanded to include tacrolimus, a new anti-rejection drug similar to cyclosporine but with a slightly different side effect profile. More recently, other new anti-rejection drugs have arrived on the market. These include mycophenolate mofetil, sirolimus and a generic version of cyclosporine. Even after the addition of all these new agents, corticosteroids remained a cornerstone of the drug cocktail.

However, recent studies show that it is possible to avoid using corticosteroids altogether, or to use them only for short periods (seven days or less). Most of these studies involved what is known as an “induction agent.” These powerful drugs are given at the time of the transplantation surgery and are continued for a short while afterward.

Induction agents work by a couple of different mechanisms. The first is to inhibit the activation of cells that can harm the kidney, and the second is by elimination.

The list of side effects for these agents, to name just a few, includes increased risk of infection, tremors or dizziness. Cost is another issue, because induction agents are expensive, adding greatly to the cost of transplantation.

This treatment approach is a brand-new area of interest with different programs using different medication combinations. Over time, more standardized regimens will become available.

**Curious About Laparoscopic Kidney Transplants?**

Thanks to the technology of the Internet, anyone who wants to learn more about laparoscopic transplant can watch a video of the procedure. On October 27, 2003, MeritCare Health System in Fargo, North Dakota, broadcast a live Web cast of a hand-assisted laparoscopic donor nephrectomy.

Bhargav Mistry, MD, a transplant surgeon, and Timothy Monson, MD, a general and laparoscopic surgeon, performed the kidney removal from a living donor. Both Dr. Mistry and Dr. Monson narrated during the surgery and were available to answer questions from the public and from health care professionals around the world.

The surgery will continue to be available for the public to view anywhere in the world, at any time. To view this amazing life-saving procedure, go to [www.or-live.com/meritcare/1145](http://www.or-live.com/meritcare/1145)
patients before my dialysis. The young lady who sat next to me during dialysis was someone I knew years ago. She was one of my first clients that hired me to do motivational programs for her employees. We made a game out of beating people to the unit so that we could pray for healing for others, peace in our unit and for ourselves.

What convinced me that I should consider a transplant was hearing a friend tell me that I could do something about my situation. At that point, I got busy contacting the transplant department and asking questions. The greatest gift that I gave myself was working to make my lab numbers good every month. I wanted to be as healthy as I could be. I sailed the ship compliance into greater health and a brand new life.

I was going to keep my ship in the water and hold on through the storm. In the process I could hear and understand the invaluable information which was put before me. Whatever they told me to do, I did it without apprehension. I was now developing a new team. I was now on the transplant waiting list. Several people offered me a kidney. It was as if God was smiling on me daily. Little did I know that my baby brother wanted to give me a kidney. He had researched and found out that we had the same blood type—O positive. My brother called me and wept as he told me what he wanted to do. I got excited.

All tests revealed that my baby brother was very healthy. He could give me one of his kidneys. The surgery was scheduled for June 19, 2002. It was a success. I raised my brother from infancy to the age of 10. I never knew that I was taking care of my kidney all along.

This has been an awesome journey for me. I am glad that I remained captain of my ship and endured the storms of life and overcoming chronic kidney failure.

Tamra Lewis
Successful Kidney Transplant Recipient, June 2002

**SPOTLIGHT on DONATION**

The National Kidney Foundation (NKF) is proud to announce that on April 19-21, during National Organ Donation Awareness Month, the Empire State Building will be awash in green and white light to honor transplantation.

**HOW DID THIS HAPPEN?** Karen Kennedy, a Ph.D. candidate at Fordham University in New York, approached the NKF with the idea in fall 2003. Karen had a passion for donation ever since she donated a kidney to her mother, Verna, 10 years earlier. Karen currently conducts research on transplantation issues.

Though her mother is now deceased, Karen doesn’t regret her decision to donate for a minute and is thankful for the extra time both she and her entire family, including Verna’s two grandchildren, had with her. The NKF national office is just one block from the Empire State Building, and as Karen researched the experiences that recipients and nonliving donors have when attempting to communicate with each other, she remembered a discussion she and her mother had about how wonderful it would be to light up the Empire State Building in honor of transplantation. With the NKF as the host organization, the idea went from conception to reality. The green and white lights will honor transplantation and the generosity of living and nonliving donors and their family members.

**Online Resources for Quitting Smoking**

- [www.cdc.gov/tobacco/index.htm](http://www.cdc.gov/tobacco/index.htm)
- [www.cognitivequitting.com](http://www.cognitivequitting.com)
- [www.quitsmoking.about.com](http://www.quitsmoking.about.com)
- [www.whyquit.com](http://www.whyquit.com)
How Exercise Can Help You Kick the Habit

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

One of the common barriers to smoking cessation is that it is equated with weight gain. On average there is a 12 pound weight gain for both women and men in the first year after quitting smoking, and an 8.5 pound and 5.7 pound further weight gain in years one through five, respectively. Many people are willing to accept a small weight gain of 3 to 5 pounds, but their efforts to stop smoking are undermined when weight gain exceeds this tolerated limit.

By making exercise a part of your program to quit smoking, you can prevent or minimize weight gain. If you are aware that you smoke when bored, a well-rounded program would encourage you to substitute the negative behavior with more positive choices. Instead of eating fast foods when bored as a substitute for smoking, you could eat a healthy snack like nuts and vegetables, take a walk or complete a task around the house.

There are many benefits to participating in a regular exercise program besides weight management. You can increase muscle and bone strength, which will assist in prevention or management of osteoporosis and the adverse effects of prednisone use. Exercise decreases the risk of heart disease and strengthens your immune system to fight off infections. People who purposefully participate in exercise report an increase in their mental flexibility, concentration, memory and attention. Other significant benefits of being active include an increase in confidence, well-being, and self-control. There is also a reported reduction of anxiety and depression. These self-image variables are many times the same variables that are identified by smokers as reasons that they smoke. Therefore, participating in exercise can be a means to suppress smoking.

The American Heart Association, Center for Disease Control and the American College of Sports Medicine have recently redefined the recommendations for exercise. It is recommended that everyone exercise at least a half-hour a day at least five days a week. The 30 minutes can be done all at once or completed in 10-minute increments throughout the day. The exercise can include such activities as walking, cycling and gardening or housework done at a moderate level of intensity. Participation in an exercise program has been shown to reduce weight gain, decrease the desire to smoke and lessen withdrawal symptoms in abstaining smokers. Finally, individuals who exercise, while participating in a smoking cessation program, report less tension, anxiety and stress than individuals who stop smoking alone.

It is important that you select activities that are enjoyable to you. It may be helpful to exercise with a partner to improve your compliance and obtain support of your family and friends. It is important to select a time of day that can be routinely used for exercise. This will help set up a health habit. The intensity does not have to be strenuous. It is helpful to use the Rate of Perceived Exertion Scale (RPE Scale – see Table 1) to judge an appropriate intensity level, particularly if you are a heart transplant recipient or are taking high blood pressure medications. It is recommended to begin an exercise program at a pace or intensity between 2 and 3 for at least six weeks. At that time, if you are not having any difficulty like persistent soreness with the exercise, you can increase your effort to exercise between 3 and 5 on the RPE Scale.

Table 1: Rate of Perceived Exertion
This is a scale that allows one to identify how hard an individual is working during exertion or exercise. Zero means that there is no stress during the activity, such as sitting in a chair doing nothing; Five means that the activity is perceived as hard to complete and 10 means no further work can be done; the maximal limit has been reached and the individual needs to stop immediately.

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Continued on page 15
Senate Organ Donation Bill Takes Next Step

By Troy Zimmerman

Weeks of negotiations between key Senators and Representatives on legislation designed to expand organ donation have resulted in a consensus bill that should soon be on its way to President Bush. The Senate’s last order of business on November 25, 2003, before leaving for Thanksgiving was passage of S. 573, the “Organ Donation and Recovery Improvement Act,” sponsored by Majority Leader Bill Frist (R-TN). The House of Representatives is expected to approve the bill in December or early 2004.

The National Kidney Foundation (NKF) worked closely with Senator Frist, Senator Judd Gregg (R-NH), chairman of the Senate Health, Education, Labor and Pensions Committee, and Senators Chris Dodd (D-CT) and Edward Kennedy (D-MA) to help craft a substitute to the original version of S. 573. One of the bill’s key provisions is the establishment of a grant program to assist living donors with non-medical expenses related to donation, such as travel and subsistence. This has been an NKF public policy priority, as we believe it will improve transplant opportunities for individuals of lower socioeconomic means who are often precluded from considering living donation.

Equally important, the legislation does not include a provision contained in the earlier Senate bill that would have amended the National Organ Transplant Act (NOTA) to authorize demonstration projects to determine if financial incentives would increase non-living organ donation (NOTA prohibits “valuable consideration”). While many transplant societies and organizations supported demonstration authority, the NKF remained steadfastly opposed, with its belief that payment for organs undermines our values as a society. However, the legislation examines the issue by directing the Secretary of HHS to submit to Congress, by December 31, 2004, a report that evaluates the ethical implications of proposals to increase non-living donation.

S. 573 authorizes funds for organ donation awareness activities for the public and health professionals; authorizes grants to organ procurement organizations and hospitals to establish programs designed to increase donation; directs the Secretary of Health and Human Services to conduct studies on organ donation, recovery, preservation and transportation of organs; and authorizes the Secretary to establish mechanisms to evaluate the long-term outcome for living organ donors.

About the Author
Troy Zimmerman is the NKF Director of Government Relations in Washington, DC.

In the Spring issue of Transplant Chronicles...

How Do the Changes in Medicare Affect Recipients?

The new Medicare drug bill, signed into law by President George W. Bush in December, does not immediately change the current Medicare Part B coverage of immunosuppressive medications. Transplant recipients who have current Part B immunosuppressant coverage (ESRD beneficiaries with 36 months coverage, or aged or disabled who have lifetime coverage) will continue to have Medicare pay 80 percent of immunosuppressant costs. However, not later than January 1, 2005, the Secretary of Health and Human Services is required to report to Congress on recommendations regarding methods for providing under the new Part D outpatient drugs currently provided under Medicare Part B.

On the other hand, aged or disabled transplant recipients who do not qualify for the Part B immunosuppressant coverage (e.g., they were not Medicare-eligible at the time of transplant), will be able to receive immunosuppressants through the new Part D drug benefit.

The law will not take full effect until 2006, and in the spring issue Transplant Chronicles will provide further analysis of how the new rules affect recipients.

Getting in Shape for the U.S. Transplant Games

Whether you are a first class athlete like Chris Klug or just beginning to exercise for the first time, you will be welcome at the U.S. Transplant Games, and there will be events for you. This year’s Games will be July 27-August 1 in Minneapolis - St. Paul, MN. Find out about getting in shape in our next issue!
There are several strategies that can be used to increase your activity level and assist with weight management. Short 10-minute exercise bouts can be scheduled when your cravings to smoke peak. For example, if you have a tendency to smoke after meals, it may be helpful to schedule an activity such as walking or cleaning up after eating. Fill the work time breaks with health snack eating and a stretching or yoga routine that can be completed in your office chair. See Table 2 for other suggestions to increase activity levels throughout the day.

A smoking cessation program will be more successful if you examine your beliefs and habits about smoking, eating and exercise. Some degree of weight gain should be expected when you make such a difficult lifestyle change by quitting smoking, but it may be prevented or minimized by small changes to one’s diet and activity levels. Smoking cessation is not an easy task but is a large step toward leading a more healthy and rewarding lifestyle.

<table>
<thead>
<tr>
<th>Table 2: Suggestions to increase activity level throughout the day.</th>
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<tr>
<td>Choose the stairs instead of the elevator.</td>
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<td>Park the car further away from the store.</td>
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<tr>
<td>Carry the grocery bags to the car instead of using a cart.</td>
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<tr>
<td>Take a walk or complete some activities like yoga during work time breaks.</td>
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<tr>
<td>Walk to a park or restaurant to eat lunch.</td>
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<tr>
<td>Walk to the post office or mailbox to mail a letter.</td>
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<tr>
<td>Complete some household activity during TV commercial breaks.</td>
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<td>Use manual tools to complete yard work.</td>
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My wife, Mary Anne, gave me a kidney in 1991. It was a good match. But the life of that transplant was cut short by a common virus, unleashed by an aggressive immunosuppressive drug therapy.

I thought I was without any hope, but a dear friend and long-time colleague at the Washington Post, Martha McNeil Hamilton, gave me another kidney on November 20, 2001. We chronicled the episode and the various life stories around it in our book, Black & White & Red All Over: The Story of a Friendship.

Now, friends who are happy to see me alive, and acquaintances who seem surprised that I am not dead, all ask the same questions: “How are you? How is your health?”

I answer them in the moment, having learned not to take the next second or day for granted. “Now, I’m on top of the world.” They understand I have defied death, but, little do they know, the small comforts awarded me from my transplant: being able to go.

Embarrassing Moments

By Warren Brown

When ill, even a tough man can feel small or embarrassed. Dialysis patients cannot urinate and, while waiting for my second transplant, urinating was far more than just a matter of removing toxic wastes: it was a constant reminder that I was sick, and in public bathrooms, I was embarrassed.

The more fluids you drink, the more you urinate—if your kidneys are healthy. Failed kidneys can’t handle all of that water, which is why fluid intake routinely is restricted for dialysis patients. Dialysis, commonly four hours daily three times weekly, removes dissolved wastes and most of the excess water.

But back to the male ego... Males urinate in public restrooms. Often, there is no partition between one urinal and the next. It felt like everyone could see there was something not right with me.

I developed strategies for coping.

The first was abstinence. I religiously followed my dialysis center’s fluid intake rules. Not only did that strategy earn me much-needed psychological pats on the back from my dialysis nurses and techs, it also reduced my need to go to the men’s room.

My second strategy involved scouting the restroom landscape—and choosing those with fewer occupants.

My third strategy was to get a kidney transplant. In this endeavor, I was lucky for the second time in my life.

Warren Brown received a kidney from Martha McNeil Hamilton, his coworker at the Washington Post.

Photo by Brad Wilson

Warren Brown is a member of the 2004 transAction Council Executive Committee.
During hypnosis your body and conscious mind are relaxed while your subconscious mind stays alert and receptive to suggestions. When given a suggestion that is something you truly want and is within the bounds of your belief system and moral orientation, you can accept it as a new reality. For example: You can envision and accept yourself as a nonsmoker. Hypnosis is a natural, functional and noninvasive way to begin good, lifelong attitudes and habits.

Can I be hypnotized?
People of average intelligence without any organic brain damage can be hypnotized if they want to be. No one can be forced into hypnosis. The depth of hypnosis varies from person to person and is even different for an individual each time they are hypnotized. Generally it is easier to reach a deeper state of hypnosis quicker with each hypnosis session.

Is hypnosis safe?
In 1958 The American and British Medical Associations and American Psychiatry Association approved hypnosis as a viable, safe, therapeutic tool. The American Dental Association includes hypnosis in its "Guidelines For Teaching Comprehensive Control of Anxiety and Pain in Dentistry." Hypnotherapy is a consent agreement you have with your hypnotherapist. You cannot get stuck in hypnosis!

Are the results of hypnosis permanent?
New habits stay with some people indefinitely while others need periodic reinforcement. The effects of hypnosis are cumulative—the more the recorded sessions are listened to and the techniques practiced and posthypnotic suggestions brought into play, the more permanent the results become. Self-hypnosis training and practice are helpful.

How do I find a good, reputable hypnotherapist?
You can contact one of the national professional hypnotherapist organizations to check on a specific therapist or to ask for a list of members in your area. These organizations have a code of standards, professional guidelines and require at least 30 hours of continuing education yearly to maintain membership. Two organizations with high standards are the International Medical and Dental Hypnotherapy Association (www.infinityinst.com) and the National Guild of hypnotherists (ngh.net). Interview your prospective hypnotists and ask for references.

How will hypnosis help me become and remain a nonsmoker?
Your hypnotherapist will determine why you started smoking and why you have continued. What are your particular blocks to becoming a nonsmoker? What has not worked and what has worked for in the past? Then he or she will use hypnosis to change your attitudes and physical reactions to smoking. Once you have achieved success and stopped smoking, you may need follow-up for reinforcement. Your old habit did not develop overnight, and it will usually take time to cease permanently. You may be given personalized recordings and post-hypnotic suggestions to use daily. You may be taught self-hypnosis as well.

Sue Hull is a clinical hypnotherapist in private practice in Omaha, Nebraska. She received her BS in Dental Hygiene in 1978.