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(for web) 

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My Trip to the 2004 U.S. Transplant Games

By Jack Fassnacht

THE 2004 U.S. TRANSPLANT GAMES ARE HISTORY. Minneapolis was a wonderful and beautiful host city. This was my third U.S. Transplant Games and the most rewarding so far. This was also the third Games for my rooting section, my 13-year-old daughter Claire. Although Claire was not even born when I received my kidney transplant 14 years ago, she has heard the story of my transplant many times. Indeed, I occasionally remind Claire that my transplant probably made it possible for her mom and me to have her.

The opening ceremonies were held inside the Humphrey Metrodome where the Twins (baseball) and Vikings (football) play. Before marching onto the field, the transplant athlete teams took their assigned places in the stands. I sat (for what seemed like forever) with the 65 members of Team Illinois, just behind Team Hawaii. I introduced myself to the girl next to me and asked if she was an athlete. She said she was the girlfriend of a donor who had died just four months ago. She had a picture of her boyfriend made into a button that she wore on her shirt. She works as a teacher with a friend of mine who is a transplant athlete. He told her about the Games and invited her to come. I told her it was a privilege to meet her. This is the sort of encounter one has over and over at the Games—one amazing story after another.

I also met a recipient on Team Illinois who for the first time was going to meet his donor family the next day. They had been corresponding and agreed to meet at the Games. I have never met my donor family and do not know the identity of my donor.

Doctor Joseph Murray, the doctor who, along with his team, performed the first successful organ transplant 50 years ago, was at Opening Ceremonies and spoke briefly. The first transplant was a kidney from one identical twin to his 23-year-old brother. Amazingly, the living donor, Ronald Herrick, now 73, was at the Games at the opening ceremonies.

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“Do not go where the path may be. Go instead where there is no path, and leave a trail.”

This quote by Ralph Waldo Emerson seems fitting for this issue that features stories of the U.S. Transplant Games and transplant athletes. It also mirrors the actions of 50 years ago when surgeons performed the world’s first successful human organ transplant. The Chicago Sun Times did a story about the Herrick brothers, hours before they were to undergo their history-making kidney transplant. Not only was it to be the first successful human kidney transplant but it was also the first live donor transplant between twin brothers. Interestingly, on the night before their December 23, 1954, surgery in Boston, Richard wrote a note to his brother telling him to, “Get out of here and go home,” as he was concerned about putting him through such an ordeal. His brother wrote back: “I am here and I am going to stay.”

Thus started the past 50 years of transplantation; the struggles, the successes and the ongoing progress that we have seen throughout the years, and the fortitude of health care professionals, patients and families traveling on this journey. We have seen many changes over time. We have seen the operations become more “routine.” We have added more medications to our arsenal to protect against rejection and infection. We have increased the numbers and combinations of organs we transplant. There have been multiple research initiatives throughout the different health care specialties. Most importantly, we continue to witness the generosity and selflessness of donor families and living donors who provide the Gift of Life to people they know and love or strangers whom they just want to help.

We have also seen an increase in the interest and attendance at the U.S. Transplant Games. The first U.S. Transplant Games were held in Texas and attracted a small number of participants. This year’s Games in Minneapolis, MN saw an attendance of approximately 7,000 athletes, patients, family members, donor families, health care professionals and others. As you read this issue, you will see that the Games athletes came in all ages, shapes and sizes. Yet there was one underlying sentiment from all who were there: to enjoy life, to try new things and to leave a trail. Our congratulations to all the athletes and their families who continue to go where there is no path, to all the donor families who have impacted so many lives and forged so many trails and to the health care professionals who stay the course and blaze new trails for generations to come.

Laurel Williams for the Editorial Board

transplantchronicles@kidney.org

We have a new LOOK

• VISIT www.transplantrecipients.org
• POST messages on our new message board.
• CLICK on “Recipient Voices” and let us know what you think about important topics.
• POST your personal transplant story and photo.
• JOIN the transAction Council!
For decades, the concept of immune tolerance has tantalized researchers and patients alike, promising safer, more effective and long-lasting protection from transplant rejection with only a short-term or intermittent treatment schedule.

Now the secrets to transplantation without immunosuppression may well lie with a handful of rare kidney transplant recipients whose immune systems seem to be naturally tolerant to their graft.

Exceedingly rare, these individuals have maintained good kidney function, despite the fact that they have discontinued all immunosuppressive therapy. What is it about the immune systems of these “naturally tolerant” patients that allow them to achieve what scientists have been attempting to accomplish for decades? Is it possible to reprogram other recipients’ immune systems to behave in the same, tolerant fashion? These are the questions to be addressed in a new study sponsored by the Immune Tolerance Network (ITN) and headed by Emory University transplant surgeon Dr. Kenneth Newell.

The study will compare naturally tolerant patients with a variety of other groups of kidney transplant recipients, including those who have discontinued immunosuppressive therapy but rejected their transplant.

“We are aiming to learn as much about these individuals’ immune systems as possible,” says Newell. “We’ll be looking at how they differ in terms of their genes, and how the various cells in their immune systems interact to create tolerance to their transplant.”

One of the goals of the ITN team is to identify a genetic, cellular or biochemical marker that will tell physicians that a particular patient might safely reduce their immunosuppressive drug dosage or even be safely taken off immunosuppressive therapy.

“If we can come up with a series of biomarkers that predict tolerance, then we can go to certain patients and say ‘You have a 95 percent chance of being tolerant so maybe it’s worth trying to wean you off these drugs’,” muses Dr. Newell, who believes that this could be the most likely and most immediate result of his study.

However, the Atlanta-based surgeon also harbors a more ambitious plan for the study, hoping that differences noted between the naturally tolerant and “normal” recipients might change both the way we view transplant rejection and how it is treated.

“I’m almost sure we are going to come out of this with a better understanding of how the immune system works and how it makes the decision to reject or tolerate a transplant,” says Newell. “Just maybe, we’ll find something new, something that can be changed through a drug or gene therapy to create tolerance.”

Right now, however, Newell is focused on the more immediate task of finding as many naturally tolerant patients as he can.

With the ITN’s help, Dr. Newell is reaching out to transplant surgeons and specialists around the world to construct the first “Tolerant Kidney Transplant Registry,” a database of all naturally tolerant patients from across the globe. It’s a demanding task, but one that has captured the imagination of Dr. Newell and collaborators from institutions in the U.S., England and France.

“It’s really a worldwide manhunt for these patients. There are so few, and, many times, there isn’t even a record that the patient has discontinued therapy.”

In some cases, the physician may recommend discontinuation of immunosuppressive therapy due to extreme side effects or other complications. This is usually done very slowly over a long period of time. In other cases, recipients disregard doctors’ orders and stop taking their medications. For the overwhelming majority of patients, however, this leads to the loss of the transplant.

Newell emphasizes that it is extremely rare that a patient will stop adhering to their immunosuppressive therapy and not reject their transplant. Doing so, he says, can have catastrophic consequences and “will almost certainly lead to the loss of their graft.”

If you would like more information on the ITN Registry project headed by Dr. Newell, or know someone who may be naturally tolerant, please visit www.immune tolerance.org/registry or call 866-752-6245 for more information.

About the Author
Jeffrey B. Matthews, PhD, is the Director of Communications for the Immune Tolerance Network.

Study Eligibility
The ITN Registry of Tolerant Kidney Transplant Recipients is seeking kidney transplant patients who:

• Have been off all immunosuppressive medications for one year and,
  i) have good kidney function, or
  ii) who may have impaired or gradually declining renal function (believed to be unrelated to rejection)
• Have good kidney function on only minimal immunosuppression
• Are recipients from identical twin donors.

Contact the ITN Registry at www.immune tolerance.org/registry or toll-free at 866-752-6245 for more information.
IN 2003, A NEW LAW WAS PASSED to change parts of Medicare. One of the changes, the new Medicare Drug Discount Card, became available in May 2004. People can save up to 15 percent on prescription drugs with the Drug Discount Card. The card is free to some people with low incomes and can cost up to $30 for others. You can also get a $600 credit on your card in 2004, but you need to apply before January 2005 or you will not get the credit.

There are many discount cards available. You may need help with finding out if you are eligible for a card, choosing a discount card and filling out the enrollment forms. On the right is a list of programs and services for help and information on the Drug Discount Card.

A New Georgia Law Compensates Living Organ Donors

By Hannah Vahaba

An Atlanta resident and mother of two, Elizabeth Moore knew that something was not quite right with her six-month-old daughter, Helen. She had problems eating and showed delays in her development. After several visits to the doctor, Helen was diagnosed with kidney failure. Following the distressing news, Helen began to receive dialysis at home every night. Elizabeth decided to donate a kidney to her young daughter. The operation went well and, by the time she was 20 months old, Helen had returned to pre-school. Both Helen and Elizabeth are now healthy and happy.

Stories like these have inspired the state of Georgia to pass Georgia State Bill 1410, allowing living donors to receive a tax deduction up to $10,000 on costs incurred from organ donation, such as travel expenses, lodging expenses and lost wages. On April 29, 2004, Georgia’s Governor Sonny Perdue signed the bill and celebrated Donor Recognition Day at the State Capitol to recognize and honor donor family members and living organ donors who sacrificed to give others a second chance at life.

This new law will become effective on January 1, 2005, and will be applicable to all taxable years beginning on or after January 1, 2005. Georgia and Wisconsin have enacted legislation to provide tax assistance for living donors. Legislation is pending in Illinois, Massachusetts, New Jersey, New York and Pennsylvania (all of which have not adjourned for the year).

About the Author
Hannah Vahaba is a Specialist at Children’s Healthcare of Atlanta.

The Drug Discount Card


SHIP (State Health Insurance Assistance Program) Call Medicare or visit www.medicare.gov for your state’s SHIP.

AARP 888-687-2277 (TTY/TDD 877-434-7598) Web site: www.aarp.org

Visit the NKF’s Patient and Family Council Web page at www.nkfkidneypatients.org and click on “The Drug Discount Card” for more details on the discount cards.
Running has been an important part of my life. I have been running since I was a little girl. A few years ago, as my kidneys were failing, I began to experience nausea when I ran. I felt as if I had lead in my shoes. With these symptoms occurring regularly, I went to get a check-up, and I was informed that I needed to start dialysis as soon as possible. I started peritoneal dialysis. I had to take some time off to adjust and began slowly running again. The following spring, I ran a half-marathon and a few 10-kilometer and 5-kilometer races. The running was going good.

It was a day I will never forget. While doing peritoneal dialysis, I often wondered what I would be doing, where I would be and what I would feel like if I ever got the call that a kidney had become available.

Two weeks earlier, we had finalized plans with a family that was going to take care of our son Adam, whenever I got the call. Well, I remember that day as if it were yesterday. Once my pager went off and I recognized the number, I was ecstatic. I placed the call and, yes, it was my turn for a kidney transplant. I looked at my husband and he looked at me and we just hugged each other and smiled. Then, the thinking cap had to be put on about all the calls that needed to be made. First, I called our pilots from the company I work for, as they had agreed to fly me up there whenever my call came. They told me they were going to get the airplane ready for takeoff and asked what time I wanted to leave—two hours—and then we would be off to the Mayo Clinic in Rochester, Minnesota.

From that point on, my husband took over and made the rest of the calls. I was so excited, rambling a mile a minute and smiling from ear to ear while crying at the same time for someone else’s loss. Once home, we packed our suitcases and called our son’s school to let him know that we were off and running.

Soon after my transplant, I was able to start running again and, within three months, I participated in a five mile corporate run with my “Thanks to an organ donor, I can do this” T-shirt on.

I continue to run, despite any difficulties that come my way. Last fall, I came down with the West Nile Virus (I got bitten by a mosquito while I was out for a run), was down quite a while and away from exercise and running for six months. With thoughts of the 2004 U.S. Transplant Games on my mind, I was still determined that I was going to participate. I started running again in March, when the Games were four months away.

The training paid off! I am happy to share that I won three medals in running events. But the medals were just a bonus. The real gift was the ability to be able to participate because of a wonderful gift of life through organ donation and transplantation. Got to go—running, that is.

About the Author
Sharon Mulder received her kidney March 2002.

Off and Running
By Sharon Mulder

Illness to Wellness: Life After Transplant is a new book written by transplant recipients for transplant recipients. The booklet is full of practical tips and emotional support for recipients who are adjusting to a newfound wellness after transplant and includes sections about pregnancy, employment, family matters, insurance and more. Transplant professionals assisted the booklet’s development.

National Communication Guidelines
Originally published in 1997, this 2004-updated edition was developed for transplant nurses, social workers and physicians to assist them in facilitating communication between their recipients and the families of deceased donors and living donors who donated to an unknown recipient. Written in conjunction with 16 transplant organizations and more than 50 individuals, the Guidelines can be adapted to fit individual transplant programs.

Call our information specialists Anita or Yvette at 800-622-9010 for a free sample copy. For multiple copies, and shipping and pricing information, contact Crystal Tucker at 800-622-9010 x176; e-mail: crystalt@kidney.org

Also available...

Writing to Transplant Recipients
A Simple Guide for Donor Families and Living Donors
Writing to Donor Families and Living Donors
A Simple Guide for Organ or Tissue Transplant Recipients

Sharon Mulder participating at the 2004 U.S. Transplant Games

About the Author
Sharon Mulder received her kidney March 2002.
That just shows you can live a long time on one kidney. Also introduced at the Games was the recipient with the longest functioning kidney transplant from a nonliving donor. Encouragingly, his transplant is now 38 years old and counting.

I competed in table tennis and the softball throw. I didn’t win any medals this time, but that’s OK. I’m thrilled just to be competing. Besides, I am always surprised by the high caliber of some of the athletes at the Games.

I volunteered Claire to help retrieve softballs hurled by the contestants during the softball competition. She didn’t particularly like chasing all those softballs! To make up for this, I took her to the Mall of America for an afternoon of shopping.

The highlight of the Games for me was having the honor of co-hosting the Coffeehouse with two donor moms. The Coffeehouse is a chance for donor families and recipients to get together and talk about whatever is on their minds. Boxes of tissues are available at each table. Many donor moms and dads took the opportunity to talk about their loved ones who donated organs. Two people read poems (which can be found at www.transweb.org). Most just talked about their child/sister/brother. One recipient, fresh from the basketball court, thanked her donor for letting her see her kids grow up.

One donor father, whom I spoke with for a few minutes, told me all about his son. He said his son didn’t die to donate organs, he just died. Then this tough looking dad from Arkansas gave me a hug. That hug meant more to me than any gold medal I could have won.

As I said at the Coffeehouse, since I do not know who my donor family is, I consider all donor families to be mine. I thank God every day for the kindness and generosity of those who agree to donate during such a difficult time. As long as recipients are around, the donors and their families will not be forgotten.
2004 U.S. TRANSPLANT GAMES SNAPSHOT

Marisa McFate of Team Upper Midwest slices the surface during the swimming competition.

Calvin Nakamoto of Team Hawaii shows a strong backhand during the table tennis competition.

Transplant athletes Terri and Alan Seastrom got to know each other in an online Games chat room, met in person at the 2002 Games, and became engaged at the 2004 Games.

Children of all ages attended the Games. Here, a Philadelphia attendee gives a competitive smile.

Ronald Herrick who, 50 years ago, donated a kidney to his twin brother Richard in the first successful human transplant operation, lights the torch at Opening Ceremonies.

Olympic gold medalist Carl Lewis (left) and NKF CEO John Davis, at Closing Ceremonies.

Maggie Coolican, donor mom and past Chair of the National Donor Family Council in front of “Patches of Love” — The National Donor Family Quilt, which has over 1,300 squares. Maggie personally sews all of the submitted patches onto the quilt.

David Quir crosses the finish line at the 5K Race for Organ and Tissue Donation Awareness with a time of 18:02.

Photo Eric Miller

Photo Jason Arnold
It should come as no surprise that some transplant recipients are among the most enthusiastic supporters of organ and tissue donation. Some choose to channel their passion into volunteerism, educating the community about donation and opportunities for ordinary individuals to do something extraordinary. Giving a gift of time is a great way to give back. However, for many recipients, there is a desire to do more—the desire to become a donor and pass on the Gift of Life. This wish is frequently coupled with confusion or misinformation about donation facts. You may believe that receipt of an organ transplant makes you medically unable to donate life. In truth, every person—regardless of age or medical history—should consider himself or herself a potential donor. However, because of technical problems, the transplanted organ most likely cannot be re-transplanted, unless death ensues shortly after transplantation. Telling your family, signing a donor card, or including donation on a driver’s license is the means to signify your commitment.

At the time of our deaths, health care professionals will weigh many medical issues in considering what can be safely donated to help others. Your transplant status will be among those issues thoroughly reviewed. Recipients have participated as organ and tissue donors. So go ahead and sign your donor card. Carry it with pride, tell your family, and encourage others to join you. One day your decision may result in the gift of a lifetime.

### Pass It On

By Robert A. Metzger, MD

It should come as no surprise that some transplant recipients are among the most enthusiastic supporters of organ and tissue donation. Some choose to channel their passion into volunteerism, educating the community about donation and opportunities for ordinary individuals to do something extraordinary. Giving a gift of time is a great way to give back. However, for many recipients, there is a desire to do more—the desire to become a donor and pass on the Gift of Life.

This wish is frequently coupled with confusion or misinformation about donation facts. You may believe that receipt of an organ transplant makes you medically unable to donate life. In truth, every person—regardless of age or medical history—should consider himself or herself a potential donor. However, because of technical problems, the transplanted organ most likely cannot be re-transplanted, unless death ensues shortly after transplantation. Telling your family, signing a donor card, or including donation on a driver’s license is the means to signify your commitment.

At the time of our deaths, health care professionals will weigh many medical issues in considering what can be safely donated to help others. Your transplant status will be among those issues thoroughly reviewed. Recipients have participated as organ and tissue donors. So go ahead and sign your donor card. Carry it with pride, tell your family, and encourage others to join you. One day your decision may result in the gift of a lifetime.

### About the Author

Robert A. Metzger, MD, is Medical Director of TransLife and President of the United Network for Organ Sharing.
Recommendations to Increase Organ Donation

The Joint Commission on the Accreditation of Healthcare Organizations (JCAHO), the nation’s predominant standards setting accrediting body in health care, released a series of recommendations in a white paper entitled “Health Care at the Crossroads: Strategies for Narrowing the Organ Donation Gap and Protecting Patients.” The paper calls for hospitals, physicians, other clinicians, organ donation coordinating groups, regulators, educators, public policy makers, community leaders, researchers and advocacy groups to work together to increase donation and protect patients. The paper identified three strategies to change existing attitudes and behaviors related to organ donation.

Here is how JCAHO explained them in a press release:

- Make organ donation a priority by focusing efforts on the hospitals having the greatest potential to identify organ donors and implement national “best practices,” including education of hospital staff.

- Bring equity, fairness and safety to the transplantation process by employing grassroots efforts to raise awareness, change behavior and increase the rate of donation among ethnic and minority groups.

Research is needed to better understand why disparities in transplantation rates exist. African Americans wait longer for organs than their Caucasian counterparts, [they] are offered transplantation far less often, and frequently have lower survival rates than Caucasians. The legitimate transplantation needs of persons with disabilities also must be addressed. In addition, the increasing reliance on living donors requires that their safety be protected and underscores the need for a national living donor registry that could track complications and outcomes.

- Seek new ways to meet the demand for organ donation by emphasizing responsibility of hospital personnel to honor the prior wishes of organ donors without requiring consent from the donor’s family and developing protocols that would provide for and encourage donation after cardiac death.

Other strategies include curbing demand by expanding preventative and health promotion programs aimed at preventing organ failure.

A complete copy of the JCAHO white paper is available at www.jcaho.org

Presumed Consent

Despite concerns that it might increase minorities’ distrust of the U.S. health care system, The American Medical Association (AMA) has voted to review a proposal to change the U.S. organ donation system to one of “presumed consent.” Presumed consent is an “opt-in” organ donation system where, if a person dies, there is an assumption he or she will donate their organs and, unless the person has made arrangements not to donate, the organs will be donated. This system is being used in many European countries.

A committee would also study other ways to change the current organ donation system, including evaluating “mandated choice” which would require all people to declare their intention to donate, or not, when getting their driver’s license or performing some other government task.

Transplantation and HIV in Illinois

Illinois has become the first state to allow HIV-infected people to donate their organs to others also infected with HIV. Upon signing the legislation, Governor Rod Blagojevich emphasized that the law will help people with HIV “live longer, healthier and more productive lives.”

Continued on next page
The risk for acquiring rabies: How are potential health care workers who may be organ transplant recipients at risk? I am a health care worker: I am an organ transplant recipient. Am I at risk for rabies? A: The risk for acquiring rabies from a transplant is extremely low. No human rabies cases associated with solid organ transplants have previously been reported, despite over 20,000 transplants being performed every year. Human rabies is uncommon in the U.S. and, on average, only 1–3 cases are reported each year. A: Health care workers who may have handled an infected organ to be transplanted are at low risk for exposure because the virus is contained within the nerve tissue of the organ. Organ manipulations that might generate sprays or splashes containing nerve tissue theoretically pose a risk for exposure to the rabies virus. The use of Standard Precautions (i.e., gowns, gloves, and mask with goggles or face shield when indicated) would prevent such exposure; rabies PEP would be recommended in this situation only if Standard Precautions were not used and an exposure occurred.

A Rare Incidence of Rabies Transmission in Transplantation

Four organ transplant recipients at the Baylor University Medical Center (BUMC) in Dallas, TX, died this summer from rabies transmitted by an organ donor infected with the disease. All four recipients were transplanted with organs donated by a 20-year old Arkansas male who died in May but showed no symptoms of rabies. The Arkansas Department of Health determined the donor contracted the rabies after being bitten by a bat. The CDC is working with federal and organ procurement organizations to review donor-screening practices.

Jay Fishman, MD, President of the American Society of Transplantation and director of the Transplant Infectious Disease and Compromised Host Program at Massachusetts General Hospital in Boston, issued a report immediately following news of the rabies transmissions. He explained, “The majority of rabies cases are caused by bites by rabid mammals. Non-bite exposures, including scratches, contamination of an open wound, or direct mucous membrane contact with infectious material (e.g., saliva or neuronal tissue from rabid animals), rarely cause rabies. The risk for health care-associated transmission of rabies is extremely low; transmission of rabies virus from infected patients to health care providers has not been documented.

The following are a few questions and answers from his report that are of importance to the transplant community:

1.) Question: How are potential donors screened to help ensure that their organs don't present a risk to transplant recipients?

Answer: All potential organ donors in the U.S. are screened and tested to identify if they might present an infection risk. Eligibility is determined through a series of questions posed to family and contacts; through physical examination; and by blood testing for evidence of organ dysfunction and selected bloodborne viral pathogens and syphilis. Organ donors with evidence of active infection are deferred. The lifesaving potential from transplanted organs currently outweighs their risk of transmitting infectious diseases.

2.) Q: I am an organ transplant recipient. Am I at risk for rabies?

A: The risk for acquiring rabies from a transplant is extremely low. No human rabies cases associated with solid organ transplants have previously been reported, despite over 20,000 transplants being performed every year. Human rabies is uncommon in the U.S. and, on average, only 1–3 cases are reported each year.

3.) Q: I am a health care worker who "handled" rabies-infected organs as part of the procurement or transplant procedure—am I at risk?

A: Health care workers who may have handled an infected organ to be transplanted are at low risk for exposure because the virus is contained within the nerve tissue of the organ. Organ manipulations that might generate sprays or splashes containing nerve tissue theoretically pose a risk for exposure to the rabies virus. The use of Standard Precautions (i.e., gowns, gloves, and mask with goggles or face shield when indicated) would prevent such exposure; rabies PEP would be recommended in this situation only if Standard Precautions were not used and an exposure occurred.

A complete copy of the Illinois law can be found at www.legis.state.il.us/legislation/93/hb/09300hb3857ham001.htm

*The law defines solid organ transplant as “including, but not limited to, the liver, kidney, pancreas, lungs, or heart.” Bone marrow transplants and blood transfusion are specifically excluded from the law.

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The CDC has developed a special Web site for information on rabies and the deaths of the four recipients: www.cdc.gov/ncidod/dvrd/rabies

Changes in Allocating Donor Organs is Expected to Save Lives

The first patients to be affected by the change, which will be known as “transplant benefit,” will be those waiting for a life-saving lung transplant. Candidates who are most urgently in need of a transplant and who are expected to receive the greatest survival benefit from the transplant will receive priority when a donor lung becomes available.

Previous distribution of donor lungs was based on the amount of time candidates had waiting for a transplant. The new policy, which was unanimously adopted by the United Network for Organ Sharing (UNOS) board of directors, will allow transplant candidates to receive priority for donor lungs based on an individual determination of their waiting list urgency and expected benefit, based on their own clinical diagnostic factors.

This policy is the result of years of discussion among transplant professionals and patient advocates and was developed using sophisticated analysis of the latest transplant data available.

The New Zealand Kidney Foundation hopes the government will implement a payment scheme, similar to maternity leave, where the employee would be paid 80% of their income. It costs up to $60,000 a year to keep someone alive on dialysis, which is funded by district health boards, while a transplant patient’s medication and follow-up care costs were only about $11,000 annually.

Growing New Kidneys in Rats Could Open Door to Similar Results in Humans

Researchers at Washington University School of Medicine in St. Louis, MO, report that growing new organs to take the place of damaged or deceased ones in humans is moving from science fiction to reality.

In a new study, led by Mark Hammerman, MD, researchers have removed a rat’s original kidney and placed a new kidney in position to take over for them.

The result? The new kidneys were able to successfully sustain rats for seven to eight days. “Seven to eight days may not seem like a long time,” Hammerman noted. “However, what we have done is akin to building the first airplane and showing it can fly, if only for a few minutes. It’s just as revolutionary.”

A Donor Gives Life and then Receives Life in Return

By Sue Miller, RN, CCTC

Trina Casillas of North Platte, Nebraska was diagnosed with Type I Diabetes Mellitus at the age of four. By age 30, she had kidney failure and was quickly approaching the need for dialysis. Trina was very interested in pursuing a kidney/pancreas transplant. Trina’s expected waiting time on the list would be three to four years and living kidney donation was discussed. Unfortunately for Trina, her family members were unable to be donors and she once again considered going on the long waiting list and “patiently” waiting!

Behind the scenes, Kristi Hund, also from North Platte, Nebraska, watched Trina, a patient at the medical clinic where Kristi worked, as her kidney function deteriorated.

One day, after X-raying Trina during one of her many doctors’ appointments, Kristi felt compelled to help and decided to see if she could be a kidney donor for Trina. Kristi scheduled a blood draw to see if they were a match. She asked that the test be kept confidential. She was concerned that the disappointment would be too hard for Trina if the results were incompatible. The crossmatch was compatible. Meanwhile, Trina had started dialysis and was hospitalized several times.

Continued on next page
One day while in the hospital, Trina received a phone call that she will never forget! "This woman named Kristi calls and says not only is she willing to give me a kidney, but she already knows that we are a match," Trina said. "I was completely overwhelmed and speechless." Trina was even more amazed by the offer because she and Kristi were almost complete strangers, Trina wasn’t even sure who her donor was until they met in person and she recognized Kristi as the kind X-ray technician at the doctor’s office. "I was so surprised that this woman I hardly knew, and who hardly knew me, was willing to give me one of her kidneys!"

As the women got to know each other, Trina found out that Kristi had been going through a personal struggle of her own. For more than seven years, Kristi and her husband had tried to have a baby without success. Preliminary fertility tests didn’t find any obvious problems, so the couple decided to keep trying and wait.

A month after the very successful transplant surgery that took place on August 7, 2002, Kristi was feeling tired and sick. On a whim, she took a home pregnancy test and got a positive result. Trina was one of the first to know about Kristi’s pregnancy. Baby Skyler Hund was born happy and healthy in June 2003. "I guess there were some things in my life that I needed to do first before I could be a mom," said Kristi.

There is no obvious medical link between Kristi’s kidney donation and her surprise pregnancy according to transplant surgeon, Lucille Wrenshall, MD, PhD, “but perhaps this is God’s way of giving the gift of life to someone who gave so selflessly of herself.”

"She saved my life so God blessed her with a new life of her own,” Trina said. “It was a two-for-one miracle!”

A Donor Gives Life and Then Receives Life in Return

Continued from page 11

The average person fails to recognize how oral health affects the body and how the body affects oral health. Good oral health care promotes overall good health. Dental health, before and after transplantation, is critical. Pre-transplant, there is a dental charting of existing teeth, missing teeth, fillings, crowns, bridges, cavities, partials and dentures.

X-rays are taken. This is to diagnose cavities and gum disease, to find unerupted teeth, and to screen for oral cancer. Typical X-rays include a panoramic film (used for an overall picture of the head). The patient bites on a small piece of plastic and the x-ray head rotates around the patient’s head. A full mouth series of x-rays is also taken inside the mouth. These x-rays are essential in diagnosing cavities and gum disease. A full set consists of 18 to 20 films—all of different angles inside the mouth. The final exam is a “periodontal charting.” This is an evaluation for gum disease. Gum disease is a chronic bacterial infection resulting in bone loss, which can lead to tooth loss. Smoking, diabetes, a history of infrequent dental cleanings and poor oral hygiene are all high risk factors.

After a thorough dental assessment, the patient will be given a treatment plan to establish optimal oral health. Only after all sources of infection are eliminated will the patient receive dental clearance for transplantation. This is the first step for the transplant recipient.

Good oral hygiene is the first step to oral health. The teeth should be brushed two to three times a day. Flossing should be performed every 24 hours. Studies show flossing at bedtime yields the best results. You should change toothbrushes every three months or after any oral or upper respiratory infection.

Fever, pain, swelling, bleeding gums, tenderness, foul odor, or exudate (puss) are signs of infection. Should any of these signs/symptoms appear, seek dental treatment as soon as possible.

Dental infections caught early can be easily treated. Dental infections that are ignored may lead to rejection or even death. After transplant, we all have something to smile about. Let’s keep those “pearly whites” beautiful and healthy!

Cheryl Thomas is a dental hygienist and kidney recipient.

Cheryl Thomas is a dental hygienist and kidney recipient.
Tannesha was five years old and on peritoneal dialysis. She had been living in the hospital, waiting for a foster placement. After assisting in her speech therapy, John and I became her parents. At the time, she was on peritoneal dialysis with the diagnosis of membranoproliferative glomerulonephritis. Our hopes were for her to have a successful transplant and lead a life without dialysis for a period of time.

I somehow felt led to be a kidney donor. Tannesha had been placed on hemodialysis after two serious peritonitis infections. What a blessing to find that I was a match and able to donate!

On January 9, 1998, we had our surgeries. Everything was going well until day five, post-transplant. Tannesha became ill with flu-like symptoms. Her blood pressure increased to dangerous levels, platelets dropped, her hemoglobin was dangerously low. What was happening? After a kidney biopsy, she was given a diagnosis of Atypical HUS. I had no idea what that was. [Hemolytic Uremic Syndrome (HUS) is a complication of an E. coli bacterial infection and a common cause of kidney failure in childhood.] What was supposed to be a five-day stay turned into two months. She never had her central line removed.

We started daily plasmapherisis. That lasted almost a year, without it controlling the disease. So many ups and downs. This disease has a mind of its own.

After two years, Tannesha was back on hemodialysis, never having had any time off a machine or with a good kidney. Ohio would not transplant her again, but The University of Minnesota was willing to list her. She was listed and, six months later, called for a perfect match. After a 12-hour surgery, Tannesha had her native kidneys removed and received a new kidney. We prayed the disease would not return. Unfortunately, three months later it reoccurred. Tannesha was back on dialysis by July 2000.

“Today is a Gift”
By Joni Venet

Having worked at the Children’s Hospital Medical Center of Akron for 10 years, I had met several children who had touched my heart. Then there was Tannesha. The day I saw her was the day it was clear what my husband and I were to do.

“On the Wings of Hope”
Painted by Tannesha Venet

Tannesha Venet

words—but not to Tannesha. She does not look at herself as sick. At age 15, 70 pounds, four feet six inches tall, she is full of life. Her body aches most of the time, but she takes riding lessons every Tuesday because she loves horses. Her life is not all dialysis; it is her own after she leaves. She would never miss Kappa Kappa Kidney Camp. I rarely hear her complain, though she has reason to. Her art is a gift from God. With it, she expresses her feelings and brings joy to others. Faith in God is where she gains strength. She loves church and her youth group. Riding in the car one day, Tannesha told me she knew she had almost died several times. “Don’t be afraid Mom,” she said, “heaven is more beautiful than the Bible says.” Needless to say, I learn from her every day. Even though there are serious difficulties from almost 13 years of dialysis, life can still bring joy and hope. Our hope is that Tannesha may touch your life through her art and her courage. May you find hope and joy despite any obstacle you might face.

About the Author
Joni Venet lives in North Canton, Ohio with her husband John and daughter Tannesha.
It is estimated that by the year 2010 there will be more than 48 million men and women over the age of 50 suffering from a silent bone disease. Osteoporosis is a disease that quietly and progressively causes the deterioration of the delicate architecture of the skeletal system. With the increase in chronic diseases and decrease in physical activity in our children, the number of people who will suffer the consequences of osteoporosis is expected to rise rapidly and appear at a young age.

The skeletal system is comprised of two types of bone tissue. Cortical bone is a dense, compact tissue that makes up the outer layer of the bones in the human body. Trabecular bone, which has a honeycomb-like structure, is primarily found in the ends of the bones of the arms and legs, and in the pelvis and spine. Trabecular bone has high turnover rate and is very susceptible to bone loss. Your bones are constantly remodeling themselves. When stress or damage occurs, bone cells called osteocytes are activated to reabsorb the bone tissue within the injured area. The absorption phase is followed by new bone being laid down by osteoblast cells.

Osteoporosis is the imbalance between osteocytes and osteoblast activity with more bone absorption occurring. Osteoporosis usually occurs in older people. Women are more susceptible after menopause. The reduction of estrogen results in an increased rate of bone loss, particularly trabecular bone. As age advances into the 70s, the body’s ability to absorb calcium and vitamin D decreases; there is a decrease in osteoblast activity and production of sex hormone. The age-related changes cause the loss of density in both trabecular and cortical bone. Chronic disease, various medications and adverse lifestyle behaviors cause secondary osteoporosis.

Transplant recipients of any age are very susceptible to osteoporosis not only because many recipients have a long history of illness and inactivity, but the exposure to many medications like prednisone, cyclosporine, antacids and anti-seizure drugs greatly increases the incidence.

Osteoporosis is dangerous because it can cause fractures, which lead to a significant decline in function, quality of life and life expectancy. Over 1.5 million fractures annually are related to osteoporosis, including 300,000 hip fractures. After a hip fracture, mortality increases the first year afterwards and gaining functional independence, including the ability to walk, can be difficult. Besides hip fractures, osteoporosis results in spine or vertebral body fractures, which result in severe pain and immobility as well as loss of height, poor posture, and increased risk for pneumonia. The third most common fracture site related to osteoporosis is wrist fracture, which causes significant pain and long-term disability of the hand.

There are many things that you can do to decrease your risk of osteoporosis and fractures. Ideally, the time to

**Taking Steps to Keep**

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

Photos: Chris Wells
Your Bones Healthy

start your prevention program is in your youth, but you can make a difference at any time by changing your lifestyle. Lifestyle changes include eliminating or at least decreasing the amount of caffeine and alcohol you consume. You should also stop smoking, because all of these substances interfere with bone formation.

The most important thing you can do for yourself is to exercise. Your bones need a certain level of stress through weight bearing activities and muscle contractions in order to maintain a healthy level of bone density throughout your life. Bone density, and therefore the strength of bones, peaks in the early 40s for most people; therefore, the higher your bone density is by the time you reach 35, the lower your risk for fractures related to osteoporosis will be.

Many research studies have shown that weight-bearing exercises like walking, jogging, stair climbing, dancing and playing recreational sports increase bone density of the spine and hip up to three percent, and decrease the incidence of hip fractures by 50 percent. It is recommended to participate in these weight bearing activities for 30 to 45 minutes, three to four times a week.

Research has also looked at the effects of a resistive strengthening program. Various types of strengthening exercise have shown improvements in bone density, particularly of the spine. There have not been sufficient studies examining resistive exercises for the legs and arms to state how the density of these bones change with resistance.

I would advise performing the following exercises to improve the strength of muscle and increase the weight bearing of the bones of your arms and legs and spine. It is recommended to complete a strengthening program two to three times a week.

To reduce your risks of falls and to decrease your risk of fractures related to osteoporosis, it is important to participate in a general flexibility program. Some studies have shown that people who participate in a Yoga or Tai Chi program improve their flexibility and balance, therefore reducing their risk of falls. It is important to make sure you have your eyes examined and review your medications, including supplemental calcium and vitamin D, with your physician regularly. You should have a DEXA scan to evaluate your bone density annually and discuss the use of various medications to treat bone loss. Avoid placing small objects on the floor and remove throw rugs to decrease the chance of falling. Finally, be sure to have proper lighting throughout your house.

Osteoporosis is a silent disease that typically makes its presence known after the person has fallen and suffered a fracture. Take action to prevent, slow the progression of and treat osteoporosis to avoid the debilitating consequences. Important: Speak to your doctor or physical therapist for more information before attempting any of these exercises. Keeping yourself active and engaged in a regular exercise program is very important to maintain your health and quality of life.

Chris Welles, PhD, PT, CCS, ATC, is a physical therapist at the University of Maryland in Baltimore.

Wall Push Ups Start Position

Wall Push Ups End Position

Hip Extension Start Position

Hip Extension End Position

Chris Welles, PhD, PT, CCS, ATC, is a physical therapist at the University of Maryland in Baltimore.
The National Transplantation Pregnancy Registry (NTPR)

By Lisa A. Coscia, RN, BSN, CCTC; Michael J. Moritz, MD, and Vincent T. Armenti, MD, PhD

The National Transplantation Pregnancy Registry (NTPR) was established in 1991 to study the outcomes of pregnancies in female transplant recipients and pregnancies fathered by male transplant recipients. To date the NTPR has received reports on more than 2,400 post-transplant pregnancies, which include all solid organ transplant recipients who have had a pregnancy or have fathered a pregnancy. To enroll in the registry, recipients sign and complete a one-page questionnaire, including a consent form.

Transplant coordinators and health professionals are encouraged to contact the NTPR if they need forms for their recipients who want to enroll. After we receive the questionnaire, the recipient is contacted via telephone for an initial interview. Once enrolled, recipients are called annually for follow-up. The registry follows both recipients and their offspring.

The NTPR fields questions by mail, by phone, and by e-mail, from physicians, nurses, transplant coordinators, and recipients and their families. Some of the most commonly asked questions include:

1. Can I become pregnant after transplant?
Yes, following a successful transplant, female recipients should be aware that their fertility can quickly recover and they can become pregnant, even shortly after transplant. Appropriate birth control measures should be implemented. (See question 3.)

2. Is pregnancy safe for female transplant recipients?
Remember that “safe” involves the mother, the baby and the transplanted organ. For the majority of female recipients, pregnancy does not cause problems if the function of the transplanted organ is adequate and stable prior to pregnancy. A small percentage of recipients may develop rejection, graft dysfunction and/or graft loss that might be related to the pregnancy. Each type of solid organ has issues specific to that organ and each individual may have other factors that need to be examined prior to pregnancy.

3. Is there a minimum time interval that should transpire between the transplant and becoming pregnant?
It makes sense to wait at least one year after the transplant to reasonably assure that the function of the transplanted organ is adequate and stable, and to allow for the immunosuppressive medications to be at stable maintenance levels. However, favorable outcomes have occurred when the recipient has become pregnant less than one year after having the transplant, although the risks of pregnancy related problems may be greater. Again, this should be based on the stability of organ function and on the organ transplanted.

4. Do immunosuppressive medications need to be adjusted and/or specific drug levels checked?
Medications may have to be adjusted and close follow-up of immunosuppressant drug levels during pregnancy is usually necessary. In a small number of cases, rejection has occurred during pregnancy.

5. Are there any particular problems among the newborns of female recipients?
For female recipients, there is at least about a three times greater risk of having a premature (less than 37 weeks gestation) or low birthweight (less than 2500 grams, about five and one half pounds) baby compared to the general population. Close monitoring during pregnancy is warranted, and many recipients are cared for by obstetricians specializing in high-risk pregnancies. However, there has been no pattern of birth defects reported in the newborns. The incidence of birth defects among the offspring of transplant recipients has been similar to that of the general population which is about 3-5 percent.

There is little information as yet available on female recipients taking mycophenolate mofetil (MMF) or sirolimus during pregnancy. Female transplant recipients maintained on newer adjunctive therapies and who are considering pregnancy should be aware of the limited clinical data currently available. After a discussion with the transplant team, the recipient taking MMF or sirolimus must weigh the risks and benefits of taking these medications during a subsequent pregnancy.

6. How are the children doing?
Typically, at follow-up the children are reported healthy and developing well, although occasional health or development problems have occurred. Newborns may also have problems related to familial patterns of inheritance or genetic disorders.
7. Can I breastfeed my infant?
This is a controversial topic for transplant recipients, yet a commonly asked question. There are benefits to breastfeeding. However, there is the concern that the limited exposure to immunosuppressive medications could be detrimental to the infant. There are recipients who have chosen to breastfeed with no apparent problems reported in the children related to breastfeeding. Any recipient considering breastfeeding their infant should consult with their obstetrician, transplant team and the child’s pediatrician before choosing to breastfeed.

8. What about more than one pregnancy?
Some women have reported multiple post-transplant pregnancies to the registry. As in first pregnancies, recipients should have stable transplant function before subsequent pregnancies.

9. Are there recipients who are at higher risk for complications during pregnancy?
Yes, recipients with deteriorating graft function before pregnancy, such as kidney recipients with a creatinine greater than 2.5 mg/dL or liver recipients with recurrent hepatitis C may be at an increased risk. Pre-pregnancy counseling is especially advisable in this setting.

10. What about pregnancies fathered by recipients?
Overall, for transplant recipient fathers, the outcomes are generally good with gestational ages, birthweights, frequency of prematurity, and frequency of birth defects that appear similar to outcomes of the general population. No apparent problems have been reported to the NTPR in recipients fathering children while taking MMF or sirolimus.

11. How can I receive more information?
All recipients and health care providers are welcome to contact the National Transplantation Pregnancy Registry (NTPR) with any questions. To register a pregnancy with us, please contact the NTPR toll free at 877-955-NTPR (6877), fax: 215-707-8894 or e-mail: NTPR.Registry@temple.edu

Summary
Overall, pregnancy can be safe and successful in women with solid organ transplants. There are a small number of cases with problems reported and these can occur unpredictably. Outcomes of pregnancies fathered by male recipients appear similar to the general population. Recipients are encouraged to first contact his or her transplant team and obstetrician before considering parenthood.

Acknowledgments
The NTPR acknowledges the cooperation of the transplant recipients and over 200 centers nationwide that have contributed both their time and information to the Registry.

The NTPR is supported by grants from Novartis Pharmaceuticals Corp., Fujisawa Healthcare, Inc., Roche Laboratories Inc., and Wyeth Pharmaceuticals.

About the Authors
Lisa A. Coscia, RN, BSN, CCTC has been involved with transplant recipients in varying capacities for 13 years and has been a research coordinator for the NTPR for the past seven years.

Michael J. Moritz, MD is Professor of Surgery, Drexel University College of Medicine and Director of Abdominal Transplantation, Hahnemann University Hospital, Philadelphia, PA, and an NTPR co-investigator.

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You know you’re at the U.S. Transplant Games when:

1. The license plate on the car in front of you reads LUNGS.

2. The crowd claps hardest for the athlete who comes in last.

3. The athletes have pudgy cheeks from taking prednisone.

4. You see athletes wearing T-shirts bearing the names and faces of their donors.

5. You don’t think twice when the guy in front of you limps to the starting blocks.

6. The loudest applause at the opening ceremony is saved for the donor families.

7. Athletes ask for time out to take their medications.

8. You introduce yourself to your opponent as “a kidney” and your opponent says “I’m two kidneys and a liver.”

9. The major sponsor is not Nike but Novartis.

10. Every athlete’s goody bag includes a bottle of sunscreen, SPF = infinity.

11. Every place—and I mean every place—is wheelchair friendly.
A Giant Wish: Just A Normal Life

By Louisa Edgeworth Lynn

Prior to my transplant, I was on dialysis four days a week, six hours at a time. I do not remember being “sick” because I was born sick; sickness was a way of life for me. Then, in 1978, at the age of 14, I received a kidney transplant. My donor was a 19-year-old boy, who had been killed in an automobile accident.

I was a pretty normal teenager and young adult. I went to college and graduated. I took my medicine and attended my scheduled appointments. But, through the years, I lost sight of my Gift of Life. It was not that I didn’t appreciate it anymore—I felt good and all I wanted to be was normal and not sick. I found out later that being “normal” could be more difficult than being sick! Like many normal people, I married, divorced, married again, and then I divorced again... but this time I was pregnant with twins! Howard University took me on with no insurance, husband or emotional support. I became the first kidney transplant in the world to successfully have twins and they also believe (“they” meaning the statisticians) that I also have had the most children as a kidney transplant recipient—four in all.

However, having the twins sent my transplanted kidney into a tailspin. I waited too long to see a doctor and when I did she gave me an ultimatum: two weeks to live or dialysis. It was not a choice. That Saturday, I left for dialysis. I was not living; this was simply existing.

In desperation, I made a deal with God. If He would save my life and the call would come for a new kidney I would stop smoking, express my gratitude, confess all that I had done wrong and come clean with other human beings, God and myself. As I waited for a kidney I worked to change and made plans to give back.

It has taken me 23 years to write a letter to my first donor family. In 1978, it was against regulation to contact the donor family and I was only 14. I began writing my second donor family hours after I woke up from my transplant operation. Gratitude is significant in my life today. I hope the transplant center will be able to locate the very special family in Minnesota who donated in 1978. I hope that they are still alive and able to receive my letter—a letter that is long overdue. Because of these two young boys, I have been saved. I have given life to four children, and today I am preparing to get into a nurse practitioner program. Today I am learning about love and forgiveness. Those boys gave those special gifts to me.

About the Author

Louisa Edgeworth Lynn is a grateful recipient and mother.

Take Care...Believe...

(Free Verse in Prose)

By Morgan Murphy

Can you believe what a year it has been? / Does it seem like you've lived and died, over and over again? / ...laughed so hard? / ...screamed so loud? / ...been so ashamed? / ...felt so proud? / Did you wage the worst war you have ever faced? / Were you blessed with the best love, time could never erase? / Were you on top of the rise or under the fall? / Did you never give up? / Did you hit the wall? / Did you happen upon an angel one day? / You looked into his eyes. / You discovered she was humanity. / Crying under disguise. / Did you ever meet a devil at night? / You thought she was! / You realized he was greedy. / Wanting everything you had. / Did you take away the trust you gave? / ...witness a birth? / ...seal a grave? / Did you watch the world turn to attack? / ...have everyone by your side? / ...then no one at your back? / Did you ever hate the person you thought you were? / Did you ever love the person you knew you could be? / And, after all of that, did you learn / GOOD or BAD, THIS IS ME! / Some will like you. / Some will loathe you. / Some will listen to you. / Some will just hear you. / Some will need you. / Some will fear you. / Some will love you. / Some won’t want to be near you. / Just remember. / ...Life is complicated. / Don’t forget the simple things! / DON’T let your “grave”-est mistake. / Be that you realized all too late that LIFE IS TOO SHORT!!! / LIVE & LEARN...(always)... / Tears will fall...mistakes will be made... / So, cry. / Then, laugh. / And although you may never really forget... / FORGIVE! (Let go and move on.) / LOVE those who have touched your life in one way or another. / FOREVER! / I know I do. / So...To: All of you. (known and unknown) / From: My beating heart. / Thank you for teaching me how to really live. / Love always and forever.

Morgan Murphy is a pen name for a 30-year-old kidney/pancreas recipient from Minneapolis.
Nick is the youngest of our four children. He was born with a congenital heart defect. We were totally surprised by his problem. When he was one day old, he was diagnosed with hypoplastic left-heart syndrome, which is a fancy name for a three-chambered heart. The doctors told us that he would need to have a surgery done called the Norwood Procedure. That surgery was performed when Nick was only five days old. This was a staged surgery so we knew that Nick would have to have another operation when he was two.

He had to have an unplanned surgery to repair his right pulmonary artery at three and a half months old. There were complications during the surgery and, because of those, he remained on a respirator for seven weeks in ICU. He lost a lot of developmental time during that hospital stay. It took him about six months to finally catch up.

Just after his first birthday, he again had to have another pulmonary repair—to the left side this time. He recovered much quicker after this surgery. When Nick got close to two, Dr. Kirk Kantar asked us about the heart transplant.

Nick was listed for a heart and we waited six weeks for a heart to become available. There was even one call when Dr. Kantar said he may have a heart for Nick, then called us back and said it was a “no go.”

In March 1991, Dr. Kantar called again. This time Nick got his new heart. That was 13 years ago. With the exception of one rejection episode, Nick has done exceptionally well.

Today, Nick is 15 years old. He is a happy and healthy teenager. He hates to clean his room, wants to play Nintendo all the time and picks at his brothers and sister. He enjoys snow and water skiing, going to sporting events and swimming. He also is a member of his school wrestling and tennis teams.

Nick has traveled all over the United States and Europe. He has participated in the U.S. Transplant Games since he was four years old. His first was in Atlanta, GA, then Columbus, OH, and twice in Orlando, FL. He has even won medals in swimming. This year, he participated at the Games in Minneapolis, MN in tennis and table tennis and won a bronze medal in men’s singles tennis.

Nick is truly making the most of his second chance at life. Now his parents’ biggest worry is if they will survive him learning how to drive.
Transplantation is a Family Affair

Hello,
My name is Joshua G. I am 13 years old and will be entering eighth grade this September. I love to play tennis. As an avid sports fan, I like to follow the Lakers, Dodgers and 49ers in their respective divisions. I also love to play video games (much to my parents’ frustration).

In 1994, my mom, Maureen, was diagnosed with kidney failure. I was three years old at the time and I really didn’t understand what was happening. When you are very young, the concept of “transplant” doesn’t exist. What I did know was that my mom was slowing down and could not do the things other moms were doing. It’s a scary experience, knowing someone you love might be in danger of losing their life.

I was lucky to have a wonderful support system led by my courageous dad, family members and friends 24/7 to make me feel safe and taken care of, during this difficult period. With reassurance from my parents and my mom’s physician Dr. Alan Wilkinson at U.C.L.A Medical Center, everything turned out great.
I thought that the scary times were behind our family but then, in 2001, we had to deal with the same situation again.

Now that I was older, my fears became more overwhelming. I was so worried about my mom that I lost interest in all of the things I found enjoyable or that I excelled at. In school, my grades slipped and I found myself forgetting to complete classroom assignments. With my tennis game, I couldn’t focus, lost my competitive edge and gave away matches.

My dad taught me a lesson I will never forget. He taught me that you have to stay strong and never give up hope. Once again, the unbelievable Gift of Life was given again by my mom’s cousins. (Her first transplant was given with love by cousin Karen and the second transplant given with love by cousin Lisa.) My mom pulled through and she came home two weeks after her transplant. We were all so happy to have her home.

In thinking about my family’s experience with kidney disease, I thought how valuable it would be to have a column just for kids to write in and ask questions or share concerns with another kid. So this is my first column.

Grownups have their own way of coping, just as kids do. In this way, kids talking with another kid who’s “been there and done that” will really be a wonderful tool in staying strong. Believe me, it’s not a great situation but you have to stay strong, never lose hope and, as my mom says, “make every day count.”

You can contact me at transplantchronicles@kidney.org I look forward to hearing from you.

Your pal,
Joshua

Are You Getting Enough?

By Kay Atkins, MS, RD, and Nancee Vander Pluym, MS, RD
Banner Good Samaritan Hospital
Transplant Center, Arizona

Vitamin D is particularly important to transplant recipients in maintaining healthy bones. Vitamin D is one of the oft-forgotten, fat-soluble vitamins. Calcium receives much of the press. However, without vitamin D, calcium cannot be absorbed. Vitamin D assists in depositing calcium into bones and teeth. It helps to remember that bones and teeth are living tissue in the body. The body is always rebuilding bones and teeth.

Where do we get vitamin D? Foods that have vitamin D include: sardines, herring, liver and egg yolks. Since these foods are not consumed daily, some foods are now fortified with vitamin D. These foods include milk, breakfast cereals and some orange juice. The skin can also make vitamin D from sunlight if enough is absorbed by the body.

Who is at risk for being low or deficient in vitamin D? Anyone! At-risk groups are: children, adolescents, young adults, middle-aged adults and the elderly. Living in cloudy, cold climates limits sun exposure for vitamin D production. Dark-skinned people cannot synthesize enough vitamin D from the sun alone. Also, sunscreen, though beneficial in other ways, blocks Vitamin D.

To determine if you are getting enough of this crucial vitamin, check with your Transplant Team.