On April 16, 1995, I received a liver and got my life back. The University of Nebraska in Omaha made the skies blue again for a very sick 12-year-old girl.

Today, at 18, I never take life for granted. Every time I sail, skate, jetski, hug someone, breathe, or dream, it is with great respect for someone who unselfishly gave a piece of themselves to me and gave me a whole world of unending possibilities.

As our lives pass day to day, the petty, shallow and trivial distract us from seeing what is truly important—life. Life is a gift. We are only given one life, and we strive to fill it with precious memories.

Six years ago, my life was threatened by a condition known as Budd Chiari Syndrome. To put a novel in a nutshell, it was a blood clot that constricted the flow of blood out of my liver. When it was finally correctly diagnosed, the condition was beyond repair. As a result, cirrhosis damaged my liver. I needed a transplant.

My journey for life took me from my home town of Tampa, Florida to Omaha, Nebraska. I arrived in Omaha in a wheelchair and came home running.

Within six months of having my transplant, I was back out on a softball field.

Unfortunately, I still harbor feelings of fear and unacceptance. These feelings often keep me from telling people about my surgery. When people, teens among them, hear the words "liver transplant," they associate it with a "sickly, fragile, frail" person. I don't want people to think that I want sympathy or special treatment. I want people to just see me, Julie. When I tell people about my transplant, they are usually shocked. Some even say "Oh my God, you would never know, you are so healthy." I believe they respond this way due to lack of public education about transplants. I also believe the shortage of organs can be linked to this lack of information. I knew nothing of transplantation until I was facing my own. Everyone whom I told about my transplant was extremely cool with it.

My best friend, Brittainy, travels to Omaha with me each summer for the annual transplant reunion. The reunions are awesome. Transplanted teenagers from all over the country...
Happy New Year to all!! In 2001 the NKF has brought new faces to the Chronicles editorial board. Our new editors have many interesting and informative articles and stories to bring to you over the upcoming year. Living donation and humanitarian donation, updates on the immunosuppressive drug bill and new immunosuppressives in transplantation are hot topics this year that will be discussed in the Chronicles, as well as many other interesting topics including body image and self esteem, informed consent in living donation, faith healers, sexuality and intimacy, legislation in donation, employment, islet cell transplantation and post-transplant diabetes management.

As always, along with the topics we have planned for the year, we still love to hear from our readers and always save space to print many of your stories, pictures and poems. We look forward to your submissions and comments.

Happy New Year.

Beverly Kirkpatrick
for the Editorial Board

Sign Me Up...

FOR A FREE MEMBERSHIP IN THE TRANSACTION COUNCIL

to receive all of the benefits of membership: a membership card and pin; quarterly issues of TransAction Council Connection membership update and Transplant Chronicles newsletter; information on transplant athletic programs, a voice in legislative and public policy issues; participation in NKF educational programs and activities.

Just fill out the form and mail it to the transAction Council, National Kidney Foundation, 30 East 33rd Street, NY, NY 10016.

Name: ________________________________

Address: ________________________________

City, State, Zip: ________________________________

Phone: ________________________________ E-Mail: ________________________________

☐ I am not interested in joining the transAction Council but would like to continue receiving Transplant Chronicles at no charge.
Transplant Chronicles, Vol. 8, No. 3

Medicare Bill to Help Organ Transplant Recipients

New legislation signed into law at the end of 2000 has extended Medicare coverage of critical immunosuppressive medications for certain organ transplant recipients.

The new legislation covers transplant recipients who are age 65 or over or disabled according to Medicare. Anyone who receives SSDI meets the Medicare definition of disabled. Most kidney transplant patients who are considered disabled will likely have severe diabetes or hypertension, but theoretically they could be collecting SSDI for a back injury or some other condition and qualify for transplant coverage as a result of their disability.

Here are answers to the most commonly asked questions:

What kinds of transplants does this include? Medicare pays for heart, lung and liver transplants if the recipients are aged 65 or disabled. These people will be eligible for indefinite immunosuppressive drug coverage, as will kidney transplants who meet age or disability requirements.

Who is not covered? Anyone whose kidney transplant was covered by Medicare solely based on the diagnosis of ESRD.

How many people will this extension affect? According to estimates from the Institute of Medicine, more than 34,800 people will have extended coverage in 2001, growing to more than 44,500 people in 2004.

What about kidney transplant recipients whose transplants are paid for based solely on ESRD? These people will continue to received drug coverage for 36 months after their transplant.

What’s the next step? The National Kidney Foundation played a major role in accomplishing a dramatic extension of the Medicare benefit to cover the most vulnerable, the aged and disabled. What we want to do now will require expanding the entitlement, a far bigger job. The NKF will continue to work to enact legislation that would provide indefinite Medicare coverage of immunosuppressive medications for all Medicare transplants.

Just Julie...

gather for the annual transplant group photo. One time, someone mistook Brittainy for a transplant recipient and asked her to be in the photo.

I think the things that set me apart from what is considered "the norm" are purely physical. Living in Florida, the "sunshine state," a.k.a "the land of bikinis," isn't easy. I have never seen anyone walking around showing a scar. I don’t do that, either. I would like to wear a bikini with pride, but I cover up. I also take costly medication and will continue to do so for the rest of my life. Some side effects of the immunsuppressants are that I get sick more frequently. I miss school a lot and the teachers don’t always understand. It makes it pretty tough to keep up. The high cost of the medication has made it necessary for me to attend college full time right after I leave high school in order for my parents’ insurance to cover the medication.

My parents are, and always have been, my biggest cheerleaders. They stood by me through every second of the transplant process. They even requested to see the nine pound monster liver that was removed from me. My parents are protective. I would not say they overdo it, but they maintain a parental strictness that I don't argue with. As expected, they worry about me not taking my medications. But they shouldn't be concerned. I would never not take them. Right now, things are going too well for me to not swallow a couple of pills a day. Yes the medicine is expensive, but my life is priceless.

If I had to describe my life today, I would say that it is fun, busy and productive. I work part-time at a fabulous little airport, which I love. Aviation is a passion of mine. I fly whenever possible with my father or brother. They are both licensed pilots. I am a senior in high school and looking forward to college (I want to be a Nebraska Corn Husker someday). I have a group of awesome friends. I love to party and shop. I can do all of these things because someone gave me the opportunity to do so. Day to day, I run around and live my life—for myself and for that special someone whose opportunity to live was cut short.

So when I am dancing the night away, going 60 on a jet ski, riding a moped up and down the sandy strip of Panama City Beach, or laughing with my friends—just being a normal teenager—I think of my organ donor and think "This is for you."
The arrival of every new year prompts many of us to resolve to make changes and improve our lives through better nutrition and exercise. I believe that every choice we make determines our destiny. Investing in a healthy lifestyle and in your well-being should be a resolution for the rest of your life.

Adherence is the most difficult part of beginning an exercise and fitness program. Sticking to a program is tough. Convenience is the key when it comes to exercise. Many of us don’t have the luxury of a health club membership. You may not have the time, the finances or the desire to go to a gym. So your next choice would be to work out at home. Home exercise equipment is a huge industry and can often be overwhelming.

Before you buy a piece of equipment here are some things to consider:

1. Will I use this piece of equipment? Be realistic.

2. Will this equipment help me to meet my goals? If the advertisement claims "it will melt fat away," be very cautious. A reasonably fit person can burn 400 to 600 calories per hour in any rhythmic class that involves your major muscle groups (legs).

3. What is the quality of equipment? Is it well made? Do not just look at it. Try using the machine. Is it solid and durable? Does it seem to flow smoothly?

4. Is it comfortable? Pay attention to how your lower back, joints and muscles feel when you use it. A seat should be comfortable and stable, bars should be padded and move freely, controls should be easy to read, noise level and the stability should be tolerable.

5. What machine is best? This is a personal choice. Machines that use arms and legs, burn more calories but may not feel good to you.

6. What is the best deal? Be prepared to spend a few hundred dollars on exercise equipment. Non-motorized treadmills are inexpensive, but very clunky to use. You do not need to spend several thousands of dollars either. Some machines cost more because they have features that monitor your heart rate, time elapsed and calories burned. Programmable machines that automatically adjust your workload are good for some, but manual controls work just as well.

TREADMILL

Why Buy?
Walking stresses the joints least, but you can burn more calories by jogging or running.

Choice —The surface can be hard; chose one that has some give to it.

 enlisted
An incline-motorized track is important.
It should be at least 5 feet long.
The handrails should support your weight in case you lose your balance.

STATIONARY BIKES

Why Buy?
Exercise bikes provide a good workout with little stress to the knees.

Choice —Bikes have electronic brakes that adjust the pedal resistance automatically to keep workload constant as pedaling speed changes.

Make sure you can adjust the resistance of mechanical brakes with an easy turn of a knob to increase the rate of pedaling speed.

Avoid brakes that add resistance with rubber pinchers—the result is a jerky ride.
Look for bikes that use either a friction belt or wind resistance.
A recumbent (reclining) bike reduces strain on lower back.
Racing handlebars may be uncomfortable for some people.
Chuck Foster was an average seventh grade student who loved the outdoors, playing football and spending time with his friends. The things that I remember him loving the most were the connections that made us friends. He loved to read and write science fiction. I was his English teacher and I loved to read everything that he wrote.

Chuck was a lover of nature and all things around him. He was kind-hearted, loved the animals at the dog pound, loved to plant trees and take nature walks through the woods and by the lake near his home. He was just a sweet kid who had his whole life in front of him, until one day changed everything.

Chuck died on June 11, 1996. He had complained a day earlier about his back hurting, but with his usual level of physical activity of playing football and romping with his teenage friends, that seemed like a normal childhood complaint. When he didn’t improve, his mother took him to the hospital. One minute Chuck was fine, and the next he was comatose. Doctors worked to save his life by finding the problem and treating it, but they were too late.

Chuck was transferred to Erlanger Medical Center, in Chattanooga, in an effort to save him. Surgeons repaired a weak spot in a blood vessel in his chest, but Chuck had already lost too much blood and his brain had gone too long without oxygen. He was declared brain dead, which meant he was dead.

Dead at age 13, this young boy so full of life would never play that high school game of football that he loved so much. He wouldn’t get to graduate from high school and attend college. He wouldn’t get to grow up and have children and grandchildren and worry, like all parents do.

His life was over until his mother did something completely miraculous: she chose to have his organs donated. Without a selfish thought, she gave his heart to a grandmother in Kentucky, who would live to see her grandchildren grow up. A young Tennessee man and an even younger Tennessee woman were given new lungs to have prolonged lives with their families. A teacher and volunteer in Florida is free from kidney dialysis, and she now lives a completely new spiritual life with her new kidney, fondly named "Chuck."

Two people were given the gift of vision and can now see a sunset and the colors of the rainbow. Other recipients were given a new chance at life with a new kidney and liver.

In one moment, a young 13-year-old boy taught me more about living and dying than I could learn in a lifetime. I found solace in knowing that Chuck gave something even in the end. When I returned to school to find that I was again teaching Chuck’s classmates after being moved to the 8th grade, I knew that I had to do something, but I had no idea what that would be. I was devastated with Chuck’s death; I knew the students were going to be, too.

I pondered on this for many weeks before finally contacting Tennessee Donor Services. I knew that I wanted to remember Chuck, but I wasn’t sure that it was the right thing to do for my students. I was so afraid that what I was about to do would hurt someone even more than they were already hurt. But I carried on with my plan.

I wanted to write a book about Chuck and his life, but what I wanted to do most of all was to tell Chuck’s whole story. I wanted everyone to know how he had lived and most of all how he continued to live in the lives of so many people. I thought Chuck’s story was unique and worth telling.
In the past, my students had written books about various topics as part of a reading assignment. Writing a book about Chuck seemed like a good idea, but it would not be complete without mentioning all the lives that he had saved. That’s how I met Deirdre McAdams, RN, CPTC, with the Tennessee Donor Services. I called her and asked her to help me. Deirdre and Tennessee Donor Services, the organ procurement organization that had coordinated Chuck’s donations, contacted all of the transplant centers where the organ recipients had received their transplants. They asked if the recipients would be willing to anonymously correspond with us. Most of them said yes.

The students wrote letters to the recipients telling them about their young friend. These letters were some of the best materials my students had ever written. They had agreed to remain anonymous and to keep Chuck anonymous by giving him an Indian name. They chose Freebird, the title of the song by Lynyrd Skynyrd, because that was one of his favorite songs by his favorite band. The students also chose Indian names for each of the recipients. Each name was chosen with care; many of the names reflected stories that had been read by the students while they were in my reading classes in 7th and 8th grade.

The recipients wrote back and told the students their individual stories. I will never forget the first day that we got a letter from “Daganwida,” the recipient of one of Chuck’s kidneys. The students were a bit shocked, and I was wary. I read the letter aloud, and I know my voice was quivering. I was trying so hard to be strong because I was the teacher and the project idea had been established to help us all through the grieving process. I couldn’t fail them now.

The students immediately wanted to write back to her. She had asked them questions about Chuck and wanted them to know about him. With more enthusiasm than going to the county fair, these teenagers went to work. And that was exactly the response that every recipient got when they wrote letters to the students about their lives, their families and their illness and especially their recovery from the transplant.

The correspondence brought new life to our project. The students were learning, reading and writing and somewhere, deep down, I could see that healing was taking place. They worked all year on getting just the right poetry and artwork for their book. Everything that went into that book was a reflection of something they had done to satisfy the state curriculum for reading, but suddenly learning and reading and writing was a personal thing—more important than any project I had ever seen them produce.

On many days I would find myself on the brink of tears from both happiness and sadness at seeing my students finding things about themselves and their friends that were almost too much to bear. One day, while discussing organ donation, a young bright-eyed student raised her hand. The girl, Autumn, told us that she thought her brother Joshua had also been an organ donor. I was so shocked, I wasn’t sure how to respond. She told us how she dusts a plaque in her home that said her brother had given life to many people. She had learned that these plaques are issued to the families of donors. She was sure her brother had been a hero in his death, but she told the class that she was afraid to ask her parents.

I promised her that I would find out. I went to her father and told him what she had told us. He said that Autumn had been so young when it happened, they never dreamed that she would want to know more. That night her family sat down together and discussed Joshua. The next day, Autumn shared what she had learned. We all listened, with tear-filled eyes, to her story. Her mother had made a scrapbook about the recipients of her brother’s organs. It satisfied Autumn’s hunger to know, and it was so fulfilling for the students that when the bell rang that day, no one wanted to leave; not even me.

Continued on page 7
More cherished memories were made that year than in any of my years of teaching. I know that it was a chance in a lifetime to learn about myself and my students. I learned one thing for sure—I have a year of teaching that not many teachers will ever have. I have a special love in my heart for 129 eighth grade students who are seniors this year at the school where I teach, and I have one special hero named Chuck that will never be forgotten.

With the help of Tennessee Donor Services and the Tennessee County Clerk’s Organ Donor Awareness Foundation, “Our Hero, Freebird: An Organ Donor’s Story” is now a real, hardback book filled with the students’ work in beautiful full color. It has all of the recipients’ letters in real envelopes so the reader can share in the intimacy of each communication. Two thousand copies have been printed and assembled. These copies have traveled all over the world; even to Pope John Paul II. It has been very well received. We are very proud of our labor of love. And this is what some of my students had to say...

**Lindsey Frizzell**

“\nWhen Chuck died, we were not able to deal with our feelings as his friends and classmates. When we learned that Chuck was an organ donor, we were very puzzled. But through our learning and experiences, we’re now educated on organ donation and the impact it makes. 

Our book about Chuck gives a picture to each and every person who reads it to know how great the gift of life is. I am proud to have helped with such a wonderful piece of work.”

**Emily Nash**

“\nIn the summer when I was in seventh grade, going into the eighth grade, a close friend of mine died from an aneurysm. After he died, his mother chose to donate his organs, and since then his friends and I worked writing a book about him called "Freebird." This year when we, Chuck’s friends, graduate, we will think of him and be happy, not sad, because he gave life to others instead of just dying.”

**Analisa Ciuffetelli**

“As an eighth-grade student, I truly did not know the impact of Chuck’s gift of organ donation. Now, looking back I see what an amazing gift he gave. I will never forget knowing and being a part of the class that had such an amazing person.”

**Jon Williams**

“Chuck’s book had a big influence on my life. It taught me the importance of organ donation. It saves lives. It really had an impact on me when I saw the look on the faces of the people who worked on Chuck’s book. I believe I’m smarter about organ donation. Without it, there would be fewer happy families in the world.”

**April Dunn**

“Chuck was a very special friend and it was very hard to let him go, but he still lives in those eight people who received his organs. I used to get very emotional over his death until we started writing Chuck’s "Freebird" book, I started to feel better and it helped me feel a little more comfortable about his death. I know he gave life to people and that would make my friend Freebird so proud. I don’t think Chuck will ever die and that really makes me feel better about death and love and the gift of life.”

**Clay Shiner**

“In 1996, when Chuck died, I was crushed. I had no real way of expressing my emotions. When we stared writing Chuck’s "Freebird" book, I started to feel better and it helped me feel a little more comfortable about his death. I know he gave life to people and that would make my friend Freebird so proud. I don’t think Chuck will ever die and that really makes me feel better about death and love and the gift of life.”

**Autumn Martin**

“I was very shocked with Chuck’s sudden death. It was the first time that someone so special to our class left us so soon. We talked about Chuck as a hero and kept his memory alive. It also brought back memories and questions that I had about my older brother Joshua. Putting the book together made me understand the importance of organ donation. I am so thankful to see this book published and to have been a part of it. Freebird and his book will live in my heart forever.”
To use it, set the seat so that your knee is only slightly bent at its lowest point.

Use pedal clips to help you to push and pull the pedals.

**ROWING MACHINE**

**Why Buy?**
Proper rowing gets 75 percent of its force from the legs, although it appears to be upper body.

However, it is difficult to read or watch TV when rowing.

**Choice** — There are two types, hydraulic and wind resistance. The latter has a more natural feel.

The seat should move back and forth freely, and there should be uniform tension throughout the movement.

**CROSS COUNTRY SKI MACHINE**

**Why Buy?**
This machine engages the upper and lower body muscles more vigorously than any other machine.

- You burn more calories per minute.
- The impact forces to the body are low.

**STAIR CLIMBER**

**Why Buy?**
You can get an intense workout without exposing your legs to severe impact.

**Choice** — Some models have linked pedals in which pressing down on one forces the other one up. Unlinked models provide a more natural rhythm.

**EXERCISE RIDER**

**Why Buy?**
This machine provides a combination of rowing and leg pressing movements, offering a total body workout. The average person should get a good workout on the rider, but highly fit people probably won’t get a high-intensity ride.

Physical Fitness is fundamental in creating a strong mind and feeling empowered.

In Health & Happiness!

Vanessa A. Underwood, ACSM, AFAA, is a fitness trainer at Wellness Consultant, and a motivational speaker. Two-time transplant recipient.

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**A Donor Family Writes an Open Letter to Transplant Recipients**

Dear Transplant Recipient:

As a transplant recipient you have so much to deal with. In addition to the normal inconveniences from major surgery, you must now also contend with a new regimen of medications required to ward off rejection. You may also be dealing with another major issue that has nothing to do with the actual surgery or post-operative care. Many of the transplant recipients we have met tell us that they struggle with the concept that someone “had to die” so that they could live. If you have ever experienced these feelings, we hope the following words will put your mind at ease.

Seven years ago we spent a torturous night in a local hospital hoping against hope that our 18-year-old daughter would recover from the injuries she suffered in an automobile accident. Despite the heroic efforts of the entire medical staff, there was to be no miracle that night. That dark July night in 1994, Melissa was declared brain dead. Shortly thereafter, we were approached about organ and tissue donation. The decision to donate was not as difficult to make as you might think. We chose to donate for two reasons. First, we had agreed on this as a result of a family discussion a few months earlier, so we know that is what Melissa wanted us to do. Second, we agreed because we knew that there were people like you in such a desperate need. We felt that if one family could be spared the pain that we had just endured, then Melissa would not have died in vain.

from her parents,

Patti and Mark Norquist
Despite the failure of Congress once again to reauthorize the National Organ Transplant Act (NOTA), last minute maneuvering did result in the passage of two bills of importance to organ procurement organizations (OPOs) and to children waiting for transplants.

The Organ Procurement Certification Act of 2000 imposes a moratorium on the Health Care Financing Administration’s (HCFA) current recertification process and the use of population-based performance measures. The immediate beneficiaries of the bill, which was passed on October 27 as part of the Public Health Improvement Act of 2000, were three OPOs due to be decertified by HCFA, the Arkansas Regional Organ Recovery Agency (ARORA) in Little Rock; the Northeast OPO and Tissue Bank in Hartford, CT; and Lifelink of Puerto Rico.

The Pediatric Organ Transplantation Improvement Act of 2000 increases children’s access to organs for transplantation. The act was contained in the Pediatric Organ Transplantation Improvement Act of 2000 spearheaded by Representative Diana DeGette (D-CO).

A last-minute effort to reach a compromise between the House version of NOTA and Senate version failed in mid-October when the House refused to accept a counter-offer to its proposal.

The House bill “championed by Representative Thomas Bliley, Jr. (R-VA) “was heavily tilted towards the United Network for Organ Sharing (UNOS) and would have given UNOS significant new authority over setting US transplant policy.

The Senate compromise authored by Senators Bill Frist (R-TN) and Edward Kennedy (R-MA) “retained the authority of the Department of Health and Human Services (HHS) to set policy but created a Scientific Advisory Committee on Transplantation to oversee disputes.”

Congress has not passed NOTA legislation since 1990, despite the fact the program is supposed to be reauthorized every three years. The failure to pass the legislation became less important to HHS with the announcement in early October that UNOS had signed a new contract to administer the Organ Procurement and Transplantation Network (OPTN). That contract which contained a provisions requiring organs to be shared on the basis of medical urgency, not geographical location.

By signing the contract UNOS, legislation or lawsuits aimed at overturning the HHS regulation, implemented on March 16, are considered much less likely. “We would have liked to have had a bill, but the contract goes a long way to ensure a fairer transplant system in the future,” an HHS spokesperson said.

Organ Procurement Certification Act of 2000

The legislation was co-sponsored by Senators Susan Collins (R-ME), Christopher Dodd (D-CT) and others contains the following provisions in addition to the moratorium:

✦ requires that the certification of qualified OPOs remain in place through January 1, 2002, for those OPOs that were certified as of January 1, 2000, and that meet other qualification requirements apart from the current performance standards;
✦ requires the Secretary of HHS to promulgate new rules governing OPO recertification by January 1, 2002. The rules are to rely on the outcome and process performance measures based on evidence of organ donor potential and other relevant factors, and recertification for OPOs will be required until they are promulgated;
✦ provides for the filing and approve of a corrective action plan by an OPO that fails to meet the standards, a grace period to permit a corrective plan, and opportunity to appeal a decertification, and a four-year certification cycle.

Pediatric Organ Transplantation Improvement Act of 2000

The bill was part of the Beneficiary Improvements and Protection Act (BIPA). The bill (HR 4008) requires the OPTN to: (1) recognize the differences in health and organ transplantation
issues between children (individuals under the age of 18) and adults and adopt criteria, policies, and procedures that address children’s unique health care needs; and (2) carry out studies and demonstration projects to improve procedures for organ donation procurement and allocation. The bill also requires the Secretary of HHS to study and report to congress on the costs of immunosuppressive drugs provided to children prior to transplantation and the extent to which health plans and health insurance cover the costs, including recommendations on issues particular to the special health and transplantation needs of children.

The Secretary is also required to study the following:

- The extent of denial of organs to be released for transplant by coroners and medical examiners;
- The special growth and developmental issues that children have pre- and post-organ transplantation; and
- Other issues that are particular to the special health and transplantation needs of children.

HCFA announces Medicare will begin covering intestinal transplants under certain conditions

After 15 months of intense analysis, the Health Care Financing Administration (HCFA) announced that for the first time Medicare will cover all types of intestinal transplants. The coverage is specifically for patients with irreversible intestinal failure who have certain life-threatening complications from long-term intravenous nutrition, commonly referred to as total parental nutrition (TPN).

Under the criteria released by HCFA through its website on October 4, three US hospitals are known to qualify for Medicare reimbursement for performing the procedure, however there could be others. They include the University of Miami, Miami, FL; the University of Nebraska Medical Center, Omaha; and the Pittsburgh Medical Center, Pittsburgh, PA.

HCFA’s criteria for the approved centers include an annual volume of at least 10 intestinal transplants and a one-year actuarial survival rate of at least 65%. The agency determined the criteria after assessment of survival rates and cost effectiveness.

The number of patients affected by the Medicare decision is small. Only 700 intestine transplants have been performed worldwide on patients who have failed TPN and 2/3 are done in pediatric patients who do not qualify for Medicare, according to the HCFA spokesperson. In its decision memo, HCFA also pointed out that only 439 total intestinal transplants have been performed in the US as of October 2000.

The long-term impact of the decision could be huge however, because most state Medicaid and other third-party payers usually follow Medicare reimbursement guidelines.

“While these procedures have been approved by some third-party payers at our facility and at other transplant centers in the United States... without Medicare’s approval, it has been a real battle with insurance companies for most patients,” said Kareem Abu-Elmagd, MD, director of intestinal transplantation at the University of Pittsburgh Medical Center’s (UPMC) Thomas E. Starzl Transplantation Institute. The procedures have also been recognized by European and Canadian governments as standard procedures and eligible for reimbursement, he said.

HCFA noted that the Institute made the request for coverage on June 29, 1999. In their appeal for coverage, UPMC reported a 72%, one-year patient survival rate and a five-year survival rate of 52%, figures that are comparable to lung transplantation, which has been covered by Medicare since 1995. UPMC said to date it has performed 160 transplants in 150 patients with irreversible intestinal failure.

There are three ways to transplant the small intestine, according to UPMC: (1) alone, (2) in combination with the liver, or (3) in combination with the liver, pancreas and stomach. The majority of patients at UPMC required intestinal transplants because of short-gut syndrome, the loss of more the 70% of the intestine due to trauma, surgery or disease.

In its decision memo, HCFA pointed out that intestinal transplantation is a high-risk procedure and can only be considered as “reasonable and necessary when it is a procedure of last resort.”

“Intestinal transplantation should be reserved only for patients with life-threatening complications from TPN who are expected to die without transplantation,” HCFA said. “Therefore, we are limiting Medicare coverage of intestinal transplantation only to patients who have failed TPN.”
Patients with intestinal failure must be sustained nutritionally with TPN. Unfortunately, liver failure often results after long-term use of TPN which leads to the need for a life-saving combined liver and intestine transplant in some patients.

HCFA said Medicare will cover intestinal transplantation only in the following clinical situations when TPN fails:

- Impending or overt liver failure due to TPN induced liver injury; 
- Thrombosis of the major central venous channels; jugular subclavian, and femoral veins; 
- Frequent line infection and sepsis; and 
- Frequent episodes of severe dehydration despite intravenous fluid supplement in addition to TPN.

No other transplant procedures are presently being considered for Medicare coverage, HCFA's spokesperson said.

The Medicare coverage notice can be found at the following Web site address: http://www.hcfa.gov/quality/8b3-gl.htm

Increased graft survival of HLA-matched kidney transplants supports national sharing, study finds

A superior graft outcome with little increase in the duration of cold ischemia justifies national sharing of HLA-matched kidney transplants, according to the results of a study published in the October 12th issue of the New England Journal of Medicine.

Steven Takemoto, MD, and colleagues from the University of California at Los Angeles (UCLA) compared the rates of rejection and actuarial graft survival for 7,614 HLA-matched and 81,364 HLA-mismatched cadaveric kidney transplants reported to UNOS between October 1987, when a program for national sharing of HLA-matched kidneys was launched, and September 1999. To assess the effects of the extended period of ischemia associated with shipping HLA-matched kidneys, the investigators identified 3,562 pairs of cadaveric kidneys in which one kidney went to an HLA-matched recipient and the other was transplanted into an HLA-mismatched recipient.

"The estimated 10-year rate of graft survival was 52% for HLA-matched transplants, as compared with 37% for HLA-matched transplants,” wrote Takemoto and co-authors. "The estimated half-lives of the transplants were 12.5 years and 8.6 years, respectively."

After adjusting for the effects of demographic characteristics, at 10 years, the overall rates of graft survival and the rates of functional-graft survival (with data censored on patients who died with a functioning graft) were 10% and 11% higher, respectively, for HLA-matched transplants than for HLA-mismatched transplants, the researchers reported. Among 3,562 pairs of kidneys, HLA-matched transplants had higher rates of survival, a lower incidence of episodes of rejection, and a reduced risk of loss due to rejection.

"Before kidney-sharing program was initiated, only 2% of transplants were HLA-matched, the investigators wrote. "After the program was initiated, 5% of kidneys were transplanted in HLA-matched recipients with use of the six-antigen matching criteria. Use of the phenotypic criteria increased the percentage to 7%, and use of the no-mismatch criteria increased it to 13%. The survival rate of HLA-matched kidney transplants was similar regardless of the criteria by which they were selected.” The percentage of HLA-matched transplants could be further increased, according to the authors, by extending the organ-sharing network to include Canada, as many Canadian cities are close to those in the United States.

Since UNOS established the national kidney-sharing program in 1987, many have argued that the resultant increased duration of cold ischemia would offset the benefit of shipping kidneys to HLA-matched patients. Indeed, in their analysis of nearly 64,000 cadaveric renal transplants reported to UNOS between 1990 and 1998, researchers at the University of California at San Francisco (UCSF) recently reported that recipients of kidneys with zero mismatches but with cold ischemic time greater than 36 hours had no survival advantage over patients with mismatched kidneys kept cold for less than 24 hours (Transplant News, September 24, 2000 page 8). In the UCLA study, more than 83% of the HLA-matched kidneys in the UCLA study were shipped to distant transplant centers, whereas 77% of the HLA-mismatched kidneys were shipped within the local service area of the organ procurement organization. Nonetheless, the mean duration of cold ischemia was comparable—23 hours for patients given HLA-matched kidneys and 22 hours for patients who received HLA-mismatched
kidneys—and well within the cut-off point set by the UCSF investigators.

During the study period, the researchers noted that the proportion of kidneys from older cadaveric donors steadily increased in response to the growing demand for transplants. In 1988, 6% of transplanted cadaveric kidneys were from donors over age 55 years; that fraction increased to 13% by 1997. Donor age had a significant effect on 10-year graft survival among recipients of HLA-matched kidneys: 68% in patients whose donor was age 15 years or younger, 32% in those whose donor was older than 55 years. Because an estimated 70% of kidneys from donors older than 60 years of age will be lost within 10 years of transplantation, the authors recommended that "young recipients should not undergo transplantation with organs from older donors, even if they are HLA-matched."

Organ donation in the US increased 4% in first half of 2000 compared to 1999, AOPO, HHS report

Organ donation in the US increased by about 4% in the first half of 2000 compared to the first six months of 1999, according to the Department of Health and Human Services (HHS) and Association of Organ Procurement Organizations (AOPO).

According to data gathered by AOPO through monthly reports from the nation’s 59 organ procurement organizations (OPOs), the number of organ donors through the first 6 months of 2,000 was 2,978, compared to 2,875 in 1999 for the same time period.

SEOPF launches Living Organ Donor Network designed to track health status of living donors

The South-Eastern Organ Procurement Foundation (SEOPF) has launched a Living Organ Donor Network (LODN) that is designed to provide living persons considering donating a kidney to a relative, friend or relative the opportunity to have their future health status tracked and protected. The LODN will consist of two parts – a living donor registry and financial safety net to help cover unexpected financial costs.

The living donor registry will follow donors indefinitely to assess long term outcomes of being a kidney donor, explained Tom Armata, SEOPF executive director. The registry will combine existing data on the donor and recipient compiled by the United Network for Organ Sharing (UNOS) with additional data collected at the time of donation and at 3, 6, and 12-month follow-ups with the donor.

The financial safety net will be in the form of $250,000 life, disability and medical insurance to cover complications which might arise to affect the living related or unrelated donor.

SEOPF will offer the LODN to all kidney transplant centers in the US.

“We are hoping that all transplant centers performing living kidney transplants will participate in our program” Armata told Transplant News. “The criteria for donations are the same as the American Society of Transplant Physicians.”

In early November, the United Network for Organ Sharing (UNOS) reported that more than 72,000 Americans were on the transplant waiting list.

Thumb-sized Jarvik 2000 heart successfully implanted permanently into 61-year-old man

A thumb-sized intraventricular assist device has been permanently implanted into a 61-year-old man with end-stage heart failure with initial success, UK researchers reported in the September.

Stephen Westaby, MD, from the John Radcliffe Hospital in Oxford, UK and colleagues implanted the Jarvik 2000 heart into the patient’s left ventricle in June as part of a prospective clinical trial that eventually will enroll six patients with cardiomyopathy. A team from the Texas Heart Institute in Houston, who had implanted the device in three patients this summer as a bridge to heart transplantation, flew to Britain to participate in the 14-hour operation.

The tiny, silent, titanium impeller pump is powered by a cable that passes from the device to the chest, then through the neck to a pedestal screwed into the skull behind the ear. The unobtrusive pedestal, based on cochlear implant technology, transmits the cable to an external portable controller and battery, both of which are worn on the patient’s belt. The controller has a single dial, enabling the patient to regulate the impeller speed according to activity level.

After six weeks of use, the researchers found that the Jarvik 2000 sustained the patient’s circulation and improved exercise tolerance as well as cardiac and end-organ function, resolving his symptoms of heart failure. No significant hemolysis or device-related complications occurred.
For most people, getting a transplant means a new lease on life. The days of being sick are replaced with days, months and sometimes years of feeling better, being more active and returning to as normal a lifestyle as possible. Clinic visits, blood tests and medical follow-up procedures tend to get farther and farther apart.

The main responsibility we have is taking our medications on a regular basis. As contact with the medical team decreases, we learn to assume the role of caretaker and start monitoring our own health status. Some people do this as part of a strict daily routine that has been the same since being discharged from the hospital. Others drift away from that routine and do not pay as much attention to their general health. Either of these methods works fine, as long as things are stable and no problems arise. As most of us learn over time, this is not the norm. Many people plan for the transplant to be problem-free and to last forever.

Most long-term recipients will attest to the fact that things do not always go as planned. Being on anti-rejection drugs brings up an endless list of possible complications we may have to deal with. For people who have continued to follow the routine of taking their blood pressure and temperature, recording their weight and keeping lab appointments as scheduled, it may be easier to detect the early warning signs of problems before they become a major crisis. These daily maintenance items may seem small and not important after years of stable medical history, but can play a big role in heading off a possible disaster.

Many serious medical complications of transplantation have early signs and symptoms that outwardly seem not to be connected with the transplant. If we write these off to things like the flu, allergies or the common cold, we could be taking a big risk with our long-term health. Hepatitis, CMV infection and pneumonia are just some examples of complications that have slow, sneaky beginnings. If caught early, in most cases, they can be managed and not present a major threat to a transplant recipient’s general health or the life of the transplanted organ.

A communication issue for long-term recipients is centered on when to pick up the telephone and call the medical team who is following them. In the early days and months after transplant, most people do not think twice about calling when they have a fever or a cold or when things just do not seem right. After all, most transplant programs encourage us to call them no matter how small or trivial the situation seems to be at the time. As the transplanted organ’s time line gets longer, some people feel they can answer their own problems. They don’t want to bother the health care team, or they feel like they have been through the situation before and nothing major came of it, and they do not make the call. How the team responds to calls can sometimes discourage calling. If the standard response of the team is to tell the person to go to the emergency room, many people will not want to go through that experience for what they see as a minor fever or cold symptoms. You should consider how serious the symptoms are and decide if you need to contact your team.

No matter how we deal with the day-to-day situations that all transplant recipients have, we must be in touch with our health issues enough to realize when something is really wrong and not hesitate to take appropriate action quickly. Even though we know our own bodies better than anyone else, we are not doctors or nurses who are trained to recognize early signs of potential problems. Some of the worst cases of rejection have no immediate outward symptoms. Keeping in touch with your health care team on a regular basis increases the chance that major complications can be detected and treated before your transplant is in jeopardy of being permanently damaged or lost.
Salt. For most transplant patients, even a pinch is too much. By limiting salt consumption, you can decrease fluid retention and blood pressure. Salt is composed of 40 percent sodium and 60 percent chloride. The fact is sodium, alone, is the culprit. Sodium will act like a sponge and hold water in the body. Extra fluid in the body causes edema and increased blood pressure.

An average American acquires 10 percent of ingested sodium by adding salt to food, 10 percent from what naturally occurs in foods and 80 percent from eating processed foods. Processed food is by far the biggest source of sodium. Salt has been and still is the most widely used of all food preservatives.

Salt was the first food preservative. Even in ancient times (before refrigeration) salt was considered power. Salt-preserved food would last longer and armies could fight longer, thus winning wars. In general, the more processed a food is, the higher the sodium content. For instance, old-fashioned cooked oatmeal has 1 mg of sodium per serving, whereas instant has 285 mg per serving.

To Reduce the Amount of Sodium in Your Diet:

- Do not add salt to your food at the table or during cooking. Flavor your foods with herbs and spices. In most recipes, you can omit the salt completely or add only half the amount called for without changing the quality or the taste of the item (the exception is baked products). Experiment with recipes and you will find you can reduce the salt and have an even better tasting meal.

- Read labels and decrease your intake of processed foods. Become a sodium sleuth. A good general rule in the grocery store is to stay on the outside edge of the store. Most processed foods (canned, boxed, frozen foods) are in the aisles and the less processed foods are on the perimeter (fresh meats, vegetables, fruits, milk, breads).

Try to limit your sodium to less than 3000 mg a day. Just one teaspoon of salt contains 2400 mg of sodium! So remember the old saying but with a new ending “A pinch is all it takes” to give you problems.

### Homemade Herb & Spice Blends

#### Season-All (mix for meats and vegetables)

- 1 tsp. Basil
- 1 tsp. Marjoram
- 1 tsp. Thyme
- 1 tsp. Oregano
- 1 tsp. Mace
- 1 tsp. Ground cloves
- 1 tsp. Parsley
- 1 tsp. Savory
- 1 tsp. Black pepper
- 1/4 tsp. Nutmeg
- 1/4 tsp. Cayenne

#### All-Purpose Spice Blend

- 5 tsp. Onion powder
- 2 1/2 tsp. Paprika
- 1/2 tsp. Ground white or black pepper
- 2 1/2 tsp. Mustard powder
- 1 1/4 tsp. Thyme
- 1/4 tsp. Celery seed
- 2 1/2 tsp. Garlic powder

#### Herb Seasoning Blend

- 2 tbsp. Dill weed or basil
- 2 tbsp. Onion powder
- 1 tsp. Crushed oregano leaves
- 1 tsp. Celery seed
- 1/4 tsp. Grated lemon peel (dried)
- 1/16 tsp. Black pepper

#### Spicy Blend

- 2 tbsp. Crushed savory
- 1 tbsp. Powdered mustard
- 2 1/2 tsp. Onion powder
- 1 1/2 tsp. Curry powder
- 1 1/2 tsp. Cumin
- 1 1/4 tsp. Cumin
- 1 1/4 tsp. Black pepper
- 1/2 tsp. Garlic powder
Complications Following Organ Transplantation:
The Need for Careful Medical Follow-up

By Ira D. Davis, MD

Over the past two decades, patient and transplant organ survival have improved dramatically to the point that quality of life issues are now the primary focus when monitoring a patient in the post-transplant period. However, several potential medical problems may arise in the post-transplant period that may have a negative impact on quality of life. These include infection, cancer, high blood pressure, elevated blood lipid levels, heart disease and diabetes. In addition to these problems, delayed growth needs to be addressed in the pediatric population.

THE PROBLEMS

Organ transplant recipients are at an increased risk for numerous infections due to the effects of anti-rejection drugs such as prednisone, azathioprine (Imuran), cyclosporine, tacrolimus (Prograf or FK506), sirolimus (Rapamune), and mycophenolate mofetil (CellCept) on the immune system. These drugs, referred to as immunosuppressive agents, block the body’s immune system in order to prevent rejection and blunt the ability to fight off infections due to bacteria, viruses and other infectious agents. Although transplant recipients sometimes have less common infections, they primarily have infections such as the common cold, influenza (“the flu”), diarrhea-causing viruses and sexually transmitted diseases.

Urinary tract infections (UTIs) are the most common bacterial infection during the initial three months following a kidney transplant. People with UTIs may have no complaints or they may have a fever, stomach pain, urination discomfort, or feel very weak and run down. Thanks to better methods of detecting these viruses at earlier stages, before serious illness develops, and improved therapies in preventing serious disease, fewer problems from viral infections such as cytomegalovirus (CMV) and Epstein-Barr virus (EBV), which may cause fever, weakness, pneumonia and liver problems, occur today.

High blood pressure is another problem commonly experienced by transplant recipients. It may be due to side effects from medications such as prednisone, cyclosporine and tacrolimus, or poor kidney function.

Up to 80 percent of organ transplant recipients have elevated blood levels of cholesterol or triglycerides, referred to as hyperlipidemia. These problems are of major concern because they increase the risk of developing serious heart disease and hardening of the arteries in the heart and vessels of the legs.

Weakening of the immune system with anti-rejection medications also predisposes organ transplant recipients to several forms of cancer that occur at a higher rate compared to the general population. Skin and lip cancer are the most common forms of cancer seen in transplant recipients. Cancers of the blood, liver, muscle and female genital organs also occur in transplant patients. Cancer of the blood is typically related to a new EBV infection in transplant recipients, while liver tumors may develop as a complication from Hepatitis B infection.

Diabetes mellitus occurs in approximately 10 percent of adults and children following kidney transplantation and increases the rate of rejection. It usually occurs within 4-6 months following transplantation and is seen frequently in African Americans and Hispanics. Diabetes mellitus in the post-transplant population is either due to an inability to respond to insulin, which is a hormone that normally lowers the blood sugar level, or decreased insulin production. Diabetes may result from side effects to medications such as prednisone, cyclosporine or tacrolimus. Genetic factors and obesity also predispose transplant recipients to diabetes.

Continued on page 16
The Greatest Gift of All

By Patsy Roeme Lakeland

Dedicated to her father waiting for a liver transplant

When my days have passed
And come to an end
What will I leave behind?
Of course they'll have their memories of me
And material things of each kind.

But did I give the most of myself
When I was part of the living?
I guess if I didn't, there's still
that chance.
When I'm gone I can still keep giving.

The most precious gift you could remember me by
Would be that I helped another.
I gave the gift of life to someone,
A child, a spouse, father or mother.

I made a difference
Even at my end.
Although I don't know you
I've made a new friend.

I changed someone's destiny.
They can now go on living.
And it was so simple
It was all in the giving.

It's a wonderful feeling
To know I have something more
to give
That when my end approaches
Someone else has a chance to live.

I'm glad I've made this choice in my life
Before my time grows near.
My soul will go to heaven someday
But my organs will stay here.

medical beat

continued from page 15

Diabetes also increases patient mortality, primarily as a result of increased infections. Other complications from long-term diabetes mellitus include nerve injury, eye disease, heart disease, and poor kidney function.

Growth in children following transplantation is often delayed during the initial 12 months. This appears to be due primarily to high doses of glucocorticoids such as prednisone. Although children undergoing liver and heart transplantation often catch up in growth following their transplant, children with kidney transplants often do not. Long-term studies in kidney transplant recipients demonstrate that children receiving a transplant before age 1 show the greatest improvement in growth during the next five years. Children who receive their transplant after age 5 fail to show significant improvement in their growth rate.

Strategies used to improve growth in children following a kidney transplant include low-dose prednisone, alternate-day steroid withdrawal or daily injections of human growth hormone, a substance that is responsible for normal growth of bone and cartilage. Although several studies suggest growth hormone is a safe and effective drug in kidney transplant recipients with short stature, further long-term studies are needed before this drug becomes an accepted standard of therapy for these patients.

What can you do?

Transplant can take recipients several measures to ensure optimal health and help reduce their chance of having a serious adverse outcome. These include:

- Contact your primary doctor when you are ill or have a fever above 101°F.
- Visit your transplant doctor regularly.
- Eat a balanced diet low in salt and fat.
- Perform regular aerobic exercises for 20 minutes, 4 times per week.
- Stop smoking.
- Monitor your blood pressure at home.
- Get regular skin exams and use sunscreen with a high sunblock rating.
- Female transplant recipients should receive regular pelvic exams.

In addition, studies are needed to evaluate the safety of reducing the doses of cyclosporine and tacrolimus with the addition of newer drugs such as sirolimus and to assess the safety of steroid withdrawal.
What about the use of mycophenolate mofetil (CellCept, MMF) during pregnancy?

There is a concern based on animal studies that MMF could increase the risk of a birth defect in newborns of mothers taking this medication during pregnancy. The NTPR has reordered seven pregnancies with use of MMF during pregnancy by female kidney recipients, resulting in four babies with no birth defects and three miscarriages. No apparent problems have been reported to the NTPR in male recipients fathering children while taking MMF. Thirty-eight male recipients taking MMF fathered children with no birth defects reported. After a discussion with the transplant team, the recipient taking MMF must weigh the risks and benefits.

Are there any particular problems among the newborns?

For female recipients, there is at least about a three times greater than normal risk of having a baby who is premature (less than 37 weeks gestation) or low birthweight (less than 2500 grams, about five and one half pounds). There has, however, been no pattern of birth defects reported in the newborn.

How are the children developing?

Typically, the children are reported healthy and developing well, although occasional health or development problems have occurred.

Is breast-feeding advisable?

The American Academy of Pediatrics has advised against breast-feeding, although a small number of recipients in the registry have chosen to breast-feed with no specific problems reported in their infants. The potential risk of ingesting immunosuppressives via breast milk must outweigh the benefits of breast-feeding in this potentially high-risk infant population.

What about more than one pregnancy?

Some women have reported additional pregnancies to the registry. As in first...
On February 13, 1993, I married a wonderful man, George Bowers. Little did I know that five and a half years later, we would celebrate more than a wedding anniversary. This "other" anniversary would be my successful kidney transplant.

The other anniversary actually began before our marriage, when I was diagnosed with kidney disease in 1992. Despite my following a special diet, an exercise regime and daily blood pressure medication, my kidney function continued to deteriorate. I can still hear the doctor’s words in December of 1997: "You will need a kidney transplant within a year and you will need a living donor."

I was in denial, but then came the anemia, exhaustion and constant fatigue that often accompany kidney failure. I soon began the pre-transplant testing. My world started to crumble again when none of my family members could be my donors. Then came the miracle! My husband could be my donor and most important, he offered to give me the gift of life.

On June 3, 1998, George donated one of his kidneys to me! Within five days of the surgery, we were both home from the hospital, recuperating under the able care of our family and friends. Their care and support still remains a wonderful part of our lives.

Celebrating our kidney anniversary is no longer just a June 3 event. We celebrate our success everyday. Exercising, working out and eating healthy are priorities for us. Each summer we still ride approximately 500 miles in RAGBRAI (Register’s Annual Great Bike Ride Across Iowa). Although I was able to compete and win medals in badminton and biking at the recent National Kidney Foundation’s 2000 U.S. Transplant Games in Orlando, my husband received the best medal, the Gift of Life Donor Medal.

Along with remaining healthy, we are also committed to being role models for other people in need of transplantation. Giving our support to those in need brings such happiness for both of us. We enjoy being volunteers for the Donor Network of Arizona. As guest speakers, we share our good news, show the positive results of the Gift of Life and encourage future recipients. We feel a sense of pride and accomplishment when others join our donor/transplant community.

Our daily lives have taken a new perspective since our transplant. We appreciate our time together, share our happiness and take time for just us. As the recipient, I realize that I am one of the lucky ones. I am blessed with the gifts of love and life all in one package from my best friend, my husband.
Sirolimus (Rapamune) is the latest immunosuppressive drug to be approved by the Food and Drug Administration (FDA) for use in the prevention of kidney transplant rejection. The drug has a chemical structure that is similar to tacrolimus (Prograf), but acts in an entirely different way and is associated with some unique side effects and drug interactions. Clinical trials conducted in the United States and Europe evaluating the use of Rapamune in combination with cyclosporine and prednisone in kidney transplant recipients have been promising. As a result, investigators have been prompted to study the effects of Rapamune in combination with other immunosuppressive drugs and other types of transplanted organs.

Unlike cyclosporine and tacrolimus, which prevent your body from reacting to the transplant, Rapamune "stalls the engine," disabling the body’s ability to reject to the transplanted organ. Because of this, doctors may be able to prescribe lower doses of cyclosporine when it is combined with Rapamune, minimizing unwanted side effects such as kidney toxicity, hypertension, electrolyte disturbances, unwanted hair growth, tremors and high blood sugar, etc.

The side effects patients on Rapamune most frequently encounter include high cholesterol and triglycerides, decreased blood counts (white blood cells, platelets, red blood cells), impaired wound healing, diarrhea, nausea and headache. These effects may increase with higher doses of Rapamune. In clinical trials, transplant recipients have been able to lower elevated cholesterol and triglyceride levels related to Rapamune with changes in diet and exercise. For patients who do not respond to lifestyle changes, drug therapy has been used successfully. Consult your transplant doctor and team for the best approach to management.

Rapamune is only available in liquid single-use pouches containing 1 ml, 2 ml and 5 ml each and multiple dose bottles containing 60 ml and 150 ml. It is expected that the manufacturer will gain approval from the FDA to market a tablet form of Rapamune within the next year. Rapamune must be kept refrigerated and protected from light when not in use.

“Researchers will further define the role of Rapamune in the coming years and propose ways to optimize its effectiveness while reducing and managing unwanted side effects.”

Rapamune is a welcome addition to the line of drugs available to prevent rejection in organ transplant recipients. It has a unique mechanism of therapeutic action, providing potential advantages when taken in combination with other anti-rejection drugs. Rapamune has some side effects, but is not toxic to the kidney. Drug interactions that occur with Rapamune are similar to those seen with cyclosporine and tacrolimus. Researchers will further define the role of Rapamune in the coming years and propose ways to optimize its effectiveness while reducing and managing unwanted side effects.
Are there some recipients who are at higher risk for complications during pregnancy?

Yes, recipients with deteriorating graft function prior to pregnancy, such as liver recipients with recurrent hepatitis C, may be at an increased risk. Pre-pregnancy counseling is especially advisable for them.

What about male recipients?

Overall, for male recipients who become fathers the outcomes are generally good, and the frequency of prematurity and birth defects in the newborns appears to be similar to that of the general population.

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. To participate in the NTPR, recipients are requested to complete a single page questionnaire, followed by a telephone interview and continuing follow-up. To report a pregnancy or request further information, please contact the NTPR toll free at 1-877-955-NTPR (6877), fax (215) 923-1420 or email NTPR.Registry@mail.tju.edu.

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A healthy Elizabeth Alexis Carlin was born on November 13, 2000 to Alex and Faith Carlin. Faith had a kidney and pancreas transplant on July 7, 1991.

The National Kidney Foundation recognizes the significant contributions made by Novartis Pharmaceuticals Corporation to transplant recipients around the country through its sponsorship of the following NKF programs: 2000 U.S. Transplant Games; Transplant Chronicles; and transAction Council programs.

National Kidney Foundation
30 East 33rd Street
New York, NY 10016