This is a true story about a group of Oregon and Washington transplant recipients who didn’t like the way a lot of the public perceived them after transplantation. They were seen practically as vegetables who were hardly able to care for themselves. They wanted to change their image by doing something bold and daring that said, “We are just like you, except we have a few used parts!”

An idea formed in the mind of Larry Huot, a liver recipient, who knew someone who had participated in the 1996 Portland-to-Coast 125-Mile Relay Walk. Portland-to-Coast is the largest relay race on this continent. The event involves 19,000 people, including 2,000 support people and 3,500 volunteers. The race-walk event starts in Portland and finishes 125 miles west at the Pacific Ocean. There are 24 relay legs to cover over the 125 miles. Each leg ranges from 3.8 miles to 7.6 miles, with an average distance of 5.2 miles. Some of the legs are flat and on asphalt roads, while others are on dirt or gravel and are very hilly.

Larry got together with several other transplant recipients to see about forming a team to enter in the next race. With the assistance of the Oregon Donor Program and the National Kidney Foundation of Oregon & SW Washington, a team was formed and called Transplant Trotters. The team was led by captain and manager Richard Moody, who received a heart transplant at the age of 49, and Richard and I served as the two group leaders. Our two groups included Bill Bray, Sabrina Feldman, Bert Fox, Stuart Hudson, Don Johnson, Marie Kent, Sue Mercer-Cory, Theresa Palla, Jennifer Rigert and Rob Wheaton. Each group had six team members, one van and a volunteer driver. Also, according to the relay race rules, each team provided three volunteers for race control assignment.

I would like to tell you a little about the ordinary, yet extraordinary, people who make up the Transplant Trotters. The team includes seven men and five women, plus our two volunteer drivers. Our ages range from 16 to 63, and we cover almost all of the major transplant...
Happy New Year! Chronicles is ringing in the New Year with additions to our publication. First, we have two new editorial board members. Janet Karlix, PhD, is a PharmD at the University of Florida in the Transplant Division. We look forward to providing you with the most updated information through Janet’s experience in transplant pharmacology. Charlie Thomas, CISW, ACSW, also joins the editorial board as the social work editor.

You will also notice a new column in this issue, “Between Donor Families and Recipients,” that was added to share the flood of communication received from recipients and donor families. These letters, stories and articles will hopefully encourage recipients to communicate with donor families who play the most integral part in their transplant.

Have a great year and keep those stories and comments coming!

Beverly Kirkpatrick
for the Editorial Board

Transplant Recipients Join Together at NKF Annual Meeting in Philadelphia

NKF’s 48th Annual Meeting took place October 23-25 in Philadelphia, Pennsylvania. Transplant recipients, donor families and kidney patients joined together to share common experiences and learn from each other. More than 260 members of the transAction Council, National Donor Family Council and Patient and Family Council attended the program, which focused on “Taking Control of Your Life.”

A meeting highlight included a dinner symposium held by the transAction Council, “Optimal Drug Use, Be a Team Player.” Attendees participated in an interactive workshop and tested their knowledge about current immunosuppressant options. Janet Karlix, PhD, director of the Clinical Pharmacology Program at the University of Florida, was the presenter. She emphasized that quality of life after transplantation is directly linked to following a medication regimen.

A joint council session on “To Write or Not to Write? What It Means for Recipients and Donors” was presented by the transAction and National Donor Family Councils. Donor families and transplant recipients came together to share their feelings about corresponding with each other.

Another highlight of the meeting was an open-mic Coffee House, at which people shared personal stories, read poetry and gave thanks and acknowledgment to their loved ones and donors. As participants shared smiles, tears and embraces with new friends, the bond and energy between patients, recipients and donor families grew stronger.
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Transplant Trotters...
Continued from page 1

organs, including bone marrow and cornea. Our race-walk minute per mile times ranged from 13-minute miles to 15-minute miles. Guess who was the slowest and oldest? It was none other than this author! Our vocations are a teacher, engineer, cab driver, construction worker, students and retirees. Our volunteer, Dave, turned out to be a real card and a constant source of strength when we needed it. You wouldn’t believe that a group of men and women of all ages could converse like they were family or old friends. Thinking back on it now, though, I feel it was the common bond of transplantation that drew us together so quickly. I had similar experiences last year at this same event, as well as at the U.S. Transplant Games, presented by the National Kidney Foundation.

The Transplant Trotters entered the 1997 Relay Walk in two groups, and I’m proud to say that we not only finished, but we received a sixth place medal in our division. When we first formed that year, the Transplant Trotters decided upon several team rules and intentions. The first rule was that you must be an organ transplant recipient to race. Our primary intention was to have fun and celebrate life as a team, and our second intention was to finish the race. We entered the race-walk again in August 1998 and also added a third intention to our list. We dedicated the August 1998 race to our original team founder, Larry Huot, who had passed away in April.

During the race, everything went smoothly for group one’s two legs of the race, as well as for group two’s first leg, but then a transfer problem occurred at 5 a.m. on the second day. The last race-walker of group one approached transfer station No. 30, where he was supposed to be relieved by group two’s first race walker — me. But I was 4.4 miles to the west, at the next transfer station. How could I have made such a mistake, you might ask? It was midnight and I was tired, and I was trying to get to my next transfer station to catch a couple hours sleep before I had to get up and run another 4.4 miles. I traveled over 1½ hours, and as I came to the transfer station, I asked the volunteer if I was at station No. 31. He said I was, but he didn’t tell me that this was the west end of leg 31, not the beginning!

Richard Moody, our organizer and captain, is a quiet, 52-year-old grade-school teacher who showed true grit and exceptional leadership in the pre-dawn hours of the race. Because of a similar mistake by group two last year, Richard was awake and standing at the correct transfer station when the member of his group was seen approaching the transfer point. When Richard looked around and didn’t see me (since I was waiting at the next station), he stepped in to take the transfer bracelet from his teammate and began the next 4.4-mile leg. Just imagine training to race-walk two 5.2-mile legs with little or no rest in a 24-hour period, and then suddenly finding out you have to do a third leg. Trust me, you are out of gas after two legs. So, if any of you harbor any notions that a grade-school teacher isn’t very gritty or inspiring, then you haven’t met Richard Moody.

In spite of my blunders, the Transplant Trotters finished the race-walk in about 30 hours and placed ninth in our division. We had indeed celebrated life and gladly dedicate our accomplishment to Larry Huot for helping to get the Transplant Trotters “on the road.”

The III Winter World Transplant Games took place January 10-15 in Snowbird, Utah. Athletes from 13 nations competed to determine the world’s best alpine and nordic skiers. More details on these Games will appear in next issue of Chronicles. To view results and audio visual event highlights, visit our website at www.kidney.org and click on “Winter World Transplant Games.”
Since many of the technical challenges of transplantation have been overcome, quality of life following pediatric transplantation has become the primary focus of health care providers. As a result, school re-entry and improvement of school performance are major considerations of all individuals who are responsible for a child’s well-being, including parents, physicians, nurses, social workers, psychologists, teachers and school officials. This article reviews the issues involved in children returning to school following organ transplantation and discusses ways to help provide your child with a more enriched school re-entry experience.

Successful re-entry into school following transplantation requires preparation on the part of the child, family, school personnel and classmates. Several issues must be addressed before a child returns to school, including the effects of treatment, social and emotional difficulties, academic difficulties, caregiver attitudes and school resources.

The treatment effects of transplantation are very important and may have an impact on school re-entry. For example, changes in physical appearance due to medications may impact a child’s willingness to go back to school. Frequent physician visits and school absences can also pose problems with returning to the classroom. Prolonged absences from school and changes in body image also often result in lower self-esteem and limited interaction with school peers. Furthermore, young children, such as elementary school students, may avoid a transplant recipient due to a fear of contracting an illness.

Academic difficulties may also affect a child’s ability to return to school in a timely manner. Frequent absences may have prevented the child from building the fundamental knowledge base necessary for further learning. Also, learning disabilities may limit academic performance.

Attitudes of caregivers are extremely important in optimizing re-entry into school. Parental overprotectiveness and fear for the child may result in absences. School personnel may be overwhelmed, uninformed and unable to recognize the true capabilities and limitations of these children. Finally, limited school resources for daily health care services, special services for physical or learning disabilities, and homebound instruction may also curtail the child’s ability to return to school.

There are many ways that parents can help ease their child’s re-entry into school following transplantation. We suggest that you take several steps to make the process of school re-entry a positive and satisfying experience. These include:

- Talk to your child about his or her concerns and fears about going back to school.
- Talk to your child’s teachers and arrange a plan for school re-entry that is appropriate for your child.
- Begin with short periods of school attendance and slowly increase this time to a full day.
- Ask your child’s doctors and nurses to provide teachers and school officials with information regarding your child’s transplant. This information should include a brief description of your child’s medical condition, a description of some of the side effects of the medications, and a list of symptoms that may require evaluation by your doctor if they are present. Finally, it is important to inform these individuals that your child will require frequent doctor visits and may be hospitalized for extended periods.
- Request that your school district provide your child with an Individualized Educational Plan (IEP) to allow for special services at school and provide for home tutoring when necessary. These services are required by law in most states for children with chronic illnesses, but are not always implemented due to school district financial constraints and a lack of understanding by school officials regarding a child’s overall medical condition.

Following these guidelines and realizing the importance of your child returning to school when the time is appropriate will help ensure a successful and healthy academic future.
Intra-Institutional Donor Exchange
by Beverly Kirkpatrick, LSW

In Transplant Chronicles, Vol. 5, No. 4, Cheryl Jacobs discussed “paired exchange” and “donor swapping” as an alternative to waiting on the cadaveric kidney list. Donor exchange is the process whereby a person wishes to donate to a loved one, but can’t because their blood types are not compatible. However, he or she may be a candidate to donate to someone else, and will donate a kidney in exchange for that recipient’s loved one (who is in the same situation) donating to his or her loved one. UNOS (United Network of Organ Sharing) has appointed a committee to look into the possibility of a nationally based exchange program or an intra-institutional (occurring within the transplant institution) living donor exchange proposal that would involve multiple transplant centers within a UNOS region.

The committee is looking closely at the exchange proposal that Francis L. Delmonico, MD, published in a medical journal in August 1998. In this proposal, a panel of interested physicians from kidney transplant centers within a UNOS region would be assigned to review donor/recipient pairs. The panel would work toward a potential match and review donor/recipient blood types, donor ages and donor/recipient locations. The date of submitting the donor/recipient pair for exchange matching would be recorded. Final matching by the panel of blood type compatibility of the donor/recipient exchange pair would be based on proximity of centers and the date of listing.

The donor could travel to the recipient’s center for the surgery or the donor kidney could be transported to the recipient center. The transplant procedures would be scheduled on the same date, with simultaneous start times. There is always the possibility of either donor breaking the agreement to donate or deciding against the surgery, which is why transplants would be performed on the same day with simultaneous injection of donor anesthesia. In this way, there is no danger of a recipient or donor being vulnerable to a person’s changing his or her mind unexpectedly.

This is an idea that has been discussed for many years but only recently has a committee been formed to investigate the feasibility of such an idea and to develop a plan of how best to put the program in motion. It is hoped that this will open a door that will shorten the ever-growing list of individuals that await a kidney transplant.


This Issue’s Hot Topic

Should a system for donor swapping be developed on a national level? Why?
(See above article for information)

What do you think? Call the Hot Topic hotline at the NKF, (800) 622-9010 ext. 855, to leave your response.

Hot Topic Response (Issue 6:3)

Following is a sample of responses to the Hot Topic from the last issue: Should an individual on death row be forced to donate his or her organs prior to being put to death? Should an incarcerated individual be eligible for a transplant?

- It is the privilege of a person on death row to give back a life for the one he or she took away. An incarcerated individual should definitely not be eligible for transplant.

- I don’t believe a person should be forced to donate—it’s their body. And any human being, whether in prison or not, should have a chance to have a transplanted organ.

- I do not believe anyone should be forced to donate organs. I believe incarcerated individuals should not be eligible for transplant, and taxpayer money should not be spent on people who gave up their privileges by being put into jail.
Has the drudgery of pushing yourself out the door to jog your daily course got you down? Has the thought of that 200th aerobics class taken the hop out of your get-a-long? If you don’t feel motivated to follow your exercise regimen, you might be in a rut. Exercise is essential to keeping you and your transplant healthy, and making your routine fun is a great way to assure that you stick with it. Here are some traditional and more innovative exercise techniques to put the bounce back into your step.

**SPINNING**: Spinning is fairly new in the fitness world. If you enjoy biking and are looking for a bit more of a challenge, this could be quite enjoyable. The spinning bike is specially designed with a weighted wheel in the front. It is stationary, but the design of the bike makes the ride quite different from the old stationary bike you’re used to. Spinning classes are instructor-driven, meaning that the instructor will guide you through your ride. Your instructor may take you up hills, through valleys and over mountains! Some classes will stay at a set pace, while others will change speed and resistance.

**PEAK BAGGING**: Peak bagging takes a simple approach to climbing. You just choose a high point that you’d like to reach and hike toward it. You may hike to the top of a tall building, an interesting rock outcropping or, in mountainous areas, any of hundreds of peaks. The exercise is great and the views from the top are exhilarating.

**KICKBOXING**: This is a surefire way to kick yourself into a new exercise routine. Kickboxing is a combination of certain kinds of martial arts and boxing. You may use punching bags or move through the air while creating your own resistance. It is extremely aerobic and can be as intense as you want it to be. Kickboxing is a great workout for your mind and body, and is an especially effective way to relieve stress.

**INDOOR ROCK CLIMBING (ROCK GYM)**: This is a relatively new activity that has followed the popularity of the extreme sports craze in many cities. Basically, the rock gym consists of many man-made cliffs that you can climb. Each participant rents rappelling equipment and shoes. You work in tandem with a partner who will secure you while you climb, and vice-versa. It is a pretty wild, yet safe, way of exercising your whole body. I highly recommend that weightlifters and swimmers give this a try. I will forewarn you, though, that there is a moderate cost associated with spending time and renting equipment in a rock gym.

**BODY PUMPING**: This challenges the body and the mind as you move through a series of prechoreographed weightlifting routines covering all major muscle groups from head to toe. The weights will range from two to 10 pounds. Body pumping is a great way to learn more about weight training and proper form. It is also a very good class for those who want to have someone lead them through a light weight training program usually set to good music.

If these new exercise trends don’t appeal to you, you may want to stick to a more traditional sport. However, you can participate in sports in many ways, including acting as a coach or referee.

**SOCCER REFEREE**: Soccer is played by more children in this country than any other team sport. Adult volunteers are always needed to act as referees. Soccer is a fairly simple game and is easy to learn. Courses are taught by organizations such as American Youth Soccer Organization (AYSO) at the regional level to give you the understanding needed to referee U-10 (under 10 years old) matches. As a referee, you will get to run for 50 minutes each game, chase a ball and 20 children around a rather large field, teach fair play and have fun. And if 50 minutes is not enough, you have the opportunity to referee older and faster kids for up to 90 minutes.
COACHING YOUTH (ANY SPORT): Coaching is not for the timid. Kids want to run, throw, shoot, hit, block, catch, kick, slide and dribble, but most of all they want to do it NOW! You must have the endurance and patience to stick with them, even when you’re dog-tired. The rewards, however, are immeasurable. Teach one child to perform a skill correctly and you have given him or her the self-esteem to reach higher. Teach the group to work together and support each other as a team and you have built a community. And of course, all the while, you will be exercising with the kids as you teach them to master a sport.

Dave Stanton received a kidney transplant in 1987. He is involved in many athletic activities, including climbing, peak bagging and coaching soccer. Dave has participated in the U.S. Transplant Games since 1990.

Tattoos: The Hidden Risks

by Marlene McGregory, RN, BSN

Tattoos have been gaining popularity over recent years, especially with teens. This form of art has gradually moved from the fringes of society into mainstream America. Although the images created by tattoos may be appealing, there is a potential dark side to this procedure. To apply a tattoo, inks are pushed into the lower layer of skin to leave a permanent image. People do get tattoos without experiencing any problems. However, if done incorrectly or carelessly, tattooing can be an avenue for spreading infection, and there is a strong association with bloodborne diseases.

Bleeding during the application of a tattoo is common and sterile technique may vary from place to place. In states such as Rhode Island, this industry is highly regulated, with yearly inspections by the Department of Health for cleanliness and proper technique. However, some tattoo artists, especially underground tattoo artists, may reuse or resell tattoo kits, or use the same container of ink for more than one customer. They also may fail to advise their clients about the necessary care to prevent infection.

Having tattoo parties is now popular among teens who are not of legal age to get a tattoo. Usually, homemade kits are passed from person to person and the risk of infection or exposure to bloodborne viruses is present. Of special concern is exposure to the hepatitis viruses, particularly hepatitis B and C, both of which can result in chronic infection. The most serious complications of chronic hepatitis include cirrhosis, or scarring of the liver, and cancer of the liver. People who have recently gotten tattoos and body piercings are now turned away as potential blood donors, nor can they be organ and tissue donors right away. The Food and Drug Administration requires these people wait at least one year to donate blood because of the risk of infectious diseases from unsterilized needles, and many transplant programs also use this one year guideline. However, cases may vary.

It is important that any person considering a tattoo think about this decision. Anyone who does decide to get a tattoo should be cautious and make sure proper procedures are followed to avoid infection. Know that you are directly involved in your health care decisions. Education and prevention are your greatest defenses against unnecessary exposure to life-long illness.

Marlene McGregory is a clinical support specialist in hepatology for Amgen, Inc. She has nine years of experience in clinical practice at both University of Miami and Albert Einstein Medical Center in Philadelphia.
I was not afraid to explore the possibility of donating a kidney to my husband. My interest was sparked when his nephrologist explained about laparoscopic donation surgery and how occasionally non-related donors could be compatible with a recipient. Laparoscopic donation is when four small holes are created in the donor and a camera and medical equipment are inserted to isolate the kidney. Then, a small incision is made into the donor and the kidney is removed through this cut.

I had already experienced laparoscopic surgery several years ago. I recalled that the hospital stay was brief, my recovery was fast, and surgical scars were very small. My husband also had his gall bladder removed by laparoscopic surgery, and he, too, had a good experience. These earlier experiences helped to shape my thinking and make my decision.

When I first announced to my husband that I wanted to be evaluated to be his kidney donor, he objected. He tried to dissuade me in order to protect me from being hurt. He was also afraid to get his hopes up and then be disappointed. I explained that there was nothing to lose by being tested, and we began the testing process. The transplant coordinator was respectful of our demanding work schedules and of the 45-mile drive to the hospital. She accommodated our needs by arranging multiple tests and consults for us on the same day whenever possible.

We completed the evaluation process and found out the results a few weeks later. It was against the odds, but we were a match! I got the news first. I was astonished, relieved, and felt like I was flying. I had not felt so optimistic for a long time. How fortunate we were! My husband would not have to wait on a long list. I thought back to my first meeting with the surgeon when I explained to him that I wanted to have this surgery to improve my husband’s quality of life, and I realized I had made the right choice.

Then the time came for the surgery. We knew in advance that we would have adjoining operating rooms. I enjoyed fantasizing that my surgeon would toss my kidney like a ping pong ball in slow motion to my husband’s surgeon, who would toss it into my husband. That was my way of coping with a very serious situation. I also joked that my husband would start to eat broccoli like I do! The night before surgery, we stayed overnight near the hospital so we would not feel rushed in the morning. The next day, we had our surgery. The transplant started working right away. My stay in the hospital was three days. Five days after my hospital stay, I used city transportation to go out and do some shopping. I drove a car on the seventh day out and returned to work two weeks after the transplant. I had some soreness for a while and moved a little slower than usual for a couple of weeks, but I am back to normal now. My husband and I are both doing well.

I am an advocate of laparoscopic donation. The process is much less invasive than other methods of transplantation. I expect this type of surgery will make living donation of kidneys more desirable and less stressful for many individuals. The benefits were immeasurable. The process of kidney donation and transplant gave my husband a second chance. And we both received an unexpected gift—a closeness developed between us as we struggled and survived together.

Laurie Rosen, MSW, is a psychoanalyst and clinical social worker in Commack, New York.
Commentary: One-Year Moratorium on Implementation of HHS OPTN Regulation - Who Won, Who Lost May Prove To Be Deceptive

by Jim Warren, editor and publisher

This is a fine mess you’ve gotten us into this time, Ollie. - Laurel and Hardy

When Congress agreed to a one-year moratorium last October on implementation of federal regulation of the Organ Procurement and Transplantation Network (OPTN), conventional wisdom suggested that the United Network for Organ Sharing had won. UNOS has spearheaded the fight to resist the regulation, which would allocate organs on the basis of medical need, rather than geographic location.

If UNOS won, then conventional wisdom would also say someone had to lose. Let’s take a look at who the big winners and big losers just might be in this latest round of public confrontation over who sets organ allocation policy in the U.S.

Winners:

UNOS (at least in the short run)—In public testimony before Congress, the organization professed eagerness to seek rapprochement with the Department of Health and Human Services (HHS), which would regulate the network. UNOS’ actions tell another story, however. How else can you explain its decision to join the Louisiana lawsuit against HHS seeking to prevent implementation of the regulation? In reality, the moratorium buys UNOS time to seek relief from the regulation through legislation, which could be introduced in Congress this year.

American Society of Transplant Surgeons—The ASTS and its immediate past president Ron Ferguson, MD, led the transplant community effort to retain the current UNOS system of organ allocation. Ferguson worked tirelessly to defend the status quo and retain the private sector’s authority to develop public policy with little or no oversight by HHS.

Louisiana, Oklahoma, South Carolina, Wisconsin—These four states have passed laws mandating that organs be offered first to their own citizens regardless of their status on the waiting list. The moratorium also allows these states time to lobby Congress to block implementation of allocating organs on the basis of medical priority, not geography.

The Institute of Medicine—The IOM gets money and time to do yet another study of transplantation policy in the U.S. No disrespect toward the IOM is intended, but does anyone really believe it will recommend that decisions in setting organ allocation policies be left strictly to the transplant community and that states’ rights supercede federal agencies’ ability to regulate?

Small transplant centers—Good small centers will survive regardless of the allocation policy. Those with poorer outcomes and/or an inability to continue to operate on a financially sound basis will fail no matter who controls the policymaking.

Losers:

Patients on the waiting list—This is a no-brainer. Forget the rhetoric from both sides of the dispute saying their only interest is in what is best for the people in need of a transplant, or dueling computer models showing which allocation system would result in the most transplants. Patients are losing because the highly publicized nature of the debate has to be dampening the U.S. public’s willingness to donate organs. People do not trust the system and, according to several opinion polls, that is the major reason why people who should donate do not. When newspaper headlines and wire service stories trumpet one organization’s victory in organ allocation, every ounce of common sense says it must be hurting donation. Like it or not, perception is reality!

Organ procurement organizations (OPOs), tissue banks, eye banks—This should be a time of optimism for increasing donation, given the recently implemented Medicare Conditions of Participation that require all U.S. hospitals to notify their local OPO of all deaths and imminent deaths. However, OPOs find themselves in the middle of a no-win situation regarding the HHS
regulation. They are funded by the government, beholden to local hospitals to sign agreements to provide organs and tissues, and often seen by the public as co-conspirators in the allocation controversy. The Association of Organ Procurement Organizations (AOPO) has wisely declined to take sides during the dispute. That action alone reveals its precarious position in the policy debate. OPO’s have been unfairly used as the scapegoat for the failure to increase the number of organs over the past five years. That seems certain to continue for at least another year.

The Coalition on Donation and the federal initiative to increase organ and tissue donation—How can the Coalition possibly wage a successful public education campaign about the importance of being an organ and tissue donor in light of the negative public debate? Incredibly, the fiscal year ‘99 $10 million appropriation to the Health Resources and Services Administration, which is to be used to increase organ and tissue donation, could be wasted if the situation is not resolved amicably.

Congressional support—Gaining the backing of Congress for other issues extremely important to the transplant community, such as increased support for basic research and unlimited insurance coverage of immunosuppressive drugs, has been difficult without the current problems. Doing away with the allocation controversy would allow the transplant community to develop the cohesive legislative effort necessary to move transplantation forward in the 21st century. The shortage of organs and tissues will ultimately be eliminated through medical and scientific breakthroughs, not doubling the number of donors.

The sad thing is that it didn’t have to come to this. Both sides had publicly indicated willingness to compromise in the past few months. Claude Earl Fox, MD, director of the Health Resources and Services Administration, has said the department is not looking for UNOS to develop a policy requiring a national waiting list. “We’ve never said that we want livers to be shipped coast to coast. I think that’s a misconception,” he told Transplant News. UNOS President William Pfaff, MD, testified before a Senate committee last September that “we’re in collaboration with the department from the get-go . . . The Secretary has oversight responsibilities. I’m a little surprised that we’ve come to this tenor of thought where we’re not collaborating, and it’s time to do that.”

The reality is that the fight over setting organ allocation policy has never been completely about what is best for patients. It is about power and money. It’s about big centers versus little centers. It’s about states’ rights versus federal rights. It’s about who should have the authority to set policy: physicians who treat the patients or the government agency in charge of oversight. And it’s going to go on for at least another year if not longer unless the transplant community demands that its leadership—individuals and organizations—call a halt to the bitter public fight.

Senator Bill Frist (R-TN), chairing a joint hearing on the allocation controversy of the Senate Labor and Human Resources Committee and the House Subcommittee on Health and the Environment in June, observed that new developments in organ preservation techniques “make sharing of organs easier and changes must be made to reflect these changes.” He also expressed his own fear that “the heavy hand of government is going to come down” if UNOS and HHS can’t resolve their differences.

Despite the one-year moratorium, which will allow time for legislation to be introduced next year, and the Louisiana lawsuit, does anyone really believe that organ allocation policy in the U.S won’t be set by the federal government in consultation with the private sector? Until the situation is resolved, there will be no winners.

Laboratory-grown hearts for transplant seen in next decade

A research project focused on using laboratory-grown tissue to create hearts suitable for transplant within the next decade has been launched by a group of scientists.

“Our vision is that we’ll be able to pop out a damaged heart and replace it as easily as you would replace a carburetor in a car,” said Professor Michael Sefton of the Institute of Biomedical Engineering at Toronto University.

Earlier this year, Sefton and a group of 12 other scientists, engineers and clinicians from North America and Europe formed a partnership to examine biomedical solutions to the global shortage of organs for transplantation. The team developed a plan that uses tissue engineering techniques to create living replacement organs. The project, known as the Living Implants from Engineering (LIFE) initiative, eventually will lead to a number of organ replacements. Initially, however, it will concentrate on the heart.
“In order to ‘grow’ a heart, we first need to ‘grow’ a heart valve,” said Sefton. The creation of transplantable valves would substantially reduce the high risks of heart valve surgery, he said.

Tissue engineering combines biotechnology and bioengineering strategies to create a new generation of materials or devices. Some engineered tissues already are on the market, but other tissues, such as cardiac muscle, have been difficult to reproduce. At the present time, scientists use one of two approaches in tissue engineering. The first involves growing cells in a culture and planting them on a material in the body, bone or skin substitutes, for example. In the second approach, material is implanted in the body to precipitate a specific response, such as tissue regeneration used to induce new blood vessel formation.

**Technique for storing organs 10 times longer than normal developed by Japanese scientists**

Borrowing a trick from a tiny bug, Japanese scientists have developed a technique for storing organs that could transform the transplant industry. The bug, called a tardigrade, uses a sugar called trehalose to survive in extreme conditions. When scientists at Kanagawa University in Japan used the sugar to store rat hearts, they found the organs could be revived after 10 days in storage—10 times longer than normal.

Using current methods, the longest human organs can be stored is up to 30 hours; for livers and hearts, maximum storage time is only about four hours. If donated organs could be stored for longer periods of time, it could eliminate the frantic rush to get patients on transplant waiting lists into the operating room. It also could lead to better matches between donors and recipients.

The main problem with keeping organs in cold storage is that water at low temperatures damages cell membranes, and removing water from the tissues usually causes at least as much damage. To overcome this problem, the researchers flushed the rat hearts with a trehalose solution, then packed them in silica gel to remove water from the cells. The hearts then were immersed in perfluorocarbon, a biologically inert compound, and stored in airtight jars at four degrees C (39.2 F). After 10 days in storage, there appeared to be no damage to the heart cells.

The researchers plan to test the technique on other animal organs and hope that it can be used for preserving human organs in a few years.

**Pediatric transplant recipient donates heart to five-month-old girl after he dies**

In what may be the first case of a pediatric transplant recipient becoming an organ donor, a 10-month-old liver and bowel recipient donated his heart to a five-month-old girl when he died.

Joey Bullock, who was born with gastroschesis, a condition where the intestines are exposed because of a hole in his abdomen, received his life-extending transplant several months ago at the Nebraska Health System University in Omaha. He had been scheduled to go home to Lancaster, Texas, when he died from complications of a cold. Death was not related to his transplant.

Joey’s heart was flown from Omaha to Denver, where a five-month-old girl from Washington State received the donor heart.

**UK government advisors approve cloning human embryos for organs, tissues to treat disease**

In a move certain to cause controversy, UK government advisors have given their approval to the cloning of human embryos for the purpose of developing new treatments based on cloned tissue and organs. The recommendation appears in a joint report from the Human Genetics Advisory Commission (HGAC) and the Human Fertilisation and Embryology Authority (HFEA). Last January, HGAC predicted that, in a matter of years, human embryo cloning would lead to novel treatments for a variety of injuries and diseases.

“Cell nucleus replacement techniques might be helpful with research into—and eventually treatment of—conditions such as Parkinson’s, Huntington’s, Alzheimer’s and various types of cancer,” said Sir Colin Campbell, HGAC chairman. “Treatments might also be developed for diseased or damaged tissue. This would entail growing cells of tissue in culture and not involve human reproductive cloning.” Campbell added that although such applications still are years away, the advisors did not feel it would “be right at this stage to rule out limited research using such techniques, which could be of great benefit to seriously ill people.”

Under the 1990 Human Fertilisation and Embryology Act, embryos less than 14 days old may be used for specific research purposes, such as promoting advances in the treatment of fertility, increasing knowledge about the causes of congenital disease and developing methods for
detecting genetic abnormalities. The old law does not, however, permit research aimed at developing new forms of replacement tissue.

To separate the issue of reproductive cloning from so-called therapeutic cloning, the report recommends that the government introduce legislation banning human reproductive cloning. Another suggestion is that Health Secretary Frank Dobson consider changing current regulations, so that HFEA can issue licenses for the development of therapeutic treatments for diseased or damaged tissues or organs. The report also advises that these issues be examined again in five years to take into account scientific developments and the public’s attitudes toward them.

First child in U.S. to receive heart, two lungs and liver transplant, performed in Pittsburgh

The University of Pittsburgh Medical Center revealed in early December that surgeons had performed the first heart, both lung and liver transplant in a child ever performed in the U.S. The surgery was performed on three-year-old Brendon Ednie at Children’s Hospital of Pittsburgh in August, but it was not announced until December 12 because they wanted to make sure Brendon has a good chance for survival.

Physicians said only a handful of adults have undergone the 20-hour procedure worldwide. The United Network for Organ Sharing (UNOS) told the press that a heart, lungs, liver transplant had only been done once in the U.S., in an adult in 1996. Davina Thompson reportedly was the world’s first recipient of a similar operation in 1986 in the United Kingdom. Thompson died in August this year at the age of 47.

Brendon had waited 10 months for the organs. He suffered from LaGille Syndrome—a rare genetic disorder that has only been diagnosed in about 100 people worldwide.

Photopheresis may reduce risk of heart transplant rejection

Photopheresis, a process in which white blood cells are reinfused after exposure to a photoactive compound and ultraviolet light, may reduce the risk of acute rejection in cardiac transplant recipients. When used in combination with standard triple-drug immunosuppressive therapy, photopheresis significantly decreased the risk of cardiac rejection without increasing the incidence of infection, according to a study of 60 heart transplant patients conducted by the international Photopheresis Transplantation Study Group that appeared in the December 10 issue of the New England Journal of Medicine.

The photopheresis procedure involves removing a sample of the patient’s T-cells—cells that play a key role in graft rejection—and exposing them to ultraviolet A light and the chemical methoxsalen. This treatment causes the T-cells to develop what the researchers call a lethal defect. Shortly after the cells are reinfused into the patient, they begin to die. And like all dying cells, the treated T-cells are recognized as waste and engulfed by other immune cells, which learn to target healthy T-cells as well. The net result is a decrease in the overall number of T-cells, thereby reducing rejection risk.

Comparing six-month outcomes of 33 heart transplant patients treated with immuno-suppressive drugs plus photopheresis with 27 patients receiving immunosuppressants alone, “the likelihood that a patient would have no rejection episodes in the photopheresis group was 2.1 times that of the standard therapy group,” said lead investigator Mark Barr, MD, of the University of Southern California, Los Angeles. Thirteen of the photopheresis patients had no rejection episodes compared to just five of the drugs-only group.

The research team emphasized that larger, longer-term studies will be needed to confirm the effectiveness of the technique. Nonetheless, they suggest that “photopheresis is a mildly invasive treatment without important toxic effects [that] appears to lower the rates of acute rejection in recipients of cardiac transplants.”

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Don’t “Wait” to Start Managing Your “Weight”

by Becky Weseman, RD, CNSD, LMNT

Obesity is a growing problem—no joke intended! Nearly one third of adult Americans are obese, and transplant recipients are no exception. Weight gain is a complex issue that may be influenced by family history, how you metabolize or burn foods as energy, and how much you exercise. Many people have “triggers” that affect weight gain, such as stress, depression or being overtired, all of which cause them to overeat. Not only do transplant recipients have these reasons to overeat and gain weight, but a new set of issues may arise following transplantation.

It has been reported that anti-rejection medications, such as steroids, can cause a false sense of hunger that often leads to overeating. In addition, freedom from pre-transplant diet restrictions and an improved sense of well-being may also lead to weight gain after recovery from surgery. Does any of this sound familiar to you? If so, now is the time to take charge of your weight and habits!

Weight Assessment: Do you wonder how your weight sizes up? You can figure out your body mass index (BMI) quickly and easily:

Body Mass Index = \( \frac{kg}{m^2} \)

\[
kg = \text{weight in pounds divided by 2.2} \\
m = \text{height in inches x 2.54 divided by 100}
\]

For example, a 5 foot 4 inch woman who weighs 140 would do the following:

\[
64 \text{ inches x 2.54 divided by 100} = 1.625 \text{ m} \\
140 \text{ pounds divided by 2.2} = 63.6 \text{ kg} \\
63.6 / 1.625 \times 1.625 = 24 \text{ BMI}
\]

A body mass index of 25 to 29.9 is considered overweight, while a BMI of 30 to 39.9 is considered obese. If you have a BMI over 25, it may be time to take action. Being overweight can lead to health risks of high blood pressure, heart disease and increased blood sugars. Excessive weight gain can also limit your activity and affect your ability to carry out your daily routine with ease. If your BMI is 21 to 25, keep up the good work! Remember, though, that being too thin with a BMI that is too low also has health risks. Therefore, maintaining a healthy weight is very important.

Getting Started: There are some things you can control and others that you can’t. If your weight is partially due to family history and how your body breaks down food, it may be more difficult to change your body size. If medications you take cannot be changed, this is out of your control as well. However, we can all control our diets and exercise. If you have ever tried a “fad” diet, you have probably figured out that it didn’t produce long-term results. The new approach to looking at our diets is actually to eat more, not less!

Research is currently being conducted on ways to help you lose weight by feeling full. The key to eating healthy and until you feel full centers on your food choices. Selecting foods that are lower in calories and still high in nutrient content allows you to eat until you are full, while still maintaining a healthy BMI. The false sense of hunger that can result from anti-rejection steroids might be easier to cope with if you could still eat until you were full, without worrying about excessive weight gain. Try following these guidelines:

1. Select fewer high-calorie foods. For example, choose apples instead of apple pie.
2. Fill up on nutrient-dense vegetables, such as broccoli, asparagus or green beans, with your meals, which add bulk, not to mention fiber and vitamins.
3. Enjoy a warm cup of broth-based soup before a meal or a hot beverage, such as apple cider or low-calorie hot chocolate, after a meal.
4. Be careful not to select foods just because they are low in fat. Remember that you also have to pay attention to calories.

Your weight doesn’t just affect the way you look—it has a great impact on your health and the way you feel. If you continually balance foods eaten and calories burned, you’ll be on your way to maintaining a healthy weight for life. 

Transplant Chronicles, Vol. 6, No. 4
With results continually improving in heart, liver, kidney and lung transplantation, it is no longer acceptable to view survival as the most important outcome for a transplant patient. We must also focus on the quality of patient survival as an important factor in the success of transplantation. One such factor in the quality of survival is the presence of bone disease, which can greatly impact a patient’s capacity for rehabilitation.

Bone disease, a problem that often goes unrecognized and untreated, can lead to severe health problems both before and after transplantation. Patients with cardiac, liver, renal and lung disease often experience bone loss (osteoporosis) prior to transplant for a variety of reasons, including their nutritional and hormonal status. Specifically, patients who are malnourished may develop bone disease from inadequate intake of calcium and vitamins, namely vitamins A and D. Those patients who cannot walk or who become bedridden because of the severity of their disease will experience a rapid loss of calcium from their bones, thus weakening the bones and increasing the risk of developing a fracture. Significant bone loss results in a substantial risk of fractures, especially of the spinal column and hips. It is likely that a significant number of transplant patients have compromised bone strength before the transplant and may be at great risk of developing fractures.

Many patients will experience a greater weakening of their bones following transplant. The commonly used anti-rejection medicines, including the steroids cyclosporine and tacrolimus, are all associated with the development of bone disease. This is an especially well known complication of the use of steroids like prednisone. The incidence of fracture in transplant patients ranges from eight to 65 percent in the first year following transplantation. In general, the fracture rates are lowest in kidney recipients and highest in patients who receive liver transplants for cholestatic liver diseases like primary biliary cirrhosis. A number of studies have pointed out that bone loss and fracture risks are greatest in the first three months after transplant, but continue to be significant problems up to a year after transplantation. After the first year, most patients are on lower doses of anti-rejection drugs (especially steroids) and their bones actually become stronger.

Post-menopausal women and men who have inadequate testosterone levels appear to be at the greatest risk of developing fractures following transplantation, but other factors also increase a patient’s risk. These factors include the amount of anti-rejection medicines the patient needs to prevent rejection, the number of rejection episodes (especially those rejection episodes treated with high-dose steroids) and the patient’s nutritional status and level of activity. Even individuals who seem to have normal bones before transplantation may develop fractures in the first three to six months after transplantation.

According to the available data, it seems that the best way to prevent bone problems following transplantation is by taking an aggressive approach before the transplant. All patients awaiting transplantation should be evaluated with x-rays of their spine; bone density studies; thyroid function tests; and serum calcium, magnesium, phosphorus and vitamin D level tests, as well as tests for the levels of parathyroid hormone, testosterone levels (in males) and estradiol levels in females. Abnormalities in any of these tests should be treated before the transplant, if possible. Also, patients should attempt to remain as active as possible in order to avoid the bone loss that happens due to inactivity.

Following transplantation, all transplant centers attempt to keep the levels of anti-rejection medicines as low as possible, which helps to lower the risk of bone disease. In addition, a variety of drugs have been used to prevent bone loss in transplant patients. Most transplant programs are encouraging the use of calcium supplements and appropriate hormonal replacement in certain patients. New drugs such as calcitonin and biphosphonates have been beneficial in preventing bone loss in some studies, but have not yet proven to be effective in all transplant patients. One interesting study in heart transplant patients...
**Can Smoking Affect My Transplant?**

by Janet Karlix, PhD

Since the mid-1960s, there has been an increase in information that convincingly describes the health hazards of smoking. Numerous research papers have been published documenting that cigarette smoking can cause cancer and lung complications, as well as contribute to many other diseases. Ad campaigns have dramatically emphasized the negative effects of smoking on the skin and lungs. And tobacco companies have been in the spotlight as individuals and state governments sue to force them to take responsibility for selling an addictive and health-compromising agent. As unhealthy as smoking is for the general population, it is important to realize that it can have even more significant consequences for the health of a transplant patient.

One of the most interesting aspects of cigarette smoke is its ability to affect the liver, thereby also affecting anti-rejection drug levels. At least one of the byproducts of cigarette smoke can cause the liver to “rev up.” If a drug is broken down by the liver, a “speedy” liver can cause the drug to be broken down much quicker, which would result in decreased drug levels.

Here’s a case that shows the dangers of smoking and how it affects a transplanted organ:

Jack Jones had a kidney transplant three days ago. His cyclosporine level is in the desired range and is stable. He has been given permission to leave the transplant floor in his daily walks, and he is relieved to be able to go outside and smoke. Three days later, his cyclosporine level is too low — it has slowly drifted down to a subtherapeutic range.

What happened? This case is a classic example of how cigarette smoke can cause an interaction with a drug that is broken down by the liver, such as cyclosporine. This scenario is not uncommon in the transplant ward. When Jack started smoking after his surgery, it caused his liver’s metabolism to increase, which consequently resulted in a decrease in his cyclosporine level.

Cigarette smoke can change the levels of many drugs, including cyclosporine and tacrolimus. Ideally, if you smoke, you should quit. However, if you do intend to keep smoking, be consistent. Increasing or decreasing the amount of your smoking can potentially change your cyclosporine or tacrolimus levels, which are important in maintaining the function of your transplanted organ.

There are many support groups and resources to help you quit smoking. Ask your transplant center for help locating these aids. Also, most health care professionals are knowledgeable about the benefits of over-the-counter nicotine supplements, which can assist in decreasing the irritability and other physiological nicotine withdrawal symptoms you may experience. You have a second chance at life. Why compromise it by smoking?

**medical beat continued**

did show that early progressive resistance exercise reversed bone abnormalities within the first six months after transplantation. It would therefore seem reasonable that transplant patients should be encouraged to exercise as much as they can, especially while on higher doses of anti-rejection medications.

At least some degree of bone disease is almost universal in patients both before and after organ transplantation. It is hoped that newer drugs will be available in the future to treat this common problem. Addressing bone disease is an important consideration in improving the quality of transplant patients’ lives.
Being an Effective Advocate

by Charlie Thomas, ACSW, CISW

Taking your medications, sticking to your diet and exercising are essential to maintaining the health of your transplanted organ, but your well-being as a transplant recipient depends on much more. There must also be legislative and public policies in effect that support programs to keep you healthy, and you play a key role in making sure these policies exist. It is very important that transplant patients and their families become advocates for their health.

Advocacy involves direct and indirect methods of securing and defending your rights as a recipient, including educating community agencies and legislators on the needs of recipients so services can be made available to you. A positive way to influence policy is to join and become active in transplant support groups. The leaders of the support groups should form coalitions with other support groups and identify common issues. Legislative advocacy training should be conducted for coalition members.

Effective advocacy is defined in large measure by how a person communicates with legislators on a specific issue. There are many different ways to influence legislators, but a good first step is to get acquainted with them. Most legislators will be interested in hearing your views on an issue that affects you personally. Here are some ways to build a relationship with legislators:

- Attend a town hall meeting and introduce yourself as a constituent.
- Schedule a group meeting (maybe with your transplant support group or coalition) with a lawmaker in his or her office.
- Invite the lawmaker to speak at a meeting at your transplant center.

Appealing to local, state and federal committees can help ensure that programs, monies and access to services include transplant recipients instead of excluding them. For example, the NKF Office of Scientific & Public Policy, aided by grassroots support from individual recipients, has worked to enlist congressional support for the elimination of the 36-month limitation for Medicare coverage of immuno-suppressive drugs for transplant recipients. The Immunosuppressive Drugs Coverage Act of 1997 was introduced by Congressman Canady (R-FL) and Senator DeWine (R-OH) to eliminate the limitation for certain kidney transplant recipients. While Congress did not act on these measures prior to the end of the legislative session, the Public Policy Office worked very closely with congressional staff and there is every reason to believe that the legislation will be reintroduced in the 106th Congress.

You can also become involved in public policy advocacy efforts through grassroots organizations in your local area. For example, the Arizona Public Policy Forum on Transplantation (APPFT) is a grassroots transplant recipient organization that achieved a major victory for all transplant recipients in the state of Arizona in 1998. A House bill was introduced to create a “safety net” medication program for qualifying transplant recipients in Arizona. The program was modeled after the NKF of Arizona renal medication program. The new bill would appropriate $200,000 from state tobacco tax revenues to create a similar option for non-renal transplant recipients. The bill unanimously passed both the House and Senate and was signed into law.

Writing letters, calling your representatives, testifying at hearings and educating the media are all proven methods of advocacy. If you’d like to get involved or want more information on advocacy efforts, call the Public Policy Office at (800) 889-9559, or find out about local grassroots organizations from your transplant center, local NKF affiliate or organ procurement organization.
Thoughts from a Donor...

I lost my husband in July 1996 due to a horseback-riding accident. The accident happened on a Saturday night, and in less than 48 hours, he was declared brain dead. I was asked to let him be an organ donor and my first response was no. But then I thought it over and knew that something good had to come from his death. This may sound strange, but I just couldn’t bear for his heart to stop beating. He had such a “big heart,” I felt as long as it was beating that part of him was still alive.

For me, the decision to donate was one of the best decisions I’ve ever made. I haven’t been contacted by any recipients, except one young man in Wisconsin who received a kidney about how it has saved and changed his life. It was such a blessing when he contacted me. I’d love to someday meet all the recipients who, by my loss, have a better and healthier life.

My husband was only 45 years old when he died, and I miss him so very much. But I know that I made the right choice and I’m glad I did.

Carolyn Rowe

Thoughts from a Recipient...

Dear Donor Family,

Your daughter lives in the hearts, souls and body of our family. As a mother of five children, I have often thought of love as a rubber band…it always stretches to hold more. Awesome is the word of choice to describe our gratitude. We may not have known Nicole, but now we sure feel her presence and love in our lives. There are no words I know to thank you for the life you have given my daughter, Lisa.

Lisa’s story is filled with courage, faith and hope. She is a single mom of a two-year-old daughter named Taylor Rose. Her story is lengthy and I hope some day to share it with you, our donor family. Your daughter’s kidney adds so much to Lisa’s life, especially the hours spent with her young daughter—you have made this possible. We are open to sharing our lives with you since we now call you “family.”

Above all, in our joy, we share so deeply in your loss. Not a day goes by that my heart doesn’t feel such pain as I think of walking in your shoes. As our Taylor Rose opens her gifts this holiday season, little does she know that the greatest gift was received by her mom. You wrapped it so beautifully with all your love.

We wish to share our lives with you as a living testimony to your daughter. And most of all, we wish you peace, love and serenity.

Joan Reardon

This letter was written in December 1997. Since then, the Reardons have made contact with their donor family and dedicated a square on the National Donor Family Quilt to Nicole.

Editor’s Note: The NKF has developed communication guidelines for health care professionals to help donor families and recipients communicate with each other. For more information, call the NKF at (800) 622-9010 or view the guidelines on the NKF Website at www.kidney.org.
Exploring the World Wide Web on the Internet

by Gary Green

The Internet is considered one of the most important developments of the late 20th century because of the possibilities it has for educating and connecting people all over the world. It is estimated that in five years, over one billion citizens on this planet will have access to the Internet. It is unquestionably one of the most important developments ever in human communication. This article is intended to provide you with basic information about using the resources of the World Wide Web available on the Internet.

What exactly is the Internet? It is a network of computers, large and small, that stretches to every corner of the world. It is as near or as far as the closest computer with the necessary software and hardware. Any computer with access to the Internet is actually part of the Internet—it is not just the routers, cables and connection that carry information.

So then what is the World Wide Web? According to the World Wide Web Consortium (http://www.w3.org—more on what this means later), “the World Wide Web (known as ‘WWW,’ ‘Web’ or ‘W3’) is the universe of network-accessible information, the embodiment of human knowledge.” So the word “Internet” refers to the computers and the connections, while the phrase “World Wide Web” refers to the information available via the Internet.

Electronic mail (e-mail) is the application that drove the development of the Internet to what it is today. For many “wired” individuals, e-mail has almost replaced all other forms of communication. In addition to written communications, “chats” are possible on the Internet, and, recently, audio and video conversations have become possible.

The most common use of the Internet is to access the World Wide Web. To explore the Web, three things are needed: a computer, access to the Internet and software that allows the computer to connect to the Web:

- Many of you may already have a computer. If it has a modem or is part of a network that allows it to connect to the Internet, then you have all that you need. If you don’t have a computer, call your local public library—many have computers with Internet access for public use. Also, there are now coffee shops and stores that provide Internet access for a small fee per hour.

- Access is provided by an Internet Service Provider (ISP), a company or other entity that you use to connect to the Internet, such as AT&T WorldNet, UUNet, Earthlink, America Online, Netcom, etc. The ISP will provide you with instructions for using its service.

- The necessary software for accessing the Web is at least a “browser,” which, as its name implies, allows you to browse the Web and usually includes an e-mail program so that you can send and receive messages. Sometimes both of these functions are integrated into one software package. The most popular browsers in use today are Netscape Navigator version 4.5, and Microsoft Internet Explorer version 4.0. Both are available for free. Alternatively, the software that you need may come from your Internet Service Provider, as is the case with America Online.

You’re almost ready to go. The only thing left is to become familiar with a few more terms so that you will be able to find your way around. Remember the strange-looking computer lingo a while ago—http://www.w3.org? This is an Internet address and is called a Uniform Resource Locator (URL). It has several parts that are separated by punctuation and symbols.

So, now you’re all set! To begin your Internet travels, start your browser (or if you’re on America Online or a similar service, click on your connection to the Internet). It should open...
transplantation on the World Wide Web, you might want to learn a bit more about the Internet and the Web. An excellent beginner tutorial on these subjects can be found at http://www.northernwebs.com/bc. Another good site for beginners is Microsoft’s guide to the Internet at http://www.microsoft.com/magazine/guides/internet/default.htm. For definitions, terms and phrases on these subjects, help is available at http://www.whatis.com.

Now, where should you go? You can find hundreds of references to sites regarding transplantation if you use a search engine, a program that indexes the pages on the Web and can guide you in finding information. Some of the most popular are: Yahoo! (www.yahoo.com), Excite (www.excite.com) and Hotbot (www.hotbot.com). Each engine works a little differently, so the best approach is to select one and read the online help to guide you in your search.

Following are a few sites that you should be aware of:

The transAction Council’s page at the National Kidney Foundation’s Website. Go to http://www.kidney.org and click on “Transplant Recipients and Donors”. This site provides up-to-date information on issues in transplantation, including medical and government relations updates and the latest on transplant athletics programs, as well as transAction Council events and meetings.

TransWeb (http://www.transweb.org). This comprehensive site offers a tremendous amount of useful information and related links for recipients.

United Network for Organ Sharing (http://www.unos.org). The official site of UNOS, these pages contain data and statistics on organ donation and transplantation in the U.S., information for patients, and a comprehensive list of links to transplant centers that have a website.

The Coalition on Donation (http://www.shareyourlife.org/) has information on organ donation as well as related links.

We’re also here to help! If you have questions about any of these subjects or would like additional information, you can e-mail us at transplant@kidney.org. We’ll be happy to help you on your Internet journey!

Gary Green, Director of Informatics, works on the NKF’s cyberNephrology project, a collaborative effort with the University of Alberta in Edmonton, Alberta, Canada.
This drawing hangs in the hall at Children’s Hospital in Boston, MA, and sums up how many kids feel about transplantation.