Recently, I was having a conversation with a fellow heart-transplant recipient, when I explained to him that I was also a double-lung transplant recipient. He replied, "We hearts get all the attention, but you lungs get all the complications." Begrudgingly, I agreed that he was correct. It is a fact of life, or should I say a fact of transplant life, that lung transplantation is problem prone.

From the beginning of my ordeal, I ran into difficulties. My pulmonologist referred me for transplantation when I was told I had a year and a half left to live. Unfortunately, he didn’t realize that the wait for lung transplants had grown much longer and could take three years. I was listed at the local center, but I knew if I stayed there, I would die while waiting. Lungs, unlike kidneys, must be in the recipient’s body and working within four to six hours of removal and are only shared within a 500-mile radius of the donor’s hospital. Therefore, I needed to find a transplant center in another part of the country with a shorter waiting list.

I also found out it was not going to be easy to get a lung. Out of the approximately 5,000 organ donors each year only 10 to 20 percent of them have suitable lungs to donate. Lungs are fragile and easily damaged by mechanical ventilation, trauma and infection, which are common circumstances surrounding brain death. Because of the shortage, I was told that I could only get one lung. This way the lives of two people could be saved instead of one. While this may seem admiral in the face of the organ donor shortage, it would, unfortunately, still leave me with one diseased lung after the transplant.

My diseased lung could become a source of infection and, because of its over-inflated size, interfere with the function of my transplanted lung. I also knew most of the people I talked to who received a single lung noticed they had shortness of breath doing simple tasks, while the people who had two lungs transplanted were playing tennis, hiking or swimming. The other problem I saw with a single lung transplant was that it would leave me with less lung reserve if and
Welcome to another issue of Transplant Chronicles. Summer is in full swing and if getting into a pool or some type of water is an activity you participate in during this time of the year, I’m sure you’ll find the article on “Water Workouts” beneficial to staying or getting in shape. Our “Summertime Eating” will also give you some great tips to complete the summer.

Many of our readers have asked us to address pre- and post-transplant insurance issues, which we have done in this issue. However, due to the complexity of this topic, we will be spreading it out over several issues.

Depression is also a topic that is prevalent among transplant recipients. As with any chronic disease, it is not unusual for recipients to experience periods of depression. I think you will find the article on depression and the pharmacist’s recommendations of treatment to be very informative. As always, consult your transplant team with your concerns.

This is the year off from the U.S. Transplant Games, unless you are attending the World Games (see the next issue for results), but it’s not too early to plan for the 2002 U.S. Transplant Games in Orlando, Florida.

Need information? Call the NKF (800) 622-9010. Enjoy the rest of your summer! 🎉 Beverly Kirkpatrick for the Editorial Board

Stuffee Helps Out for Organ Donor Awareness

Stuffee is a nine-foot one-of-a-kind ambassador for organ donation. He has a zipper down the middle of his chest and abdomen so you can listen to Stuffee’s heartbeat, take his pulse and hold soft sculpture reproductions of the heart, lungs, intestine, stomach and other organs. Stuffee is a great educational tool to teach children about organ donation and transplantation and how the body works. Stuffee travels to schools and all sorts of events to promote organ donation through local organ procurement organizations. 🎉
when chronic rejection set in. The current rejection rate in lung transplant recipients is high, approximately 50 to 70 percent in the first five years.

I figured, if I was going to have to go through with the transplant, I wanted to give it my best shot. So, I searched the country to find a center willing to give me two lungs. After about six months of numerous phone calls, faxes and rejections, I finally found a center that would consider me for two lungs. I went for an evaluation and was accepted into their program. Within two weeks, I sold all my things and moved to Florida where the center was located.

I was very fortunate to have only waited 13 months for my transplant and when I received my call, my transplant went off without a hitch. Unlike some patients, who commonly experience what is called a dry run (they're called when a lung becomes available, only to be told the lung is not suitable for donation), my lungs were suitable for transplantation. Unfortunately, one-third of the trips made by the transplant team to inspect donated lungs turn out to be unsuccessful.

The first year after my transplant was the most difficult. Lung transplants are unique among other organs because the lungs are the only major organ regularly exposed to an outside environment that is teeming with deadly viruses, bacteria and fungi. For the first six months, I had to wear a mask in public places, which really didn’t bother me, since I was on oxygen all of the time prior to my transplant. To this day, I wear a mask whenever I’m in an area where I’m likely to encounter sick people, such as a doctor’s office, a hospital or an airplane. I even wore one during the Transplant Games. You wouldn’t think that I would need a mask at the Games, but I encountered several participants there who were sick. You can always spot the lung transplant recipients in a crowd. We’re the ones wearing surgical masks!

Since my transplant, I have become an expert at not getting sick. In order to do so, I have adopted some unusual habits. I wash my hands frequently, especially before every meal. I know that doesn’t sound unusual, but I am constantly surprised by the number of people who don’t. I use my elbow or a paper towel to open the door to a public restroom. And if I think you are sick, I may not want to shake your hand. Dodging germs is no easy task, but it becomes an essential skill to learn after any transplant.

Now that I have survived five years, I don't take any chances. I love gardening and yard work, but will wear a mask and gloves to do it. I only travel by car or train unless flying is absolutely necessary. I don’t pet strange dogs and cats like I do my own beloved pet. I take time off from work if I get a sore throat and I am meticulous about taking my medications regularly.

Lung transplantation is a difficult road to travel, but one that I wouldn't trade for any other. Yet, I don’t want people to think that being a lung transplant recipient is any harder than any other type of transplant. They are all difficult. I’m not complaining either. I’d rather be able to breathe when I laugh, cry or have sex. Anything more is just gravy. I often look at my transplant scar, which spans the width of my chest and think to myself “these are my war wounds.”


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**Did you know...?**

**Medicare Has Two Parts**

**PART A** — Offers 100 percent coverage for inpatient hospitalization and transplant surgery. The deductible is $776.00 per admission for 61-90 days, then a co-payment must be paid if the admission goes beyond 60 days. If you are readmitted within six months, the deductible does not have to be met again. After six months, it must be paid.

**PART B** — Covers 80 percent of outpatient charges, for example, clinical appointments, blood work and immunosuppressant medications. There is a $100.00 deductible. The cost is $45.50 per month. If you are receiving Social Security, it will be deducted from your check, if not, you will be billed quarterly.
Summer Time Eating

By Kimberlee Rast, RD

Summer is the time for barbecues, picnics, pool parties and outdoor fun. Part of the fun is the great food of summer time. From barbecued chicken, potato salad and homemade ice cream to shrimp and crab boils, fresh fruits and ice cream cones. The summer abundance of low fat foods is wonderful for transplant patients. Using the grill to cook is an excellent way to keep the fat content down, without losing flavor. Eating outdoors is also one way Americans enjoy getting together to eat as a family.

The one concern for outdoor eating is food safety. Keeping foods at the wrong temperature can lead to food-borne illness. People with decreased immune function are at a higher risk of “catching” a food-borne illness. Following some simple rules can help ensure no one in your family will come down with food poisoning. Antibacterial soaps, sponges and sprays will not make up for sloppy kitchen hygiene.

In general...

✦ Wash your hands with soap and warm water before and after handling foods.
✦ Promptly wash cutting boards, plates and counter tops that come in contact with meat juices or raw meat, using hot, soapy water. To sanitize after cleaning, put items through the automatic dishwasher or rinse them in a solution of one teaspoon of chlorine bleach to one quart of water.
✦ Avoid contamination by handling raw meat, poultry, seafood and eggs as if they were contaminated with bacteria. Even if they do not start out with enough bacteria to make you sick, if mishandled they could. Do not use the same kitchenware for raw and cooked meat. Avoid cross-contamination.

When grocery shopping and preparing...

✦ Dented or damaged cans—Do not eat foods from dented or damaged cans.
✦ Freshness dates—Do not use food products after the freshness date has expired. An exception is milk, which has a sold by date and is still good for another week.
✦ Raw eggs—Do not eat raw eggs or uncooked dough which contains raw eggs.
✦ Wash produce thoroughly with water—Use a scrub brush to remove dirt from potatoes, carrots and turnips. Peel and discard outer leaves and rinds. Wash prepackaged salad mixes and vegetables, even if the label says they are pre-washed. No soap or detergent is needed.
✦ Purchase fresh produce. Do not buy any produce that is shriveled, moldy or slimy. Buy only what you can use within a few days.
✦ Thaw frozen foods in the refrigerator. Not on the counter.
✦ Separate your cutting boards—Use one board for raw meat, poultry and fish and use another board for salads and other foods.
✦ Buy fresh fish. Seafood should have a clean smell. The fish eyes should be clear, shiny and bulging (not sunken).

When cooking...

✦ Always cook thoroughly. Only thorough cooking will destroy any harmful bacteria in the food. Freezing or rinsing foods in water will not kill the bacteria.
✦ Avoid interrupted cooking. Meat and poultry products must be cooked thoroughly the first time. Afterward, they can be refrigerated and reheated safely.
✦ When microwaving food, follow manufacturers’ instruction carefully. Use microwave safe containers, rotate them during the cooking process and let the food stand for the recommended time.
✦ Use a meat thermometer to check meat and poultry. Cook roasts and steaks to at least 145 degrees, ground beef and pork to 160 degrees and whole poultry to 180 degrees.
✦ Make sure meat, poultry and fish are cooked thoroughly. Fish should be opaque and flake easily with a fork. Beef should look gray or brown inside. Chicken and pork should look white or tan. Beef, chicken and pork juices should be clear, not pink.

Handling leftovers...

✦ Divide large quantities into small units and store them in shallow containers for quick cooling before refrigerating

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We may not be Esther Williams, but a jump into the water can provide a very effective workout, as well as offer the power to soothe, calm, and refresh.

Many of you are familiar with water aerobics, aerobic exercises performed in the water. The cushioning of the water minimizes injuries and is soothing to your body. It allows you the benefits of exercise and saves wear and tear on muscles, while protecting the joints.

Over the past several years the popularity of water aerobics has grown because it appeals to all ages and fitness levels. But water workouts have been around for years. In the past, water aerobics were used mostly for rehabilitative therapy. The water’s buoyancy, resistance and therapeutic massaging effects contribute to the healing process. In addition to it being an effective workout, it also soothes the mind and the spirit. We can emerge from a swim feeling refreshed and rejuvenated. It has given us the time to work our cardiovascular system, tone our muscles, stretch our bodies, relax our minds and find a bit of solitude.

Many of the characteristics that doctors found to be effective for injuries, athletes found irresistible as a cross-training tool. Water training is a good way of improving and maintaining your fitness level without suffering any kind of impact. It is especially beneficial to transplant recipients and dialysis patients, as long as it comes with a physician’s approval. Many of us have other physical problems that we must deal with. Water exercises are a way to get fit and stay fit.

In order to swim or walk in the water, the body works in opposition. This movement between the arms and the legs is the basis for all human coordination. While immersed in water, you are working wonders for your overall balance and coordination. These activities will assist you in gaining strength, endurance and flexibility. It will help you to perform daily activities with greater ease and to gain strength for other activities that you may perform.

Building a stronger body through increased strength is another advantage of exercising in the water. You use more muscle fibers and the water provides 12 times the resistance of air. So the same movement done on land will be 12 times more difficult in the water. Those of us who need to counteract the side effects of disease and medication need to build those muscles in a big way! Exercising in the water forces you to use both parts of the muscle pair. You’ll use your biceps with your triceps, your quadriceps with your hamstring, etc. By balancing the work on both sides, you provide equal strengthening, thereby reducing the risk of injury and overuse.

Stretching in the water is a comfortable way to maintain flexibility and increase your range of motion. If you have not begun any kind of exercise program, and you have access to a pool, begin with simple water stretches. The tension in your body will slowly dissipate and the warm water will promote relaxation and comfortable breathing. It is a wonderful way to get your body to cooperate with exercise (and your mind).

Don’t underestimate the power of the water. Although the water has its own cooling system, your heart rate will be about 10 beats less per minute than on land. It places a sufficient demand on your heart and circulatory system. To improve efficiency, a water fitness program should include the same components as any workout. Start with warm-up, then 20 to 30 minutes of aerobic activity, strengthening movements, stretching to enhance flexibility and, finally, a cool down. You may choose to participate in a water aerobics class with friends, or take a swimming lesson. You’re never too old to learn deep water running. Deep water running is a more intense exercise. You should learn it from someone with experience. Getting the posture and motions correct takes time and practice. Ask about lessons at your health club, your local Y pools or running clubs. So grab your goggles and a towel and come on in! The water’s great!

In Health & Happiness,

Vanessa A. Underwood BS AFAA ACE ACSM is a fitness trainer, wellness consultant and motivational speaker.

Editors Note: Be sure to check with your doctor before beginning any kind of exercise program.
**Depression: Could It Happen to Me?**
*By Stephanie Johnstone, LCSW*

If you have a chronic illness or a transplant, depression could happen to you. Although you are grateful for receiving your transplant, you are now more at risk for depression than people without a chronic medical illness. There are many reasons why depression occurs. One reason is that living with a chronic illness can be difficult to handle for some people. The daily stress of following strict medical routines, adjusting to physical changes, explaining to others about your illness and fighting to fit into a world where you are not quite sick and not quite well can take its toll on your mood. If you begin to feel powerless under the stress and you lack a sense of control over your illness, it could contribute to depression. Combined with stress, the inability to solve life’s everyday problems can lead to depression. Your risk of depression can increase if you are socially isolated and have lost contact with loved ones, or your health care providers. This isolation can make stress even harder to tolerate.

When people are forced to live with a chronic medical illness, it can lead to changes in self-esteem that can be another factor contributing to depression. In a world focused on beauty, strength, health, vitality and power, changes that you are experiencing in body image, financial earning power and social roles can leave you feeling less worthy than you truly are. The way you view yourself, and how much you perceive your illness to limit you, can contribute to depression. This is called self-illness schema and has been shown to be a key contributor to depression in patients with a chronic illness.

Another cause of depression can be your illness itself. Metabolic changes and medication side effects are two ways your illness can contribute to depression. For this reason, it is always important to check with your doctor when you are experiencing depression. He or she can assess if your illness or the treatment itself could be contributing. If you have been on dialysis prior to receiving a transplant, or have not felt well for an extended period of time, your depression may be harder to detect.

Additionally, depression is more likely if one or both of your parents suffered from depression. Since society was not always as open about the disease of depression as we are now, it is possible your parent did not openly discuss depression with you. Your parent might have self-medicated depression with so-called nerve pills or alcohol. Perhaps he or she simply withdrew for periods of time. Your doctor or social worker can use a depression screening instrument to help assess the role, if any, depression plays in your life. If you think you have a family history of depression, or have had a history of depression yourself, you should monitor yourself for depression more regularly.

If you have determined that you may be depressed, you are not alone. Until the last few decades, depression has often been misunderstood. In the past depression was mistakenly seen as a weakness of character or a personality problem. Today, depression is more clearly understood as a medical disease. The Surgeon General’s Report on Mental Health (1999) brought home the fact that depression affects a large part of the population at some time in life. Occurring across all classes, cultures and ages, depression is affecting the wellness and survival of the world. The World Health Organization has even declared it a leading cause of death worldwide.

There is some good news. Since we have brought depression "out of the closet," treatment for the condition has improved and is considered safe and effective. There are many ways to manage depression today. For some, emotional and social rehabilitation alone can help. Increasing your contact with others and planning enjoyable activities on a regular basis can help improve your mood. Returning to an active life can be an important step to help relieve your depression. If you can include physical activity in your newfound life, it is even better. Physical activity has been shown to help alleviate depression in some people. If you are new to activity, mall-walking programs, artho-swim classes, no-impact classes for seniors

*Continued on next page*
and for the disabled, are gentle start-up activities that can help. Just make sure to check with your doctor before beginning any physical activity.

For others, depression management training might be indicated as a form of treatment for depression. The NKF is developing support materials that can be used by your clinic social worker in depression management programs. If a program is not available at your clinic, it is most likely widely available in your community. Ask your transplant center social worker to refer you to a clinical social worker or psychologist in the community that specializes in the treatment of depression. Many in this field use an effective intervention called Cognitive-Behavioral Therapy (CBT). In six to 20 weeks, this type of therapy can be effective, not only in lifting depression, but in preventing it from returning. CBT focuses on retraining the way you think about yourself and situations in your life in order to lift your mood and improve your quality of life. Other types of therapy, such as Interpersonal Therapy have also been found to be very effective within the same amount of time. Interpersonal Therapy focuses on restoring your social and problem-solving skills and providing the support you need to adjust to stressful situations and life transitions (such as living with medical illness). Medicare and other insurances usually cover treatment programs and services to reduce depression.

For many patients suffering from depression, especially if that depression is greatly interfering with their day-to-day functioning, anti-depressant medication is recommended. Your doctor can discuss the benefits of medication in treating your depression. Because depression is often affected by the neurotransmission of certain brain chemicals, medication that helps our own brain chemistry work better can often lift depression. Anti-depressant medications are not addictive or habit forming. Many are considered safe and effective for people with a chronic medical illness. Check with your doctor to learn which anti-depressants you can safely use. If your depression has been causing you to neglect your care, medication may be important for your recovery. According to research, medication and depression management training can work very effectively together. Many medical clinics and hospitals nationwide are combining the two forms of treatment for depression to achieve the best results for people with medical illnesses.

Just because you have received a long awaited transplant doesn’t mean that your adjustment to living with chronic illness is over. There is still the potential to become depressed. Your rehabilitation after transplant is not just a physical process, but an emotional one as well. Defining new roles for yourself requires acquiring, or polishing up on, social and emotional skills. It probably means renewing existing relationships and entering new ones. It is a journey that may take awhile and require the right type of support. Feelings of fear and inadequacy are common, especially during the first few years following a transplant. So don’t neglect the emotional aspects of adjusting to transplantation. Watch over yourself for depression (see signs and symptoms below) and seek the support you need to prevent depression. If you do become depressed, reach out to your doctor or transplant clinic nurse or social worker to seek a referral for depression management training. Don’t delay. Studies show that the sooner you seek treatment and support for depression, the less chance the depression will worsen. The more you can prevent or manage depression, the less depression will affect your health and wellness. Lucky for all of us, depression is a very treatable disease. Remember, you deserve to feel good about yourself and enjoy your life!

Some Signs and Symptoms of Depression:

Speak to your social worker or doctor if you notice the following:

- Feeling down (sad) most of the day, almost every day for the past two weeks
- Feelings of worthlessness
- Feeling hopeless
- Wanting to just give up
- Loss of pleasure in things that you once enjoyed
- Excessive irritability or anger
- Changes in sleeping patterns, appetite or concentration

Note: These changes can also be related to your medical condition.

About the author:

Stephanie Johnstone, LCSW, has been a nephrology social worker since 1983. She is currently working as a clinical social work supervisor for Fresenius Medical Care-NA in San Diego, California. Stephanie is developing depression management materials for the NKF Council of Nephrology Social Workers that can be used to enhance the emotional rehabilitation of patients with chronic kidney disease.
Symptoms of depression or clinical depression requiring medical treatment are common in some patients before and after transplantation. Factors such as mental and social well-being, issues related to the transplant process, coexisting medical conditions and the many medications that transplant patients take can contribute to depression. Consequently, transplant physicians and psychiatrists take a lot of things into consideration when evaluating a transplant patient for depression and potential drug treatment.

It is important for you as a transplant patient to talk to your transplant team about the side effects and symptoms you are experiencing and provide a list of any new drugs or herbal preparations you have been taking. Symptoms of depression include, but are not limited to: difficulty concentrating, change in appetite, change in sleep habits, fatigue, difficulty performing daily tasks, state of unhappiness and feelings of worthlessness. Disclosing this information makes it easier for your doctor to pinpoint the cause of your symptoms and proceed with proper treatment. This may be as simple as changing the dose of one of your medications or as complex as selecting and prescribing an antidepressant.

Corticosteroids (methylprednisolone, prednisone, etc.) are used in high doses after a transplant and, in many cases, are continued throughout life. Corticosteroids can cause central nervous system (CNS) side effects ranging from irritability, euphoria and difficulty sleeping to depression, extreme changes in mood and concentration. Depression related to corticosteroid use appears to occur more frequently in patients taking larger doses.

Tacrolimus (Prograf) and cyclosporine (Neoral, Sandimmune, Gengraf) have also been associated with CNS side effects. Tacrolimus and cyclosporine have been reported to cause headaches, tremors, dizziness, agitation, seizures, hallucinations and depression. Although these effects are seen in kidney transplant patients, they have occurred with greater frequency in liver transplant recipients. In many cases, these side effects correlate with the dose of cyclosporine or tacrolimus used and can be decreased or eliminated with a reduction in dose. This emphasizes the importance of monitoring your blood level with your transplant team.

Although patients receiving mycophenolate mofetil (Cellcept) have reported CNS side effects, most of these transplant patients were also receiving cyclosporine or tacrolimus as part of their immunosuppressive regimen. Most of the side effects attributed to mycophenolate mofetil affect the gastrointestinal tract (diarrhea, nausea, cramping, etc.). Sirolimus (Rapamune) CNS side effects include headache, tremors and insomnia. To date, depression has not been reported as a side effect directly attributed to the use of azathioprine (Imuran) mycophenolate mofetil, or sirolimus.

To manage depression in transplant patients a doctor may try to reduce the dosage of the drug causing the problem. If the depression continues after a reduction in dosage, your transplant doctor may consider switching you to another immunosuppressant. Drug therapy with an antidepressant may be considered when the above options have failed. Antidepressants that have been reported to interact with cyclosporine and tacrolimus, include nefazodone (Serzone), fluvoxamine (Luvox), and St. John’s Wort. Nefazodone and fluvoxamine increase the levels of both cyclosporine and tacrolimus, whereas St. John’s Wort has the opposite effect. Antidepressants that have been used safely in combination with immunosuppressants include: fluoxetine (Prozac), paroxetine (Paxil), sertraline (Zoloft), nortriptyline (Pamelor), and amitriptyline (Elavil). Cyclosporine blood levels may be slightly increased when fluoxetine is being taken concurrently and should be monitored. Herbal products, sometimes called alternative medicine (see Transplant Chronicles, volume 8, number 2, page 19), that are marketed as supporting mental health or emotional well-being should be avoided. These products may interact negatively with other medications and cause potential harm.

As a transplant patient, you should be aware of the signs and symptoms of depression and express your concerns to your transplant team. Symptoms of depression can often be managed without drug therapy. If you suspect you may have clinical depression, transplant centers have the personnel and resources available to treat your condition and provide follow-up care.

Parmjit Rai, is a candidate for doctor of pharmacy at the School of Pharmacy in Ohio Northern University, Ohio.
LIVING DONATION SOARS; CADAVERIC ORGAN, EYE DONATION REMAINS FLAT IN 2000

The number of living donors in the U.S. experienced its largest one-year increase ever recorded — 16.5 percent, but cadaveric organ and eye donors remained almost flat in 2000, compared to 1999, according to new data released by the United Network for Organ Sharing (UNOS) and the Eye Bank Association of America (EBAA).

The record increase in living donors accounted for almost half of a modest 5.4 percent gain in organ transplants performed in 2000 — 22,827 compared to 1999’s 21,655 transplants.

The number of living donors rose from 4,747 in 1999 to 5,532 in 2000, while the number of cadaveric donors increased by only 159, a modest 2.7 percent — from 5,825 in 1999 to 5,984. Eye banking data revealed a similar pattern. The EBAA reported there were 46,949 corneas transplanted in 2000, compared to 45,765 in 1999, a 2.6 percent increase. However, the number of corneal donors in 2000 actually declined by 1.5 percent over 1999.

MOST WHO VOLUNTEER TO DONATE KIDNEY TO Unknown Recipient End Up Not Donating, MINNESOTA STUDY FINDS

With living organ donation enjoying a major resurgence in the past several years — there was a 16.5 percent increase in the U.S. last year — much attention is being focused on living non-directed kidney donation to help ease the shortage of organs for transplantation. However, a new study out of Minnesota yielded sobering data that few individuals who volunteer to donate a kidney to an unknown recipient ever become donors.

Arthur Matas, MD, and colleagues at the University of Minnesota in Minneapolis evaluated the outcomes of 118 individuals who expressed an interest in donating a kidney. All of the inquiries were unsolicited, consisted of about the same number of men and women, and averaged 51 years of age. All were sent information on the surgical procedure and the evaluation process was mailed to all individuals who contacted the program.

The end result revealed that more than half did not contact the program again after receiving the information or discussing the procedure with transplant center staff. 32 were evaluated and denied, nine are still completing the evaluation, and seven have donated a kidney. The researchers said medical reasons accounted for 17 of the denials. 11 were for psychological reasons and four for ethical reasons — one of the ethical reasons for denial was “unreasonable demands” including a request for payment.

KIDNEY TRANSPLANTS FARE BEST WHEN PERFORMED BEFORE DIALYSIS IS NEEDED

Kidney allografts from living donors survive longer when transplanted before the recipient has started dialysis, according to a study in the March 8th issue of the New England Journal of Medicine.

Compared to patients who received transplants after being on dialysis, patients who had never undergone dialysis experienced a 34 percent reduction in allograft failure during the first year post-transplant, a 44 percent reduction during the second year, and a 62 percent reduction thereafter, reported Kevin Mange, MD, and colleagues from the University of Pennsylvania in Philadelphia. In their review of data from the U.S. Renal Data System, the authors also found the magnitude of benefit was even greater after adjusting for the cause of kidney disease, the racial relationship between donor and recipient, and the presence or absence of delayed allograft function. Only the adjustment for acute graft rejection slightly attenuated the effect of transplanting before dialysis.

Based on their findings, the researchers speculated that preemptive transplantation might modulate immune mechanisms that shorten allograft survival. "As physicians, we need to identify patients with kidney problems and refer them to nephrologists sooner than what is presently..."
happening in the United States," said Mange. "Approximately 25 percent of recipients of kidneys from living donors receive their organs prior to dialysis initiation. This proportion should increase, if patients are referred early in the course of [end-stage renal disease]."

**HCFA BEGINS MEDICARE COVERAGE OF SOME INTESTINAL TRANSPLANTS**

The Health Care Financing Administration (HCFA) began offering Medicare coverage of intestinal transplants on April 1. (See note at end of section.)

Three transplant centers — the University of Pittsburgh Medical Center, Pittsburgh, PA; Jackson Memorial Hospital Transplant Center in Miami, FL; and The Mt. Sinai Hospital, in New York City — are the only centers in the U.S. that have been approved by HCFA for coverage to perform transplants for Medicare beneficiaries with irreversible intestinal failure.

To qualify, centers must have performed ten transplants per year with a one-year actuarial survival rate of 65 percent.

The transplant procedure will benefit only the small portion of the Medicare population with intestine failure who can no longer be treated with intravenous feeding tubes, a procedure called total parenteral nutrition (TPN). These patients are often not able to tolerate long-term TPN because the process may cause liver failure, the patients’ veins become clotted, the lines to deliver the nutrients become infected, or the process caused severe dehydration.

"Although only a few people may benefit from this coverage, it reflects our commitment to providing all of the nearly 40 million Medicare beneficiaries with access to proven new treatments and technologies," Secretary Thompson said.

Fewer than 1,000 intestinal transplants have been performed in the U.S., with approximately two-thirds of the patients being children.

**NOTE:** Health Care Financing Administration (HCFA) has changed its name to CMS, the Centers for Medicare and Medicaid Services.

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**INFORMAL COALITION OF TRANSPLANT — GROUPS SEND DEPARTMENT OF HEALTH AND HUMAN SERVICES SECRETARY TOMMY THOMPSON SOME IDEAS TO EASE THE DONOR SHORTAGE**

Eight national transplant-related organizations have proposed that the federal government implement a dozen initiatives designed to make it easier and more attractive for Americans to donate organs and tissues.

The list, which includes proposals to offer subsidies and grant leave time to donors, was sent to Secretary of Health and Human Services Tommy Thompson.

The informal coalition of organizations signing off on the proposals include: American Association for the Study of Liver Diseases; American Association of Tissue Banks; American Liver Foundation; American Society of Transplantation; American Society of Transplant Surgeons; Association of Organ Procurement Organizations; Juvenile Diabetes Research Foundation, International; National Kidney Foundation, and Transplant Recipients International Organization.

"By developing consensus around a set of comprehensive proposals designed to increase the rate of organ and tissue donation in this country, the signatories to this document have attempted to provide timely input into an important initiative of the new Administration," the organizations said in a memo to the Secretary.

The coalition recognized that each signee has "different points at which they will no longer be able to support the details" of certain proposals. Nevertheless, it emphasized, "a large portion of the transplant community is strongly supportive of the Secretary’s initiative and stands ready to work with the Administration and Congress to implement the most comprehensive and effective strategy possible to dramatically increase the rate of organ donation."

Here is the list of "provisions" offered to the Secretary in no order of priority with some of the explanatory information to support the provision.

1. **Payment for Travel** and Subsistence Expenses for Living Organ Donors — This provision is contained in organ donation legislation (H.R. 624) recently passed by the House of Representatives.

*Continued on next page*
2. Leave Time for Living Organ Donation — A legislative strategy would focus on amending the Family Medical Leave Act to require employers to offer this benefit to its employees, while a non-governmental strategy would involve the encouragement of large private employers to offer this benefit to their employees.

3. Organ Coordinators — Legislation has been introduced that would provide federal grants to hospitals and organ procurement organizations to fund staff positions for organ coordinators who would be responsible for coordinating organ donation and recovery in a hospital or group of hospitals.

4. Regional Hearings Conducted by HHS/Follow-up Report to Congress — A series of HHS-sponsored hearings would help generate input into the process from a grassroots level and provide opportunity for a national debate on some of the more controversial organ donation proposals.

5. Honoring Consent — Legislation proposal seeks to enact a federal law (or have HHS encourage states to amend their Anatomical Gift Act law to provide such binding legal effect) requiring that an organ donor card or an indication of organ donor status on a driver’s license be given binding legal effect, regardless of familial objections.

6. Support Stronger Demonstration Project Authority for HHS — Currently, HHS’ demonstration project authority does not allow it to fund grants that might involve use of financial incentives to increase donation, because of the prohibition in Title II of NOTA (National Organ Transplant Act) against the purchase of organs for transplant. Proposal would loosen these demonstration project restrictions while requiring outside entity to conduct ‘ethics’ check on each proposal.

7. National Registry of Organ Donors — There seems to be a broad consensus for developing an information clearinghouse where an organ procurement organization could determine almost instantly, at any time of the day or night, the intentions of an individual to be an organ donor.

8. National Donor Outcomes Registry — Create a registry to track outcomes of living organ donors and recipients to create a rich database to help researchers and clinicians in maximizing the potential for successful living organ donations and transplantations.

9. Study Disparities in Organ Transplantation — Recent reports have cited significant disparities in the racial diversity of people listed for kidney transplants. Federal funding should be made available to study the reasons for these disparities in various parts of the country and identify possible solutions.

10. Tissue Donation — FDA should accelerate finalization of its regulatory agenda, including requiring registration of tissue banks, enhanced donor suitability screening and testing, and the use of good tissue practices, including informed consent safeguards.

11. Organ Donor Awareness — Increase activities, including urging President Bush to issue proclamation on importance of organ donation, encouraging congressmen to speak out in favor of donation, etc.

12. Semi-postal stamps — A semi-postal stamp to encourage organ donation would raise awareness and, because it would cost more than a normal postage stamp, would fund organ and tissue donor awareness.

(Editor’s note: A semi-postal stamp is like the cancer awareness stamp that has been available for several years. The additional cost above the going first class postage rate is donated to the cause.)

U.S. RESEARCHERS FIND STEM CELLS IN HUMAN FAT

Researchers at the University of California at Los Angeles (UCLA) and the University of Pittsburgh (PA) said they have isolated human stem cells in fat removed from patients during routine liposuction.

Since many Americans would be more than happy to donate their fat in the name of science, this finding suggests a plentiful—perhaps unlimited—supply of stem cells for medical research. An estimated 600,000 liposuction procedures are performed each year in the United States.

“Fat is perhaps the ideal source [of stem cells],” said Marc Hedrick, MD, a UCLA plastic surgeon. “There’s plenty of it, it’s easy and inexpensive to obtain, and [its removal] even has a secondary cosmetic benefit.”

In the experiment detailed in the April issue of the journal Tissue Engineering, the scientists took the fat and fluid sucked from the hips, buttocks, and stomachs of patients during elective liposuction surgery, washed and purified it, and treated it with an enzyme to break down the matrix holding the cells together. They then compared the fat stem cells with the stem cells obtained from bone marrow samples. According to Adam Katz, MD, a plastic surgeon at the University of Pittsburgh.

Continued on next page
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approximately a half-pound of fatty material can yield 50 million to 100 million undifferentiated stem-like cells. These cells appear to have the potential to grow into bone, fat, cartilage, or muscle tissue, and studies in animals are underway at UCLA to determine if this is the case.

MOVE FROM WISCONSIN GOVERNOR TO HHS SECRETARY RESHAPES THOMPSON’S VIEW OF TRANSPLANT SYSTEM’S NEEDS

Jim Warren, co-producer of Transplant Video Journal, sat down with Department of Health and Human Services Secretary Tommy Thompson on April 17, 2001, following the unveiling of his initiative for reducing the nation’s organ and tissue donor shortage. Here are excerpts from the interview.

TRANSPLANT NEWS/TRANSPLANT VIDEO JOURNAL: You have announced a series of initiatives to address the organ donor shortage. Will you briefly explain what they are?

SECRETARY THOMPSON: Well, basically, they’re very simple. But I am very passionate about making sure that we make them work. We’re trying to build up a partnership between businesses – large, medium and small, and with labor unions, to try to make sure that they allow for the work place to be a place for employees to sign up to be organ donors, blood donors, tissue donors or bone marrow donors.

Second, we want to make sure that individuals sign a new national donor card, not that the ones they’ve already signed aren’t good enough, we just want to replicate the act so that more people get involved. And we have two witnesses on there, so people will make sure that they talk to their loved ones.

Third, we want to develop a national gift of life medal. I want to thank the donor families. We did that in Wisconsin. It was one of the most moving days of my life when I invited the donor families to come into the capital and I was able to give them a gift of life medal. They were so appreciative of the fact that somebody recognized them and wanted to say thank you.

Fourth, we want to have a national dialogue about whether or not we should have a national registry of organ donors. I’m going to ask HRSA (Health Resources and Services Administration) to hold a mini-convention to discuss what direction we should go and how we might accomplish that.

The fifth came out of something I did in Wisconsin. A young girl named Kelly was killed in a freak accident with her boyfriend right after her 16th birthday and she had gotten her driver’s license. She had signed her donor card on the back of the driver’s license and her family fulfilled her wishes. As a result, she was able to help two families in Wisconsin, and a woman in Missouri. Kelly’s family wanted to do something in her memory. So we set up a program that mandates every child, when they reach their 16th birthday and before they get their driver’s license, to take a 30-minute program on organ donation. I’d like to replicate that in every state in America.

TN/TVJ: In the past, the government hasn’t done a whole lot in terms of promoting living donation, and yet, the new statistics out this year show that almost half the increase in new donations came from living donors, what does your department plan to do to support living donation?

THOMPSON: I think that living donation is the way of the future. Living donation went up 16 percent last year and cadaveric donations only went up by three percent. So you can see the growth is living organ transplants. This department is going to encourage living donors. We’re going to give out information that it is not harmful to your body.

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TN/TVJ: What message do you have for the transplant community?

THOMPSON: First - thank you for being such wonderful dedicated people doing the necessary heavy lifting to solve our problems. Second, I want to be your partner. I want to work with you in a unified way in which we can accomplish the most good for America. Third, I’m going to use my office wherever I possibly can to encourage people to sign up as donors. Or at least to pique their curiosity, get them involved, to ask some more questions about donation and its importance.
We entered the patient floor and knocked on the locked patient room doors that first weekend on daily rounds in our new Lied Transplant Center. To our surprise, not one patient or family member was available. We immediately knew that we had entered into a new concept of providing in-patient hospital care. It’s called Cooperative Care and part of the goal of such a facility is to promote patient privacy. We learned from that first experience that our daily rounds had to be scheduled at the same time every day, so patients and their families were available to us when we arrived. The incident also supported another benefit of Cooperative Care. It allows patients and their family members to become an important part of their own treatment and recovery team.

So what is Cooperative Care? It is a practice that allows patients and their care partners to participate in the treatment and recovery process, supported by multidisciplinary health care professionals, in a home-like environment. Care partners are usually family members or close friends who stay with the patient, throughout the course of treatment.

The Cooperative Care setting at the University of Nebraska Medical Center/Nebraska Health System is part of the Lied Transplant Center. The Cooperative Care accommodations look like hotel suites. They consist of a bedroom, sitting room, bathroom and kitchenette. Patients leave the traditional hospital quickly to move to the Lied Transplant Center for the remainder of their hospital stay. To qualify for Cooperative Care the patient must meet in-patient hospital criteria, have a care partner and be strong enough to get up and go to the bathroom with minimal assistance.

The care partner provides needed support and encouragement to the patient and can accompany the patient to tests or appointments, attend educational sessions to learn about care and home needs (such as medication and diet), and learn additional skills that are necessary to assure a confident and comfortable return home (like taking blood pressures, weights, changing dressings and hanging intravenous medications).

The Lied Transplant Center provides hotel-type amenities like soap and shampoo. The bathrooms are all handicapped equipped. Patients and care providers have access to their own cafeteria, an exercise room, play rooms and a resource center. Families have free access to computers, fax machines, video games, movies and educational materials in the resource center.

The first priority of Cooperative Care is to continue to provide high quality care in a more relaxed, private and educational setting. Using this kind of facility has resulted in high patient satisfaction. Other centers using this concept also report faster patient recovery times and fewer medication errors, falls and re-admissions. Lower costs may be an added benefit of this innovative care.

The Lied Transplant Center also has a 24-hour staffed emergency and treatment center. Patients avoid the waiting times associated with a traditional emergency room. Certain procedures such as biopsies can be performed in the treatment area thus avoiding an overnight stay and additional in-patient hospital costs. The building has state-of-the-art research laboratories, bringing patient care, education and research under one roof. It also has rooms to house outpatients who need to stay in the area.

Transplantation of all organ types continues to grow each year. We have seen the survival rates improve in all types of transplant patients as we continually look for new ways to provide the most modern medical care. Not only do we strive to provide the most up-to-date medical, surgical and nursing care, we also look at new ways to provide care in different types of settings. Cooperative Care is just one of the newer concepts in providing a more personalized, in-patient hospital experience for transplant patients and their families. With time, we might be able to see even greater benefits from caring for people in this unique setting.
Early efforts of the transAction Council executive committee revolved around looking into issues that affected many transplant recipients. We recognized that the cost of or lack of immunosuppressive medications, the side effects of these drugs, financial and insurance issues and the constant threat of rejection or infection had a real hold on all of us who make up the transplant recipient community. These are life-altering concerns. In many cases, resulting problems are handled uniquely by each of our transplant centers and, by in large, these issues are being dealt with appropriately. So we asked ourselves the harder questions — the ones that those who have struggled with other issues post transplant had underneath the surface. These were the thoughts we would not mention to our transplant teams for any number of reasons or had mentioned and received less than a sufficient answer.

We all viewed our transplant professionals as lifesavers. They gave us a second chance and we walked out of the hospital feeling better than we had in a long time. However, transplants not only saved our lives, but also changed our lives having a unique impact on each recipient. We found it was not unusual for our transplant teams to send us on our way, with little support, to cope with how this life-changing transplant would affect our lives at the psychosocial level. In some cases, transplant professionals were able only to take the approach of “we saved your life — now move on.”

In talking to many recipients we found that many issues that have not been addressed effectively. Some of these issues include:

- Depression
- Post-traumatic stress and daily stress
- Relationships
- Sexuality
- Health care management issues
- Disability
- Returning to work or not
- Physical activity and exercise
- Nutrition
- Access to health care of all types
- Having a voice and being our own advocates.

These discussions revealed to us that a transplant recipient’s bill of rights might be a good tool to create and to discuss with the transplant professionals. However, if we were asking transplant professionals to honor our concerns we needed to balance that with our responsibilities as transplant recipients. Those responsibilities include everything from adherence to transplant medical regimes, to reporting any signs or symptoms of a problem to financial responsibility and all things in between.

It is the hope of the transAction Council executive committee that the “Transplant Recipients’ Bill of Rights and Responsibilities” will help and empower transplant recipients in their quest for all the care they need and deserve. By recognizing that many issues come from this life-changing event we hope that it will free you to ask the hard questions and receive the answers you need. We encourage each of you to read this document and, better yet — use it.

John Landers had a heart transplant nine years ago and is a donor family sibling. He is a member of the NKF’s transAction Council executive committee and a former member of the National Donor Family Council executive committee.

For a copy of the “Transplant Recipients’ Bill of Rights and Responsibilities” booklet call NKF at (800) 622-9010 or write to:

National Kidney Foundation Information Center
30 E. 33rd Street, New York, NY 10016.
During a cold evening in Salt Lake City, Utah, while I attended the National Kidney Foundation meeting, I came upon a shivering group of people gathering outside our hotel. They asked if I wanted to come along and see a polygamist compound that had been turned into a Transplant House. After hearing the many stories of the polygamists in the area, I was curious to see a former polygamist’s house now housing transplant recipients. I decided to join the group. We piled into a large van and took off for the approximately 45-minute drive up the mountains on the outskirts of Salt Lake City.

By the time we arrived, it was dark. We entered the large gates that brought us onto five acres of ground with five existing homes. The largest of the homes is 29,000 square feet! Overlooking the edge of the property lies the City of Salt Lake, which became a mass of glittering lights at night.

The facility, which has the potential to house between 60 and 80 people, is the home of Common Thread, a non-profit organization that provides organ and bone marrow transplant patients and their families with a place to stay while they undergo medical treatment in the Salt Lake City area hospitals.

In February of 1998 Jason Ivers, a heart transplant recipient, established Common Thread. Kally Heslop, also a heart transplant recipient, joined Jason in November of the same year. Kally and Jason had met 10 years earlier in the hospital. They began a campaign seeking $750,000 in donations to build or purchase a facility to house transplant recipients.

Not long afterwards, Jim Morse, a real estate developer, happened to be watching a local television broadcast about Common Thread. It was Common Thread’s lucky break. Mr. Morse became interested in the cause and two days later he was showing Jason and Kally the compound he and his business partners had recently bought from polygamists who vacated the grounds. A lease agreement was worked out and Common Thread moved their offices into the complex. Since May of 2000 over 25 families have stayed at the complex, paying a small fee, or in some cases none at all.

The Common Thread facility will also be home to Team Utah, the team that competes in the U.S. Transplant Games. There is a pool, basketball, table tennis and volleyball on the grounds, with tennis courts soon to be added, as well as ample space for team meetings. Kally is the team manager, just one of the many hats that she wears.

As our tour ended and we headed back to the city, we felt totally in awe to have seen such a phenomenal home away from home for transplant recipients and their families. It will enable the patients to continue their care, yet be able to relax and forget the clinical piece of the hospital or clinic. I believe that it is places such as this that allow for the patients to recover faster as their minds are at ease.

Refrigeration guidelines...

✦ Refrigerate leftovers promptly. Discard foods that have been left out longer than two hours.
✦ Reheat leftovers thoroughly to 165 degrees, or until hot and steamy. Bring soups and gravies to a rolling boil.
✦ Clean out your crisper bin once a week and discard items that are no longer fresh.
✦ Store raw meat, poultry and fish on the bottom shelf of the refrigerator so juices do not drip onto other foods.
✦ Leave raw meat, poultry and fish marinating in the refrigerator, not on the counter. Discard the marinade after use. If you want to use the marinade as a baste or sauce, reserve a portion of it before you add the raw food or boil it.
When Eating Is Just Not Enough

By Adela T. Casas-Melley, MD

There is a group of children and adults who cannot get enough calories and vitamins from the foods that they eat because of a disease of their intestines. These patients have to get additional calories and vitamins in their veins from a formulation of electrolytes, amino acids and fats called hyperal. Hyperal can be given as either a supplement to intestinal nutrition or as a substitute for it. Some of the complications from hyperal are:

- Infections from the line that is needed
- Clotting of the vessels from the line
- Liver failure.

Why does this happen, and what can we do about it?

Intestinal failure is a very complex problem that has many causes. The most common cause is short bowel (intestine) syndrome (SBS). Short bowel syndrome can be the end process of many diseases. Some children are born with short bowel length because of problems during a pregnancy; others are born with normal bowel length but develop SBS because of the need to surgically remove a part of their intestine that is diseased. When this happens, the children cannot take in enough liquid and calories to support themselves. They then need to be started on hyperal to get enough calories and fluid to survive and grow. Some children eventually adapt to the length of their intestine and can begin to take food by mouth and get weaned off the hyperal. These are the lucky ones.

Unfortunately, some children with SBS either do not have enough length of intestine left to adapt or their intestines are too sick to adapt. Therefore these children cannot come off the hyperal. This would be acceptable if the hyperal did not cause any side effects. Unfortunately, especially in small children, hyperal can cause damage to the liver. After long-term hyperal, the liver can be damaged so severely that the patient would need a liver transplant to survive. When this happens, transplanting the liver alone would not be enough because there would still be the need for hyperal after the transplant, which would start the cycle of injury again. These children need a small bowel transplant.

Small bowel transplantation offers hope to adults and children with intestinal failure and life-threatening complications of hyperal. Intestinal transplantation is a relatively young field. The first intestinal transplants were attempted in the 60’s, but it was not until the late 80’s that real success with intestinal transplantation was seen. Intestinal transplants are not as successful as other types of organ transplants; however, results have dramatically improved over the last few years with long-term organ and patient survival exceeding 50 percent. As of December 2000, 38 centers in the United States had active clinical intestinal transplant programs, although the majority of transplants are done at a handful of programs. The Intestinal Transplant Registry reports that a total of 474 intestinal transplants have been performed.

Patients with intestinal failure who develop end-stage liver disease, have episodes of recurrent infections from central lines, or have clotted their veins and have no access for future central lines are candidates for intestinal transplantation. These patients should be referred for evaluation to an active intestinal transplant center. Many patients will need concurrent liver transplantation, and the extent of their liver disease is what dictates the timing of transplantation. The one-year patient survival rate after combined liver/small bowel transplant is 65 percent, compared with a one-year survival rate of 30 percent for patients who did not undergo transplantation. For patients who are referred to centers early and have not developed end-stage liver disease, an isolated intestinal transplant can be done. The one-year patient survival rate for this procedure is 92 percent. It is a life-saving procedure.

Continued on page 18
Several times a year, the National Kidney Foundation offers an educational series, in the form of a full-day workshop, to aid patients in coping with chronic illness. The workshops, for patients, family members and donor families, are given in different parts of the country. The foundation’s transAction Council’s “Taking Control of Your Life” workshop in Orlando, Florida (also the site of the 2002 U.S. Transplant Games) offered several sessions aimed at awareness and other patient issues.

Dr. Robert Metzer, from the Florida Hospital and Translife, hosted a session entitled “Long Term Survival with Transplant.” He explained the issues with an excellent slide show. Some of his slides dealt with different types of skin cancers, which can occur post-transplant. Dr. Metzer also helped the attendants understand the chart that rates the various complications stemming from immunosuppressive drug therapy. Today, doctors are discovering new viruses that affect people with transplants due to their suppressed immune systems. Some of the best advice Dr. Metzer gave the session’s attendants was to use sunscreen daily, exercise, be compliant with medications and eat healthy foods. It will help you keep your transplant for a long time. Obesity and heart disease are issues all Americans face; for transplant recipients the concerns are significantly increased. Dr. Metzer strongly advised transplant recipients to get annual cancer screenings.

“Nutritious Cooking Tips with Chef O” was another session featuring professional chef and transplant athlete Oliver Hale (Chef O) along with Peggy Harum, RD, CSR, LD. The food that was being cooked during the demonstration smelled wonderful, but session rules prevented any tasting or sampling. The point of the session was to show how easy it is to cook delicious, healthy meals using basic ingredients like pesto sauce, basil, cranberry juice and “Oliver” oil. Chef O convinced the attendants that anyone can become a chef.

An after-lunch session discussed various resources and ways to become involved with the local ESRD Network 7 and the Florida Coalition on Donation, as well as national organizations like the NKF transAction, Donor Family and Patient and Family Councils. The three national membership groups for recipients of all organs, donor families and kidney patients are free.

A donor mom, Mary Ann Carpenter, gave an interesting talk on her involvement with donor families and transplant awareness and how it has changed her life. Other donor families and recipients shared their personal stories during a coffee house sharing, which began during the Transplant Games.

One roundtable discussion was entitled “Relationships After Transplantation.” There was some discussion on transplant recipients trying to be just like everyone else and the difficulties they encounter in relationships because they have a transplant or chronic illness.

“Movement For Mind, Body and Soul” was a session about the benefits of massage. One host, John Hurdle, discussed the benefits of massage therapy and demonstrated with a short massage. Barbara Wallace, another host, discussed Yoga and taught the attendants some simple movements and breathing exercises. She closed by taking the room on a guided relaxation meditation. The group was so relaxed that no one wanted to leave.

At a general session about the Donor Quilt and its history, three donor families added their Patches of Love to the Quilt. It was an emotional moment for everyone in attendance. The event closed with a candlelight ceremony. Several inspirational tributes to donors and transplant recipients were read aloud.

Catch the next “Taking Control of Your Life” workshops in New Orleans on Saturday, September 8, and in San Francisco on Saturday, October 13. Call the NKF at (800) 622-9010 for more information.
Care after intestinal transplantation is very complex and it is not unusual to spend an extended period of time in the hospital. There are several areas that the transplant team are concentrating on for post-operative care.

**(1) Rejection** – this is the most likely complication after transplantation, and the most common cause of graft loss. For the first few weeks after transplantation, the patients will undergo endoscopy. This is a procedure in which a special scope is placed into the intestine so that a doctor can examine and biopsy areas of the intestine that look suspicious for rejection. If there is rejection, then the immunosuppression medicines that prevent rejection need to be adjusted and occasionally new medicines are added.

**(2) Infection** – Infection and sepsis are associated with high mortality after intestinal transplantation. Because of the intense immunosuppression needed in these patients to prevent rejection, they are more likely to develop significant infections. Viral infections with cytomegalovirus (CMV) and Epstein-Barr virus (EBV) are also common. CMV is the most common viral infection after transplantation and can lead to infection of the graft itself. EBV is a major concern because of its association with PTLD. PTLD is a type of lymphoma that develops in patients after transplantation as a side effect of immunosuppression. The number of patients that develop this complication is low, but it is almost universally fatal.

**(3) Nutrition and Fluid balance** – fluid balance can be difficult after transplantation because the intestine has to be trained to work normally again. This could take months and require several admissions to the hospital for intravenous fluid for the first year after transplantation. The whole purpose of undergoing the transplant is to be able to take all nutrition by mouth. The transplant team will work hard with the patient and family along with a nutritionist and feeding therapist to get the patient to full nutrition by mouth and off hyperal as soon as possible after transplantation.

This group of patients requires a lot of close supervision on the part of the medical team. There is much room left for improvement in their treatment; however, the success rate with transplantation is much better than the rate of survival of those patients not transplanted. Patients asked about their quality of life after transplantation report their lives are better after transplantation than while at home on hyperal. We have a long way to go with intestinal transplantation to equal the success rate of liver and kidney transplantation, but the treatment is presently saving lives and the success rate is improving with every case performed.

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**Making Your Own Marinade**

Follow the basic recipe to make a huge variety of great marinades for meats and vegetables. Marinate for 30 minutes to overnight in the refrigerator. Discard the marinade after it has had contact with raw meat. If you want to use the marinade as a baste or sauce, reserve a portion of it before you add the raw food.

<table>
<thead>
<tr>
<th>Use 2 tablespoons of an oil</th>
<th>To 4 tablespoons of an acid</th>
<th>To several teaspoons of a flavoring</th>
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<tr>
<td>Extra virgin olive oil</td>
<td>Vinegar</td>
<td>Garlic</td>
</tr>
<tr>
<td>Sesame oil</td>
<td>(Sherry, wine, balsamic, flavored)</td>
<td>Basil</td>
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<tr>
<td>Peanut oil</td>
<td>Fresh squeezed juices</td>
<td>Cumin</td>
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<tr>
<td>Or any other oil</td>
<td>(Lemon, lime, orange, pineapple)</td>
<td>Thyme</td>
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<td></td>
<td>Soy Sauce*</td>
<td>Bay leaves</td>
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* High Sodium Item

For Example:

- 2 tablespoons Extra virgin olive oil
- 4 tablespoons Fresh squeezed lime juice
- 2 teaspoons Scallions, finely chopped
- 1 clove Garlic, minced
- 1/4 cup Cilantro, chopped

Submitted by Kimberlee Rast, RD.
Our lives continued, but eventually Shirley became sick. She never referred to her transplanted kidney as her own, but always as “Shawn’s kidney.” It was pointless for me to argue otherwise. I have no idea what it is like to reject a kidney, but I witnessed how emotional it was for Shirley to lose Shawn’s kidney. She believed she had failed me and she expected our friendship to end when she received another kidney. I assured her that it would not. I told her that I remained friends with people whom I had meet through Shawn. When he died, they remained my friends. However, I did admit to Shirley that I understood our friendship was different and most certainly had a unique beginning.

In 1996, I received a call from Shirley. She had four tickets and a special request. She announced that she and Shawn’s kidney were graduating from nursing school (they did everything together). I laughed reminding her that nursing would not have been Shawn’s first career choice. She asked if my husband, Bill and I could attend her graduation along with her husband and daughter. She quickly added that my wishes of not meeting her would still be honored. She suggested we sit in the back of the room to avoid a chance meeting. Screams of joy came when I informed Shirley that I did not want to sit in the back and that it was time for us to meet. The timing was perfect! We celebrated Shirley’s graduation and our first meeting with her and her family and friends.

In 1998, I went to visit Shirley at her home for the first and last time. Shirley was dying. I had come to say goodbye to my friend and she told me “no tears” were allowed. She thanked me for the time our gift gave her and I thanked her. She could not imagine what I thanked her for. I placed the first letter she ever sent me in her hands and the tears quietly rolled down her cheek as I heard her whisper, "Wow, I am good." I agreed. I believe there is no such thing as a bad “Thank You” letter.

In 1998, Shirley died that October, but today her legacy lives on with Shawn’s. In one of our first phone conversations she told me that she would have given her life for my son and meant it with every fiber of motherly love. I miss picking up the phone and hearing, "Do you know who this is?” as if all my friends who called had a strong Tennessee accent like Shirley did.
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: U.S. Transplant Games; Transplant Chronicles; and transAction Council programs.

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