

Transplant Chronicles

Volume 7, Number 2

A publication for transplant recipients of all organs and their families,
published by the National Kidney Foundation, Inc.

Fall 1999

Heart and Soul

Every day millions of Americans go off to work, knowing exactly what they can expect to happen during the course of the day. They are greeted by familiar co-workers, with whom they spend almost as much time as their own families. Sometimes, co-workers become trusted friends, and other times, they become a lot more. Carol Hagan's co-worker Linda Greaves literally became a life saver, when on April 21, she decided to donate her son John's heart to Carol's husband, Chris.

At age 34, Chris Hagan had been on the waiting list for a heart transplant since September 1998, when doctors at the University of Pennsylvania told him his heart was failing. Chris had always been physically active, and his condition greatly affected his lifestyle. He was a carpenter and a volunteer firefighter whose duties included being an emergency first responder with

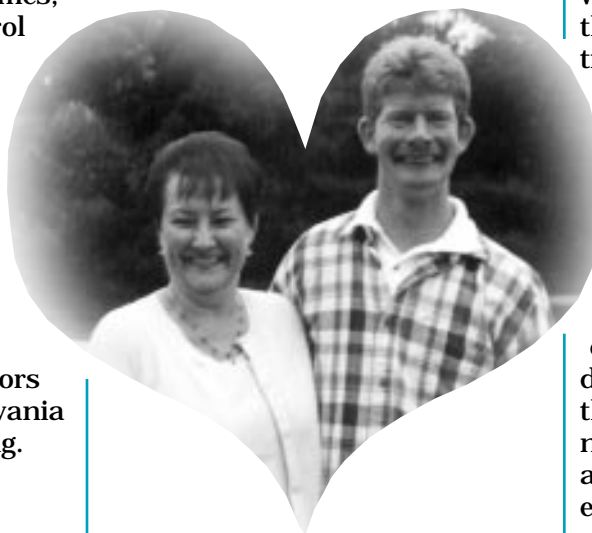
the Goshen Ambulance Company in Pennsylvania. Chris hadn't worked at either of these jobs since September. He spent most of his time at home with Carol and his children, 13-year-old Christopher Jr., and 11-year-old Katie. He joined a local support group, Hearts From

Heaven, for recipients and people on the waiting list, to help him through this difficult, frustrating time.

Linda noticed how dejected Carol looked when she came to work during this waiting period. Carol explained how they were waiting for the fateful phone call that would bring Chris a transplant. Linda says

that the Hagan's situation really had an impact on her. She thought about their two young children and how scared they were not knowing what would happen to their father. Linda says that through it all, though, Carol came to work and dealt with the daily stresses of her job, a feat that impressed Linda. She had no idea that she would play an active role in Chris and Carol's experience.

On April 21, after seven months of stressful waiting, Chris found out, through a set



Linda Greaves gave Chris Hagan the gift of life with her son John's heart.

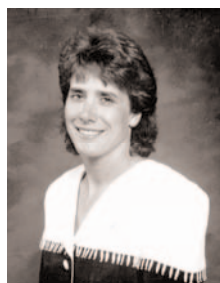
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NKF National Kidney Foundation
Making Lives Better


editor's desk



Beverly Kirkpatrick

It is hard to believe that summer is coming to an end, kids are getting ready to go back to school, and we are all trying to get back into some kind of routine again. This is the time of year when the editorial staff takes a look at what we've brought to our readers over the years and what we should include for the coming year. This issue of *Chronicles* is a little different in content from the content of past issues. We have concentrated more on psychosocial issues and less on medical topics.

Having worked in the area of transplant for 19 years, I'm always amazed that we have so much to talk about. Transplant is a small world in which incredible changes and advances occur all the time. As always, we want to hear from our readers. Let us know if we haven't covered a topic of interest to you.

The transAction Council will once again be offering an educational workshop, in conjunction with the NKF Annual Meeting this November in Miami. Look for details inside this issue. Hope to see you there! 

*Beverly Kirkpatrick
for the Editorial Board*

Transplant Chronicles

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Heart and Soul

continued from page 1

of unusual circumstances, that he would receive a heart. Shortly before Carol was ready to leave the office, she received a phone call from Linda. Linda's son, John Greaves, had been in a motorcycle accident seven days earlier and was declared brain dead. John, a 27-year-old machinist and avid motorcyclist, had been struck by a car after being thrown off his bike one evening. Ironically, the emergency technicians who cared for John were part of Chris Hagan's squad. Linda stood vigil at his room for over a week praying for his recovery, but to no avail.


A transplant can't take place without a donor, and Linda Greaves realized this when she generously gave the gift of life. Linda had never met Chris Hagan. But even in her grief, she immediately thought of him and hoped that he could receive John's heart. John had recently decided to be an organ donor by having it marked on his driver's license when it was renewed. Carol confirmed that Chris had the same blood type as John, meaning they might be a match, and she called Chris to tell him. Chris was taking a late afternoon nap and was awakened by her phone call. He was stunned by the news. He immediately started calling members of his family, and then he and his kids began frantically packing for his stay in the hospital.

Chris and John were indeed a match, and within a week, Chris was out of the hospital with

his new heart. Chris met Linda Greaves soon after the surgery, and although this was his first time meeting with her, he felt he had known her for much longer. Chris has since met Linda's daughter, Janice, and plans to meet her son, Jim. While Chris received John Greaves' heart, his liver, kidneys and corneas went to other recipients.

Linda Greaves says that organ donation "gives a tragedy meaning." She thought that if there was one good thing that could come out of her grief, it had to be done. She encourages more people to follow suit and try to make the best of terrible circumstances.

This experience has undoubtedly changed Chris' perspective on life. He says, "I live every day like it's my last because you never know what could happen." He is eagerly awaiting being able to return to work and to his post as a volunteer firefighter; he'll be out of service for almost a year, until he can lift again. However, that doesn't mean he's sitting around passing time. Chris is involved with organ donation awareness activities, such as passing out materials at fire company fairs. He also spends time with the Greaves, to whom he is grateful for turning their tragedy into his triumph. He acknowledges that if he were part of the donor family, he would want to know the recipients.

Chris has some advice to offer patients on the transplant waiting list. He says, "Hang in there. If things are meant to be, they will." They were certainly meant to be for Chris Hagan. 

Help Save the



The organ and tissue donation stamp was unveiled one year ago at the 1998 U.S. Transplant Games. However, this year's postage-rate increase put the stamp out of circulation. The U.S. Postal Service currently has no plans to reprint the stamp at the new postage rate. To voice your concerns and opinions on this matter, you may try writing to:

William J. Henderson
Postmaster General
U. S. Postal Services Headquarters
475 L'Enfant Plaza SW
Washington, DC 20260-0010

Setting Limits

by Robin Stone, MSW, LICSW

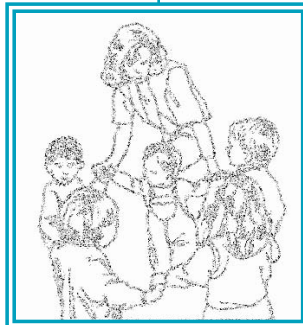
Setting limits for chronically ill children or children who have received a transplant can be a huge challenge and can raise many issues for parents, including feelings of guilt. However, parents have to realize that these children need limits as much as any other children. It would be a disservice to any child not to provide the safety that comes from setting limits.

Limits are boundaries that we all live with in our daily lives. Schedules, routines and structure all set limits and help to provide a safe environment that allows your child to reach his or her maximum potential. It is our job as parents to love our children, keep them safe, advocate for them and guide them toward good behavior. Setting limits around undesirable and antisocial behaviors can help your child understand parental and societal expectations of acceptable behavior.

Parents can begin the lifelong process of limit setting when their children are infants. Sticking to a set schedule helps infants feel safe and lets them know their basic needs—including being fed, changed, cuddled and allowed to sleep—will be met. Often, the routine you have established can continue even if your child needs to be hospitalized. Write down your baby's schedule, post it in the hospital room and ask medical care providers to follow it when they can. As your child grows, a schedule will continue to provide structure and safety, and you should stick to one whenever possible—in any setting.

Setting limits is part of the job description of being a responsible parent and does not have to involve screaming or anger. If your child questions the limits you set, use a firm voice, make a clear statement at your child's eye level and explain why the limit is important. For example, "I do not like it when you hit your brother because you could hurt him." It is also important to identify bad behaviors in a way that doesn't make your child feel like a bad person. "I do not like it when you pull your sister's hair. That is a bad behavior that hurts your sister." This avoids sending the message to your child that he or she is bad, but rather stresses that the behavior is unacceptable.


Children will test limits, so limit setting requires constant reinforcement. You may need to set the limit many times before your child responds. "Time outs" can be a helpful tool. These allow children a few moments (one minute per year for their age) to pull themselves together emotionally. Following the time out period, discuss why the limit is there and why it is important. These discussions show that you respect your child and trust his or her ability to maintain the limit. This respect will help build your child's self-esteem.



Parents with a chronically ill child will need to be flexible, depending on the child's current medical condition. You should talk with your child's medical team and have a good understanding of any issues brought on by your child's condition, including any behavioral side effects of medications. During times of acute illness, it may be harder to maintain schedules. As a parent, you will need to modify and adjust limits accordingly, but do not remove them. Work with your child's medical team to come up with appropriate behavioral expectations.

Parents also have the responsibility to understand when their children are not at their best because they are tired, hungry, stressed or feeling sick. Any of these can get in the way of their ability to adhere to limits. Bad days are part of life, even when your child is medically at his or her best. It is inevitable that there will be days when it feels like limits and scheduling have "gone out the window."

The work of consistently setting limits will pay off over time as your child grows into a caring, responsible person. Consistent limit setting is difficult, but the rewards for your hard work can be great for both you and your child.

Robin Stone, MSW, LICSW, is a liver transplant and bone marrow transplant social worker at Children's Hospital in Boston. 

ask the pharmacist



What Types of Immunosuppressive Medications Are Available to Transplant Recipients?

by Janet Karlix, PhD

One of the greatest advances in transplantation over the last several decades has been the introduction of more immunosuppressive (anti-rejection) drugs to decrease the rejection of transplanted organs. This movement began in 1983 with the approval of cyclosporine (Sandimmune®), and continued into the 1990s, when many new drugs were approved. The number of drugs available to prevent graft (organ transplant) rejection has increased particularly in the past five years.

Graft rejection is a very complex process that varies from person to person. Therefore, combinations of drugs, or “immunosuppressive cocktails,” are often used to stop the recipient’s body from attacking the transplanted organ. Tacrolimus (Prograf®), the first anti-rejection drug introduced in the 1990s, works similarly to cyclosporine in protecting the transplanted organ from rejection. Mycophenolate mofetil (Cellcept®) was introduced in the mid-1990s. It is similar to azathioprine (Immunan®) in the way it works, but it targets a slightly different chemical and may be

more specific for blocking white blood cell function. Mycophenolate mofetil is very effective, however it sometimes causes stomach pains. Combining it with other drugs in your immunosuppressive cocktail may be an option, especially if you have an unexpected complication.

A new class of medication, interleukin 2 receptor blockers, was approved in spring of 1998. There are two types of interleukin 2 receptor blockers (Simulect® and Zenapax®), which are both given through your veins and have very few side effects. These agents are given during the very first part of your transplant surgery. It appears that both help prevent acute graft rejection. Here’s how they work:

- When white blood cells become activated against the graft, they change their form and make different types of proteins on the outside of the cell.
- These various proteins act in different ways. One such protein found on activated white blood cells is called the interleukin 2 receptor. The interleukin 2 receptor binds to white blood cell “food,” or interleukin 2, which allows more cells to become activated and attack the graft.
- The interleukin 2 receptor blockers stop the ability of the cell to multiply and attack the graft.

In the future, other drugs, including rapamycin or sirolimus (Rappimmune®), may become available to prolong your transplanted organ’s life. These should be approved by the Food and Drug Administration within the next year. Rapamycin’s exact role in the immunosuppressive cocktail is still under investigation at this time.

You have received a second chance at life by getting a transplanted organ. It is very important that you take your medications as prescribed. Do not stop taking your medications at any time unless you have discussed it with your transplant doctor. If at some point you have some unexpected complications from your immunosuppressive medications, your doctor may be able to prescribe alternative medications. **Tc**

Save the Date!

The transAction Council’s annual educational program, held in conjunction with the NKF Annual Meeting, will be on November 6 in Miami, Florida. Some of the topics for this year’s program include medical challenges after transplantation, nutrition, coping, organ and tissue donation, self empowerment and exercise.

For more information, call the National Kidney Foundation at (800) 622-9010.

keeping fit



Psychic Energy

by Vanessa A. Underwood, BS, AFAA, ACE

You should pray to have a sound mind in a sound body," wrote the Roman poet Juvenal nearly two thousand years ago. Whether for an athletic competition, a presentation or another of life's events, the first step toward achieving peak performance is preparing both your mind and your body for action. Psychologists say that the trick to harnessing psychic energy is to reach a state of readiness prior to your event, without becoming overly nervous and anxious.

As an athlete, I like to "walk" the playing field before I compete. By this I mean that I like to familiarize myself with where the event is taking place. I feel more comfortable and it is easier to visualize myself performing the event before I actually do it. This mental training goes way beyond sports. Whether a teacher, CEO, musician or athlete, everyone's goal is to achieve peak performance.

Today, with technology and tools for viewing the brain in action, it was found that this age-old wisdom is actually rooted in biology. A crucial aspect of peak performance—a state of intense concentration—is associated with changes in brain activity. Each side of the brain specializes in certain activities; the left brain is more involved in language and analytical skills and the right brain is focused on spatial and pattern recognition. During peak performance, the mind relaxes its analytical side. The result is the trancelike "flow" state that athletes report experiencing when they are intensely engaged in their events. Being able to enter this deep concentration is key to developing an athletic skill, even though people are not always aware of it.


Athletes can learn to bring their minds into a flow state by going through a pre-set mental routine with each shot, jump, stroke, serve or action. For example, "plant feet, arm up, breathe deep, focus, release." A fixed routine is also very important off the playing field. Between moments of peak performance, an athlete must make the most of down time. Athletes must train to savor a winning move, dismiss an error, or relax and psyche up for the next event or play.

Whether you are an athlete or an amateur, a critical component of preparing for peak performance is letting the automatic process of the mind take over and move the muscles. When you are beginning to learn a new task, many areas of your brain are working at the same time—you are literally scatterbrained. As you become more proficient at a task, your brain becomes more focused directly on the movements needed for the task. Physically moving muscles is not the only way to practice a new skill. Simply imagining the movement can also bring enhanced performance. Mental rehearsal of an action puts the mind

through a workout. Imagining can help people prepare for peak performance by anticipating successful strategies or potential pitfalls.

Image banks or mind movies are key in learning to perform at your peak. These are visual movies that you can play in your mind to relax, get psyched up and build confidence. When an athlete is preparing for action, heart rate and blood flow increase, the body floods with adrenalin and the breathing process speeds up. If this happens, you may find yourself unfocused, out of control and feeling as though you want to run away! This is why you must learn to harness your energy or bring

yourself to the peak of readiness without going over the edge and psyching yourself out!

It has been said of athletes that there is not much difference in performance based on physical talent or training, and that it eventually comes down to the ability to use their minds. "Focus only on those things you can control," says sports psychologist Shane Murphy.¹ You must be in the zone—a state of total attention to the task at hand. So remember, as you lie in bed at night or have some down time, visualize yourself performing your event, do this over and over in your mind, and you will find that your performance will improve markedly! 



Mental preparedness can help you reach your peak performance.

1. Science & Society, U.S. News & World Report, 1996.

Walt Disney World® to Host 2000 U.S. Transplant Games

Whether or not you've participated in the U.S. Transplant Games in past years, the 2000 Games promise to be an experience unlike any other. The National Kidney Foundation has announced that *Disney's Wide World of Sports™* Complex has been selected as the host site for the 2000 U.S. Transplant Games, to be held June 21-24, 2000.

Once again, athletes who have received life-saving organ transplants of every type—kidney, liver, heart, lung, pancreas and bone marrow, will compete in Olympic-style events in 13 different sports including track and field, swimming, tennis, basketball, cycling and golf. Presented biennially by the National Kidney Foundation since 1990 and sponsored by Novartis Pharmaceuticals Corporation, the U.S. Transplant Games draw participants from all over the country who are organized into 50 state teams.

“More than 64,000 Americans are currently on the waiting list for life-saving organ transplants and ten people die each day while waiting. The Transplant Games showcase the success of transplantation, demonstrating the life-saving power of organ donation,” says Representative Karen L. Thurman (D-FL), whose husband is a kidney transplant recipient.


According to Fred Herbert of Ocala, National Kidney Foundation vice chairman, “The Transplant Games were poised for a first-class facility and we are thrilled to partner with *Disney's Wide World of Sports™*—the most inclusive state-of-the-art sports complex in the

country. We hope our spirited competition will slam home the message that every American should consider becoming an organ donor.”



Attendance at the 2000 U.S. Transplant Games is expected to surpass the record-breaking participation in the 1998 Games of 5,000 people including transplant athletes, their families and friends and the families of organ donors. In addition to athletic competition, the Games will feature four days of special workshops for donor families and an educational program for professionals involved in transplantation. A 5K Road Race open to the Orlando community will be held at Epcot Center during the four-day event.

“This is a tremendous opportunity for us to partner with the National Kidney Foundation,” says Mike Millay, director of events for Disney Sports Attractions, Inc. “The Transplant Games is a vivid example of how athletes celebrate life by overcoming obstacles through sports achievement.”

For more information on the 2000 U.S. Transplant Games, contact your local NKF affiliate or call the NKF National Office at (800) 622-9010. You can also visit www.kidney.org/recips/athletics/ for the latest on the Games and transplant athletics programs. 

Are We Missing You?

If you or someone you know would like to receive a free home subscription to *Transplant Chronicles*, send your request to *Transplant Chronicles*, National Kidney Foundation, 30 East 33rd Street, New York, NY 10016, or call (800) 622-9010.

How Long?

by Maurie Ferriter

The words “how long” usually start the two sentences many transplant recipients ask at some point during their transplant experience:

- How long will my transplant last?
- How long will I live?

These may seem like very simple questions, but there are no simple answers. In an attempt to come up with answers, some people look at statistics and averages. Others come to their conclusions through word of mouth.

Most health care team members will try to determine survival rates using statistics and averages. There are two ways to consider transplant survival statistics. The first is by looking at the survival rate or mortality rate of the patient. This information is pretty straightforward as long as the transplant center can keep in touch with patients. The criteria for calculating these rates is whether a person is alive or not one year after transplant; the status of the transplanted organ does not factor into these results. Let's assume that 150 people are transplanted at a given center in one year. If 147 recipients are alive one year later, the one-year patient survival rate for that center is 98 percent. The one-year mortality rate for the center is two percent. ($147 \div 150 = .98$)


The survival rate of the transplant (graft) itself is the second way transplant statistics are presented. If a transplanted organ is working one year after the operation, the transplant is considered to be successful. Follow-up data is kept by the transplant center for as long as the organ is working. It is then possible to figure five-year, ten-year and continuing graft survival rates.

When the results from each transplant center are lumped together, national data can be compiled. This is where medical professionals get the answers to questions about survival. There are several sources of this data. The United Network for Organ Sharing (UNOS) publishes patient and graft survival rates for every transplant center in the United States. These rates are adjusted for several variables, called case mix, such as other diseases the person had at the time of transplant, like diabetes. The UNOS data is presented in terms of expected-to-observed rates. Expected rates for each center are calculated based on the case mix data. The observed rates are the actual

performance of the transplant center in patient and graft survival. The two figures are then compared to each other, resulting in fairly easy-to-understand rates for each center. You may access this information on the UNOS website at www.unos.org. Kidney-specific data are also published by the United States Renal Data System (USRDS), which collects kidney transplant data over time for all United States transplant centers. USRDS also looks at patient survival or mortality over time. You can access their website at www.med.umich.edu/usrds.

Medical professionals and statisticians look at these numbers and are able to determine the average life expectancy of patients, average graft survival and other numeric values. These values have changed significantly over the years. For example, kidney one-year graft survival rates in the 1960s and early 1970s were 50 percent at one year. Now the first-year graft survival rates are over 90 percent for cadaveric kidneys and higher for living donor kidneys. Heart and liver one-year success rates were well below 50 percent when they began transplanting those organs and now are also much higher.

No one can tell you exactly how long you will live or how long your transplant will last. However, people can get educated guesses based on statistics and averages. Just remember that an average is between two extremes. This is why you will hear some people talk about keeping an organ for two years and others for 10 years. You will also hear about people who rejected their first organ in three months, were re-transplanted and have had their second organ for many years. This kind of word-of-mouth research usually uncovers the fact that for every rule there is an exception.

There are many other variables that need to be looked at when trying to answer these two simple questions on “how long,” including advances in immunosuppressive drug therapy, progression of the primary disease that caused the organ failure in the first place and medical issues in long-term chronic rejection. Another significant factor is how well we, as organ recipients, keep our part of the bargain. Keeping medical appointments, taking medications on a regular basis and making lifestyle changes are things that we should do to maximize our chances of keeping a transplant for a lifetime. 

Transplant News Digest

From the editors of *Transplant News*

Organ donation increased 5.6 percent in U.S. in 1998, UNOS reports; first noticeable increase since 1995

by Jim Warren, editor and publisher

For the first time since 1995, the number of cadaveric organ donors in the U.S. showed a noticeable increase in 1998 — 5.6 percent — according to preliminary data released by the Department of Health and Human Services and the United Network for Organ Sharing (UNOS). The agencies reported there were 5,791 solid organ donors in 1998, an increase of 312 over 1997. In addition, the number of living donors increased to 4,122, up from 3,626 in 1997. The total number of donors combined increased to 9,913, compared to 9,073 in 1998.

The number of cornea donors also showed an increase of almost seven percent over 1997, according to the Eye Bank Association of America (EBAA). A total of 48,081 corneas were donated in 1998, compared to 44,917 in 1997, the EBAA reported. As in 1997, the Central Florida Lions Eye and Tissue Bank in Tampa performed the most cornea transplants in the U.S. — 2,479, an increase of 333 over 1997. The Donor Network of Arizona in Phoenix moved from fifth to second, transplanting 1,824 corneas in 1998, an increase of 448 over 1997.

The record number of cadaveric and living organ donations resulted in 20,961 transplants, which is the first time the number has exceeded 20,000. UNOS reported that preliminary figures showed the following number of transplants by organ in 1998: kidney/pancreas-965; kidney-11,990 (4,016 from living donors); pancreas-253; liver-4,450; heart-2,340; heart/lung-45; lung-849; intestine-69.

The increase in organ donations was due mainly to an increase in donors 60 years or older — (706 in 1997 to 782 in 1998), and an increase in donors ages 40-59 (1,781 in 1997 to 1,952 in 1998).

Although it is impossible to attribute the increase to any single reason, the government used the information to tout the Clinton administration's national donor initiative, launched in 1997, and the regulation implemented last year requiring hospitals that

participate in Medicare to routinely inform their organ procurement organization of all hospital deaths and near deaths.

“An increase in donations gives us added incentive to find out what works and replicate it across the country,” said Claude Earl Fox, MD, administrator of the Health and Resources and Services Administration (HRSA), the agency which oversees the U.S. organ donation and transplantation system. “Our plan is to fund creative, collaborative programs with rigorous evaluations so we'll know where to focus future efforts.”

Here are a number of 1998 organ donation trends reported by UNOS:

- The number of Caucasian and Hispanic donors increased substantially (6.6 percent and 7.8 percent respectively), but the number of African-American donors remained relatively unchanged and the number of Asian donors decreased 8.4 percent (1997 to 1998).
- Female donors increased by 8.3 percent (2,232 to 2,417) and male donors increased by 3.8 percent (3,247 to 3,371).
- While donor numbers vary considerably by month, May had the largest number of donors in 1998 with 524. Over the last three years, the highest monthly total of donors has occurred in May.
- The central region of the U.S. had the largest increase in donors; UNOS Region 10 (Michigan, Indiana and Ohio) had the largest increase with 13 percent. UNOS Region 8 (Iowa, Missouri, Nebraska, Kansas, Wyoming and Colorado) and Region 4 (Oklahoma and Texas) were not far behind with 11.3 percent and 9.1 percent increases respectively.

Despite the increase, the waiting list for organs continues to increase dramatically. UNOS reported the waiting list registrations had increased from 56,716 in 1997 to 74,423 at the end of 1998. Conversely, the EBAA reported the

number of people in the U.S. waiting for a cornea transplant at the end of 1998 was 1,863, a decrease of 28 percent compared to the end of 1997.

Pennsylvania to launch pilot program offering \$300 stipend to cover funeral expenses of families of organ donors

In a plan that is already stirring up ethical questions over the “sale of organs,” Pennsylvania is about to launch a pilot program that will offer a \$300 stipend to each family of organ and tissue donors to cover funeral expenses.

The stipend, which is expected to begin early next year, will not be paid directly to the relatives of the deceased donor, but will go to the funeral home. The pilot program, which will run for three years, will be monitored by medical ethicists from the University of Pittsburgh and University of Pennsylvania to see if it affects donation rates.

“This has been touted as money for buying organs and that is absolutely untrue,” Howard Nathan, executive director of the Gift of Life Donor Program (formerly the Delaware Valley Transplant Program) in Philadelphia, told *Transplant News*. “This is a voluntary death benefit for people who have given the gift of life. It is not an incentive per se because the money is nowhere near enough to be an incentive. It is a way of saying thank you informally to Pennsylvania residents who donate.”

The pilot program, which was funded by donations from Pennsylvanians renewing their driver’s licenses, will be administered by the state Department of Health. Nathan expects there will be about \$120,000 available early next year.

“I’m guessing we will make payments to about 400 donors,” Nathan said. “The idea is that it will be an automatic part of the normal consent process as long as the donor family tells us who the funeral home is. The credit will then be applied to the family’s funeral expenses.”

Once details are finalized, the state will sign contracts with Pennsylvania’s two organ procurement organizations (OPOs) — the Gift of Life Program and the Center for Organ Research and Education (CORE) in Pittsburgh — to administer the pilot program. The two OPOs, however, are quick to point out the payment scheme was not their idea, but that of legislators.

Whether the program will result in increased organ donations is also debatable. “The question on many people’s minds is, ‘Will incentives increase donation?’” Brian Broznick, CORE

executive director, told the *Philadelphia Inquirer*. “I’m not sure this amount of money is enough to test that theory.”

Nevertheless, Broznick feels the arguments for trying the program outweigh the moral and ethical arguments against it. “Imagine a young woman who just lost her husband and who, through organ donation, provided life to seven people,” he said. “She tells you she doesn’t have enough money to bury him and you’re supposed to say, ‘Sorry, we can’t help you.’”

In one of the few studies conducted on the public’s attitudes about financial compensation for donation, the National Kidney Foundation (NKF) found in 1991 through a nationwide telephone poll that 49 percent of Americans favored some form of compensation, 42 percent opposed and nine percent were undecided.

Based on those numbers, Dolph Chianchiano, NKF’s director of scientific and public policy, stated that the NKF Public Policy Office supports the Pennsylvania pilot. “Our position is that this should be tested to see whether it serves a purpose,” he said. “We are not talking about the highest bidder, or that there should be a market for organs. We are talking about a limited, specified amount of money paid to a third party.”

Medicare finally to pay for pancreas transplants done simultaneously with and after renal transplants

After years of persistent lobbying by transplant surgeons and the diabetic community, the Health Care Financing Administration (HCFA) has decided to provide Medicare coverage for pancreas transplants performed simultaneously with or after kidney transplants. The coverage will begin on or after July 1, 1999.

“I first started to press the government to cover pancreas and kidney/pancreas transplants in 1991 when I was president of the American Society of Transplant Surgeons,” said David Sutherland, MD, director of pancreas and kidney transplant surgery at Fairview University Hospital in Minneapolis. “The coverage will do away with some inequities that have existed in the past for patients who needed a pancreas transplant. It was kind of hard for a patient in one bed to be denied a pancreas transplant while another with Blue Cross coverage got one.”

There is still a bit of work to be done, however, Sutherland said. “The new coverage takes care of people over 65 but not those who don’t have kidney failure,” he said. “I hope we can get that

taken care of in the future.”

For additional information, contact Deborah Butterfield, executive director, Insulin-Free World Foundation, phone: (314) 727-4246, fax: (314) 862-3713, e-mail: dbutterfield@bridge.com, website: www.insulin-free.org.

Rep. Thurman introduces legislation to reduce financial disincentives for living donors

Representative Karen L. Thurman (D-FL) introduced legislation in the House of Representatives aimed at increasing the number of Americans willing to be living organ donors by reducing financial disincentives.

H.R. 1857, the Living Organ Donation Incentives Act of 1999, introduced by Thurman on May 18, would amend the Family and Medical Leave Act (FMLA) to allow living organ donation to qualify as a reason for taking time off from work. In addition, the legislation would allow the Secretary of Health and Human Services (HHS) to develop a grant program to aid individuals with the high costs associated with living donation.

“We know that living donors are faced with a loss of income due to time away from work needed for evaluation, surgery and recovery,” said Thurman in a statement when she introduced the bill. “This often makes it difficult to pay rents, mortgages and other bills. There are also costs associated with their donation which are not reimbursable by Medicare, for example, travel, lodging, meals and childcare. If we really want to increase the number of organ donations, we need to tear down some of these barriers.”

The FMLA currently covers employers in the private sector with 50 or more employees, and most public employees at the federal, state and local level. Under FMLA, employers are required to grant 12 weeks unpaid leave in any one calendar year to parents to care for their newborn or newly adopted child or a seriously ill child, spouse or parent, and to temporarily disabled workers. The new provision would specify that living organ donation would qualify as a reason to take leave.

H.R. 1857, which has 14 co-sponsors, also contains a provision that would increase the payment amount by 2.9 percent for renal dialysis services under Medicare. Thurman noted the current rate has remained essentially unchanged since 1983, and that the Medicare Payment Advisory Commission recently expressed concern that quality of dialysis services may decline if the rate is not increased.

Kids who need liver transplants often die because pediatric organs go to adults, Pitt researchers charge

As the nationwide demand for liver transplants has increased, more adults than children are receiving pediatric livers. And as a result, more youngsters are languishing—and dying—on waiting lists, according to a study done by researchers at Pittsburgh’s Children’s Hospital (PCH).

Over the past eight years, two-thirds of livers donated by children were transplanted into adults, in part because of a system of allocating organs that stacks the deck against children, said Jorge Reyes, MD, chief of pediatric transplantation at PCH and one of the study’s authors. Reyes and colleagues found that 4,299 of 6,028 livers from children were implanted in adults between 1991 and 1998, even as surgeons scrambled to find adult livers to cut down to fit children.

Meanwhile, the number of children with chronic liver disease or in acute liver failure on transplant waiting lists keeps growing. According to another study done last year at the Medical University of South Carolina, 1,285 youngsters were awaiting transplantation in 1996 compared to 768 in 1990, and 75 to 80 children die each year before suitable livers can be found.

Reyes favors a national system for distributing children’s livers to kids first, based on medical need. A similar allocation system is used in Europe, whereas in the United States, organs are allocated locally to those in greatest need, with no distinction made between adults and children. Not everyone agrees that children deserve first consideration, however. Some surgeons argue that extending a child’s life is not inherently of greater value than extending that of a young or middle-age adult.

Arguments about life worth aside, the real issue may be that liver disease is fundamentally different in children and adults. For youngsters, liver failure tends to afflict either infants and toddlers or teens and progress rapidly, making transplantation an urgent necessity. In adults, disease onset often is more gradual and survival is usually prolonged.

“The reality is, in my area, children can’t live long enough to rise high enough on the waiting lists to get transplants,” said Paul Colombani, MD, chief of pediatric surgery at Johns Hopkins

Hospital in Baltimore. “There somehow has to be a way to balance the playing field for these kids.”

Data on pediatric liver transplants is currently being analyzed to determine if there is a medical rationale for giving sick children preferential claim on pediatric livers. Last January, after reviewing extensive data, UNOS changed its policies to give teens needing heart transplants preferential access to teen hearts. Evidence presented in May at the American Society of Transplantation annual meeting in Chicago suggests a good case can be made for a similar policy on livers. A study done at the University of California at Los Angeles found that children who receive pediatric livers do better than youngsters given livers from adults. Conversely, adults who receive livers from kids derive less benefit from the pediatric organs.

World's second heart-liver-kidney transplant performed at University of Chicago Hospitals

Transplant surgeons at the University of Chicago (UC) Hospitals performed the world's second heart-liver-kidney transplant in a 14-hour operation on May 7 on patient Kent Slater, age 64, of Rockford, Michigan.

Fewer than 30 triple transplants of various kinds have been performed over the years in the United States. The heart-liver-kidney triad requires an especially rare alignment of the right patient, a suitable donor, and a surgical team experienced in the complexities of many different procedures. Thomas Starzl, MD, retired head of transplant surgery at the University of Pittsburgh Medical Center, performed the only other heart-liver-kidney operation in 1989. His patient, a 26-year-old woman, was considered a qualified success; she died of aggressive kidney disease four months after the operation.

Starzl praised the Chicago team's accomplishment. “It's a big deal. Every stage of the enterprise is more complex than in a normal transplant,” he said.

Slater's operation was a veritable relay race between surgical specialists. Valluvan Jeevanandam, MD, transplanted the heart first, then passed the baton to the liver and kidney teams, both headed by Michael Millis, MD. The liver transplant was probably the riskiest part of the operation, since the solution used to preserve the liver prior to transplantation contains potassium, which can be deadly even to a healthy heart if not flushed out properly. “Adding

a kidney adds time, but not much more complexity,” said Millis.

Tissue-engineered kidney passes test in dogs; human trials on horizon

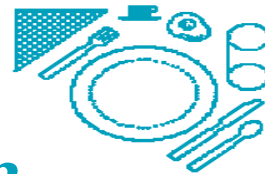
A tissue-engineered kidney tested in dogs in acute kidney failure successfully replaced all renal functions, University of Michigan researchers report.

“These results, upon FDA approval, set the stage to start clinical trials as early as the end of this year, perhaps in patients who develop ischemia or nephrotoxic acute renal failure,” writes lead author David Humes, MD in an article appearing in the May 1999 issue of *Nature Biotechnology*.

The kidney developed by Humes and colleagues is a renal-tubule-assist device that utilizes proximal tubule cells from pigs. Unlike hemodialysis, which can perform only some renal functions—removing excess water and soluble wastes—the tissue-engineered kidney also is capable of replacing transport, metabolic and endocrine functions of kidney tubular cells. When the device was connected to the dogs in series with a hemofiltration unit, the pig cells remained viable and well-differentiated. Ammonia excretion rates were 10-20 percent of normal, and plasma glutathione values were improved, the authors report.

The result of this study suggest “a functional capacity of the proximal tubule device ranging from 10-50 percent of that of the normal kidney,” notes Clark Colton, PhD of the Massachusetts Institute of Technology in Cambridge, adding that the system seems ready for human testing.

eating right



What is the Best Diet for Me?

by Becky Weseman, RD, CNSD, LMNT


With all the attention the media has given to various diets recently, have you become increasingly confused about which diet is best for you? If your answer is yes, don't feel bad. Even as a health care professional, I have had my own questions! Is there a better way to eat for well-balanced nutrition and improved health? Should our diets be "high carbohydrate and no fat" or "high protein and low carbohydrate," or should they be "all foods in moderation"?

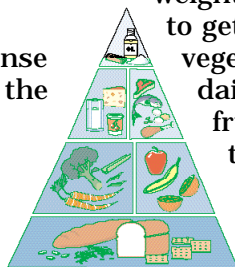
I have considered all aspects of these questions and concluded that common sense is the answer to how to eat. For example, the high-carbohydrate and no-fat diet has led many people to eat products such as fat-free cookies and pastries, frozen yogurt and low-fat candies. Though they are low in fat, all of these foods have calories, and eating them in excess has caused many Americans to gain weight.

In addition, eating too many of these foods could lead to hyperinsulinemia, or high levels of insulin in the blood. After eating carbohydrates, it is natural for your body to produce insulin to control your blood sugar. These high levels of insulin in the blood may lead to an increased risk of cardiovascular disease. So eating carbohydrates without a balance of protein in the diet, while also increasing calorie intake, may actually go against what you are trying to accomplish. Nevertheless, it is essential to eat some carbohydrates; a rise in blood sugar and insulin production allows needed sugar to enter your cells. This gives you energy and keeps you feeling good.

Consider the high-protein, low-carbohydrate diet for a moment. Many meats are high in fat and saturated fat. Many experts would agree that a high-saturated fat intake is not healthy for the heart. This diet has been promoted for losing weight. However, it may lead to potential harm and lack of energy for many people. Also, without consuming grains, fruits and vegetables that contain beta carotene and antioxidants like vitamins C, E and A, you may be missing out on

protective dietary factors in the fight against diseases such as heart disease and cancer.

So what diet should you choose and what is a balanced diet? Remember the age-old saying "all foods in moderation"? Common sense tells us to eat a variety of foods from all food groups. However, many people feel that the common sense, well-balanced diet seems boring, and that it's not a magic bullet or an easy answer to weight loss or improved health. Our challenge is to get excited about eating a variety of fruits, vegetables, grains, and low-fat meats and dairy products! Why not try a vegetable or fruit in the grocery store produce section that you don't typically choose? Whether you're a transplant recipient or not, this is a healthy way to eat. Depending on how you look at it, eating a variety of foods in moderation can be the tastiest and easiest way to stick to a well-balanced diet! 



MEXICAN RICE AND BEAN SALAD

Try this recipe and add some variety to your diet!

- 2 cups cooked rice (cold)**
- 1 chicken breast, cooked and chopped**
- 1 can kidney beans, drained and rinsed**
- 1 can whole kernel corn, drained**
- 1/4 cup Italian dressing (regular or fat-free)**
- 2 sliced green onions, including tops**
- 1/2 cup picante sauce**
- 1 teaspoon cumin**
- 1 teaspoon cilantro**
- pepper or hot sauce to taste**

Combine all ingredients and chill before serving. Enjoy!

My New Heart

by Becky Tarkoff

The 2000 U.S. Transplant Games are less than one year away (see page seven)! In the coming year, Transplant Chronicles will celebrate the spirit of the Games and transplant athletics by highlighting the accomplishments of transplant athletes. We'll see you at the Games!

Walking into the gray-tiled bathroom, I was greeted with the scent of hospital antiseptic. I closed the door behind me and took a deep breath. This was it. As I reached for the blue hospital gown, I caught a glimpse of myself in the small mirror above the sink. This is the last time I'll see myself without a scar, I thought. When I wake up tomorrow—if I wake up tomorrow—I'll have a long cut down the middle of my chest. I'll have someone else's heart beating inside of me.

The doctors said that I had idiopathic cardiomyopathy, which meant that my heart muscle was getting weaker and weaker, but they didn't know why. My only chance for survival was to let go of this heart and get a new one.

I slipped the hospital gown over my head and struggled with the ties in the back. After gathering my clothes, I opened the bathroom door and returned to the hospital room where my husband, Dan, sat waiting. We knew that a team of doctors had flown to Alabama to get my new heart, but we didn't know how long we would wait before they returned to Pittsburgh. Surgery couldn't start until the heart had arrived.

I thought of the donor and her family. While I was about to get another chance at life, they had just experienced a terrible tragedy. Yet, in their pain, these people had agreed to give their loved one's heart to a stranger, to me. I could think of no greater gift. Thinking of my donor's death was too much right now, so I pushed the thoughts



Dan, Becky and Sarah attended the 1998 U.S. Transplant Games in Columbus. Becky is gearing up for the 2000 Games.

away. Knowing that I would live only because someone else had died was an unsettling feeling.

The wait stretched on and on. I wondered how my sweet two-year-old, Sarah, was doing. She was staying with some friends that night. Dan and I were too frightened to talk about the surgery, and everything else seemed insignificant. Finally, around

midnight, a nurse came into my room. "They're ready for you," she said.

I moved onto a stretcher, and an aide wheeled me down the hospital corridors. Dan walked next to us, holding my hand. We arrived at the operating room. Dan leaned over and kissed me. "I love you," he said. I looked into his eyes and saw that they were filled with fear. "I love you, too," I said. I wonder if I'll ever see you and Sarah again, I thought. I waved goodbye as they wheeled me inside.

Opening my eyes, I looked around the small white room. Tubes were hanging everywhere, and they all seemed to be coming into my body. As I looked around, I realized that I was in ICU. I had made it through surgery. I was alive! I saw my mom and smiled. "You're awake!" she said happily. She had flown to Pittsburgh from Oklahoma to be with me after the surgery.

I tried to talk, but no words came out. I pointed to my throat and frowned, indicating that I didn't understand why I couldn't speak. "You have a ventilator in," Mom explained. "Wait just a minute." She rummaged through her purse and returned with a pencil and a pad of paper.

I took them from her and, with unsteady hands, I wrote, "I'm so happy." I had never felt such joy. I had another chance to live.



Two weeks had passed since the transplant, and I was still in the hospital recovering from surgery. I was grateful for this gift of life. I felt guilty to feel anything except gratitude. People die every day waiting for transplants. But still, I missed my old heart. Even when it was sick, it had such a soothing beat, not this racing rhythm that seemed so wild and out of control. The doctor had explained that transplanted hearts usually beat faster than normal hearts, particularly in the first months after surgery. I was constantly reminded that this heart, with its rapid rate and stronger beat, was foreign to me.

Perhaps I had never really accepted my illness and the need for this transplant. When the cardiologist first mentioned that I might need a transplant, I had laughed. I was 26 years old with a one-year-old daughter, and I was working part-time as a CPA. My only symptoms were that I seemed to tire too easily, and I felt chest pain when I tried to run. How could I possibly need a heart transplant? Although I grew sicker in the coming months, I continued to deny my illness. Rationally, I knew that I would die without a transplant, but I hadn't fully accepted it.

Over the next few months I grieved the loss of my donor's death as surely as I grieved the loss of my heart. I talked with her spirit, and the pain I felt began to subside. "You've given me this gift, and I want to live my life in a way that honors that gift," I told her. "I feel like your spirit is connected with mine."



Five years later, dressed in my black shorts and black and gold Team Pittsburgh t-shirt, I waited at the starting line for the 100 meter dash finals. I was in Atlanta, Georgia, for the U.S. Transplant Games. Earlier in the day, I had run the preliminaries for the women's age 26 to 39 race, and I had made it to the finals.

I shot away from the starting line and raced down my lane. Out of the corner of my eye, I could see that I appeared to be in the lead. As my feet hit the track and my arms pumped at my sides, I strained to accelerate. I knew

that the last 20 meters were the hardest for me; that was about the time my body was screaming for oxygen, but my heart hadn't yet gotten the message. Because the nerves are cut during a transplant, a transplanted heart is slow to get the message to beat faster during exercise.

The medal ceremony was later that day. As I stood on the podium in the center of the field, the announcer called out, "The gold medal in the women's age 25 to 39 100-meter finals—Becky Tarkoff." As she placed the medal around my neck, I felt my heart pounding with excitement. We had done it. My heart and I had won.

When I returned home, I hung my medal in my bedroom where I could look at it every day. It reminded me of how much this wonderful new heart could do. In the coming months, I realized what I wanted to do with my medal. I wrote the following letter, which the organ procurement agency forwarded for me:

To my donor's family,

It's been several years since your loved one died, but I think of her and you every day. I'm so grateful for the gift of life that she has given me.

I'm healthy, and I'm taking great care of the heart she gave me. I keep quite busy. My husband and I have started a business together, and I work almost full-time there. I'm a Girl Scout leader and a Sunday school teacher, and I help out occasionally at a homeless shelter. I also run, hike, rollerblade and ski.

More than anything else, I'm grateful for the opportunity to see my daughter grow up. She was an adorable toddler when I received my heart and now she's a sweet 10-year-old. Because of your loved one's gift, my daughter has a mom.

I recently participated in the U.S. Transplant Games. I won a gold medal in track and field, but I feel like the medal really belongs to your loved one. I'm sending it as a small symbol of what her gift has meant to me.

You are in my thoughts and in my prayers.

*Love,
Your Heart Recipient*

Rebetron Therapy for Hepatitis C

by Shelley J. Kruse, RN, BSN, CCTC

Hepatitis C has become a serious health concern and is one of the leading causes for adult liver transplantation in the United States. The identification of patients infected with hepatitis C has increased due to the availability of advanced testing methods, proving that the disease has reached near epidemic proportions. At least four times as many Americans are infected with the hepatitis C virus as with the HIV virus. Hepatitis C is a blood-borne virus most commonly transmitted by persons receiving contaminated blood products, getting tattoos or sharing intravenous needles. The way it is transmitted has no impact on how the disease will affect an individual.

Approximately 85 percent of individuals with hepatitis C become chronically infected with the virus. Of these, 20 percent will develop cirrhosis (scarring) of the liver with its related complications and may require transplantation. In addition, one to two percent of those people may develop liver cancer. If the virus is not controlled, the hepatitis C may cause symptoms of fatigue, depression

and excessive itching due to an increase in bile salts, or metabolites, in the blood stream. Once the disease has advanced and cirrhosis has set in, the symptoms may become life threatening.

Patients may experience changes in their quality of life; they may be unable to work or perform daily functions due to extreme fatigue, encephalopathy (changes in the ability to concentrate) and vomiting blood due to the increased pressure in veins around the liver. Most patients have reached the end stage of their liver disease by the time these symptoms occur. The fortunate ones will have been referred to a transplant center to be evaluated as a potential candidate for liver transplantation.

Once transplanted, nearly all patients continue to show evidence of the hepatitis C virus in their bloodstream. Between 20 and 50 percent of patients develop clinical reinfection of the transplanted organ with evidence of hepatitis C, shown by elevated liver enzymes or biopsy. These patients usually have a decreased chance of developing the related complications, and only a few patients require retransplantation for recurrent disease.

In 1991, the Food and Drug Administration (FDA) approved interferon for the treatment of chronic hepatitis C, but it has had limited success, and much research has been focused on other treatment options. In December 1998, the

FDA approved Rebetron (interferon plus ribavirin) for the treatment of hepatitis C. Combination therapy has significantly improved efforts to eradicate the hepatitis C virus in patients prior to transplantation.

Interferon is a human protein that the body makes to defend itself against foreign substances. This is accomplished by

“boosting” the immune system. Interferon is artificially produced and administered as an injection under the skin. Ribavirin is given in conjunction with interferon to fight the hepatitis C virus. The side effects associated with interferon therapy are flu-like symptoms, which are most severe the first few weeks and diminish as time goes on. Suicidal thoughts, attempts and successful suicides have also been associated with interferon therapy. A small percentage of patients treated with interferon have developed thyroid problems that require medical therapy. Ribavirin is toxic to a developing fetus. Therefore, any patient of child-bearing potential must not become pregnant or impregnate a partner while on these medications. Therapy carries risks; you

“Approximately 85 percent of individuals with hepatitis C become chronically infected with the virus. Of these, 20 percent will develop cirrhosis (scarring) of the liver with its related complications and may require transplantation.”



Coverage Available for the Working Disabled

Legislation has been voted on that will allow the disabled to return to work without losing access to health care benefits. The Work Incentives Improvement Act (H.R. 1180) passed the Senate by a 99-0 vote in June. The House Commerce Committee passed the legislation on May 19 with a unanimous voice vote, but it must be still voted on by the House Ways and Means Committee. The legislation would allow disabled individuals to return to work and buy into the Medicaid program. It also provides for rehabilitation, job training and placement services.


Currently, disabled Americans lose their Medicaid coverage if they earn more than \$500 per month. This limitation discourages disabled people from entering the work force.

President Clinton had issued a statement

praising the committee for approving the legislation and urging House Speaker Dennis Hastert (R-IL) and Senate Majority Leader Trent Lott (R-MS) to move the legislation for a floor vote. The president had previously endorsed the legislation during his State of the Union address.



During the Commerce Committee vote, the bill was praised by members of both political parties. However, the bill will face some obstacles when the House Ways and Means Committee considers the legislation. The Committee is concerned about the \$791 million price tag and the fact that the bill does not include an income cap.

For more information on the Work Incentives Improvement Act and how it affects you, contact the NKF Office of Scientific Policy at (800) 889-9559 or visit our public policy webpage at www.kidney.org. 

Rebetron Therapy...

continued from page 16

should discuss these with your physician prior to starting medications.


A new form of slow-release interferons that is injected once a week under the skin, as opposed to the standard interferon injection that is given three times a week, may be available in the future. This therapy is still in clinical trials and has not been approved by the Food and Drug Administration for the treatment of hepatitis C.

Some patients choose herbal combinations as therapy, which are relatively safe agents that may help patients feel better. However, patients need to be aware that these compounds may allow their liver enzymes to return to the normal range in the bloodstream, but they will not get rid of the hepatitis C virus.

Before any treatment begins, patients should have a liver biopsy to confirm that they have hepatitis C and not liver rejection. Once

diagnosed, patients should discuss possible treatment options with their doctor. Due to the higher levels of virus as a result of anti-rejection medications, transplant patients may not have as favorable a response as other patients prior to transplant.

Advances are being made in the treatment of hepatitis C in patients prior to transplantation. Patients who receive Rebetron before their liver disease advances have about a 43 percent chance of getting rid of the virus. More information is needed to establish the effectiveness of medications in patients who have already had liver transplants. It is hoped that as therapies continue to improve, they will have an equally favorable outcome on patients that have been reinfected with the virus following liver transplantation.

Shelley Kruse is a research coordinator who has been involved in clinical studies for hepatitis since 1995. Prior to that she has been a liver transplant nurse coordinator at the University of Nebraska Medical Center for eight years. 

Depression Following Transplantation

by Thomas DiBartolomeo, PhD, ABPP

One thing I learned while going through the organ transplant process is that daily health and survival concerns dominate the lives of transplant patients and their families, which can take their toll. Many patients and family members of patients waiting for a transplant experience anxiety and depression. During the pre-transplant period, anxiety and depression are considered to be reasonable responses to the difficult circumstances of life at the time. Generally, there are services available through transplant programs to help deal with all of the emotions that surface during this time, and participation in these programs is encouraged.

However, after successful transplantation, everyone assumes that life is good once again, and experiencing depression and anxiety at this time is not usually expected or often acknowledged. Everyone would like to believe that the organ recipient is “cured” and that “back to normal” is just around the corner. So why is it that recipients and their families experience periods of depression and anxiety in the months and sometimes years following transplantation?

When one steps back and looks at life through the eyes of a transplant recipient, it's easy to see that there are a number of challenges to face that might result in anxious or depressed feelings. The surprising thing is that some transplant programs do not help patients anticipate these feelings, nor do they even ask about them following discharge from the hospital. Some recipients report feeling alone and somewhat ashamed when these feelings arise.

Transplantation is a complicated, time-consuming, and physically and emotionally draining process for recipients and their families. Big lifestyle adjustments must be made even after returning home with a successful transplant. Recipients are continually coping with significant immune system suppression,


infections, changes in appearance and other health concerns. In addition, we are busy trying to reclaim or reinvent our lives; we are forced to confront the difference between our wishes and the reality of our physical condition.

Our psychological health needs and those of our families are no less important than our physical needs. We must be just as willing to acknowledge and address these needs as we continue on our quest to live healthy lives. Since we are all different, it should not be that surprising that no single treatment approach is a good match for all recipients. For some, continued involvement in support group activities may help, while for others, individual or family counseling may be a better match. Intermittent support over many years may be helpful as different life challenges surface.

Medication can also be an essential part of a plan to address depression and anxiety.

It is now clear to me that we must continue to be our own advocates in these matters if we are interested in quality, not just length, of life. It is important to understand that depression and anxiety are common feelings for recipients and spouses,

and are not a sign of weakness or inadequacy. Your transplant program or primary care physician may be able to direct you to resources in your community to address these feelings. Often, your local mental health association or state psychological association can help find providers that may have some expertise in these issues. Remember, you have worked hard to acquire the opportunity to enjoy living, so take care of yourself during this part of the transplant experience, too.

Dr. DiBartolomeo is the director of child psychology at Phoenix Children's Hospital. A two-time liver transplant recipient, he is also a member of the transAction Council Executive Committee. 

“It is important to understand that depression and anxiety are common feelings for recipients and spouses, and are not a sign of weakness or inadequacy.”

Learning About Our Donor

by Dave Luallin

On February 21, 1998, my wife Lil was taken to surgery shortly after midnight; hours later, she had a new kidney. The surgery had gone very smoothly. After a short time in recovery, Lil was taken to her room. It was at this time I began to make phone calls to family members. I was pretty tired. I'd worked all day and had been up all night, riding an emotional roller coaster. As I sat there, looking at Lil and our three daughters, Lil's mom asked where the kidney had come from. At that point, things overwhelmed me.

I knew that somewhere there was a family going through the most difficult time. While I sat there with my heart intact, another family had just had its heart ripped out. I started crying and I couldn't talk anymore. I knew that I somehow had to thank this family for giving us this gift at such a horrible time. Lil and I have known so many people over the years who have had to bury a child. I was always so thankful that I never had to do it.


By mid-April, I had finally decided I had procrastinated long enough. I sat down and wrote a letter to our donor family. I told them about Lil's illness, our family, how much their precious gift meant to us, and I tried to thank them. How do you thank someone for such a gift? What can you do to repay them? I told myself that if I had donated the organs of one of my kids, I would want to know where they went and how the recipients were doing. I owed them that much and more. I gave the letter to the hospital's transplant coordinators to send, along with a brass and crystal angel that I had bought in the hospital gift shop one day. I couldn't explain why, but it was just one of those things that a person is compelled to do. Sometimes you just HAVE to do something.

On June 12, we received a letter from our donor family! We learned that our donor was a beautiful 15-year-old girl from Pierce, Nebraska, named Holly Lea Nelson. We learned the tragic details of her automobile accident and her passing from this life. Holly's mother, LeAnn, had written the letter. The love that poured from its pages was truly touching and humbling. It left me in awe when I found out that after giving us such a gift, she also prayed for us every day. LeAnn sent a

picture of Holly and told us about their family.

We now exchange letters, e-mail, birthday and holiday greetings, and have spoken on the phone a couple times. We have also met in person several times during the past year. We really look forward to and treasure each letter, message and meeting. For instance, in one letter LeAnn described that she has a bay window where she burns a light or candle every night for Holly and her recipients. I often think about that small town in Nebraska where a light burns in a bay window. It is a comforting feeling. In another letter she wrote of Holly's desire to be an organ and tissue donor, and how she (LeAnn) feels driven to let people know of Holly's legacy by promoting organ and tissue donation.

The bond that we share with the Nelsons is unique and heartfelt. They will always have a very special place in our hearts. To Holly's parents, Jeff and LeAnn, and Holly's sisters, Heather and Haley, thank you all so very, very much. We were so fortunate that organ donation had been a subject of conversation in your home and that Holly had made her wishes known to you.

Editor's Note: The NKF has helped to develop 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. 



The Luallin and Nelson families meet to share donor Holly's legacy.

Kids

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Elizabeth received a kidney from her mother in 1997. The transplant took place before Christmas, and this letter was Elizabeth's Christmas gift to her mother. She is now doing well and attending college.



Elizabeth and her mother, Sarah, share a hug—and a kidney!

Dear Mom,

I just wanted to write a little note to let you know how special you are to me. You are always the one who stands right by my side no matter what is happening. You can always make everything all right. You have never doubted me, even when almost every other person in the world has. You have always sacrificed yourself to put me first. For all of these things, I love you.

I always counted on you and you've never let me down. Next week is going to be scary and hard to get through, but I know when I wake up I'll be more a part of you than ever. I guess what I'm trying to say is no matter what I need, you're always there to provide it, and if it wasn't for you, I wouldn't be as happy and healthy as I am.

Mom, thank you for always being there and for being my hero.

*I love you,
Elizabeth*

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

Organ & Tissue
DONATION
Share your life. Share your decision.™

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