

Transplant Chronicles

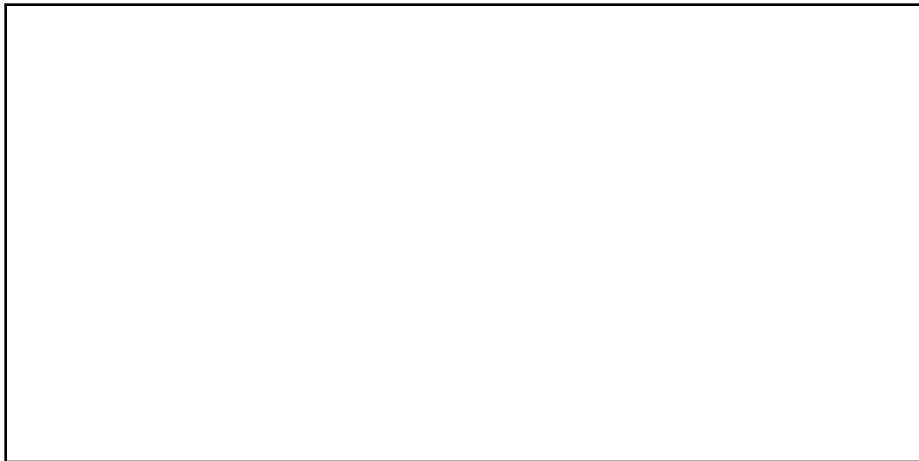
Volume 5

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

Number 1

Writing to Your Donor Family Is a Special Experience

by Faith Taylor



Left to right: Paul Shriver, Faith Taylor, Dorothy Shriver, Doug's daughter, Jodi, and a feline friend

My mother, Barbara, and I recently made the three-hour trip to Gettysburg, Pennsylvania, where we were warmly welcomed into the home of Paul and Dorothy Shriver, the parents of Doug Shriver, my organ donor. We spent the day with Doug's parents and many other Shriver family members.

It was a special and unique experience to see where my donor lived and meet the people closest to him. When we arrived, my first view was of a beautiful farm with fields that went as far as my eyes could see. I thought of Doug working with his father in these fields and how much he is missed now.

When we walked inside the Shriver's lovely home, we were greeted by a room full of Doug's family members. It was wonderful to meet his 12-year-old daughter, Jodi. We all sat together and enjoyed watching family videos of Doug working with his father on the farm and helping Jodi find eggs during the family's Easter egg hunt.

My mother and I enjoyed hearing about the many practical jokes Doug loved to pull on his mother. I felt proud to know that my donor was such a handsome, strong and witty young man who cared about others and was such a great help to his father. And I felt blessed to meet such a loving and close family. Doug's sister, Karen, invited my family to the Shriver family picnic. "You are now a part of our family," is how she put it.

The Shriver's have missed Doug ever since he was killed in an automobile accident in July 1992, but they find comfort in knowing that many lives have been saved and blessed because he was an organ donor.

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NKF National Kidney Foundation®

editor's desk



National Organ and Tissue Donation Awareness Week has come and gone. It is a time when I reflect on the changes that have occurred in the area of organ donation during the past several years. After 17 years of working in the transplantation field, I still find myself filled with feelings of disappointment when I think about the small increase in donation and sadness for the many who die while waiting for their second chance.

Beverly Kirkpatrick

This week in Philadelphia, a nine-year-old girl named Sarah died before a donor heart could be found. Sarah should not have been denied her second chance, nor should the many others who await an organ. As transplant recipients, friends and family, I urge you to get involved with organ donation promotion so that all of the Sarahs of the world will live on and our disappointments will change to joyous amazement. For more on getting involved, see Robert Gruenenfelder's "Messengers of Life" on page five. 

*Beverly Kirkpatrick
for the Editorial Board*



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1998 U.S. Summer Transplant Games Site Announced


Columbus, Ohio, has been selected as the site for the 1998 U.S. Summer Transplant Games, the National Kidney Foundation announced in February. Sandoz Transplant, a division of Novartis Pharmaceuticals Corporation, was named primary sponsor of the event.

The Games, which are scheduled for August 5-8, 1998, will be held at the athletic facilities of Ohio State University (OSU). The event features more than a dozen sports, including golf, tennis, swimming, cycling, basketball and track and field, and is open to individuals of all ages who have received a life-saving solid organ transplant (heart, lung, liver, kidney, pancreas) or a bone marrow transplant.

"The U.S. Transplant Games provide an excellent form of rehabilitation for transplant patients and the opportunity to generate awareness of the tremendous success of transplant surgery," says Wendy Brown, MD, chairman of the NKF. "Transplant recipients who participate in the Games dramatically illustrate the power of organ donation to restore life.

"At the same time," she continues, "the spirited competition calls attention to the vital need for more organ donation in this country and pays respect to the unselfish gift from the families of organ donors."

Hank Rosenzweig, chairman of the NKF's Transplant Games Committee, says that the commitment and cooperation of local government and local host organizations' personnel, in addition to ample athletic facilities and excellent climate, were significant factors in selecting Columbus as the 1998 Games site. OSU's housing facilities will serve as lodging for the athletes and their families.

Attendance for the 1998 Games is expected to surpass the record-breaking participation in the 1996 U.S. Summer Transplant Games of 1,200 transplant athletes, who ranged in age from 3 to 77. The Olympic-style athletic competition has been organized biennially by the NKF since 1990. 



The Essence of Life

by Vanessa Underwood, BS, AFAA, ACE

As I write this, it is National Organ and Tissue Donation Awareness Week. I feel compelled to dedicate this writing to all donors, especially to my own.

On November 21, 1996, organ donation took on an even more profound and startling meaning for me, but it was also the saddest day of my life. On this unforgettable day I lost my donor, my confidant, my teacher, my best friend—my mother.

Often, I have thought about the gratitude that recipients feel toward their unknown donors and the hopeless feeling that they may never know anything about the person who has given them a second chance at life. I have thought about the donor families and the pain they feel after losing their beloved. I have thought about the unselfish, altruistic gift of life. Despite these thoughts, I don't think I ever could have clearly understood the feelings of these recipients and donor families, as I had a living-related donor who was always with me. She was a donor I could kiss and hug and thank. But now it's different.


My mother, who I could never have thanked enough and who certainly found her thanks in seeing me healthy, is now gone from this world. So many things take on different meanings now.

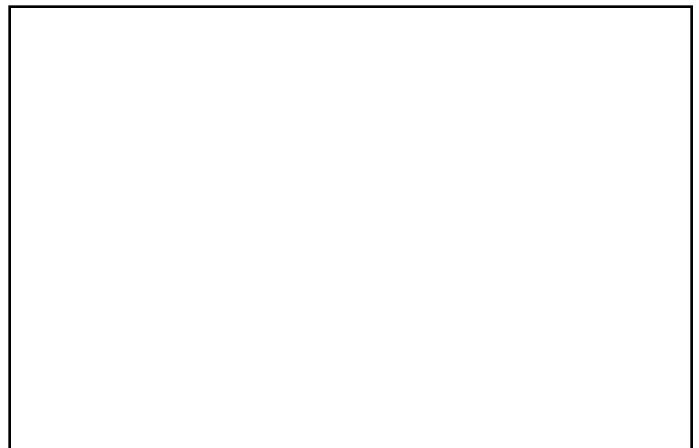
Now I understand! She lives on! When said in this context, it is so much more profound than when we normally say, "She lives on through you!" to someone grieving over the death of a loved one. In all my pain and grief, I think about life and its meaning. Somewhere underneath the tears and the sorrow I found that flicker of hope, the twinkle of light. I realize that I hold the essence of my mother and her life right here in me and through me. What a peaceful feeling to know that she is truly a part of me, not just emotionally and spiritually, but physically, too.

My mother brought me into this world and she taught her lessons with pride and love. I am everything I am because she loved me. When my life was threatened she gave me life again. Now,

if she were here, she would say, "I do live on, with you, in you and through you!" It's a miracle that the sadness of death can transform into a bittersweet joy for those who grieve over loss and those who receive a second chance at life. In my case, I am experiencing both.

I have been blessed, as have all recipients, donors and donor families. I cherish the love of my mother and of my sister, Grace (who also donated an organ to me), for their gifts of life to me. To all the donors and donor families, I thank you from the very depth of my heart.

The passing of my mother has become another stepping stone in my life—another level at which I try to understand. When I think of her and "our transplant," I have a deeper understanding of the entire experience. Although I grieve and my pain is intense, I smile, knowing that she is truly a part of me. I pray that all donor families can find this sense of peace and well-being, and that the smile will return to their faces, as life continues because of them and their loved ones. 




Vanessa (middle) cherishes the love of her mother, Caroline Freije (left), and sister, Grace Freije, both of whom donated kidneys to Vanessa.

Organ and Tissue Recipients...

Continued from page 1

Two days after he died, Doug's pancreas and one of his kidneys took over for my failing pancreas and kidneys. His pancreas has produced the perfect amount of insulin, allowing me to end my daily insulin shots. His kidney has purified my blood and kept me off dialysis for more than four years.

The Shrivvers would love to hear from others who received Doug's organs, but so far, they have not. It is so important for us, as organ recipients, to write to our donor families. Of course, this is done anonymously and the names of both parties are not released unless both agree that they want it to happen. If you are blessed to be an organ or tissue recipient, please contact your local organ procurement organization when you are ready to write to your donor family.

Faith Taylor lives in Horsham, Pennsylvania. In her spare time, she loves to draw. 

Miracles

by Faith Taylor

The greatest miracle happened nearly 2,000 years ago.

The gift of God is eternal life through Jesus Christ, our Lord.


Another miracle happened nearly five years ago.

The gift of organ donation from Douglas Shriver still lives on in his recipients.

Doug's heart and liver saved two lives.

One of his corneas restored sight to a blind woman.

One of his kidneys freed a man from years of dialysis.

His other kidney freed me from dialysis and his pancreas freed me from daily insulin shots and probable blindness. 

Support an Organ Donation Stamp




Four years ago, kidney transplant recipient Ed Heyn sparked a petition drive to convince the U.S. Postal Service that a postage stamp honoring organ donation would help increase the number of people who sign organ donor cards. Ed collected nearly 250,000 signatures from all 50 states and 12 countries, in support of the stamp.

Before his goal could be reached, Ed died. He left behind family and many friends, and the world of transplantation lost one of its most loyal and colorful supporters. Although he died, Ed's vision and work continue. The support group that he co-founded, Organ Transplants of

Southwest Michigan, is determined to make the organ donation stamp a reality. Members are asking you to send more signed petitions to the U.S. Postal Service.

One person who is carrying on Ed's hard work is Tony Papa, a postal employee from Pennsylvania. Tony says that despite the fact that the signature total has risen to 400,000, the Citizens' Stamp Advisory Committee has voted against the organ donor awareness stamp twice in the past 12 years. Still, Tony is not letting this stop him. In March 1996, he solicited letters to be sent to Postmaster General Marvin Runyon, on behalf of everyone awaiting a transplant.

Nine months later, the U.S. Postal Service sent him a letter thanking him for his "support for the issuance of a commemorative stamp that would create awareness of organ donation." The stamp is once again before the Citizens' Stamp Advisory Committee.

If you are interested in becoming involved with the postage stamp campaign, you may obtain more information from Gary Rouse, of Organ Transplants of Southwest Michigan, at (613) 423-6450. Get involved in raising organ donation awareness. Your support of a "Gift of Life" postage stamp is a great way to do so. 

Messengers of Life

by Robert Gruenfelder, RN, CPTC



As organ procurement organizations (OPOs) evolve, the role that volunteers play in the development of successful organ and tissue donation programs cannot be underestimated.

Most volunteers are either donor family members or organ transplant recipients. Giving at a time when they are grieving over the loss of a loved one makes donor families the critical links to transplantation for those who wait. For donation programs to continue to grow, we must recognize that donor families are the special individuals who we really serve. Without such families, donation and transplantation would not exist on the scale that it does. OPOs that provide a forum for these individuals to be heard will be richly rewarded with insights that can only be gained by those who have experienced the peace that can be achieved by donation following the loss of a family member. I personally have learned more about how to request organs and the consent process from donor families than from any other source since entering the field of organ donation and transplantation. Many other organ procurement professionals would agree with me.

The second group of volunteers is organ transplant recipients. Many of you have a renewed outlook on life after experiencing not only a life-threatening illness, but also the uncertainty of whether or not you would receive an organ. This new outlook often leads to a new set of priorities, like living life to its fullest and expressing thankful sentiments for this new hope. By involving positive and appreciative people in an OPO's volunteer program, the

organization's mission becomes obvious to the public. Organ and tissue recipient volunteers are not only recipients of organs, but recipients of the core value of being human, the ability to give and love.

The role of volunteers in an OPO's mission is important to me for two reasons. First, as a director of an organ donation program in western Texas, and, historically, in my role as an organ procurement coordinator, I have been working to increase awareness about organ and tissue donation during my career. Second, and perhaps more important, in March 1996, I started to tell my experience as a donor family member. I learned that as donor families we have a need to talk about our unique experience and share our loved one with everyone. This not only helps us deal with our loss, but also increases awareness about organ and tissue donation. Whatever the motivation, career or donor family experience, the mission has endured and the community has been served.

It has been said that by the year 2000, one-third of the U.S. population will know someone who has been involved with organ donation or transplantation. If OPOs can capture the life experiences and talents of even a fraction of this group, an end to or at least an easing of the organ shortage may be in sight. After all, who will move the community to action—the organ procurement organization or Bob Smith from down the street?

Robert Gruenfelder, RN, CPTC, is the managing director of the West Texas region of Life Gift. 


transAction Council to Meet at Annual Meeting

transAction!
COUNCIL

The first open membership meeting of the transAction Council will be held October 31 - November 1, 1997, during the National Kidney Foundation's Annual Meeting in San Antonio, Texas.

The meeting will feature sessions for all organ recipients, including "Medications: Friend and Foe"; "Healthy Lifestyles"; "Financial Issues"; and "Presence in Presentation: Are You Making

an Impact?" as well as a panel discussion on stress management, sexuality, nutrition and family issues. Aron Eisenberg, a kidney transplant recipient who plays Nog on "Star Trek: Deep Space Nine," will also speak at the meeting.

Registration information will be sent to all members of the transAction Council. For membership information, contact Gary Green at (800) 622-9010, or join online at <http://www.kidney.org>. Membership is free. 

Rehabilitation: What's the Big Deal?

by Maurie Ferriter, BS

For part two of Transplant Chronicles' five-part rehabilitation series, Maurie Ferriter, a kidney transplant recipient from Lakeland, Michigan, discusses why transplant recipients need vocational and functional rehabilitation.

“**R**ehabilitation” is a word we are hearing a lot lately. Rehabilitation means the restoration of the whole person. Our bodies need to recover from the shock of a major surgery like transplantation. That may seem obvious, but what we need to do in the long run with our bodies and with our lives is not as obvious. Some of us were very ill for a long period of time before our transplant, and we became used to a low level of activity. Now, even with newfound energy and a new lease on life, many people are tempted to stay stuck in their old habits. This makes both vocational rehabilitation and functional rehabilitation important.

Vocational rehabilitation has to do with employment. Many of you will return to your former job; others will need training or more education so that you can perform another job. Young people may be looking for their first job. It may mean full- or part-time employment.

Functional rehabilitation means returning yourself to a fulfilling, productive life. This does not always mean employment. For some of you, this may mean volunteering your time to a worthy cause or organization. For others, this can mean taking back a part of your life you had to give up while waiting for a transplant, such as raising your young children at home instead of sending them to a relative's house or a day care center.

★ Why Rehabilitation? Quality of Life


All of us have had to make adaptations or trade-offs in our lives because we had a chronic illness that required a transplant. Some of the trade-offs we made we did not think twice about because there weren't many alternatives. We had to take medications and keep endless medical appointments. Some, however, were major life

decisions and required us to weigh all of the potential consequences: Should I stop working or take a medical leave, and how will that affect my family financially? Should we stay here or move in with or close to my parents because of the demands of living with chronic illness? For people in need of a kidney transplant, the decision to ask a family member for a kidney is a tough one.

Now that we have a successful transplant, it is important for us to recover as much of our “normal” lives as possible. This is not only important for us as transplant recipients, but also for our families and friends. We need to maximize our rehabilitation so that we can have the best quality of life possible. For some, this means changing our previous goals for a “normal” life. For others, this means getting back to goals we had before we needed a transplant.

★ Why Rehabilitation? Survival of the System

We are products of the system that paid for our care and our transplants. Medicare, Medicaid, SSI and SSDI, among others, are part of this system. We are also products of a system that promotes education about organ donation and the great things that transplants do for us. We have a responsibility to our donor families to make the most of the gift they gave us.

There are many people at the state and federal government levels who analyze the costs of continuing to pay for organ transplants and funding the disability system. We must show them that we are striving to reach our potential after transplantation. We can reach this potential through rehabilitation. If we don't do this, the people who need transplants or access to the disability system for short periods of time in the future may not have the same opportunities we have now. This could also affect us. Transplants don't always last forever. We may be in need of another one someday, and we will need access to the system again. So let's do our part now to ensure it is around in the future. 

On the Road Again—How to Travel with a Transplant

by Cheryl Jacobs, LICSW

One of the many pleasures and conveniences of receiving a transplant is having the ability to travel comfortably again. Whether you travel for work or pleasure—upcoming summer vacations, the World Transplant Games in Australia or the possibility of spontaneous travel (considering the occasional airfare price wars)—there are some things you should always remember before you leave.

✓ Pack any relevant medical records or identifying information, including a list of daily medication, allergies and the names and phone numbers of your physician, transplant center and family members. A medical ID bracelet can be purchased at a nominal fee from most National Kidney Foundation Affiliates.

✓ Inform your health care team of your travels and where you can be reached if you will be away for an extended period of time. Complete any routine checkups or blood work prior to your departure. Finish any tests or specialist consultations before you leave. Obtain the names of physicians or transplant centers nearby your travel destination in case you need a contact during your time away. Your transplant center may be familiar with professionals wherever you're visiting.

✓ If appropriate, obtain proper vaccinations for your travels before you leave the country. Ask your physician or consult a local travel clinic for the vaccinations that are required for certain countries; make sure they know that you are a transplant recipient. Some vaccinations need to be given a long time before you travel in order to be effective.

✓ Keep your medications with you, not packed in luggage that will be checked. Your flight(s) could get delayed, or your luggage could get lost. Your traveling buddy or strangers may have aspirin, but it's highly unlikely they will have anti-rejection medicines.

If you're away for an extended period of time, make sure that you will be able to replenish your

supply, and understand how you will be billed. Mail-order pharmacies may be able to ship them to you at your travel destination(s).

✓ Bring an emergency allergy kit if you have allergies.

✓ If you're diabetic, bring glucagon and diabetic supplies so you can make a quick adjustment if necessary.

✓ Bring bottled water to keep you hydrated. In some countries, you should only drink bottled water.


✓ Inform your travel agent, airline carrier and final accommodations in advance if you have any special dietary requirements. You should also tell them if you have any special needs during your travels so they can plan for appropriate assistance, transportation and seating arrangements.



✓ You may want to ask your agent about travel insurance in the unlikely event that you might need to cancel or change your travel plans.

✓ Surf the World Wide Web if you, your family, friends or travel agent have access to a computer and the Web. It's amazing how much information you can find on the Web about destinations, accommodations, restaurants and activities.

The Web has information for travelers with disabilities about vacations such as safaris and raft trips. These Web sites can help travelers with disabilities plan a hassle-free and fun vacation. Disability Travel Services (<http://www.dts.org>) may be a good place to begin the search. Access-Able Travel Source (<http://www.access-able.com>) and the Society for the Advancement of Travel for the Handicapped (<http://www.travelagency.com/page12.html>) are other sites worth a look.

You will find that the extra effort that you put into planning your next trip will be worth it. Happy trails. 

The Grievance Process

by Peggy Janssen

What Is a Grievance?

A grievance, for individuals with kidney failure, is a problem concerning the services that they receive related to treatment for end stage renal disease (ESRD). You may be concerned with the quality of the care you are receiving, your access to care or the difficulty you are having communicating with a member of the health care team.

How Do I Express My Concerns?

A grievance or concern can be resolved informally, through discussion, or formally, using the unit's or facility's grievance procedure.

The Informal Process

You can talk to the transplant coordinator and work out a solution to a given problem, or you can request a health care team meeting to discuss the issue. It is essential that you are an informed and active participant in your health care. If your concern is not resolved to your satisfaction, you may use the unit's or facility's grievance procedure or report the problem to your local renal network.

Unit Grievance Procedure

You may need to submit your concern in writing to file a formal grievance. The grievance procedure will define the process, including the delegation of responsibility and timelines. You can get a copy of the grievance procedure from your social worker or transplant coordinator. When you write your grievance, it is important to be clear and concise. Briefly state the facts—when, where, who, what. You may include what you feel should be done to resolve the issue. Most issues can be resolved with the dialysis or transplant center using either the formal or the informal process; however, if the response to your grievance is not satisfactory to you, you may report your concern to your local renal network.

What Role Do the Renal Networks Play in the Grievance Process?

Each renal network is under contract with the Health Care Financing Administration (HCFA) to fulfill a set of defined requirements in its specific geographic area. These requirements mandate each network to be active in the following areas: quality improvement, grievance resolution, vocational rehabilitation, information sharing and management of provider and patient information. All networks have a grievance process, which enables you to voice your concerns about services for ESRD directly to an objective third party. You or your representative can file a grievance without restraint, interference and fear of discrimination or reprisal. All grievances are confidential and they must be in writing. The

network can perform one of three roles: investigator, facilitator/coordinator or referral agent. You will be notified of the outcome in writing.

Editor's note: This article was written for people with kidney failure who receive dialysis or have had a kidney

transplant. People with other kinds of organ transplants should file any grievances with their local peer review organizations (PRO). PROs only investigate complaints from people with Medicare, and there is a PRO in every state. PROs mainly focus on what happens in a hospital; however, they will pursue quality-of-care complaints from people treated in an outpatient setting.

There are several ways to locate the PRO in your area. You can find a listing in the back of your Medicare Handbook, or call the insurance carrier listed on the explanation of benefits (EOB) form you receive from Medicare. Ask the insurance carrier for the local PRO phone number, or call the Health Care Financing Administration (HCFA) at (800) 638-6833. You should be given a one-page flyer, titled "Important Message from Medicare," when you are admitted to a hospital. This flyer should contain information telling you how to contact your local PRO.

Peggy Janssen is the consumer services coordinator for ESRD Network Eleven in St. Paul, Minnesota.

"It is essential that you are an informed and active participant in your health care."

Transplant News Digest

From the editors of *Transplant News*

Administration Proposes 18-Fold Increase in HRSA; 1998 Fiscal Year Budget to Address Donor Shortage

by Jim Warren, editor and publisher

While the transplant community wrangles publicly about organ allocation policies in the U.S., the Clinton administration has indicated it has been listening to experts who say the biggest problem is a lack of organ donors by seeking the largest single budget increase for organ procurement and transplantation since the program was established in the mid-1980s.

In its annual budget for the 1998 fiscal year, the Clinton administration is requesting an appropriation of \$3,891,000 for the organ procurement and transplant program of the Health Resources and Services Administration (HRSA). This includes a whopping increase of \$1.6 million, all of which is specifically earmarked for public and professional education programs designed to increase the number of cadaveric organ donors.

To understand the magnitude of the appropriation request, consider the following: the HRSA's Division of Transplantation (DOT) has \$88,000 to spend on donor awareness programs; and the \$1.6 million request is almost three times the amount HRSA grants annually to the United Network for Organ Sharing (UNOS) to operate the Organ Procurement and Transplant Network (OPTN).

It is important to note that what the administration requests and what is ultimately appropriated by Congress can differ markedly; however, the request for increased funding in a time of overall budget cutbacks indicates that the administration is serious about recognizing the problems caused by the lack of organ and tissue donors.

In its rationale for the budget request to Congress, the administration observes:

"The major gap in organ transplantation today is the large difference between the number of people who need organs for transplant and the

number of donors. There are now approximately 50,000 people on the national waiting list for organs. In 1995, there were approximately 5,300 donors. Approximately 3,500 people died in 1995 waiting for an organ. Although federal funding for organ transplantation has not changed, organ donation from cadaveric donors has increased by 30 percent since 1995.

Unfortunately, this increase is not nearly sufficient to meet the need. Moreover, it is still only about 50 percent of the potential donors. The waiting list increased by almost 20 percent in 1995 alone.

"The major factors influencing organ donation are public and professional awareness and education. Therefore, there is a critical need to (1) increase organ donation, (2) standardize the process of donation, and when donation occurs, (3) to improve the speed at which organs are allocated.

"In order to increase the number of cadaveric organ donors, an increased organ donation public and professional education effort is required. Four activities that would be funded by the increase in the FY [fiscal year] 1998 request are:

- "Review high and low performing organ procurement organizations (OPOs) to identify successful strategies for influencing hospital staff to become more knowledgeable about and more committed to donation. The objective is to ensure that families of all potential donors are asked whether they will donate. Currently, about one-third of potential donor families are not even asked to donate because hospital staff are not committed to donation or have an unwarranted apprehension about the request process.

- "Develop and implement three public education programs that target key professions that can potentially affect donation; i.e., attorneys, funeral directors, clergymen.

- “Develop, test and disseminate a curriculum for grades K-12 (nationally) and provide technical assistance for its implementation. HRSA, with its contractor, the United Network for Organ Sharing, has already successfully developed two organ transplantation and donation curricula for medical schools and nursing schools.

- “Conduct 10-15 roll-out workshops in different regions of the U.S., based on the College Campus Project. This is a multi-faceted project designed to encourage organ donation awareness among college students and faculty. The objective is national implementation.”

Scottish Researchers Report Successful Cloning of a Sheep; Clinton Calls for Bioethics Commission Study

The announcement on February 14 that researchers in Scotland have successfully cloned an adult mammal for the first time, produced both positive and negative reactions that promise to impact the field of transplantation for a long time.

The Scottish research team, led by Dr. Ian Wilmut, an embryologist at the Roslin Institute in Edinburgh, created a lamb—named Dolly—using DNA from an adult sheep. The researchers were adamant in explaining that the goal of the experiment was not to clone humans but to create large herds of genetically engineered farm animals that could, among other things, contain “humanized” organs suitable for human transplantation.

Much of the debate has centered on the ethics and brave new world of successful cloning. The *Washington Post* reported that President Clinton has ordered the 18-member National Bioethics Advisory Commission to consider whether “federal policies relating to human embryo research should be reconsidered” in light of the development.

Among the commission’s duties is to study whether privately funded human embryo research in the U.S., which is legal and largely unregulated, should be more “sensitive” to the ban, which exists on such studies being conducted by federally funded researchers.

The commission was created by an executive order in October 1995 and includes experts in medicine, science, ethics, theology and the law. It

is scheduled to report back to President Clinton in about 90 days, the *Washington Post* reported.

One-Year Graft and Patient Survival on the Rise Since 1988, According to UNOS

One-year graft and patient survival rates have increased annually since 1988, according to UNOS’ Annual Report for 1996. Unfortunately, according to the same report, the waiting list for a donor organ nearly tripled during the same time period.

For the first time, the UNOS report contains data on five-year graft and patient survival rates; previous reports had tracked the rates only during three-year periods. The five-year patient survival rates range from 80.6 percent for kidney recipients to 41.4 percent for heart-lung recipients.

While the bad news was the tremendous increase in patients on the waiting list—43,983 in early 1995 compared with 16,026 in 1988—the good news was a nearly 30 percent increase in the number of minority cadaveric donors. The level increased from 16 percent in 1988 to 23 percent in 1995.

Despite the increase in the number of donors, minority registrants—particularly blacks—continue to wait longer for kidney transplants than whites, the report found. The reason for the disparity, UNOS reported, includes differential ABO blood group distribution, higher positive cross-match rates for minorities and the rarity of certain HLA antigens among blacks compared with whites, who constituted 77 percent of the cadaveric donor pool in 1995.

Here are some of the other findings contained in the report:

- Living donors: The number of living donors increased 74 percent between 1988 (1,825) and 1995 (3,180). In addition, the number of unrelated living donors nearly tripled during the period, from four percent to 11 percent of the living donor total.

- Donor age: The number of older cadaveric donors (defined as donors over 50 years of age) increased from 12 percent in 1988 to 24 percent in 1995. Correspondingly, the younger donor pool—donors who are 18 to 34 years of age—

decreased from 41 percent of donors in 1988 to 29 percent in 1995. UNOS attributed the changes to fewer motor vehicle accidents and safer automobiles—thereby reducing the number of deaths of more youthful drivers and their passengers—as well as improved technologies that make older organs more viable.

- Improved one-year patient survival rates: cadaveric donor kidney—94.1 percent in 1994, compared with 92.2 percent in 1988; living donor kidney—97.8 percent in 1994, compared with 96.7 percent in 1988; liver—83.9 percent in 1994, compared with 77.1 percent in 1988; pancreas—91.4 percent in 1994, compared with 86.9 percent in 1988; heart—85 percent in 1994, compared with 82 percent in 1988; lung—76 percent in 1994, compared with 47 percent in 1988; and heart-lung—74.2 percent in 1994, compared with 52.4 percent in 1988.

- Waiting times: Waiting times for heart and liver patients appear to be relatively short for

those with the most critical need, UNOS reports. In 1995, 50 percent of liver registrants who went on and off the waiting list as Status 1 had a median waiting time of only four days. Approximately 50 percent of registrants who went on and off the waiting list as either Status 1 or Status 2 had a median waiting time of less than 30 days. This compares to an overall 254-day national median waiting time for liver patients of all four status codes. In 1995, 50 percent of registrants who went on and off the heart waiting list as Status 1 had a median waiting time of 40 days. This compares to an overall national median waiting time for all heart registrants (Status codes 1 and 2) of 213 days.

For the first time, UNOS is making a 30-page booklet featuring data highlights available to the general public at no charge. To obtain a copy call (804) 327-1432. The 1996 Annual Report is also posted on the UNOS Web site at <http://www.unos.org>. For more information, contact Joel Newman at (804) 327-1432.

COMMENTARY

by Jim Warren, editor & publisher, *Transplant News*

When the Clinton Administration announced that it is requesting \$1,687,000 for the 1998 fiscal year for public and professional education programs designed to increase the number of organ and tissue donors, one veteran transplantation community observer told me, "If the transplant community is smart, it will begin right now to ensure that the increase is not a one-shot deal, but will remain in the budget for years to come."

Sage advice, of course. But there's one little problem. When it comes to being effective in the Washington legislative and regulatory arena, the transplant community has virtually no clout and has shown no

willingness to take the steps necessary to rectify the situation.

For the past three years, I have annually called upon the major transplant groups to: form a legislative coalition, agree to a list of legislative goals in order of importance and implement a systematic approach to achieve those goals. Unfortunately, this call to action has continually fallen on deaf ears. Waiting any longer could be a serious blow to transplantation. Each year, the stakes have gotten a little higher, as has the public profile of transplantation.

When you consider the major issues that will continue to be discussed for years—organ allocation, xenotransplantation, cloning, gene therapy, cell therapy, organ commerce—it can be argued that transplantation is at a crossroads, and the head-

in-the-sand legislative policy can no longer be tolerated.

Here is a list of legislative accomplishments achieved in 1996:

1. The Organ Donation Insert Act will result in information about organ and tissue donation being sent to approximately 70 million U.S. taxpayers.

Here is a list of three important things that did not get accomplished in 1996:

1. The National Organ Transplant Act was not reauthorized. The act has not been reauthorized since 1990, mainly because of the politics surrounding the number of transplant programs, organ procurement organization turf wars and the almost pathological struggle of the United Network for Organ Sharing (UNOS) against even

COMMENTARY

Continued

the most minimal regulatory oversight by the government. These have left lawmakers unwilling to address the issue until the transplant community achieves consensus on what it wants.

2. Legislation calling for unlimited Medicare coverage of immunosuppressive drugs, introduced by Rep. Charles Canaday (R-FL), went nowhere. Aggressively supporting this bill, even with a limited chance of passage at this time, is a no-brainer for the transplant community. At the very least it could result in extending the three-year coverage provided now to five or six years. I saw no support for the bill in 1996.

3. Neither legislation addressing rehabilitation programs nor lifetime health insurance caps for transplant recipients was introduced.

Here are some modest suggestions for addressing current and future legislative and regulatory issues.

1. Create a Coalition on Legislation. The move should be led by the American Association of Transplant Physicians and Surgeons (ASTP and ASTS); the National Kidney Foundation (NKF); the Transplant Recipients International Organization (TRIO), the NKF's transAction Council or another recipient group; and the Association of Organ Procurement Organizations (AOPO). Because of its status as a government contractor, UNOS is not included on the list, but should play a major role as an

ad hoc member. The Coalition can be UNOS' biggest benefactor on Capitol Hill.

2. Develop a legislative agenda. The first action of the coalition should be to arrive at a consensus on an achievable legislative agenda. I rank reauthorization of the National Transplant Act and an extension of the 1998 fiscal year budget appropriation earmarked to increase donation as top priorities.

3. Develop a legislative strategy. Models do exist. The NKF, which is opening a Washington legislative office, played a principle role with physician organizations like the American Society of Nephrology to craft successful legislation for dealing with end stage renal disease issues in the late 1970s.


4. ASTP and ASTS should merge as soon as possible into one organization. With such issues as cloning, xenotransplantation, managed care, Medicare physician payment system changes and new immunosuppressive drugs on the horizon, the organizations can no longer afford to function as separate entities with separate Washington representatives. They need to merge into one organization and open a Washington office with paid full-time staff members.

5. Presidents of all national transplant organizations should have two-year terms. Because of the increasing number and complexity of legislative and regulatory issues, ASTP, ASTS, UNOS, AOPO, TRIO and NATCO should take this action

immediately. The NKF and Eye Bank Association of America learned long ago that a two-year presidency (or chairmanship) is monumentally more effective than a one-year term.

By the end of the first year the new president is just beginning to understand the complexities of Washington and develop a presence (and an agenda) on Capitol Hill when the term ends. The same process then begins anew with the next president. A two-year term creates more continuity and allows the organization's paid staff to provide much more effective support. Those who argue that such a commitment takes up too much of the individual's time away from running his or her own organization are wrong. By allowing for what is essentially a six-year involvement—two as president-elect, two as past-president, in addition to two as president—many of the duties can be delegated to equally share the burden.

6. AOPO and ACORD (American Congress for Organ Recovery and Donation) must reconcile. To be effective in Washington, the 63 OPOs must speak with a unified voice to best serve their members.

With transplantation issues often seemingly dominating the medical scene, the first transplant surgeon in history in the Senate (Sen. Bill Frist (R-TN)), a proposed budget increase and a sheep named Dolly making headlines, it is time for the transplant community to get its legislative act together and bring it to Capitol Hill. 

Planning Ahead for the Inevitable

by R. Patrick Wood, MD, FACS, and Mary Claire Mahoney, RN, BSPHN, MS

Many people do not wish to speak about death, but no one can deny it is inevitable. For patients facing heart or liver transplantation, the prospect of an illness-related death is very real. Transplantation offers a new lease on life, but no matter how successful, death eventually comes.

As a liver transplant surgeon and a hospice nurse, we speak from experience when we say that those families that have clearly addressed end-of-life issues cope far better when death does occur than families that have avoided addressing them. Patients and their families should especially reflect on the issues that we have outlined below, particularly while patients are still in good health.

Personal and Family Reconciliations: We have witnessed the guilt expressed by family members who have failed to reconcile differences with their dying loved one. This also holds true for friends of the dying patient. The most appropriate time for dealing with patient and family issues is prior to the transplant. "I never got a chance to tell him . . ." or "If I only could tell her . . ." are often heard in the room of the dying patient.

Spiritual Issues: Patients may want to make peace with their God, and come to terms with concepts about death and the afterlife, especially as taught by their religion.

Loss of Potential: Patients must realize that as the end of life nears, they must be satisfied by what they have accomplished. What can still be accomplished is limited, and patients should have realistic expectations for the remaining portion of life.

Loss of Present Lifestyle: As their health deteriorates, patients may no longer be able to work or pursue activities that were important to them before. Patients must come to terms with the fact that as the end of life approaches, they must make lifestyle changes to accommodate for the change in their health status.

Inappropriate Expectations: Patients who approach transplantation expecting it to cure everything are not being realistic; discussions about death are usually not welcomed by such patients. For patients to approach the end of life with dignity, they must deal with end-of-life issues, especially while they are healthy.

Fear of Dying: Patients express a number of fears as they approach the end of life. They should openly discuss these fears with their loved ones, next of kin or those who will be asked to advocate at the time of death. Obviously, many people fear the end of their life, but beyond that, many patients fear a loss of dignity as they lay dying, especially in a hospital. Patients also fear losing control as they become unable to have input into their own medical care. The fear of losing humanity and becoming an object kept alive at all costs in the Intensive Care Unit is another frightening concept for dying patients. Finally, a fear of inadequate pain control is an issue of concern to many patients.

Physical Problems: Dying patients generally express concerns about not being able to perform activities such as maintaining personal hygiene.

Acceptance of Death by Others: While some dying patients may be content as they approach the end of life, some family members may be unable to accept their loved one's approaching death. This should be dealt with before patients undergo transplantation, so that everyone involved is comfortable with the decisions that have been made. Patients should maintain control over the end of life.

What-If Issues: Living wills and durable power of attorney for health care fall under this area. "Will I be allowed to die appropriately?" or "If I sign one, will the health care professionals or surrogates follow my wishes?" are questions dying patients may ask. Every patient should address the production of a will with an attorney. Patients, families and physicians are usually able to agree about treatment when these issues are addressed while the patient is still competent to make important decisions.

Problems arise when patients, families and physicians disagree on when treatment is to be withheld. When patients do not communicate their desires when they are competent, the family is forced to play the "what-if" game. Living wills and durable power of attorney state what treatment the patient wants or doesn't want. Patients pick a surrogate to be their spokesperson for when they are no longer competent. The surrogate is an important and sometimes difficult role, because this person must follow the patient's wishes even when the family or

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Viral Infections in Transplant Recipients

by Thomas C. Knauss, MD

As an organ transplant patient, if you experience fever, you may have a bacterial infection or a viral infection. Fever in the post-transplant period is typically caused by bacterial infections of the lung, surgical wound or urine, but viral infections can also cause fever during the initial six months following transplantation and anti-rejection therapy. Although viral infections caused by the common cold are as frequent in transplant recipients as in the general population, several types of viral infections, such as cytomegalovirus (CMV), Epstein-Barr virus (EBV), hepatitis B virus (HBV) and hepatitis C virus (HCV), commonly result in symptomatic disease in transplant recipients.

These viruses, which normally lie in a resting state in individuals who have a normal immune system and are not on anti-rejection drugs, become reactivated when individuals are placed on medications that suppress the immune system after a transplant. If you have no history of exposure to these viruses, you are at greatest risk for serious disease after you receive a transplant organ infected with one of these viruses. These common viruses pose a serious health risk for organ transplant recipients; however, preventive strategies have been developed to reduce the risk for serious disease.

CMV is a viral infection that commonly occurs between one and six months after transplantation. This virus, which affects about 60 percent of people during childhood or the young adult years, typically shows symptoms indistinguishable from a cold or flu. Pre-transplant screening for CMV is carried out by a blood test that determines if the individual produces CMV antibodies; those with prior exposure to the virus will have CMV antibodies in their blood. Although cold and flu symptoms such as a short period of fever and chills are the norm for CMV infection, extreme cases can lead to pneumonia, ulcerations of the intestinal tract or hepatitis. Kidney transplant recipients may experience direct inflammation of the kidney or even a kidney rejection episode. Fortunately, the antibiotic ganciclovir is very effective against this infection.

If you receive a transplant that contains CMV, you need to take special precautions. Your transplant physician may put you on high doses of anti-viral drugs from the time of the transplant. Another choice is to infuse high levels of CMV antibodies, which bind to the virus and help your body to clear the infection. The recent release of ganciclovir in pill form simplifies prolonged outpatient treatment.

Another important chronic viral infection is that caused by EBV, which causes infectious mononucleosis. Ninety percent of the world's adult population has been infected with EBV at some time in their life. EBV lies dormant in the body after an initial infection and leads to disease in the post-transplant period after reactivation. Transplant recipients who have no previous exposure to EBV and receive an organ from a donor with a history of EBV exposure are at great risk for EBV.

EBV infection may cause fever, sore throat, swollen glands and fatigue—symptoms similar to those of infectious mononucleosis. Although this is usually a self-limited process, in rare cases the white blood cells in the lymph glands may continue to proliferate into tumorous growths, a condition known as Post-Transplant Lymphoproliferative Disorder (PTLD). It develops in about one percent of renal transplant recipients, two percent of liver transplant patients and two to three percent of heart or lung transplant recipients. Not uncommonly, when the tumor develops, it does so in the organ that was transplanted. The risk of developing PTLT is highest in transplant recipients who have received the most intense anti-rejection therapy.

Treatment of EBV-associated disease includes the anti-viral drug acyclovir. In many instances, reduction in doses of immunosuppression is required; however, anti-rejection drugs may need to be stopped in order to control growth of the EBV-activated white blood cells.

Finally, chronic liver infections caused by HBV and HCV pose additional problems in transplant recipients because asymptomatic patients may develop liver disease after beginning an anti-

rejection drug regimen. HBV, which is typically acquired through infected blood products, is a viral infection of the liver that causes five to 10 percent of the chronic liver disease cases in the U.S. Fortunately, the frequency of this infection has diminished in recent years due to advances in our ability to successfully screen blood products for HBV, a decrease in the need for blood transfusions in dialysis patients due to the development of erythropoietin injections that stimulate the body to make blood and the use of effective vaccines against this virus.

HCV can also affect the liver. Since a reliable blood test to diagnose this infection has only been developed within the past 10 years, many dialysis patients were already exposed to this virus by blood transfusions in the past. Five to 15 percent of all dialysis patients and a similar percentage of transplant recipients have been infected. Hepatitis C can also be spread in ways other than blood transfusions. Two to six percent of potential kidney donors also carry the virus. HCV is even more likely than HBV to cause liver scarring, which occurs in 20 percent of HCV-infected individuals. Although this usually occurs over a period of 10 to 20 years in non-transplant patients, evidence shows that this may occur over an eight- to 12-year period in patients on immunosuppressive medications.


Early studies of renal transplantation in patients with evidence of HBV in their bloodstream suggested that they would have poor results due to worsened liver disease. Recent studies suggest that renal transplantation can be performed in these individuals with similar success rates to non-HBV patients. Progressive liver damage still occurs in most patients, whether they are transplanted or remain on dialysis. Patients who are infected with HBV, but do not have evidence of this virus in their blood at the time of transplantation, have a low risk of liver disease.

Currently, all potential donor organs are tested for HCV in the U.S. At some transplant centers HCV-positive kidneys are offered to possible recipients who already carry the HCV virus. It is expected that this will not put them at any greater risk of developing liver disease than they already have. This allows organs to be used that ordinarily would be discarded, and it allows recipients to receive a transplant much sooner. If your transplant center were to offer you this choice, the risks and benefits would be discussed with you so that you could make an informed decision. The risk of transplanting an

HCV-positive kidney into someone who has not previously been exposed to the virus is not clear. Certainly, before we could test for HCV this happened frequently. It is possible that some older individuals (older than 65) who are on the transplant waiting list and HCV-negative might choose to accept an HCV-positive organ and accept the risk of liver disease eight to 12 years in the future.

Reference:

Rubin, R.H., "Infection in the Organ Transplant Recipient." *Clinical Approach to Infection in the Compromised Host* (third edition). New York and London: Plenum Medical Book Company, 1994, pages 629-705.

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Planning Ahead...

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physician disagrees. Open dialogue between the family members and the surrogate decision-maker can stop problems before they arise and "what if?" will be an unnecessary question.

The living will is not used until a person is terminally ill, so having one ensures patients that their wishes will be carried out the way they decided. Patients do not need an attorney to produce a living will; a social worker can assist in filling out the document. A statutory durable power of attorney appoints an agent to act on the patient's behalf, concerning personal property transactions, bill payments and tax matters. If a spouse is unavailable, a trusted relative or friend can care for the patient's personal matters when he or she is unable. This document must be completed by a lawyer.

Fear of Being Forgotten: Often patients wonder if they will be forgotten. Writing to a friend on his birthday, a daughter on her birthday or a spouse on a wedding anniversary can help patients. Many people don't like to write, so leaving a tape is a nice personal touch. Like birth, death is an important event in our lives. Planning ahead for all the possibilities can give us and our families the opportunity to enjoy precious time together.

Mary Claire Mahoney, RN, BSPHN, MS, is a hospice nurse and the director of Palliative Care Services at Hermann Hospital in Houston, Texas. 



Strength For Seniors

by Vanessa Underwood, BS, AFAA, ACE

For transplant recipients, staying active on a daily basis is as important as keeping appointments, taking medication and having bloodwork done. This is necessary for everyone, perhaps even more so for seniors. I teach a senior fitness class whose members are more fit than the high school kids I teach, because the seniors exercise on a regular basis.

As transplant recipients or dialysis patients awaiting a kidney transplant, we have many issues to face, including the loss of strength, stamina and muscle tone. The natural process of aging also induces this same loss of strength, stamina and muscle tone. Daily functions like getting dressed, driving, shopping, cooking and climbing stairs can all become a challenge. Numerous studies have demonstrated that exercise can slow the aging process, regardless of age and physical condition.

It is vital that you begin to incorporate exercise into your daily life. For some, this may be a 30-minute walk once a day; for others it might mean parking your car further away from the entrance to the mall. Even getting up off the couch to change the channel instead of using the remote control will add a few more steps to your day.


You should always get clearance from your physician before you begin to exercise, especially before beginning a resistance program. Resistance training is a good start because it builds muscular strength, which is necessary for all other sports and activities.

Many adults limit their activity because they have lost strength, not cardiovascular endurance.

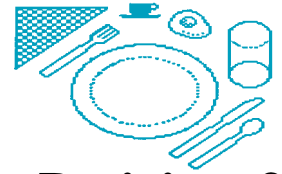
Start off with a gravity resistance exercise. You can perform these exercises with free weights, weight machines or elastic bands. I always tell my new members to start by using soup cans for weights, adding weight to increase resistance, but not so much that it makes them unable to perform the exercise in correct form. You will begin to increase muscle mass and strength by lifting the weight for a number of repetitions. Progressively increasing the weight will further enhance the results. A good rule to follow in determining how much weight to use is to lift an amount that will make your arm tired after 10 repetitions. Once the weight becomes light enough to lift more than 10 consecutive times, you should increase the weight.

Resistance training will help you increase your stamina and strength, reduce blood pressure, relax, and increase your balance, flexibility and bone density. It will also increase your metabolic rate, enabling food to be utilized more effectively. Individuals who exercise regularly find themselves eating more and weighing less.

Maintaining a balance of physical activities is a key factor in living a long and fit life. Many communities have senior

fitness programs, offering swimming, low-impact aerobics, line dancing, yoga, martial arts and stretching. Almost any physical activity will have a positive effect on your health. 

Vanessa and her pupils demonstrate the proper weightlifting technique.



Appetite Suppressants: Are They Safe for Transplant Recipients?

by Gail G. Bridges, PharmD

If you have been battling your body weight for years, or if you have gained an extraordinary amount of weight since your transplant procedure, you may have considered trying appetite suppressants. There are several drugs available; however, it is important to examine how they might affect transplant recipients.

Two of the more common appetite suppressant regimens are dexfenfluramine and a combination of the drugs phentermine and fenfluramine. Studies show that these medicines are effective in helping overweight adults to lose significant amounts of weight. According to these studies, weight loss was achieved when the medicines were used in combination with dietary restrictions. After ending the usage of appetite suppressants, weight loss was best maintained when the dietary restrictions were continued and an exercise regimen was implemented.

Unfortunately, these drugs are not without risk. Both of the aforementioned medication regimens can cause similar side effects, including: high blood pressure, nausea and vomiting, tremors, confusion, diarrhea or constipation, sleepiness or insomnia, abnormal heart rate and bad dreams. Primary pulmonary hypertension, although rare, is perhaps the most serious side effect of these medications, and can become life-threatening. Patients who already have primary pulmonary hypertension, glaucoma, high blood pressure or heart disease should not take these medications. Anyone who takes appetite suppressants requires frequent visits with his or her health care provider.

It is important to note that these studies have been of overweight, but otherwise healthy, volunteers. There have been no scientific studies of transplant recipients taking these drugs, or for that matter, of transplant recipients taking these drugs in combination with transplant medications. Transplant recipients who already experience high blood pressure, tremors or diarrhea are not good candidates for appetite suppressant usage. Additionally, confusion would not be beneficial for someone who has to take 12-15 essential transplant medications every day.

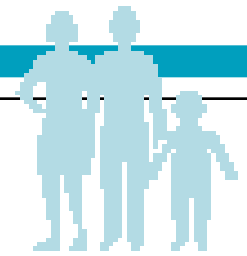
Luckily, everyone does not experience these side effects. Current thinking indicates that these drugs will be reserved for the transplant recipient who is so overweight that he or she is endangering the transplanted organ or his or her life, and has failed controlled and monitored attempts to lose weight with diet and exercise. Transplant recipients who are prescribed these appetite suppressants will be required to continue their dietary restrictions and visit their health care provider more frequently.

In the future it may become clearer who should and should not be prescribed appetite suppressants.

Until further research is completed, you should be evaluated by your transplant physician before beginning any weight loss program, and work very closely with your dietitian to determine and develop your best weight loss program.

Gail G. Bridges, PharmD, is a pharmaceutical consultant. 

“Anyone who takes appetite suppressants requires frequent visits with his or her health care provider.”



Parents Touched by Son's Offer

by Michael S. Freel, BA, CPTC, CTBS

Daniel Honaker is a nine-year-old third-grader from Omaha, Nebraska. Like a lot of kids, Daniel thinks about becoming a firefighter, just like his dad, Ray, when he grows up. Or, maybe he'll play baseball. Unlike a lot of kids, Daniel wants to give his mother one of his kidneys.

The doctors who are taking care of his mother, Tanya, in Omaha, have explained to Daniel that he's too small and his organs are too small. But Daniel doesn't care about this, nor does he care about blood and tissue type; he cares about his mother, who he sees getting weaker and weaker. When asked about his mother's dialysis treatments, Daniel says, "She's really sick and comes home tired." Tanya dialyzes three times a week and often has adverse reactions after her treatments.


One time, Tanya returned home from dialysis, collapsed and had a seizure. Daniel was with her and called his father at the fire station. Daniel remained calm, and Ray and the rescue squad arrived in a few minutes to help Tanya. Daniel has seen his mother sick for so long that he understood what was happening. "I watched her and made sure she wouldn't hurt herself or anything," Daniel says.

Beyond the seizure, Ray remembers numerous occasions when Tanya came home from dialysis, suffering from dizzy spells and hot flashes. He says Daniel has always been there to lend a hand and cool her off or retrieve her medications. When his mother needs help in the kitchen, Daniel is there for her. He takes out the trash, does some of the housework and is willing to help his mother whenever she needs it.

"He does more for his mom than he thinks," says Ray. "We really don't like him having to do more, but we think it's extra special that he does."

Daniel is a smart child who knows that his mother's health won't improve without a transplant. That's why he wants to give her one of his kidneys. Tanya says, "I don't think Daniel realizes how much it meant just to have him ask to donate a kidney." Tanya has a very high percentage of reactive antibodies, which makes finding a suitable kidney even more difficult. She received a transplant a few years ago, but her body rejected the kidney, which Daniel attributes to his mother's "stubborn tissues."

Daniel's expression of love for his mother has touched the hearts of all those who know him, as well as many professionals in the field of transplantation. Daniel allows us to experience the frustration that families experience when someone they love is waiting for a life-saving transplant. Sometimes we forget that it's not just the patient who has to go through the stress and anxiety related to a transplant. Having the support of her family has helped Tanya through the whole ordeal. The three-and-a-half-year wait has been difficult, but when Tanya finally gets her new kidney, she says it's going to be time for a vacation. She wants to go to Disneyland. Daniel wants to go to Texas and visit his cousins, and then go to Disneyland.

Michael S. Freel, BA, CPTC, CTBS, is the procurement coordinator for Nebraska Organ Retrieval System, Inc., in Omaha, Nebraska. 

Nine-year-old Daniel Honaker (center) has offered a kidney to his mother, Tanya (left). Daniel's father, Ray (right), calls his son's actions "extra special."

1997 U.S. Winter Games a Mammoth Success



Mammoth Mountain, the home of the U.S. Ski Team and the host of this year's Women's World Cup, was the site for the 1997 U.S. Winter Transplant Games, presented by the National Kidney Foundation. Nestled high in the eastern Sierras in Mammoth Lakes, California, Mammoth Mountain brought transplant recipients from across the nation together to compete in Alpine and Nordic ski events.

The wild storms of the west took a break just long enough to allow for sunny skies, 50° temperatures and 14 feet of fresh snow—ideal for racing! There was close competition among the age groups and impressive skiing by all the participants.

Brian Rothermel, a heart recipient from Denver, Colorado, won the Outstanding Male Athlete Award. Brian, who is a ski instructor, swept the men's downhill category with four gold medals. Diane Wittwer, a kidney recipient from Littleton, Colorado, won the Outstanding Female Athlete Award.

Diane, who is an elementary school teacher, won gold medals in the parallel, dual and giant slalom events, a silver medal in the super giant slalom and a bronze in the 3K cross-country competition.

Other excellent performances deserve mention. Thirteen-year-old Patrick Halabi, from Santa Ana, California, won four gold medals in the downhill events and had the fastest recorded time of all age categories in the "silly" slalom event. Michael Coonfield from South Berwick, Maine, breezed through the 3K cross-country race with a time of 21:12.

Mammoth Mountain proved to be the perfect setting for appealing to the public about the


critical need for organ donors. "While we were competing at Mammoth, more than 15,000 people witnessed our events, each hearing the facts about organ donation over a public address system that was broadcast around the mountain," said Colleen Horan, Transplant Athletics director for the National Kidney Foundation. "When they could see transplant recipients skiing aggressively and competitively on a World Cup course, it made a very powerful impact. Of course, we distributed many organ donor cards throughout the week."

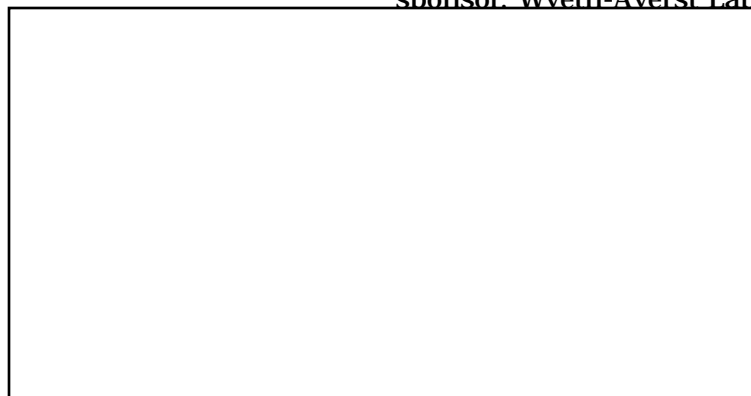
The U.S. Winter Transplant Games would not have been possible without the generous support of principal sponsor, Roche Laboratories; major sponsor, Wyeth-Averst Laboratories; and event

sponsors SmithKline Beecham, Cellular One of Bishop, Kenyon Consumer Products, PowerBar and the National Kidney Foundation of Northern California.

The U.S. Winter Transplant Games, like its sister event, the U.S. Summer Transplant Games, helps educate the public about organ

donation and transplantation issues. The Games also generate awareness in the transplant community regarding the benefits of fitness and well-being for recipients.

The National Kidney Foundation is proud to announce that the next U.S. Winter Transplant Games will be held in conjunction with the Winter World Transplant Games in the winter of 1999. All participants from the United States will compete as part of Team USA against transplant recipients from more than 18 countries. 



Marie Olson, a liver transplant recipient from Battle Ground, Washington, creates some serious snow dust.

National Donor Recognition Ceremony: Transplant Recipients Express Gratitude

by Brian T. Maguire

Attending the 1997 National Donor Recognition Ceremony (April 12-13) was special for me because it was the first donor family conference since I met my own donor family. I thought my feelings might have been different, but to my surprise, I felt even more connected than I did in the past.


I participated on a panel for a workshop titled, "Communications Between Donor Families and Recipients." We shared our experiences and the need to know each other. Many people shared their feelings about meeting their loved one's recipients and the love they feel for them. There was even a donor family whose loved one's recipients will marry each other soon. How wonderful that the family tree can grow!

Sunday's ceremony provided many highlights. Vice President Al Gore announced an exciting new Web page to be launched by the National Kidney Foundation's National Donor Family Council. The page will be an excellent vehicle for donor families to exchange information. Gore also urged for a new American tradition of organ and tissue donation.

Other speakers included Art Buchwald, who discussed his relationship with fellow columnist Erma Bombeck, a kidney transplant recipient who succumbed to kidney disease in 1996. Acting Surgeon General Audrey Manley was proud to be the first person in her position to attend the ceremony. Assistant Surgeon General Ken Moritsugu shared his personal stories on organ donation, as did singer-songwriter David Crosby, a liver recipient. All of the speakers had one basic request—for people to share their personal stories throughout their communities with the goal of educating others.

The Annual National Donor Recognition Ceremony is cosponsored by the Division of Transplantation, NKF's National Donor Family Council and many other transplant-related organizations.

Brian T. Maguire is a kidney transplant recipient.

He is also the vice president of the Manhattan chapter of the Transplant Recipients International Organization (TRIO), Inc. 

Hundreds of donors and donor families were honored at the National Donor Recognition Ceremony. Here, a donor family receives a Gift of Life medal from a recipient.

The National Kidney Foundation recognizes the significant contributions made by Sandoz Transplant, a division of Novartis Pharmaceuticals Corporation, to transplant recipients around the country through its sponsorship of the following NKF programs: The 1998 U.S. Transplant Games; Transplant Chronicles; NKF/Sandoz Research Fellowship; and the NKF Annual Meeting.

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