



Transplant Chronicles

Volume 4

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

Number 4

Giving Back to the Cause After Receiving the Gift of Enlightened Life

by James Redford

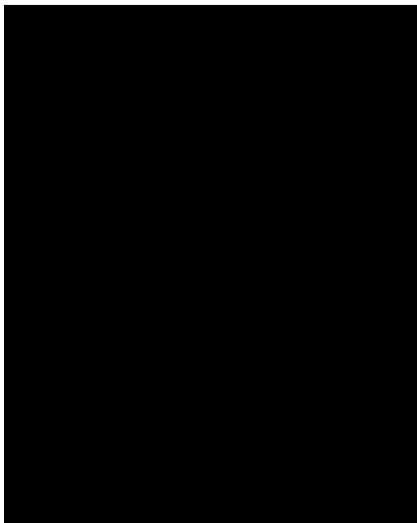
Recently, I was chatting with a good friend of mine who works in the transplantation field.

“You people are amazing,” he said. “Do-gooders would be putting it lightly.”

Exactly what people was he referring to? Transplant recipients. He is continually impressed by how much we seem to give back to the cause.

But there is something he and other professionals cannot fully understand. This activism that is so common among transplant recipients is not a matter of discipline or morality. When you owe your life to the good of others, it’s simply empowering. You realize firsthand the good that can come from selfless choices such as organ donation. Getting involved with the organ donation cause feels instinctive. Recipients will confirm this over and over again.

We know the power of life; we have a lust for it. As clichéd as it sounds, I do feel that I’m having a “love affair” with life. Even bad days have their



James Redford and his daughter, Lena, possibly a third-generation filmmaker

good moments. Things of beauty hold particular sway. The importance of family and relationships moves to the fore. Transplantation is more than the gift of life—it is the gift of an enlightened life.

But it doesn’t come easily. For me, there were many years of pain and uncertainty. Like many people with primary sclerosing cholangitis (a type of liver disease), I was well-aware of my need for a liver transplant long before it was medically necessary. Those were hard times. I alternated between denial and fear. As I grew more ill, I developed an understanding that transplantation works.

And Lord, does it ever work. After a difficult stretch (complications that required the need for two liver transplants), I reached a level of activity that I never dreamed I could. My friends jokingly tell me that I seem to be getting younger while they are getting older.

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Happy New Year to you all! Three months into 1997, I hope all of you are sticking to your New Year's resolutions. This year, as with every year, *Transplant Chronicles* promises to bring you the most informative updated news in the world of transplantation.



Beverly Kirkpatrick

This issue includes the first of a five-part series on vocational rehabilitation, which plays a significant role in patients' lives post-transplantation.

As always, we ask you to send us stories or suggest topics that you would like to see covered in the newsletter. Don't forget, we love pictures. 

*Beverly Kirkpatrick
for the Editorial Board*



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To David for His Gesture of Love

by Steven

A gesture of love . . .

To my brother, whom I love so much,
Though you're always busy, you never get out of touch.

Balanced is your life, filled with love and caring,
An example to follow, with kindness and sharing.

Now that I have your kidney that keeps me going
A sacrifice of love, that's what you're showing.
A change in my life, a positive gesture,
I'll never take it lightly, I'll be thankful forever.

You saved my life, I was gradually dying,
No self-esteem, continually sighing.
New life is mine, I feel better than ever.
Take you for granted, never!

I'll always take care of this organ for sure,
Because in my mind, this organ is pure.
Please keep praying for me that I might be whole,

With God and myself, may my thinking be under control.

The Bible says that "God gives not the spirit of fear
But of a sound mind," let's hope for a cure.
Continue to value the simple things in life,
Like Aunt Pat, Grandma and Jeff—leading the way to that ever-loving Light.

May your life and Sarah's be filled with joy.
And in your children, whether they be girl or boy.
Time is so short, so grab hold of each day.
You're in my thoughts continually, nothing but blessings for you I pray!

God bless you, for your thoughtfulness,

Your brother, Steven 

Pre-Employment Enquiry Guide

This guide kicks off Transplant Chronicles' five-part series on vocational rehabilitation. When applying for a job, you should know what every prospective employer may and may not ask you. Please note that the list below represents the federal government's Equal Employment Opportunity Commission guidelines for what a prospective employer may not ask you before you are hired. State laws may go even further in limiting questions. Some of these questions, such as "person to be notified in an emergency," may legitimately be asked after you are hired.

NAME: You may not be asked to indicate whether you use "Mr.," "Mrs.," "Ms." or "Miss" to precede your last name.

MAIDEN NAME: You do not have to answer this because it may be used by an employer to determine marital status, sex and national origin.

SEX: Your prospective employer may ask this only if one sex is a legally recognized qualification for the particular job.

MARITAL STATUS AND DEPENDENTS: Many states have made it illegal to discriminate based on marital status. Also, you do not have to answer questions regarding your spouse's name and occupation.

AGE: You may be legally asked if you are 18 years of age or older. Other than that, you may be asked your age only if there is a legal business justification for the question.

PLACE OF BIRTH: This cannot be asked because it can be used to determine national origin.

RESIDENCE: A question about whether you rent, own or board is prohibited by law.

CITIZENSHIP: The Immigration Reform and Control Act of 1986 made citizenship discrimination illegal. An employer may ask if you are authorized to work in the U.S.

TYPE OF DISCHARGE FROM THE MILITARY: In some states this is an illegal inquiry.

ARREST AND CONVICTION RECORDS: You may be asked about convictions if a statement nearby (on the application) notes that a conviction would not prevent hiring or if convictions relate to requirements of the job. Another possibility is that your prospective employer states that he or she intends to make a criminal records check.

HEALTH: Medical questions may not be asked of you. Your prospective employer may not refer to medical or physical exams until an employment offer has been made. Height and weight questions may be asked after a conditional offer of employment.

WORKERS' COMPENSATION HISTORY: The Americans with Disabilities Act prohibits this type of question.

DATES OF SCHOOL ATTENDANCE: This can be asked if your prospective employer shows a nondiscriminatory, legitimate business reason, such as to assist with reference checks.

PERSON TO BE NOTIFIED IN AN EMERGENCY:

Your prospective employer may not ask this question because it might suggest marital status.

REFERENCES, FRIENDS AND BUSINESS CONTACTS:

These may be asked of you only if your prospective employer contacts them as a matter of policy. 

James Redford

Continued from page 1

But before transplantation can work, it has to happen; unfortunately, as we all know, it doesn't always happen. There are as many reasons for this problem as there are ways to combat it. I have joined the ranks of many other recipients who are trying to make a difference. In my case, it means using the tools that are available to me—media, especially film. My first project, a documentary film, will follow a year in the life of long-time and recent transplant patients and some who are desperately hoping for a transplant. Most of the filming has been completed. A second, short inspirational film for teenagers is now in preproduction.

Once I have raised enough money to complete these efforts, I will embark on an effort to make sure that the films are seen in as many places as possible. This will include doing some publicity—an important element in

getting the word out. All too often, the film industry and other media are detrimental to the causes, with inaccurate reporting and a fixation on morbid elements. In the case of the television show, "Chicago Hope," the media can be simply irresponsible. If you didn't hear, the network aired an episode in which a man who was declared ready for organ donation (brain dead) suddenly regained consciousness.

As a professional in the film business, this irresponsibility shames and embarrasses me. I have a message of great importance, and I will do what I can do to bring this message to people. I know this and so does my family. My children are growing up with a father because of two families who heeded this message. If I manage to reach only one family, my work will have been worthwhile.

James Redford received a liver transplant three years ago. He is the son of director and actor Robert Redford. 

transAction Council to Hold Inaugural Meeting

The NKF's transAction Council will hold its first open membership meeting on October 31 and November 1, during the NKF's Annual Meeting in San Antonio, Texas. The meeting will provide excellent educational and social opportunities for transplant recipients and their families and those awaiting transplants and their families, in addition to donor families.

Aron Eisenberg, a kidney transplant recipient and actor, who plays the part of Nog on "Star Trek: Deep Space Nine," and Susan Benner, an NKF spokesperson who, last year, donated one of her kidneys to a high school classmate who she hadn't seen in more than 30 years, are scheduled to speak at the meeting.

The transAction Council was established to ensure that today's organ transplant recipients receive the finest possible care. Membership is complimentary. For more information on the council and the meeting, contact Gary Green at (800) 622-9010. 

National Communication Guidelines Await Approval

It should soon become much easier for donor families and transplant recipients to communicate. For more than a year, a work group representing the major transplant organizations and the Donor Family Council has developed, reviewed and revised a document that should help provide guidelines for communication issues at the time of donation and transplantation, and later if donor families and transplant recipients wish to communicate with each other.

Confidentiality and anonymity are still foremost for all those who wish it. However, if it is mutually acceptable to both the recipient and donor family, additional information, including names and addresses, may be forwarded.

The broad philosophy developed by the work group states: (1) Members of donor families and transplant candidates or recipients have a right to receive appropriate information about each other and to engage in mutually acceptable forms of communication; and (2) Implementation of this right shall be facilitated by health care professionals.

Although the document has been accepted by the members of the work group, it must now be published and distributed to the respective transplant organizations for an endorsement. Hopefully, the distribution will begin in early spring.

If you would like a copy of the guidelines or would like to assist in the distribution, please contact Kathleen Casey at the National Kidney Foundation, at (800) 622-9010. 

Keep Yourself Covered:

What Everyone Should Know About Health Insurance and Transplantation

by Cheryl Jacobs, LICSW

No matter when you had a transplant and regardless of your income or type of insurance, most of you will require ongoing care and anti-rejection medications. Staying informed about your health coverage and the programs and assistance that are available is important.

To learn about your health coverage options, talk to your social worker or financial counselor. Every transplant center has someone designated to assist you; this individual can inform you about programs designed for your type of transplant, even if you are not a recent recipient. Even with help, transplantation—especially the terminology associated with it—can be confusing.

Here are some definitions that may be helpful:

Employer insurance: If you or your spouse works, chances are your health insurance is covered by your employer. Study your specific coverage options and choose a plan that best meets your needs. If you are part of an HMO, you should know which providers, services and pharmacies you can use to receive full or partial coverage. If you or your spouse stops working, you may want to continue coverage for up to 18 months. (This continuation is known as COBRA, or the Consolidated Omnibus Budget Reconciliation Act, and should be discussed with your employer prior to leaving.)

Medicare (Parts A and B): You may be eligible for Medicare if you: are 65 or older; have been receiving Social Security disability for at least two years; or have undergone a kidney transplant or chronic dialysis. Part B of Medicare will cover 80 percent of the immunosuppressive drug costs for three years following a transplant. Some states have Medicare HMO plans that cover up to 100 percent of the medication costs for those three years. Contact Social Security at (800) 772-1213, or Medicare at (800) 638-6833, to obtain more information.

Medigap: Some states offer insurance coverage that supplements Medicare. Medigap may cover the remaining costs of approved Medicare services.

High-risk insurance: Some states offer insurance coverage to those who have been denied coverage by other health insurance

companies because of illness or a pre-existing condition. Contact the National Insurance Consumer Help Line at (800) 942-4242, to get the phone number of your state insurance commissioner's office, so you can find out if Medigap or high-risk insurance policies are available where you live.

Medicaid (medical assistance): You may qualify financially for Medicaid, a medical insurance program offered in every state. Medicaid can help with the copayments or deductibles of Medicare if you are a part of Medicaid's Qualified Medicare Beneficiary Program. You can learn more about your eligibility and benefits by contacting your county's Department of Human (or Social) Services or Social Security.

Drug programs: Most pharmaceutical companies have assistance programs that provide their drugs at reduced cost to patients who qualify. Ask your transplant center for the telephone numbers or how to apply for these programs.

Transplant Foundation: Another source of assistance with anti-rejection drugs, for those who qualify financially, is the Transplant Foundation. To receive an application, call (800) 489-3863.

Your social worker may be aware of other local, state or national programs that are available to you. The cost of a transplant is high, but there are places to turn for assistance. You should never have to compromise your health care because of a lack of coverage. If your insurance provider denies you a service, inquire about the process to appeal the decision, and ask your doctor to assist you with the appeal.

Some of you, with the help of transplant-related groups and state legislators, are addressing the financial cost of transplantation and changing coverage policies as a result. As insurance coverage and managed health care continue to define services and care for all of us, it is important that the insurance providers understand what transplant recipients require to maintain a healthy lifestyle. 

Tissue Donation: The Unsung Story

by Teresa Shafer, RN, MSN, CPTC

Donated corneas, bone, muscle, skin, heart valves and other tissues help an estimated 450,000 or more Americans every year.

A bright young woman preparing for college, Denise Rozboril of Fullerton, California, didn't pay much attention to the bump on her leg. It was such a minor thing. A year after it first appeared, Denise finally remembered to mention it to her doctor. X-rays showed a mass on the bone, and though there was no sense of urgency, Denise was sent to an orthopedist. Further testing revealed a hole in the bone, and Denise was referred once again, this time to Leisure Yu, MD, PhD, associate professor of orthopedic surgery at Loma Linda University Hospital.

Denise was then a student at Oklahoma State University, planning her career in nursing. The news that the tumor must be biopsied was terrifying. "It hit me hard," Denise remembers. "I never thought it could happen to me." The results of the biopsy showed a localized, aggressive adamantinoma—a malignant tumor that generally does not spread. Before the biopsy, Denise was warned that she might awake from surgery to find herself on chemotherapy, but with his diagnosis confirmed, Dr. Yu chose to remove the affected bone and muscle surgically and reconstruct the area using a donated bone and tissue graft. This procedure, called a *segmental resection* of the tibia, allowed Dr. Yu to replace Denise's damaged bone with healthy shinbone recovered from a donor.

Recovery was slow, as the graft was given every chance to heal. Denise was kept completely off her leg for three months and only allowed to walk without crutches after five months. The surgery took place in April 1995, and Denise wore a leg brace until December. In another year, she will be back to her normal activity. "Dr. Yu tells me I can

never run again, but that's okay," she says. "I didn't run before my surgery." Now 20, Denise is back in school. Dr. Yu carefully monitors her progress, and reports that the bone graft has been fully incorporated to Denise's own bone—an outcome that constitutes a cure.

Not long ago, Denise's prognosis might have been radically different. There was a time when the majority of patients with bone malignancies faced amputation of their limbs. Today, an estimated 80 percent of these patients keep their limbs, thanks to increasingly sophisticated bone and tissue transplant techniques.

An estimated 450,000 Americans receive tissue transplants each year, ranging from sight-saving corneas and hip replacements to bone repairs and heart valves. The availability of donated bone, tendon and ligament tissue for transplantation has revolutionized the practice of sports medicine, thereby extending the playing careers of athletes from sandlots to stadiums.

The average American can be forgiven for not knowing about the benefits of tissue transplantation. Although 25 tissue transplants are performed for every organ transplant, the lion's

share of attention has been garnered by the drama of organ transplantation. When a celebrity receives an organ transplant, it is headline news. When an equally popular public figure receives a tissue transplant, little attention is paid. Patients and their families may not even realize that donated tissue made their recoveries possible.

With the exception of blood and bone marrow, virtually all allograft tissue (an allograft is a transplant from one individual to another) is donated after death. As with organs, the need for donated tissue is growing at a much faster rate than donation. In part, this supply-and-demand

"When a celebrity receives an organ transplant, it is headline news. When an equally popular public figure receives a tissue transplant, little attention is paid."

problem is due to rapid advances in the science and practice of transplant medicine and the increase in medical applications for tissue. Population shifts also contribute to demand, especially among the maturing baby boomer generation and their parents, who are living longer and healthier than their predecessors.

Rad Haley of Houlka, Mississippi, will celebrate his 80th birthday soon. "Right now," says his daughter, Shelby Fowler, of Antioch, Tennessee, "Dad is twiddling his thumbs and waiting for the day he can plow the garden." A lifelong farmer, Rad still keeps his farm going with his own labor. "He has repaired the roof, put up new siding, and the last time we visited he was re-doing the plumbing," Shelby says. What makes his pace even more remarkable is that Rad has undergone hip replacement and two spinal fusion surgeries. His first neck surgery, using his own bone, didn't work, so donated bone was employed in a second and successful fusion.

The availability of donated tissue helps Americans of all ages to recover from a growing list of debilitating conditions. Viewers of "The Montel Williams Show" last year saw an emotional meeting between Tom and Becky Sander of Adelanto, California, and four-year-old Beatriz Garcia. The Sanders recounted the death of their 14-year-old daughter, Annette. The family had agreed to donate Annette's corneas and a heart valve, and on national television, they were introduced to young Beatriz. Born with double cataracts and glaucoma in both eyes, the little girl had undergone a long series of surgeries, culminating with the transplant of one of the corneas donated by Annette Sander. For the first time in her life, Beatriz could see. The Sander and Garcia families have since become close, and they all look forward to Beatriz's second cornea transplant later this year. For Tom and Becky Sander, now active supporters of donation, meeting Beatriz Garcia gave special meaning to their tragic loss: "It was like a part of Annette was still alive," they said.

The Sanders were, in a sense, fortunate to have the opportunity to donate for their daughter. Too many Americans, including medical professionals, know little or nothing about tissue donation and the donation process. For example, the donation of solid organs—heart, lung, kidney, pancreas and liver—can occur only when a patient is declared brain dead and dies in a hospital where mechanical support and

ventilation are available to keep the organs viable. Tissue donation, however, can occur in a much wider range of circumstances.

Transplantable tissue does not require a blood supply, so brain death and artificial support are not essential criteria (although organ donors can donate tissues as well). This means that individuals who die of heart failure or who die away from a hospital can be tissue donors. Even when an autopsy is required, as for homicides and some accident victims, tissue donation is a realistic possibility. Because tissue can be donated under a variety of conditions, the potential pool of tissue donors is significantly larger than for organ donors.

Another important distinction between tissue and organ donation is that most tissue, after it is processed, can be stored for later use. Organs, on the other hand, must normally be transplanted within 48 hours of donation. Donated tissues are subjected to rigorous testing and processing procedures before they are made available to transplant surgeons by bone banks, eye banks and skin banks. For tissues, there is no single national waiting list comparable to that of the United Network for Organ Sharing (UNOS), the nonprofit body contracted by the federal government to manage the matching and allocation of organs. The nation's tissue banks are, however, regulated by the Federal Food and Drug Administration.

The value of tissue donation is that it can affect so many lives. A single tissue donor, depending on the extent of the donation, can provide tissue for as many as 50 people. From the child with the congenital heart-valve defect to the cancer victim facing the loss of a limb, from the promising athlete with a potentially career-ending injury to the older citizen with crippling arthritis, from the burn patient to the visually impaired patient, the gift of just one tissue donor holds the promise of faster healing, improved function, restored mobility and the return to healthy and productive living.

For people like Denise Rozboril, Rad Haley, little Beatriz Garcia and the hundreds of thousands more whose lives have been and will be changed by the gift of tissue donation, it's time for the story to be told.

The preceding article was adapted with permission from the Musculoskeletal Transplant Foundation. 

NKF Testifies Before Congress Regarding Organ Donations

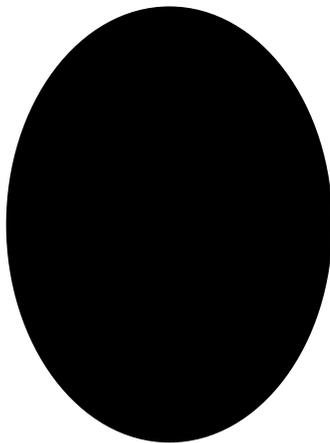
*I*n a statement presented December 11, 1996, before the U.S. Department of Health and Human Services, NKF Immediate Past Chairman, Bruce Bowden, focused on the need for new thinking in the national approach to increasing available organs for transplantation. According to Bowden, "If we could enhance the overall availability of organs, we might not have to face the difficult life-and-death choices which permeate the development of liver allocation policy."

On behalf of the NKF, Bowden proposed increasing organ donations through the following measures:

- removing financial disincentives experienced by living related donors (Bowden claimed, "The superior graft survival rates with living related donation would justify any additional expenditure.");
- permitting a test of the efficacy of financial incentives for cadaveric organ donation (Payment would be limited to funeral or burial expenses.); and
- extending Medicare coverage for anti-rejection drugs for the life of the transplant, not merely 36 months post-transplant, to cut down the need for second and third transplants.

Nearly 50,000 Americans are currently awaiting life-saving transplants. Nine to ten die each day while waiting.

The National Donor Family Council also testified at the hearing. For a brief summary, see page 10. 



A. BRUCE BOWDEN

Reduced Gravity, Tang and Organ Donation Cards

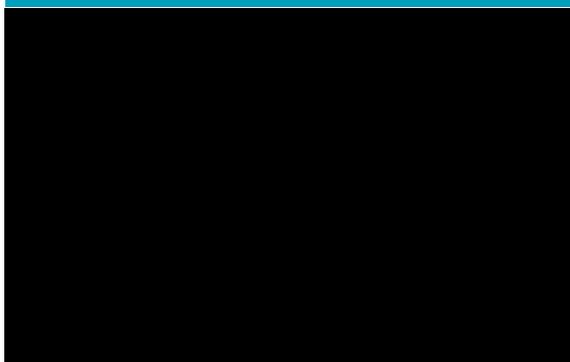


photo courtesy of NASA

On December 2, crew members of the STS-80 Columbia shuttle mission took time out to sign donor cards while in orbit on the space shuttle. In this photo, taken directly from the video, Tom Jones, of Baltimore, Maryland, is signing a donor card. At Tom's left is Tammy Jernigan, of Chattanooga, Tennessee, and behind Tom is Story Musgrave. In addition to this event, NASA is distributing organ donor cards to visitors at its facilities across the nation. For more details see the story on page 10.

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January 29 - February 1, 1997
Mammoth Lakes, California**

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Transplant News Digest

From the editors of Transplant News

Marathon Public Hearing on Liver Allocation Raises More Questions Than it Answers; UNOS Modifies Policy

by Jim Warren, editor and publisher

When the Department of Health and Human Services (HHS) announced that more than 100 people had requested time to testify at its public hearing on liver allocation and organ donation, it became obvious that this would not be a normal government inquisition.

The stated purpose of the three-day hearing, held December 10-12 in Bethesda, Maryland, was to see if a consensus could be reached on what the liver allocation policies in the U.S. should be and who should set them. After 21 hours of tantalizing, thoughtful, passionate, redundant and ultimately numbing testimony by 20 panels, the basic questions remain:

- Should liver allocation policy be mandated by federal regulations issued by HHS or by the United Network for Organ Sharing (UNOS), with HHS providing oversight?
- Under the new UNOS policy of transplanting the sickest patients first, should livers be allocated first on a local basis or should the organ go to the sickest patients on a national waiting list?
- Is an individual's or a family's decision to donate influenced by whether the organ is transplanted locally or goes to the patient most in need of the organ, regardless of location?
- Finally, is the debate being fueled by honest differences of opinion over what the fairest liver allocation policy is or by the economic difficulties of the transplant system, caused by the ever-growing donor shortage, which pits large centers against small centers?

In his opening statement, Philip Lee, MD, chair of the hearing's panel and the assistant secretary for health at HHS, said the hearing had been convened as part of the efforts by HHS "to assess the issues associated with assuring the most effective, efficient and equitable policies for patients awaiting transplants. . . . The department will review the results of these

hearings, as well as the written and other public comment we have received, in preparing to submit a final rule to OMB [Office of Management and Budget]." Upon announcing the hearing, HHS Secretary Donna Shalala implied that regulations would be announced within three months of the hearing.

James Burdick, MD, UNOS president, announced in his opening testimony that the Executive Committee approved a modification of the newly adopted liver allocation policy, designed to ensure that patients with chronic liver disease continue to have a "safety net" should their condition deteriorate. (The new policy, which redefined Status 1 to include only patients suffering from acute liver failure, with chronic patients relegated to Status 2, caused a minor uproar in the transplant community.)

The change included adding a grandfather clause in the new policy, allowing Status 1 and 2 patients who were hospitalized when the new policy was implemented on January 20 to remain eligible for an emergency status upgrade to be transplanted.

The three-day hearing was marked by fractious testimony over how the system should work. Most physicians supported having UNOS administer the Organ Procurement and Transplantation Network (OPTN) and urged the government not to issue allocation regulations, i.e., to maintain UNOS' voluntary regulations with HHS oversight. Most patients urged HHS to issue strict regulations designed to protect their interests.

The largest liver transplant centers called for HHS regulation and the development of a single national waiting list or at least a "super-regional sharing list"; while smaller centers supported the current system. (Some of the large centers include: University of Pittsburgh Medical Center; University of Nebraska Medical Center; Baylor University Medical Center; UCLA Medical Center;

University of California, San Francisco; and Mt. Sinai Medical Center in New York.)

The debate over the importance of local donation versus national donation in a family's decision to donate provides an interesting example of the divisions in perception and insight into the small center-large center struggle.

Here are two different viewpoints that represent most of the pro-con testimony delivered:

J. Steve Bynon, MD, director, Liver Transplant Program, University of Alabama at Birmingham: "Although there is no 'hard' data to suggest that local utilization of organs increases procurement, it is the general consensus by both transplant physicians and organ procurement personnel in our region that it does promote donations. Imagine the effect of a [local] transplant recipient telling his or her story to those health care providers working in the ICU that provided the liver that made the recipient's [new] life possible. Can anyone think of a more powerful way to put a positive outlook on an unfortunate tragedy and increase the confidence and ability of persons to ask for consent? This is the foundation strong OPOs [organ procurement organizations] are built upon."

Vicky Crosier, donor mother, member of the NKF's National Donor Family Council: "The gift we give takes self-sacrifice and can be a difficult decision at such a stressful time. Because of this, we hope that once we agree to donate, the organ has the best possible chances for survival and the decision to whom the organ goes is not based on politics, greed or chance, but that it goes to those who will most benefit.

"A popular opinion," Crosier continued, "is that one reason we agree to donate is the desire for the organs and tissues to stay in our community. We are credited with supporting 'local primacy.' However, this hypothesis has never been validated by asking those most intimately involved—donor families. The National Donor Family Council hopes more research can be done to either substantiate or refute this theory."

Astronauts Sign Organ Donor Cards While Orbiting in Space Shuttle

In one of the highest profile events conducted to promote organ donation, two astronauts received international attention on December 2 when they signed organ donor cards while orbiting in the space shuttle (see photo on page eight).

Tammy Jernigan, of Chattanooga, Tennessee,

and Tom Jones, of Baltimore, Maryland, crew members of the STS-80 Columbia shuttle mission, were given the idea by Anne Conforti, a nurse at TransLife/Florida in Orlando. "I've seen many shuttle lift-offs in Florida, and it occurred to me that my patients could be helped if NASA took awareness to new heights," Conforti said.

Health and Human Services Secretary Donna Shalala said the astronauts' action made "all Americans proud."

"In the hearts and minds of their fellow human beings, they've once again taken a giant step for mankind," Shalala said.

"I'm proud NASA was able to feature this life-saving program," said Daniel Goldin, NASA administrator. "When Tammy and Tom signed their donor cards more than a hundred miles above the Earth, it highlighted the critical need for organ donations, and made it clear that the work we do in space benefits life on Earth."

NASA officials have endorsed a variety of collateral public service activities over the years. This year, organ and tissue donor cards are being distributed to visitors at NASA facilities across the nation.

Photographs and a video of the signing by the astronauts are available free of charge to the transplant community. Contact Eileen Hawley at the NASA news desk, Johnson Space Center, at (281) 483-5111. Or, call Kathy Driscoll, TransLife public relations manager, at (407) 897-5560.

CDC Issues Relax HIV Screening Guidelines Slightly

The Centers for Disease Control and Prevention (CDC) have slightly relaxed the screening guidelines for testing potential organ donors for the human immunodeficiency virus (HIV). Responding to criticism from the organ procurement and transplantation community that guidelines for screening organ donors for HIV were strict and impractical, the CDC issued the clarification of the guidelines, originally published in 1994, in the November 1 edition of the *Federal Register*.

"Reports from the organ procurement and transplantation community have indicated that, in attempts to ensure the highest level of safety, the guidelines have been interpreted in a way which has further compromised the already limited supply of human organs," the CDC observed in the notice.

The 1994 guidelines required that potential donors who test negative for HIV, but have “one or more behavioral exclusionary criteria may be accepted as donors if . . . the risk to the recipient of not performing the transplant is deemed to be greater than the risk of HIV transmission and disease (e.g., emergent, life-threatening illness requiring transplantation when no other organs/tissues are available and no other life-saving therapies exist). In such a case, informed consent regarding the possibility of HIV transmission should be obtained from the recipient.”

The new guidelines address the use of organs from potential donors who test HIV-antibody negative, but have behavioral risk factors for the virus. The guidelines also make it clear that the transplant center, not the OPO, is responsible for obtaining patient consent to accept an organ from a such a donor. The CDC emphasized that the guidelines apply only to organ donors and do not change guidelines required for screening tissue, blood and other donors.

The CDC’s new guidelines read, in part, “The decision to accept an organ for transplantation should be made after consideration of the relevant risk factors for the individual recipient and with recognition of the very low incidence of HIV transmission in such situations.

“In accepting an organ for transplantation, transplant teams should assess immediately the medical and social information from the organ procurement organization regarding the potential donor. In the context of the current organ shortage, transplant teams are encouraged to accept and transplant organs from medically appropriate donors who test HIV-antibody negative but have behavioral risk criteria for HIV infections, after the transplant teams have discussed the risks and benefits with potential recipients and/or their families,” the notice said.

The CDC also pointed out that, as in the original 1994 guidelines, organ transplant recipients should be tested for HIV infections three months after receiving their transplants.

For further information contact Martha Rogers, MD, Division of HIV/AIDS Prevention, CDC, Mailstop E-45, 1600 Clifton Rd., Atlanta, GA 30333. She can be reached by phone at (404) 639-6130.

Hospitals’ Role Main Focus of Kennedy/ Moakley Hearing on Organ Donation

Many hospitals not only fail to produce sufficient numbers of organ and tissue donors, they often do not even approach potential donors and their families in the first place, members of a congressional field hearing were told September 30 at Harvard Medical School in Cambridge.

The two-hour hearing on organ and tissue donation in Massachusetts, presented by Sen. Edward Kennedy (D-MA) and Rep. Joe Moakley (D-MA), produced a variety of testimony that focused mainly on the hospital’s role, or lack thereof, in the donation process.

“One-third of the families in hospitals are not even offered the option to donate,” Moakley observed in his opening statement.

Although Kennedy was unable to attend his own hearing because he had to remain in Washington for a vote on the U.S. budget, the event attracted a full house. Moakley, who received a life-saving liver transplant in July 1995, conducted the hearing. He told participants he was “feeling great,” and there is no trace of rejection.

Representing the Harvard School of Public Health (HSPH), one of the hearing’s hosts, Lisa Berkman, PhD, said she views the shortage of organs as “an important public health problem” that can be solved “in a realistic time frame” by using the tools of public health. Berkman is a professor of health and social behavior and epidemiology, and chair of the Department of Health and Social Behavior at the HSPH.

Sheila McIntyre was among the eight individuals who presented oral and written testimony. McIntyre, who donated the organs and tissues of her husband, said she was not approached by the hospital and believes she “would not have been asked to consider donation.”

Although federal and state legislation mandates that hospitals ask family members about donation, McIntyre testified, “If the physician feels that the next of kin ‘can’t handle it’ [emotionally], the request need not be made. I believe very strongly that the hospital personnel do not have the right to make that decision for the family. The loss is so great—nothing can make it worse. . . . For whatever reason, should

the family decline, that's OK, but no one should be denied that source of comfort."

Steven Gortmaker, PhD, a senior lecturer in HSPH's Department of Health and Social Behavior, testified that the key to increasing donors lies within the working relationship between the hospital and OPOs. Gortmaker said, ". . . rates of asking eligible families can improve dramatically . . . when OPOs perform medical record reviews in large hospitals using a validated methodology, inform the hospitals of the findings and provide education on current donor criteria and referral procedures."

When such procedures were followed in a study done from 1990-1992, ". . . rates of asking eligible families to donate increased from 69 percent to 83 percent," Gortmaker said. "By instituting 'best demonstrated practices' for the organ donation request [i.e., when, where and by whom donation is offered], we estimate that the number of organ donors could increase by 5,000 per year, making transplants available to an additional 16,000 patients per year."

Carol Beasley, managing director of the Partnership, echoed Gortmaker's remarks: "Our research . . . shows that families who had a more satisfactory experience in the hospital are more likely to donate," she said. "Similarly, families that understand that brain death is really death are far more likely to donate than families who are confused about this. These factors are almost completely under the control of the hospital staff, not the OPO."

Charles Fiske, an outspoken critic of the present national transplant system, targeted much of the blame for the public's refusal to donate on the fairness issue, real or perceived. "When the public feels the system is fair, opportunities and attitudes toward donation can be affected," Fiske testified. "Any efforts to increase organ donations must be attentive to whether the current system is perceived as fair, regardless of residence, race or economics. Though "full disclosure of the facts may cause some anxiety to patients," he added, such knowledge may at the same time "encourage potential donor families that their participation is the only solution to a regional and national problem."

Fiske gained national attention in 1982 when he went directly to the American public in what ultimately was a successful attempt to get a liver transplant for his nine-month-old daughter, Jamie. The resulting publicity is widely cited as one of the key elements in persuading Congress to establish the current national transplant system.

Fiske said Jamie, who is now 14 years old and a freshman in high school, is a "prime example that transplantation works."

"On behalf of all patients and their families," he concluded, "I urge you to continue to demand that the organ transplant system be fair and equitable for all citizens."

Children's Bell Tower Unveiled

The Children's Bell Tower, a unique monument created by San Francisco sculptor Bruce Hasson in memory of Nicholas Green, was unveiled on October 26 at Bodega Bay, California.

Nicholas became a worldwide hero two years ago when he was killed by bandits in Italy and his parents, Reg and Maggie Green, donated his organs. Seven Italians ultimately received life-saving organs from Nicholas (*Transplant News*, October 14, 1994). The monument has been in the planning stages for a year and is dedicated to children everywhere, Reg Green said during the dedication.

"We've tried to create a place of pilgrimage, a place where any parent can come for solace or inspiration, a place that reminds us of the fragility and preciousness of young life, where mothers and fathers will want to put their arms around their children or hold each other's hands," Green said.

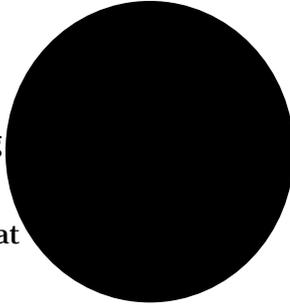
The monument, which consists of 120 bells donated by Italian individuals, schools and corporations, is 18 feet high. The centerpiece is a majestic bell donated by the Marinelli foundry, which has been making bells for the papacy for more than 1,000 years. The bell has been blessed by Pope John Paul II. The sculpture contains the name of Nicholas and the seven recipients, and is located on the west side of Highway 1 at the end of Bodega Bay. 



Liver Cell Transplantation

by R. Patrick Wood, MD, FACS

Liver transplantation, using whole or partial organs, has become a very successful procedure, saving thousands of lives each year. It has also created a demand for donor organs that far exceeds the supply.



R. Patrick Wood

More than 7,200 people are awaiting liver transplants, and last year, fewer than 4,000 liver transplants were performed. During the past four years, at least 800 people have died waiting for a liver transplant. Any procedure that would allow more patients to receive transplants would benefit those who are waiting. Fortunately, medical science is responding with innovative techniques that make use of individual liver cells.

Most patients who have chronic liver disease require the removal of the damaged liver and the replacement of a new liver. However, it is possible to supply those who have acute liver failure and children who have a metabolic liver disease with liver cells rather than a whole-liver transplant.

Two liver-cell transplantation techniques have been performed successfully in the lab and in a small number of patients. One involves procuring liver cells from cadaveric livers that are not suitable for transplantation, or using parts of the liver that are not used when only a segment of the liver is transplanted. With this technique, liver cells can be produced and frozen indefinitely. Eventually, a bank can be developed that will encompass all blood groups and provide enough liver cells for multiple infusions into a single patient. In animals, liver cells have been infused either directly into the liver through the portal vein or into the spleen.

For patients with acute liver failure, liver cells can be used for support until the patient's liver recovers or a cadaveric donor liver can be located. For patients with a metabolic liver disease, liver cells can potentially cure the disease by supplying missing enzymes or proteins. Because these liver cells are from unrelated donors, recipients require anti-rejection medicines to prevent the body from

destroying the infused cells, which must function permanently.

The results have been mixed, but it appears that this technique may be useful in treating acute liver failure. Patients who develop an organ system failure as a result of chronic liver insufficiency may also be helped by this technique. These patients could be treated with a liver-cell infusion as support until their liver can recover somewhat or a suitable donor liver is found.

The other type of liver-cell transplant will be geared toward children with metabolic liver diseases, after the technique graduates from the lab to the operating room. These children are commonly missing a specific enzyme or protein that can often be linked to an abnormality in a specific gene. If the missing gene can be implanted into the child's liver cells, then the liver disease can be cured without the need for a whole-organ transplant. With this procedure, the left lobe of the patient's liver is removed and taken to a lab where sample liver cells are gathered. Using genetic engineering techniques, the missing genes are spliced into the cells, which are infused back into the remaining portion of the liver. The advantage is that the cells are the patient's own, and there is no need for anti-rejection medication.

While this procedure has been performed successfully in labs, there has been only one clinical case, which involved a child with a form of metabolic liver disease. The results were promising, but didn't result in a cure. Some issues still need to be addressed, such as the number of liver cells that must be genetically altered to provide adequate liver function; and whether these cells will function indefinitely.

Due to the severe shortage of available donor livers, the techniques of liver-cell transplantation must be considered. For patients with normal livers—with the exception of a missing enzyme or protein—the genetic manipulation of the cells or the infusion of a cadaveric donor's liver cells are both possible treatments. For patients with acute liver failure or liver insufficiency from chronic liver disease, the use of cells procured from cadaveric donors is a possible treatment. 

keeping fit



A Cool Workout

by Vanessa Underwood, BS, AFAA, ACE

Hiding under a down comforter, donning flannel PJs, lounging on a comfy couch and exercising the remote control may be the preferred sport for the winter months, but perhaps it's time to take a second look outside. Why not go play in the snow?

The beauty of winter can enhance your mood as well as your fitness level. Remember when you spent hours sledding, ice skating, sliding, throwing snowballs and making snow angels and forts? My memories of winter are filled with fun and games. But do we remember how to play?

The joy of winter can be revived through a variety of sports. Not sure which one is for you? Take a look at your personality; if you are adventurous, then perhaps you may enjoy a snowboarding lesson. How about downhill skiing? (This way you can get fit and ready for the next NKF Winter Transplant Games!) If you prefer a more gentle sport and want to enjoy scenery while getting great aerobic workouts, try cross-country skiing or buckle into a pair of snowshoes and hit the trails. If none of these sports appeal to you, perhaps you want to stick with ice-skating or set out for a nice brisk walk. Don't forego exercise because it's cold out! Dress in layers, wear proper clothing, use safe equipment and go for the cold, er, I mean gold.

To enjoy any of these sports you need to get in good condition, and if you are in good condition, it is vital that you stay that way throughout the winter months and into your future. Each of these winter sports requires lower body strength, lateral training, stability and balance. Your leg

muscles propel you, which is why lower body strength is so essential. The side-to-side movement that is common in snow and ice sports makes lateral training important. Balance conditioning will not only improve and enhance your performance, but you will also look and feel better.

The following exercises will strengthen the quadriceps, hamstrings, buttocks and calves, and can be done at home.

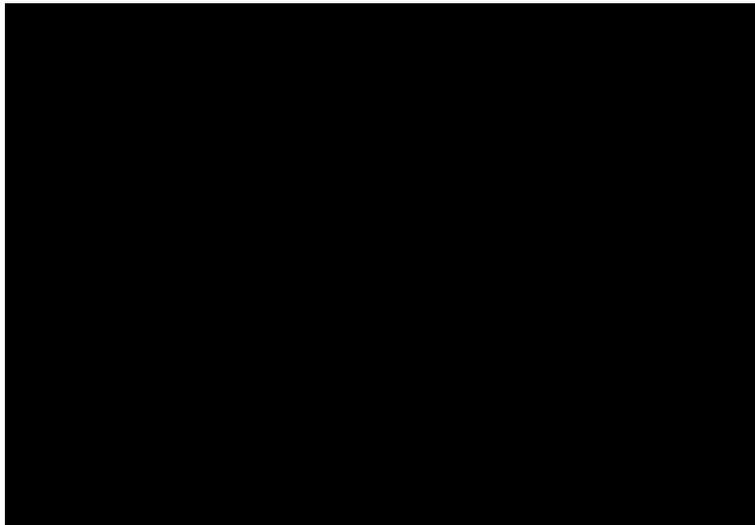
Alternating Dumbbell Lunge: Stand with your feet hip-width apart and your knees slightly

bent. Contract your abdominal muscles. Now, hold a dumbbell by your side in each hand, palm facing inward. Step as far forward as possible with your left foot, bending your left knee, which should be directly above your ankle. Your thigh should be parallel to the floor. Keep your right leg fairly straight and lift your right heel, but do not lean forward. Push off

from your left foot to return it to the starting position. Repeat with your right leg. Do one to three sets of 10-15 reps on each side.

Half-Squat (with or without weights): Stand with your feet hip-width apart, knees relaxed, pelvis in a neutral position, rib cage lifted, abdominal muscles contracted and body weight over your heels. Bend your knees as if you are going to sit in a chair, until your thighs are halfway between parallel and perpendicular to the floor. Straighten your legs to return to the starting position. Do one to three sets of 10-15 reps.

Step Up (with or without weights): You can use an aerobic step if you own one, or you



Vanessa and her daughters, Caroline and Katherine, leave the remote control behind and extend their triceps.

can use the stairs in your house. Face the step and hold the hand weights by your side (if you are using them), palms in. With your abdominal muscles contracted and chest lifted, step up with your right foot. Then, step down again, right foot first, then left. Repeat, alternating lead legs. Do one to three sets of 15-25 reps with each leg. Add weight according to your fitness level, but do not exceed 20 pounds per hand. Rest between sets for 30-60 seconds.

To strengthen your abdominal, back and hip flexor muscles, try the following exercises:

Freehand Squat-Jump: Stand with your feet hip-width apart, arms crossed in front of your chest, knees slightly bent and abdominal muscles contracted. Bend your knees to squat until your thighs are parallel to the floor, keeping your body weight on your heels. From this position, jump as high as you can, keeping your body as vertical as possible. Try to land in the same spot you started from, and then immediately squat to repeat the entire squat-jump combo, smoothly and with control. Do one or two sets of 10 repetitions. Rest for three to five minutes between sets.

Crunch Combo: This exercise is a combination of crunches and rotations. Lie on the floor with your knees bent, feet flat and

lower back pressed into the floor. Place your thumbs behind each ear so your fingertips are touching but not clasped. Lift your head, neck and shoulders upward, keeping the elbows wide. When your shoulders clear the floor, rotate your torso toward your right knee, leading with your shoulder, not the elbow. Keep both hips on the floor. Return to the center position and lower. Repeat, this time rotating to your left. Always lift first before rotating. Do two to three sets of at least 10. Do as many as you can in good form and rest when you need it, not when you want it. Slowly build up your strength.

Remember, these exercises are specifically designed for winter activities. Some of the exercises are for individuals who are at an intermediate or advanced level of fitness. Beginners (those of you who have been exercising three months or less) should start slowly.

If you belong to a gym or have equipment at home, check out the chart below for some very sport-specific exercises to get you up and ready for a fit and fun winter. Have a healthy winter and enjoy your outdoor activities.

Editor's note: Be sure to check with your doctor before beginning any of these activities, and remember to work at your own pace and fitness level. 

Vanessa's Cool Workout

| SPORT | CARDIO-CONDITIONING | SPORT-SPECIFIC STRENGTH |
|----------------------|--|--|
| Snowshoeing | Treadmill on an incline Biceps curl Lat pull-down Heel raises | Triceps extension |
| Downhill skiing | Step aerobics Stationary cycling Rowing machine Bent-over barbell row | Leg extension Leg curl Triceps extension |
| Cross-country skiing | Treadmill Cross-country ski machine Leg curl Leg extension Bent-over barbell row | Lat pull down Triceps extension |
| Ice-skating | Stationary Cycling Rowing Machine Skating Machine | Bent-over row Hip abduction |

Growth Retardation Affects Kidney and Liver Transplant Recipients

by Ira D. Davis, MD

Growth retardation, or short stature, is a serious problem in children with chronic renal failure (CRF) and liver failure, and creates a challenge in post-transplant rehabilitation. According to the North American Pediatric Renal Transplant Cooperative Study (NAPRTCS), a registry of children with CRF requiring transplantation in North America, 98 percent of children were taller than a typical child with CRF of the same age. In another study, almost two-thirds of the children with significant CRF experienced growth retardation. Children undergoing chronic dialysis also display significant growth retardation. Children with liver failure tend to experience impaired growth as well, but it is not as severe as it is in children with CRF. Studies show that height measurements of children with liver failure are typically slightly below the average for children of the same age.

Children with CRF may suffer from short stature prior to transplantation, especially if CRF begins during infancy. Resistance to growth hormone, a substance that is responsible for normal growth of bone and cartilage, may cause short stature. Malnutrition also accounts for poor growth in these children and can be caused by inadequate caloric and protein intake, poor appetite, higher-than-normal caloric requirements and protein losses on dialysis. Water and electrolyte disturbances, calcium and phosphorus imbalance and infection can also contribute to growth retardation.

In children with liver failure, malnutrition is the primary cause of growth retardation. Malnutrition occurs because of poor appetite, insufficient absorption of nutrients from the intestine, decreased production of proteins by the failing liver and chronic illness with serious infections. Insufficient vitamin levels for the healthy growth of bone and cartilage also contribute to the short stature in children with liver failure.

Kidney transplantation, it might be assumed, would foster dramatic improvements in growth rates of children with CRF; however, long-term follow-up studies demonstrate that although the rate of growth may increase following kidney transplantation, it usually does not occur fast enough for children to attain normal adult height. According to one study, only 25 percent of children transplanted before the age of 15 attained an adult height above the bottom three percent of the normal range. A child's age at the time of transplantation, the amount of prednisone prescribed and renal function all contribute to the lack of significant post-transplant growth.

According to the NAPRTCS, children who receive a transplant before they reach their first year showed the greatest improvement in growth during the five-year period following transplantation, while children who receive a

transplant between one and five years showed improvement in growth, but to a lesser extent. Older children failed to show significant improvement in post-transplant growth rate.

Prednisone is known to have an adverse effect on linear growth, but how it does this is not fully understood. Several

strategies have been adopted in an attempt to improve post-transplant growth. One approach is to withdraw prednisone after a rejection-free period of six to 12 months following transplantation. Although some children show significant improvement in growth when prednisone is discontinued, a number of children develop severe kidney rejection, requiring high-dose prednisone therapy to continue.

Another strategy to improve growth is to taper the prednisone to an alternate-day dose of 0.50 milligram/kilogram of body weight in children with stable post-transplant renal function. Acceleration in growth rate is commonly seen after one to two years without a detrimental effect

“Children with CRF may suffer from short stature prior to transplantation, especially if CRF begins during infancy.”

Continued on page 19

Empowering the Health Care Consumer

by Maurie Ferriter, BS

As transplant recipients, we must get acquainted with important health care terms and the concepts they represent.

When people have a broken leg or need an appendix removed, they often act like patients. These conditions are *acute*, which means they run a short, but severe, course. After the leg is out of the cast or the appendix is removed, people continue on with their life as if they never had a problem.

As transplant recipients or people awaiting a transplant, our medical condition is *chronic*, meaning we will have to deal with it for the rest of our lives. We must learn to act like *consumers*, not patients with acute conditions. We must obtain all the information we can about our illness so we can make informed decisions about our health care.

As transplant recipients with a chronic condition, we must *empower* ourselves. There is an old proverb about a parent and child walking by a river. The child falls in the river, and the parent pulls the child from the water, saving his life. The child then feels indebted to the parent for the rest of his life. If the parent had taught the child to swim early in life, he could have swum to safety and saved his own life. The child would not feel as if he owed his life to his parent, and the parent would have known that the child was capable of saving his own life if the same thing happened again. This is empowerment.

We have the ability and the duty to empower ourselves and others who are in the same situation as we are. Think of the possibilities that could open up for us as individuals: the world would be full of swimmers! We need to be aware of what is going on in our health care and what might be ahead of us. We need to become involved in the political process.

State control of Medicaid and Medicare is substantial. The rise of managed care and access to physical, mental, vocational and functional rehabilitation are also significant. The notion of *one-door access* to rehabilitation is being

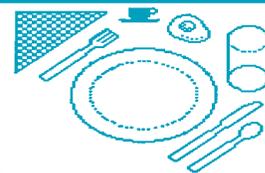
discussed at the national and state levels. Under such a system, everyone would go through the same process, with the same services available to them, regardless of their disability. Many people believe this would lead to a “survival-of-the-fittest” system, with agencies and health care systems picking the easiest cases to deal with. People with severe or time-consuming needs will not have access to services.

As transplant recipients, most of us can identify with the need for physical rehabilitation after major surgery. Many of us also know people who have needed to change jobs, go back to school or receive training. How these issues play out will have a major impact on our future. If we choose to be passive patients, we are letting others with varied interests decide about an important part of our future. If we are informed consumers, we at least have had the opportunity to say we did our best at trying to determine our future with our best interests in mind.

We do not need to run for office. We can be active at the local, state and national levels by calling or writing our legislators. This is not very time-consuming and it can have a big impact. If we empower others to do the same, more voices will be heard. When doctors, nurses and social workers speak for us, politicians don't listen as much as when we speak for ourselves, especially when we have strength in numbers. You can also become involved with organizations like the National Kidney Foundation and its local Affiliates. Most have or are developing public policy programs. The same holds true for the American Diabetes Association, the American Association of Kidney Patients, the American Lung Association and the American Heart Association, which all have either public policy programs or committees.

The challenge is to become involved. Then the bigger challenge is empowering others to become involved, so that as many health care consumers as possible are empowered.

Maurie Ferriter received a cadaveric kidney transplant in 1986. He resides in the “beautiful” town of Lakeland, Michigan. 



Who Needs Calcium Supplements?

by Linda W. Moore, RD, LDN

Have you been wondering if you need to take calcium supplements? You have probably noticed advertisements that claim calcium supplements protect bones. These ads usually target women, especially older women. They mention that women need to take supplements to avoid developing *osteoporosis*, which is a bone disease characterized by the loss of bony tissue, resulting in brittle bones that are likely to fracture. (The term “osteoporosis” derives from this; “osteo” means “bone,” and “porosis” means “open or porous spaces.”)

I recently heard a prominent endocrinologist/epidemiologist (a specialist in both hormone functions and the occurrence of disease in various populations) say that osteoporosis and *secondary hyperparathyroidism* are rapidly increasing in the United States. The doctor added that some states have developed legislation to advertise the seriousness of osteoporosis.

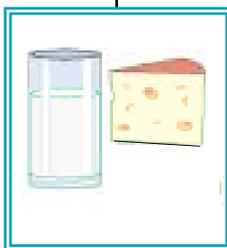
Secondary hyperparathyroidism is an enlargement of the parathyroid gland due to stimulation not caused by the dysfunction of the gland itself. Something is signaling the gland to overproduce the parathyroid hormone. It is common in kidney disease patients because the kidney is the source of production of a very important bone hormone, vitamin D, which helps strengthen bones by assisting calcium uptake to the bone. When kidneys do not produce enough vitamin D and do not clear phosphorus out of the blood, a false message is sent to the parathyroid gland. The bones do not receive the calcium they need and become weakened and porous.

Health care providers are constantly encouraging individuals with kidney disease to take their phosphate binder to help protect their bones from the bad side effects of kidney disease. The phosphate binder often contains calcium to offer more protection. Unfortunately, some patients forget to take this medication, and some find the taste unpleasant. Ultimately, kidney

disease will cause these patients to have enlarged or overactive parathyroid glands, as well as bones with calcium deficiencies. Many times, a kidney transplant causes an overactive gland to decrease in size by providing better phosphate control and by allowing a constant production of vitamin D; however, the gland does not always return to normal size. The bottom line is that the bones are weak and something must be done to improve the situation. The problem may be compounded by the fact that the medications required for transplantation may also cause bones to lose calcium. There is still a lot we do not know about how these medications do this or even if the medications are the main cause. It may be that the kidney disorder is the main cause. At any rate, no studies have shown that calcium replacement is beneficial for transplant recipients.

To help prevent osteoporosis, adults need to watch their calcium intake. Even though adults are finished growing, bones change cells every day and calcium is lost and replaced, which is known as normal bone turnover. If normal bone turnover occurs, but no calcium is replaced, the thyroid gland will enlarge in an attempt to stimulate more bone turnover because it is not receiving the right signals. The parathyroid glands also play a role in bone metabolism and can become enlarged.

Healthy adults need approximately two servings of dairy products each day to provide bones with a daily supply of calcium. Children need three to four servings of dairy products each day. Many children develop osteoporosis during their pre-adolescent and teen years because they are not getting enough calcium. Children sometimes think the calories are not worth the taste, or they simply prefer the taste of colas or something else. However, colas are not good substitutes for milk, and supplements only provide calcium, whereas milk provides many minerals and vitamins to promote good bone health.



Continued on page 19

National Donor Recognition Ceremony Scheduled for April

The Fourth Annual National Donor Recognition Ceremony, sponsored by the Division of Transplantation in collaboration with the National Donor Family Council and many other transplant organizations, will take place Sunday, April 13, 1997, at the Sheraton Washington Hotel in Washington, D.C.

This moving ceremony pays tribute to all Americans who donated their organs and tissues to save or improve the lives of others. The National Donor Recognition Ceremony features inspirational speakers, a tribute ceremony and the National Donor Family Quilt. Transplant recipients and candidates and their families are invited to attend this memorable event.

An educational and support workshop will be offered to living donors on Saturday, April 12. Following an overview of the historical role of living donors in transplantation, transplant social workers will lead discussions and exercises about the emotional effects of donation. For registration information about the ceremony and the workshop, please call the NKF's Kathleen Casey at (800) 622-9010. 

Who Needs Calcium...

Continued from page 18

As a transplant recipient, whether you are male or female, your needs for calcium are at least equal to a normal individual's. Whether you need more calcium than this should be determined by your physician, but you should be aware of this disorder and talk to your transplant team about it. They may suggest that you use dairy products (skim milk) to obtain the calcium you need, or that you might benefit from a calcium supplement.

You can also help to spread the word about osteoporosis, and help others to improve their bone health. Remember, start with dairy products (no fat), then find out if you need more than your diet can provide. Always review these issues with your health care team (your physician, dietitian or nurse) before you make changes in your diet or medications. 

Growth Retardation Affects...

Continued from page 16

on kidney function. Success with this regimen may be greatest among live-donor recipients and children treated with the immunosuppressive drug cyclosporine.

Poor function of the transplanted kidney may also have a negative impact on growth. This problem may be due to recurrent acute rejection, chronic rejection or recurrence of the kidney disease that was present in the child's native kidneys.

Due to the discouraging growth rate in the majority of children following kidney transplantation, a number of transplant centers have started using daily injections of recombinant human growth hormone in selected children and are reporting improved growth rates. Recombinant growth hormone is a synthetic substance that is currently approved for the treatment of children with chronic kidney failure and short stature due to various endocrine

conditions. Widespread use of this drug in kidney transplant recipients has caused concern because there is a risk of causing worsening kidney function. A national collaborative study evaluating the safety and effectiveness of growth hormone in kidney transplant recipients is presently underway.

Linear growth following liver transplantation appears more favorable compared to growth rates after kidney transplantation. Although linear growth may be diminished during the initial six to 12 months following transplantation, accelerated growth is seen up to four years following a liver transplant in over 75 percent of children. Limited growth during the initial twelve-month post-transplant period appears to be caused by multiple surgical procedures, inadequate nutrition and high-dose prednisone therapy. 

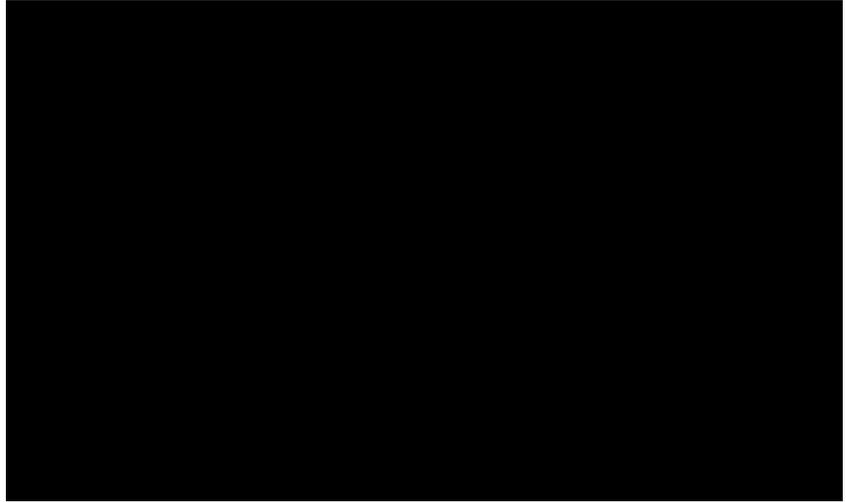
Mary Anne Shea

1943-1997

Mary Anne Shea of Sandy, Utah, a friend and inspiration to many, died on January 21 after a short illness.

Mary Anne is survived by her husband, Gerald C. Shea; her daughters, Christianne, Kerry and Suzanne; her son, Keith; her mother, Mary Diou; her sister, Eileen Macrum; her brother, Eugene; and her pets.

After receiving a kidney transplant in 1990, Mary Anne won gold, silver and bronze medals at the Los Angeles, Atlanta and Salt Lake City U.S. Transplant Games, and the World Games in Manchester, England. After winning five gold medals in five events at the U.S. Winter Transplant Games in Aspen in 1995, she was named "Outstanding Female Athlete." Last May, Mary Anne was honored by being named an Olympic torch-bearer in Salt Lake City.



Mary Anne (center); with Karren King, chair, NKF Patient Services Committee; and A. Bruce Bowden, immediate past chairman, NKF

Mary Anne, a financial adviser for Merrill Lynch and Dean Witter Reynolds, was recently appointed by NKF Chairman Wendy Brown to chair the first executive committee of the new transAction Council.

The family has requested that in lieu of flowers, donations be made to the

National Kidney Foundation, 30 E. 33rd Street, New York, NY 10016, to be earmarked for organ donation programs, particularly the Games.

The family wants all of Mary Anne's transplant recipient friends to know that her illness was unrelated to her transplant. 

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.

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