Lost and Found: 
A 30-Year Living Donation and Transplant Journey

By Maurie Ferriter

It sounds like a child’s game: how something that is lost is found again, twice. But for Barbara Plock, her life was not a game. Barbara lost her kidneys in 1966 and received a kidney from her brother, Don. Then, in 1999 she needed and received another donated kidney, this time from her husband, Jarvis. Her saga is truly an inspiring one.

The story began in 1957 when Barbara was visiting her family with her fiancé, Jarvis. Her brother, Don, mentioned that her ankles looked swollen, but she took little notice of it. She returned to work to provide for her three-year-old daughter from a previous marriage. Over the next few months, Barbara’s ankles continued swelling and her characteristic energy seemed to wane. After several visits with her physician, she was told that her kidneys were failing. She was diagnosed with chronic glomerulonephritis and nephrotic syndrome. By 1960, when she was undergoing blood work for her marriage license, the attending doctor confirmed the diagnosis and advised her to stay off her feet, take prescribed medications and limit her fluid intake. The wedding went ahead as planned.

In 1961, Barbara and Jarvis had a healthy baby boy. Jarvis, however, was wearing himself out working six days a week and assuming most of the household duties because Barbara would be so drained after work. Now, with two young children to care for, Jarvis needed help. Barbara’s parents moved in to help out. By the summer of 1966 Barbara’s kidney condition worsened and her physician said she needed either dialysis or a transplant to survive the year. With kidney transplants relatively new, Jarvis offered to contribute one of his. At the time, however, it was required that living donors be blood relatives, and Jarvis was not accepted. Barbara’s brother gallantly volunteered. During the fall of 1966, Barbara had both her kidneys removed, began hemodialysis and lost so much weight that she only weighed 83 pounds. The brother-to-sister transplant was scheduled for December and went off without a hitch.

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Dear transplant recipients and friends:

I am rewriting my original note in light of the recent tragic attacks on our country. Transplant recipients, families and friends already have a history of fortitude in the face of trauma from personal illness and are proven survivors in the face of adversity. You have given inspiration to others. The National Kidney Foundation, transAction Council’s Executive Committee and the Transplant Chronicles editorial board send our best to you during this time. We join you in summoning up our inner resources to find comfort and strength as we go forward with life.

In this issue, we bring you information about living donation, as well as tips for maximizing your health and information about medications. In safety and health...

Sincerely,
Beverly Kirkpatrick

CORRECTION: Our apologies! In our last issue we incorrectly reported Medicare Part B’s costs. Medicare Part B costs $50 a month at this time.

Transplant Chronicles is now available online at www.transplantrecipients.org

NKF’s transAction Council was established to ensure a better quality of life for recipients and increase the availability for all organs for transplantation. The council provides advice and assistance to transplant recipients with educational symposia, national surveys, health and fitness programs and educational materials. Membership in the council is free and open to all individuals who have received an organ transplant, as well as health care professionals, legislators, candidates, families and friends.

Call our information specialists at (800) 622-9010 for a membership brochure.
Transplant Chronicles, Vol. 9, No. 2

Informed Consent for Living Donors

By Laurel Williams, RN, MSN

In live donation, the risks and benefits are different from other areas of medicine. Potential donors are healthy people who rarely receive any medical gain from the procedure and would not otherwise be considered patients. They become special “patients” as they undergo testing to determine whether live donation is possible. All information about short- and long-term risks and benefits to both the donor and recipient should be discussed or disclosed. The possible complications vary with different organs. For example, the risk of being a live kidney donor is much different from that of a live liver or lung donor.

The transplant team needs to ensure that the decision to donate is voluntary and free from coercion. Ideally, there should be two different groups of medical personnel dealing with the donor and the recipient. By doing so, both the donor and the recipient have their own medical advocates. Respect for the donor’s and the recipient’s individuality and confidentiality should be of prime importance. The potential donor should be able to seek the support of the transplant team to decline donation, if he or she chooses.

To have informed consent the potential live donor must first be competent to make decisions. Therefore, most children under the age of consent are not considered. A donor needs to be able to comprehend the risks and benefits of the surgery to himself and to the recipient. A potential donor needs to understand that alternative treatments are available to the recipient and compare the risks of the operation to these other options. Professionals may tailor their presentations about living donation to the potential donor’s education and learning style to assure risks and benefits are understood completely.

Regardless of which organ is being donated, it is imperative that the donor and recipient both understand that, in some cases, live donors have died after donating. Although the number of live donor deaths is extremely low, it has happened. Also, on rare occasions, the live donor has needed a transplant after the donation. Therefore, a potential donor should not feel guilty about not wanting to take on additional medical risks by becoming a donor.

The disclosure process should permit a “cooling off period” between consent and the scheduled donor operation to provide the potential donor time to reconsider the decision to donate. The donor’s expectations should be reviewed and confirmed by the donor.

Lost and Found...

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routines, including spending summers in Michigan and winters in Arizona. In 1998, Barbara even race-walked and bowled in the National Kidney Foundation’s U.S. Transplant Games. After the Games, her doctors recommended that she pursue another transplant and she multi-listed herself in Arizona and Michigan. Barbara began noticing the same symptoms she had experienced 35 years before. The wait for a cadaver kidney was longer than expected and Jarvis did not want to see Barbara on dialysis, so he volunteered again to be her kidney donor. This time Jarvis was accepted and approved. In September 1999, Jarvis and Barbara underwent a perfectly smooth transplant operation. Jarvis had a new procedure called a laparoscopic nephrectomy, which was less invasive to his body than a traditional nephrectomy. Jarvis was in the hospital for only one day after the surgery, and Barbara was released in five days. Both recovered in time to relocate to Arizona for the winter.

Barbara and Jarvis are now making plans to celebrate their 50th wedding anniversary in 2010, with Don, their children, grandchildren and great grandchildren. They now work hard at staying healthy and sharing their story with groups and individuals all over the country to promote organ and tissue donations and transplants. Barbara, Jarvis and Don continue to be an inspiration to all of us on the transplant journey and all who know their story.
Deceased donors account for the vast majority of transplants. This is because the gift of multiple organs as well as corneas and tissues can be given at the time of death. However, due to the increasing shortage of organs available, organ procurement organizations are now expanding their traditional work to include living donors to save more lives. Living donations doubled during the 1990s, while whole cadaveric donations increased only incrementally. At the current rate of increase, living donors will outnumber cadaveric donors in a year or two.

The Department of Health and Human Services reported that organ transplants completed in 2000 totaled 22,847, an increase of 5.4 percent over the 21,655 transplants performed in 1999. To support the increased interest in living donation, several organ recovery organizations such as the New England Organ Bank, Center for Organ Recovery and Education (CORE) and the Washington Regional Transplant Consortium (WRTC), have implemented living donor registries in an effort to offer new opportunities for donation. The establishment of these registries, and the alternatives they provide, will allow more organs to become available to the entire community.

Many organ recovery organizations throughout the country have formed committees to promote more interest in living donation options. As a result, the Department of Health and Human Services, spearheaded by Secretary Thompson’s "Gift of Life Donation Initiative," is developing national guidelines regarding living donation. This initiative, launched in April 2001, includes a review of federal responsibilities for monitoring living donations and calls for a national forum on the potential of donor registries and the most effective implementation alternatives.

Some of these alternatives are a paired exchange, living donor/cadaveric donor exchange, and non-directed donation.

Paired exchange: A person may want to donate an organ to a relative or a friend, but cannot because their blood types or tissue types do not match. If another pair in the same predicament is found, an exchange may be possible.

The Living donor/cadaveric donor exchange (also called paired list exchange): If a non-matching relative or friend donates an organ to the general waiting list pool, then the relative or friend of the living donor would have priority on the waiting list for a kidney from a cadaveric donor. The exchange benefits the person who needs an organ transplant and also helps alleviate the wait by removing one person from the list.

Non-directed donation: A person who wants to donate an organ to the general pool with no specific recipient in mind.

The vast majority of living donations are kidneys, since most people have two healthy kidneys, but need only one. There were also over 300 living liver donations performed in 1999, where surgeons removed a piece of a liver from a living donor for a transplant. Both pieces of the donated and remaining liver grow to a full sized organ in the recipient and the donor.

Recent research has proven that transplants of kidneys through living donations, even from people who are not close relatives, are just as successful as kidneys transplanted from people who have died. While there are several reasons for this, the main one is that a living donor is usually healthier and the organ is transplanted quickly, allowing it to start functioning faster in the recipient.

Increasing living donations alone will not be enough to satisfy all the transplant needs throughout the country. We must continue to promote dialog and open communication about this public health issue and better educate the general public about the opportunities for organ and tissue donation. What greater gift can any person give than the gift of life?

Concurrently, the U.S. Department of Health and Human Services, as part of Secretary Tommy Thompson’s “Gift of Life Donation Initiative” announced in April, is developing national guidelines regarding living donation, including the review of federal responsibilities for monitoring living donation as well as calling for a national forum on the potential of donor registries and the most effective registry techniques.

Howard Nathan is the president and CEO of the Gift of Life Donor Program, an organ procurement organization in Philadelphia.
Much like the movie "Network," when one of the central characters is shouting out the window, "I’m mad as hell and I’m not going to take it anymore!"—recipients may find great emotional benefit doing the same thing. Telling our personal stories of loss, anger, denial, anxiety, loss of control, hope and health can heal many of the wounds and help to make sense of where we have been and why we are still here when others are not.

Many of us have struggled with illness for much of our lives and the possibility of end stage organ failure may have always been the ultimate outcome. Some of us became sick so fast, we did not have a chance to prepare in any way for the answer to end stage organ failure. The answer—"you need a transplant in order to save your life"—and the gravity of that statement will simply stun us and leave us reeling out of control. Why me? What are my chances? Will it work? What kind of life will I have? How much time do I have?

I was too sick to transplant on more than one occasion. We fight hard to live, sometimes right on the edge of death, while we wait. Though we want so much to live, the thought of someone else dying and saving our lives via donation is troubling. Yes, death happens and no one is dying to save our lives. We recognize this as rationally as possible, but it is again something that leaves us feeling remorse. Someone’s loved one will die and because that person chose, at the height of grief to donate, we receive the greatest gift, a second chance.

That is a lot to work through before a transplant. It is so powerful and so nearly unexplainable. Whom can we talk to? Who understands what it is like to get up every day and take a handful of drugs just so we can stay alive? Who understands the fear of rejection and infection? Once we are functioning, by all accounts normally, people forget we are ill. They forget that transplant is a form of therapy and not a cure. They forget we are immunosuppressed and any infection, however small, could take a turn for the worst and be deadly. How do we cope?

I was given a second chance because a family chose to donate their 16-year-old daughter’s organs. I wondered why she was taken from this world and I was allowed to live. My body was once again whole, but there were some big holes in my emotions and comprehension of what I had been through. I felt there was really no one to talk to, so I started writing...and I kept writing.

After a while, I started talking to anyone who would listen. I saw the impact my story had on others and began volunteering to speak for my local organ procurement organization. I was taking something I learned the hard way and teaching it to people I hoped would never find themselves on either side of this story.

Along the way I came to a realization. I was alive because I had a mission to help ease the path of those who followed me through the transplant experience and to help save candidates unknown to me, through educating the public and professionals that transplantation works. If you are out there wondering why, take a piece of paper and simply write what is in your heart. You just may find some answers.

John Landers received his heart transplant nine years ago. He is a member of the transAction Council Executive Committee, Captain of Team Arizona of the U.S. Transplant Games.
THE PRE-TRANSPLANT EVALUATION
A person who wishes to be a live donor should be medically and psychologically suitable. A multidisciplinary team of health care professionals including physicians, nurses, psychologists and social workers gives final approval for live organ donation.

All potential donors must undergo a careful history and physical exam, and have several blood tests performed in order to determine suitability. Radiology studies of the organ to be donated are also necessary. Special tests to assess lung function are necessary for potential lung donors. Biopsies of the liver or kidney may occasionally be necessary for donation of those organs. While donors with no smoking history are preferred for lung donation, smokers are acceptable if they are tobacco-free for at least six months before donation. Patients with significant high blood pressure (hypertension) are not candidates for kidney donation. Patients with mild hypertension who have normal heart and kidney function are usually suitable. Donors who are either younger than age 18 or older than 60, or pregnant, are not acceptable donors.

Careful assessment of the psychosocial status of a potential donor by trained mental health professionals, such as a clinical social worker, psychologist, psychiatrist, or a psychiatric nurse, is necessary to evaluate for active psychiatric disease, substance abuse, social instability and psychological readiness to be a donor. In addition, ambivalence, guilt and vulnerability to coercion are assessed.

KIDNEY
For the past three decades, kidneys have been removed from the donor through an open incision on the side of the abdomen. Over the past eight years, a less invasive procedure, using laparoscopic surgery, has become an acceptable alternative to the standard procedure. Risk of complications is similar in both groups. Potential complications include the need for a blood transfusion, repeat surgery due to injury of abdominal organs, pneumonia and wound infection.

Although the laparoscopic procedure takes slightly longer to perform, the length of hospitalization and need for pain medications is shorter compared to the standard open procedure. More important, the convalescence period appears shorter with laparoscopic kidney donation, and most patients can return to work within six weeks.

LIVER
Among living liver donors, the average length of hospitalization is three to seven days. The risk of immediate complications following surgery is relatively low, although less than five percent of patients will need a blood transfusion and an even smaller number of patients may have injury to their liver or intestines requiring additional surgery. Late complications have not been seen because of the liver’s ability to completely regenerate itself. More complications have been seen with adult-to-adult living donors using the right lobe of the liver. These risks are documented in the article “Living Donor Liver Transplantation,” by Dr. Adela T. Casas-Melley, on page 7 of this issue of Chronicles.

An individual who donates a lobe of his or her lung must be carefully monitored for signs of bleeding, inflammation around the lining of the heart and infection. These problems sometimes may require a repeat operation. A few patients develop a cough that persists for one to four months following surgery, even with a normal chest X-ray. Although lung function tests demonstrate a 10 to 15 percent loss in overall function one year following surgery, this does not appear to result in any long-term physical impairment and allows donors to return to their normal daily activities.

LONG-TERM HEALTH ISSUES
Health and safety precautions are important for organ donors. These include:

- Routine physician visits
- Monitoring of blood pressure
- Limiting the risk of trauma, especially for kidney donors, by wearing seatbelts, avoiding the use of motorcycles and three-wheeler motorized vehicles and refraining from heavy contact sports
- Not smoking in order to reduce the risk of heart and vessel disease. This is especially crucial in kidney, lung and heart donors.

Thirty five years of experience confirms that live kidney donation is a safe procedure with minimal risk of kidney failure to the donor who follows a healthy lifestyle. For living liver and lung donation, it remains critical that you carefully discuss the risks and benefits of organ donation with your transplant physician.
The shortage of livers for transplantation has led to the development of innovative surgical techniques to help patients in need of a liver transplant. Since 1989, pediatric liver transplantation has benefited from the use of living donors. To date, more than 1,000 children have been transplanted using this technique. Unfortunately, the amount of tissue that could be removed was small and the recipient usually had to be an infant or small child. Because of the organ shortage, many surgeons tried to extend the size limit for the use of the living donor. However, using the left side of the liver, the amount of tissue available excluded all but the smallest of adult recipients as potential candidates.

One country that has truly advanced the field of living liver donor transplantation is Japan. Religious beliefs prevent Japan from having a cadaveric donor program, so the only way for patients with end stage liver disease to be transplanted is with the use of living donation. In 1994, Dr. Yoshio Yamaoka reported the first case of the use of the right lobe of the liver from a living donor for transplantation. This procedure removes about 60 percent of the donor’s liver and provides enough tissue for most average-sized adults.

In the United States, the procedure was pioneered at the Medical College of Virginia. Since that time, several centers around the country have begun using it. As a result, the number of living liver donor transplants increased from 64 in 1998 to 197 in 1999.

There are still questions regarding donor safety with this operation. The donor operation is lengthy and involves resection of 60 to 70 percent of the total size of the liver. There is significant blood loss and the donor may need blood transfusions. The need for blood transfusions may be eliminated by use of a blood recovery machine where the patient’s blood may be recycled and returned to the donor. There is the possibility of injury to the remaining liver itself that may require future surgery, although this risk is small. The risks are even less if experienced surgeons who use strict criteria for donor selection perform the surgery.

There have been complications for donors of right lobes. Some have included donor deaths. But there are risks with any operation. Donors must be evaluated completely. They must undergo a battery of tests to determine if there are any underlying reasons why they should not donate. Once these tests have been successfully completed, the size of the potential donor’s liver has to be calculated. If the remaining piece of the donor’s liver is at least 30 percent of the original volume, the possibility of significant complications from liver injury is dramatically less. This does not mean that there is zero risk for complications, but it is close. Living liver donation is always difficult because a healthy donor is subject to the risks of surgery. How do you weigh the risks and benefits to both donor and recipient? You can start by discussing the procedure in detail with a surgeon who has experience in the area. Find out how many cases he or she has done, what the success rate has been and if there have been any significant complications. If there have been complications, how were they treated? How is the donor followed up after the operation? How often is he or she seen? Also, what are the outcomes for the recipients?

All of these questions are important and should be addressed when making a decision. Living donation is an important part of any transplant program, especially with the present organ shortage. Living donations have saved the lives of many patients, but we should never forget that a family member, or friend, is taking a risk for the benefit of a loved one. The donor should be able to be assured that the risk he or she plans to take is a minimal one.

Right lobe liver donation is still relatively new and in the early developmental stages. However, in the right hands, it is a safe procedure that will help to provide life to others. We should continue to offer it to our patients and continue to offer loved ones the opportunity to donate.

The Good and the Bad of Living Donor Liver Transplantation

By Adela T. Casas-Melley, MD

Kristina Villanti received a partial liver from her mom, Michelle.
JUST FOR FUN — Word Search About Transplantation

UNOS GORGANEOTACPX
ISLETCELLCVPINOAE
LJFCELLCEPTOSTOIN
HEARTQNMNIPSIRRO
EXLLIVERGTSHUGDDT
AACPCANCREASEKEEIERT
LMDONORTLRHFHNXAC
CYCLOSPORINEQVACN
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NEORALKIDNEYUCOAP
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TRANSPLANTPFZBOLT
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Antigen  Cellcept  Clinic  Coordinator  Cyclosporine  Donor
Exam  Flushot  Heal  Heart  Islet cell  Kidney
Life  Liver  Lungs  Medicine  Neoral  OPO (Organ procurement Organization)
Organ  Paired exchange  Pancreas  Prednisone  Prograf
The Games  Tissue  Transplant  UNOS  Xenotransplant

Visit www.livingdonors.org
It is designed for living donors, families, friends and professionals. Join us for a chat, post your story on the message board, join an interactive discussion listserv, read about legislation, news and visit our question and answer page!
Senators Richard Durbin (D-IL) and Susan Collins (R-ME) have introduced legislation containing a variety of provisions designed to expand and improve the nation's organ donation efforts. The DONATE Act (S.1062) calls for, among other things, the establishment of a national organ and tissue donor registry resource center, grants for state registries and the payment of expenses incurred by Americans who become living donors.

The bill would also establish a task force to advise Congress on how to improve linkages between state organ and tissue donor registries, provide federal grants to hospitals and organ procurement organizations (OPOs) to fund staff positions for organ donor coordinators and authorize creation of a congressional medal to honor donor families.

Although quite different in scope, the Senate bill is considered to be companion legislation to H.R. 624, the Organ Donation Improvement Act of 2001 passed by the House of Representatives in March. The House bill, which was introduced by Rep. Michael Bilirakis (R-FL), chairman of the Commerce Committee, contains funds for providing financial support for live donors and for increasing donor awareness.

Here are some of the main provisions of S.1062:

- **National Organ and Tissue Donor Registry Resource Center** - The center's major duties would include facilitating the "development, expansion and evaluation of state donor registries;" set up a process to allow for the exchange of donor information between state registries on a 24-hour basis; and "develop consensus guidelines on a standard registry model, including whether or not such registries should include living donor information."

- **Grants for State Organ and Tissue Donor Registries** - The bill calls for authorizing $10 million each year from 2002 through 2006 for grants or cooperative agreements to support the development of state registries.

- **Advisory Task Force** - The Secretary of the Department of Health and Human Services would be directed to establish a task force to study state registries and make recommendations to Congress on the establishment of such registries within one year of the enactment of the legislation.

- **Expenses Incurred Toward Living Donation** - The HHS Secretary would be able to award grants to "eligible entities" – e.g., OPOs, transplant centers, other qualified entities, to pay for "travel, subsistence, and other nonmedical, but necessary miscellaneous expenses related to living organ donation. The bill authorizes $15 million to be available for fiscal year 2002, and additional funds to be determined for fiscal years 2003-2006.

- **Organ Donation Public Awareness Program** - The bill authorizes $5 million for donor awareness projects, including the development of state registries.

- **Congressional Medal** - The Secretary of the Treasury would be mandated to produce a medal to commemorate organ donors and their families.

- **Institute of Medicine Report** - The IOM would be contracted to conduct an evaluation of organ donor practices of OPOs, states, other countries and other organizations that have achieved a "higher than average organ donation rate."

- **Grants Regarding Hospital Organ Donation Coordinators** - The Secretary would be able to award grants to hospitals or OPOs to establish programs coordinating organ donation activities of "eligible hospitals." An eligible hospital is defined as "a public or nonprofit private hospital that performs significant trauma care, or a public or nonprofit private hospital or consortium of such hospitals.

Continued on next page
that serves a population base of not fewer than 200,000 individuals.” The bill authorizes $3 million for fiscal years 2002 through 2005 for this provision.

GOVERNMENT FUNDS NEW STUDY ON AFTERCARE OF LIVING DONORS

With living donation the fastest growing source of organs for transplantation, the federal government announced it is funding a new study on the care individuals receive following donating the organ.

The Department of Health and Human Services (HHS) Agency for Healthcare Research and Quality (AHRQ) has awarded a two-year, $100,000 grant aimed at improving the way organ transplant centers serve living organ donors.

The award was presented to Rebecca Winsett, PhD, and colleagues at the University of Tennessee in Memphis. Building on their previous research, the researchers say they will evaluate existing organizational and operational structures at transplant centers with high volumes in living donation. In addition, they will interview living donors to determine their experiences with existing operations and will design models for care and post-surgical support for individuals who become living donors.

For information contact Farah Englert (301) 594-6372, e-mail: FEnglert@ahrq.gov, or Jane Steele (301) 594-6350, e-mail: JSteele@ahrq.gov

MAN GETS NEW LIVER, GIVES HIS TO ANOTHER

A rare liver transplant that used a diseased organ from one patient to save another may help two Illinois men to once again lead active lives.

On August 5, Arlyn Schier, 52, received a cadaveric liver transplant after an eight-month wait. The next day, his damaged but still functioning liver was transplanted into Nathan Henne, 67, who was diagnosed with liver cancer in 2000.

"Mr. Henne was not expected to receive a perfect liver in time to save his life,” said Steven Flamm, MD, medical director of liver transplantation at Northwestern Memorial Hospital (NMH) in Chicago, Illinois. "Though not perfect, Mr. Schier’s liver is a very good fix."

Schier was diagnosed with familial amyloidotic polyneuropathy 18 months ago. This rare genetic disorder caused his liver to produce a protein that eventually damages the heart and nervous system. Without a transplant, doctors estimated Schier would die within a year. The liver that is now in Henne will continue to produce the abnormal protein that, over 5 decades, sickened Schier. But Henne is not expected to experience any health problems from the slowly lethal secretion for at least 30 years, doctors said.

"Nationwide, more than 18,000 people are currently waiting for donor livers. About 20 percent of them will die before a suitable organ is found,” said Flamm. The domino liver transplant, as it is called, was first performed in Miami, Florida, in 1996. Since then, it has been used about 50 times.

COMBINED HEART-LUNG-LIVER TRANSPLANTATION IS FEASIBLE IN CERTAIN PATIENTS

Although transplantation generally is performed in patients with single organ failure, combined heart-lung-liver transplantation is a viable option for a few patients with dual organ failure, according to a report in the September 8 issue of the Lancet.

Peter Friend, MD, and colleagues at the Churchill Hospital in Oxford, United Kingdom, reviewed the case records of 9 patients who underwent combined heart-lung-liver transplantation in Cambridge between 1986 and 1999. Eight patients had end-stage lung disease and advanced liver disease; One had end-stage liver disease with compromised lung function. All but two patients had cystic fibrosis (CF).

Two patients experienced episodes of pulmonary rejection and one had episodes of pulmonary and liver rejection. But the researchers said the acute and chronic rejection rate actually was lower than that typically associated with heart-lung transplantation. One-year and five-year actuarial survival rates of the group were 56 percent and 42 percent, respectively. Three patients died within a month of transplantation, and four died between four months and 12 years post transplant.

"Combined transplantation of the heart, lung, and liver is a feasible and therapeutically effective procedure for a few selected patients,” with five-year survival for the triple transplant operation similar to that of heart-lung transplantation, said Friend and coauthors. The combined procedure, which the
investigators said involves no additional surgical skills, may be a particularly viable option for patients with CF complicated by advanced liver disease.

**PRESIDENT BUSH TO ALLOW FEDERAL FUNDING FOR RESEARCH ON 60 EMBRYONIC STEM CELL LINES CURRENTLY IN EXISTENCE**

In a long-awaited decision that both pleased and disappointed stem cell research proponents and critics alike, President Bush announced on August 9 that he would allow federal funding into embryonic stem cell lines that already exist but will not provide support for research on new stem cells created by destroying embryos.

Bush said that private research has already produced more than 60 genetically diverse stem cell lines that can reproduce themselves and be immensely valuable for medical research. Though many experts expressed surprise that as many as 60 lines exist, they also doubted that 60 would be enough to achieve the full range of hoped-for medical advances.

"Thank goodness we have 60 lines we can work with," said Duke University stem cell researcher Doris Taylor. "Unfortunately, over time, I think we'll find that 60 is not enough."

The president also announced he will create a new council on bioethics headed by University of Chicago bioethicist Dr. Leon Kass. The council will "monitor stem cell research, to recommend appropriate guidelines and regulations, and to consider all of the medical and ethical ramifications of biomedical innovation," Bush said.

Addressing the nation for the first time since his inauguration in January, the president's stance on the highly complex issue was lauded by some for finding a middle ground. At the same time his plan was roundly criticized by conservatives who felt it went too far and scientists and patient groups who felt it didn't go far enough.

Bush's decision "was a wily compromise between conservative forces and the enticing promise of stem cells for helping to relieve suffering," bioethicist Stuart Youngner, MD, said. "So far stem cells are just a promise. If they turn out to be really useful and the place where he drew the line is seen as impeding significant progress, he will find a way to allow progress." Youngner is director of the Center for Biomedical Ethics at Case Western Reserve University in Cleveland, Ohio.

One of the biggest surprises in the president's announcement was the news that as many as 60 stem cell lines exist. Tommy Thompson, secretary of the Department of Health and Human Services, said the administration only learned of the number within the past few weeks. Prior to the president's announcement conventional wisdom had the number at six to ten lines in existence.

Dr. Laura Skirboll, an associate director of the National Institutes of Health (NIH), did the research that turned up the number 60 through an international survey. Skirboll said at a press conference that the cell lines exist in five countries - the United States, Israel, Sweden, Australia, and Singapore. Institutions in the country known to have embryonic stem cells include the WiCell Research Institute in Madison, Wisconsin, and the Jones Institute for Reproductive Medicine in Norfolk, Virginia.

Bush moved quickly to deflate such speculation. Four days after his address to the nation, the president told reporters he would veto any legislation that attempts to push federal support for embryonic stem cell research beyond the parameters he outlined. "I laid out a policy I think is right for America. And I'm not going to change my mind," he said.

Congressional hearings on broadening federal funding are a possibility, but most observers feel legislation is unlikely to be passed this year, while patient advocacy groups and researchers wait to see if scientists find the existing cell lines sufficient before they mount a challenge to expand the effort.

**AMERICANS IN FAVOR OF EMBRYONIC STEM CELL RESEARCH, POLL FINDS**

A majority of Americans support federal funding for embryonic stem cell research, according to a new USA Today/CNN/Gallup Poll.

In a survey of 1,017 adults conducted August 3 to 5, 62 percent of the respondents said embryonic stem cell research is important, 55 percent support such research in general and 55 percent believe the government should fund research using stem cells left over from embryos created for fertility treatments, USA Today reported. Two out of three respondents opposed funding for research using
closed stem cells and 49 percent opposed using cells created by scientists specifically for research purposes.

The poll has an error margin of plus or minus Three percentage points.

OKLAHOMA CITY BOMB TRIAL JUDGE RECEIVES LIVER TRANSPLANT

The federal judge who presided over the Oklahoma City bombing trials of Timothy McVeigh and Terry Nichols received a liver transplant on September 16.

Judge Richard Matsch, 71, was in serious but stable condition at the University of Colorado Health Sciences Center in Denver following the five-hour surgery. Matsch suffered from a progressive inflammatory condition that restricted his bile ducts and caused a buildup of fluid that led to infections requiring hospitalization.

Surgeon Igal Kam said Matsch was doing well and would remain in the hospital for one to two weeks.

UNOS BOARD RECOMMENDS ADOPTION OF MELD LIVER ALLOCATION SCHEME

Acting with quickness and unanimity impossible in recent years because of the rancorous fight over organ allocation policies with the federal government, the United Network for Organ Sharing (UNOS) has recommended adopting a new liver allocation scheme that by all accounts will reduce the number of deaths of patients on the waiting list for a donor.

The Model for End Stage Liver Disease (MELD), a new liver allocation policy first introduced to the UNOS board last November, data overwhelmingly shows that the formula accurately predicts a patient’s short-term risk of death if they do not receive a transplant. The organ Procurement and Transplantation Network (OPTN) Board of Director’s recommendation for approval was unanimous.

While details for implementing the new system are yet to be worked out, the 18,000 patients currently on the waiting list for a liver are in no danger of having their position changed on the waiting list now. Patients who are status 1 remain the first priority to receive a liver. The new plan, when adopted, will eliminate current status 2A and 3, and replace it with the MELD scoring system.

Under the new system the standard protocol for allocating livers is modified based on a scoring system that addresses the severity of potential recipient’s liver disease. For adult patients, the system uses the prognostic factors of serum creatinine, bilirubin, and prothrombin time/INR which results in the MELD score.

For pediatric patients, the system uses the prognostic factors of bilirubin, INR, albumin, growth failure, and age less than one year which results in the Pediatric End-Stage Liver Disease (PELD) score.

In a nutshell, the MELD scoring system will replace the current Statuses 2A, 2B and 3. The unique scoring system prioritizes patients for liver allocation following allocation for Status 1 using the existing definition and protocol for Status 1 patients.

In anticipation of the approval, the UNOS staff faces an enormous task of reprogramming its computer system to eliminate, among other things, status 2A, 2B and 3. They hope to have the system fully operational early in 2002.

For information, patients, family, transplant professionals are encouraged to call Doug Heiney, Director of UNOS Membership and Policy Office (804) 330-8800.

→ Fall is the time to talk with your doctor about a flu shot. Peak flu season is between December and March. Last year’s flu shot does not protect you against this year’s new strains.
Non-Directed Donation (NDD)

By Cheryl Jacobs, LICSW

In non-directed donation (NDD) a living donor gives an organ to a candidate who is the best match on a participating transplant program or regional waiting list. Recipient selection criteria is similar to that used for allocating cadaveric organs. The donor and recipient do not know each other, and they are only able to correspond or meet following the transplant, provided both parties mutually agree and feel comfortable doing so. (This is similar to recipients and family members of cadaveric organ donors.)

Many people believe an individual must be extraordinary to volunteer to undergo such a major procedure for a stranger. As with all living donors, the complex medical, psychological and ethical considerations must be carefully examined. This is particularly important for someone undergoing a serious surgery that does not directly benefit his or her own health, or that of a loved one.

- Laparoscopic donation, a less invasive surgical technique than the traditional open nephrectomy, has encouraged people to volunteer to be non-directed kidney donors, since the recovery period is quicker than the traditional surgery and may allow individuals to return to normal activities sooner. However, the donor needs to be carefully studied in order to assure that he or she receives similar positive benefits.

People ask, "It may be normal to donate to someone close to you, but why a total stranger?" Likewise, transplant programs have traditionally responded suspiciously to such callers, concerned about the individual’s psychological well-being and whether the volunteer may have ulterior intentions or motivations to donate. Only recently are transplant programs gradually feeling comfortable in considering such inquiries. And, only after extensive medical, psychological and ethical examination do we now understand that NDD may indeed be a viable option.

Currently, there are several programs that have established NDD protocols. The number of participating centers will likely increase as volunteers pursue their local programs in order to make donating convenient and less expensive and to have access to nearby emotional support.

In an attempt to assist the transplant community in responding appropriately to NDD, the National Kidney Foundation held a meeting in June 2001, with an interdisciplinary panel of transplant professionals, including those experienced in NDD. The group examined the logistics of implementing a non-directed donor program and discussed how transplant programs could adequately address the needs of volunteer donors. A complete report is forthcoming.

Cheryl Jacobs is a licensed clinical social worker at the Fairview Hospital kidney transplant program in Minneapolis.

Editor’s Note: For a wide variety of health reasons, only a small number of people requesting to donate have so far been found to be suitable donors. It is important to remember there are many ways to help. Donating blood, platelets, plasma or bone marrow can save lives and are wonderful ways to give! NDD is expected to develop slowly. Transplant centers need time to pull together the necessary resources to establish a successful program.
Flexibility is not only very important to the success of your exercise program but it is also the easiest part of fitness to develop. Slow, deliberate stretching is the best way to improve flexibility. Stretching prepares your body for movement, helping to prevent injury by preventing tension on muscles.

First, warm up your muscles for five to seven minutes with a slow jog, dancing or a brisk walk. Then take 10 to 15 minutes of your day to stretch. Stretch only until your first point of tension and then stop. Do not tug. You want to stretch far enough to make a difference, but not so far that you tear or strain a muscle. Hold your stretch for 30 seconds and it will make a significant difference. More or less is not as effective. Bouncing may cause injury. You want to hold a static stretch, slow and steady, not fast and jerky. Over time your muscles will adapt.

**HIPS**

Lie on your back with legs straight. Interlace your hands behind your right upper thigh and pull your right knee toward your chest and hold. Repeat with left leg.

**SHOULDERS**

Lie on the floor on your back. Extend arms straight above your face, interlocking your fingers with palms pointing toward the ceiling. Keep your arms straight and slowly lower your hands until they rest on the floor behind your head.

**LOWER BACK**

Get on your hands and knees. Place your hands directly under your shoulders. While keeping them in place, sit back on your heels. Your arms will be outstretched and you will feel a stretch along your back.

**BACK THIGH**

Sit on the floor and extend your legs in front of you. Bend both knees slightly, so your knee joint is not locked. Reach with both hands toward your toes. Keep your back straight and lean from the hip.

**FRONT THIGH**

Stand touching a chair or wall for support. Bending your right knee, grab your right foot with your right hand and slowly pull your foot toward your buttocks. Repeat with left leg.

**CALVES**

Stand on a step with your heels protruding over the edge of the step. Drop your heel below the level of the edge of the step until you feel a stretch.

**GROIN**

Butterfly stretch. Sit on the floor with your legs bent frog style. The soles of your feet should be pressing together. Gently press your knees toward the floor with your hands or elbows.

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[My sister] “did not want to ask a family member to donate another kidney to her. I told her this would be the most important thing I had ever done in my life and she had no right to take it away from me. I did not have any children and I felt this would be the only chance I would have to, somehow, give life.”

— Grace Freije-McMahon
Most living donors agree that their experience donating a kidney has been a good one. Some had more pain than they anticipated, some had complications, but most of them seem happy with their decision. However, there are no statistics on the long-term outcomes for donors, an area where study is needed. There are some serious risks in living donation, but the risks tend to be rare.

For most people, living donation doesn’t change their lifestyle, or diet. There are a few things you should be aware of if you are considering living kidney donation.

When the donated kidney is removed, the single remaining kidney will grow and become larger than a normal kidney. As a result, the single kidney is more vulnerable to injury.

Once you have donated a kidney, it is important to be aware of the increased risk for injury with certain heavy contact and extreme sports. Careful decisions must be made regarding a potential donor’s participation in various physical activities.

The American Academy of Pediatrics and the American Academy of Family Physicians have suggested that people with one kidney avoid sports and activities that involve higher risks of heavy contact, collision or risk of injury. These include boxing, field hockey, football, ice hockey, lacrosse, martial arts, rodeo, soccer, wrestling, and skydiving, among others. Anyone with a single kidney who decides to participate in these sports should be extra careful and wear protective padding. He or she should understand that the consequences of losing the single remaining kidney are very serious.

Donors are encouraged to have good long-term medical follow-up with their primary care doctor. A urinalysis (urine test) and blood pressure check should be done yearly, and kidney function should be checked every few years, or more often if the urinalysis shows abnormal results or blood pressure is elevated.

In general, most people with a single normal kidney have reported few or no problems. However, there seems to be a greater chance of the donor developing high blood pressure. Again, because there have been no studies about the long-term effects of donation on the donor, it is not known how often this has occurred. Potential donors should consult with their doctor about the risks of living donation.

Pregnancy after donation is possible, but is not usually recommended for as least six months after the surgery.

Some branches of military service, police and fire departments will not accept individuals with only one kidney. In addition, if you are already in military service, certain new service career options may not be available to you. If you are currently in one of these fields, or if your future plans include these career choices, you should check to see if living donation would affect your eligibility.

These are just a few things you should think about before you choose to donate a kidney. If you would like additional information and support, you may find it on NKF’s living donor Web site at www.livingdonors.org.

Jennifer Martin is the transplant programs manager at the National Kidney Foundation.
How is Your Living Donor?

By Charlie Thomas, ACSW, CISW

The first successful transplants in the United States occurred in the 1950s. At the time, only identical twins were considered acceptable donors. After early successes with twins, the donor pool was expanded to include immediate blood-related family members, such as parents and adult siblings. In the 1960s, transplant centers began using organs donated by the families of brain dead patients. In the early 1990s, transplant centers took another step; living donation. Centers began performing surgeries between spouses; transplants between other non-blood-related family members followed. Friends and acquaintances were added to the donor pool later on. Most recently transplants have occurred between anonymous donors. Most living donors continue to be family members of the recipients, while transplants from non-blood-related relatives continue to increase.

Several years ago, an important study was conducted to find out how living donors were doing and if donating had affected their lives in any way.

Studies previously conducted had only focused on the benefits of living donation for the recipient. In the living donor study, researchers surveyed over 1,000 living donors and found that 23 percent felt depressed after donation and that 27 percent perceived that their recipient felt indebted to them. Regarding their relationship with the recipient, 80 percent felt closer as a result of the donation.

However, six percent felt a strained relationship and 13 percent felt the relationship had remained the same. The majority of living donors, about 55 percent, reported that a fear of transplant organ rejection was the most stressful part of their donation experience. Overall, 39 percent found the donation experience itself stressful. Living donors also voiced concerns over the financial impact of donating, with 23 percent stating that they experienced moderate or severe financial stress associated with lost income, increased travel and other donation-related expenses. Nevertheless, a high 87 percent indicated that they would donate again, if they could. Only four percent wished they had not donated. Many of the living donors said they felt forgotten after surgery. While they understood that the transplanted organ and the recipient became the focus of care following the surgery, they were surprised by the emotions they experienced and how much additional support they actually needed.

How is your living donor doing? How is he or she coping? Are you concerned about your relationship? If you, or your donor, have problems or concerns from the donation experience, you may contact the transplant center where you had your surgeries. Your donor may also benefit from speaking to another living donor. The staff at the transplant center can provide information and counseling if needed.
Dear National Kidney Foundation:

You have been a great help to me and my family when my husband had to have a kidney transplant. I had heard about the NKF before this happened to him, but just never really thought much about it. When I needed a shoulder to cry on and a friend to listen to me, you were there. My husband is doing fine. I gave him the kidney and I read everything you send me. All your letters, stories, etc.

I have cried more in the past week for the people of New York and Washington than I believe I have in my life. My heart goes out to each and every one of them and their families. I know how it feels to have the weight of the world on your shoulders.

This is to all people in the world, from a transplant and living donor family. Don’t give up, we will go on and we will be stronger and survive together. We are strong. The pain will ease with time and work and we will go on with our lives. It will take time.

Sincerely,

Barbara Day
Leesville, South Carolina

JOIN US!

The 2002 U.S. Transplant Games, presented by the National Kidney Foundation and sponsored by Novartis Pharmaceuticals Corporation, will be held June 25-29, at Disney’s Wide World of Sports™ Complex in Lake Buena Vista, Florida.

Featured at the Games:
- 10,000 participants from all over the country
- 2,000 athletes organized into 50 state teams
- 1,500 donor families
- 12 different sports, including track and field, swimming, tennis, basketball, cycling and golf
- Educational programs for transplant professionals, donor families and living donors.

You can find the official team for your area by visiting www.transplantgames.org or contacting your local National Kidney Foundation affiliate (check your local listings) or call (800) 622-9010.

Photos: Jay LaPrete
Family Ties: A Relative Matter

By Jaime Campbell

Four years ago, I gave a kidney to my uncle. My family has an active history of polycystic kidney disease: Seven out of 11 cousins from my mom’s generation have had or need transplants. I was the first living donor in the family. Since then, there have been two more cousins in my generation who donated to their parents.

Although I was apprehensive beginning the process, it never occurred to me not to donate. My uncle and I have always been close, and when I found out I was the only person in the family who matched his blood type, there was no question. My fears were alleviated when I realized that UCLA approached the donation from my perspective, not his. They were not as worried about getting him a kidney as they were about my health and possible risks following donation. Every test was done to ensure that the only risks to me were those simply related to major surgery itself.

The transplant took about five hours. I had an "open door" incision, as they had not yet perfected the smaller, less intrusive procedure of laparoscopic nephrectomy. I stayed in the hospital five days. The pain was significant for about 10 days, but after the third day, every day was an improvement. I was back to normal activities in four weeks, and full strength in three months. I did not have to modify my diet, and I don’t take any medication. I lead the same normal life I lived before the transplant.

Perhaps the most important part of our story is that I was adopted, so our transplant was actually living non-related. I hope that our story serves as inspiration for anyone with a loved one who needs a transplant — it can be done successfully, even if you are not related. I trusted the doctors who told us that our match and the transplant would be successful, and that I would be fine — and I am. I was 29 at the time of the transplant, and I just had my first child last year. My uncle is in perfect health for a transplant recipient. It was all worth it, and I would never regret my decision.

Jaime Campbell, a living kidney donor.
@ www.livingdonors.org

Your Questions Get Answers

Here’s a commonly asked question. Visit our Web site for more Q&As.

**Q: I need a transplant. How can I ask someone to be my living donor?**

**A:** This is a tough issue and it depends on you and your loved ones. All families are different. Many individuals facing a need for a transplant found that their family members or friends asked them about living donation. Others found that asking someone they loved to donate to them was too difficult. They didn’t feel comfortable asking people directly because they did not want to pressure anyone to donate.

Some transplant hopefuls were able to overcome the fear of asking loved ones to risk surgery, once they learned more about transplantation and donation. Taking the time to educate their families and friends about kidney transplantation and donation helped. You might want to ask your transplant center staff for brochures about donation, and share them with your friends or family members. Sharing as much factual information as you can, along with sharing your thoughts about your progress, your options, your hopes and dreams, can help you and your loved ones think about whether living donation is right for you. If you can, take your time, move slowly, and get all the information possible.

You can find a list of all U.S. transplant centers by state online at www.unos.org

Because donors are never financially compensated, you may also want to meet with a financial counselor to discuss your situation as it relates to lost work time, testing expenses, etc. Most transplant centers have a financial counselor who can help you.

Living donation is not easy. You will have many questions and, while no one venue can provide all of the answers you seek, www.livingdonors.org is designed to help you get some of them.

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**poetry corner**

**The Gift**

*By Kim Johnson*

Weak and tired
Life was a struggle
Somehow each day
Through life I would muddle

Thinking there must
Be a better way
To live without
This fight everyday

A gift of life
I needed from you
I didn’t have to ask
You just came through

A huge sacrifice
You made for me
A life-changing difference
I can already see

After only one day
I feel brand new
A second chance at life
Thanks to you

There are no words
That can express
The feelings of love
That I possess

With my new life
I can do anything
I look forward to whatever
Tomorrow will bring

I plan right now
To live each day
To the very fullest
And I also pray

That I can give back
What you have given to me
A piece of the gift
Given so unselfishly

You are my Hero
My Brother and Friend
Thanks for the chance
To live again.

Kim Johnson is a kidney recipient. She received a kidney from her brother, Kevin.
Thirty professionals from the transplant community met in Boston recently to share their experiences about non-directed donation at a National Kidney Foundation-sponsored conference entitled, "The Non-Directed Donor: What’s Next by Practice and Ethics."

Transplant surgeons, physicians, coordinators, executive directors of organ procurement organizations and ethicists met to discuss issues related to non-directed donation, including developing a standard donor evaluation process and follow-up care (medical, psychosocial, financial and post-donation data/registry).

The discussion, facilitated by Francis L. Delmonico, MD, medical director of the New England Organ Bank and kidney transplant surgeon at Massachusetts General Hospital, also addressed advertising, the components of informed consent, the ethics of recipient selection, economics, and communication issues between non-directed donors and recipients.

Recommendations from the conference are being developed for publication.

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