

Transplant Chronicles

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For the Love of Family

■ By Leslie Taylor-Bentham

I am a walking testimonial. My family and friends are the greatest. I would not trade them for anything in the world.

I have had lupus (Systemic Lupus Erythematosus or SLE), a chronic disease that causes the immune system to attack the body's tissues, since I was 11 years old. In 1989, when I was 17, my kidneys failed. I felt my life was over. Within a period of seven months not only did my kidneys fail, but I also lost my mother, my maternal aunt, and a great aunt. It was only through the tremendous support I received from my grandmother, other family mem-

bers, friends and the medical staff at Downstate Medical Center, whom I've grown to love, that I was able to stay strong. I will never forget the day Dr. Eli Friedman told me I was going to be fine and would live a long productive life.

I began Peritoneal Dialysis (PD) when I was just entering 11th grade. I went to the pediatric floor for dialysis every other day. I strove to graduate high school on time and accomplished that goal. This taught me I could do anything as long as my heart was in it. I was doing well on PD until I developed a terrible infection and had to be switched to hemodialysis. The two needles that had to be inserted into my arm terrified me. To me, this was the worst. In order to stay sane, I pursued my education and worked part-time.

Then, in November of 1993, came the day I'd only dreamt of: the transplant coordinator called asking me if I would accept the kidney they had! My reply was a firm "of course I will." I go into everything I do with a positive attitude.

Once, while I was being prepared for the surgery, I prayed. I was overcome by a feeling, and believe it was my Mom letting me know everything was going to be all right.

The surgery went well and I was ready to conquer the world! I continued at trade school and acquired the skills to work at an advertising agency. Then, I went to college part-time. Everything went well until about two years later when the kidney rejected. The doctors did everything in their power to save it, but my first transplant ended in January 1996. I do not regret this transplant experience, however. I am God's child and He has helped me thus far.

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Leslie and Elijah after her second transplant in 1996.

Read the latest issue of *Transplant Chronicles* online at: www.kidney.org/recips/transaction/chronicles.cfm

Transplant Chronicles

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Laurel Williams

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Editor-in-Chief

editor's desk

We are very lucky to have a very creative and involved editorial board. I am pleased to have Josh Goldberg, our youngest board member yet, deliver our first guest editorial message in this issue. In the words of Marcel Proust, "The real voyage of discovery consists not in seeking new landscapes but in having new eyes."

—*Laurel Williams*
Editor-in-Chief

Dear Readers:

When kidney, heart, lung, liver or any disease strikes your family, everyone is affected. Though you may not have the disease yourself, your life changes just as dramatically as if you were the patient. Through this process you must strive to stay strong.

Lance Armstrong is, as we all know, a cancer survivor. But his greatest triumph is being able to continue living despite his struggle with a life-threatening illness. What defines him as a hero for me is not his six consecutive wins at the Tour De France, but his focus on

living life to the fullest instead of surrendering to the reality that death may be "around the corner."

We can all learn a lesson from Lance. We can all be heroes of a kind, if we make every day count in spite of horrendous obstacles placed in our path. When adversity is overwhelming, the simple task of getting up in the morning and "taking care of the business of the day" can be heroic.

Family members stay strong for each other. Like relay teams, they pick up the slack for one another when one is struggling. It is this gentle balance that makes us all heroic. Having a mother with kidney failure, I know this dance all too well. Although we may step on each other's toes once in a while, I wouldn't change this dance of life for anything.

Looking forward to hearing from you,

Your pal,
Joshua S. Goldberg
(for the editorial board)
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"In the depths of winter I finally learned that within me there lay an invincible summer." —Albert Camus.

Submitted by Rachael Wong, MPH, kidney transplant recipient.



Elizabeth McIlwain, MBA, and mom, Anna McIlwain

Let Your Voice Be Heard!

Elizabeth McIlwain is 20 years old and leaving home to begin a new life! Anna, Elizabeth's mother would like to send her off with the benefit of your experience and wisdom. Elizabeth has always been diligent about taking her meds on time, but with a new routine and change of lifestyle, she could benefit from tips and tricks to remember her meds. For example, one trick Elizabeth employs is keeping a set of pills in a small plastic bag in her wallet. Let's help Anna give Elizabeth a great send-off!

Log onto www.recipientvoices.org and let Elizabeth know your best tips for remembering to take your meds.

What About the Kids...? A Heart Transplant's Challenge

■ By Jim O'Donnell

ANY ORGAN TRANSPLANT RECIPIENT knows they have a precious gift. But this gift does not come without a cost. It not only affects the patient, but also the recipient's family.

This is particularly true when children are involved. Our children had to go through this almost a decade ago.

My wife, Lizzie, and I have three sons. We learned Lizzie needed a heart transplant in 1996, a few months after moving to Indiana from Boston as my work required. I knew moving had been a big sacrifice for the woman I loved. She had to leave her familiar surroundings that included family, home and friends, and follow me with our sons to my new job. This job would help others but bring our family into a world of "downward mobility." When I learned her life was threatened, I turned my full attention to saving her. This left little time for the boys, and I often overlooked or even became impatient with their needs.

Our oldest son, Nick, was 19 years old when his mom was living at the transplant hospital waiting for a heart. He had just left for college, which was 600 miles away. It was the right time in his life for him to be more independent and mature. He needed space to discover himself, and maybe even discover that his parents had not been the worst parents in the world. He was torn when he learned about his mother's illness. He was conflicted about when, and even if, he should leave school to be with the family. Because of the great distance, he couldn't always get news about the ever-changing realities of his mother's medical condition, and he couldn't always be with the rest of the family.

It was in a sense a break for him that he didn't always have to be in the midst of the turmoil at home, but he was also isolated without any emotional support. My wife and I didn't want to disrupt Nick's college years, but sometimes we needed him at home. Maybe it was unavoidable, but we sent him mixed messages. I'm sure this just added to his confusion.

Our middle boy, Andrew, had been angry over having to move during his sophomore year in high school. He couldn't stand to see his mother suffer either. He responded to the additional stress of his mother's condition by withdrawing and becoming even angrier. He often seemed callous, or even selfish. We wanted to shake him out of what we felt was a particularly nasty case of teenage self-absorption. He tried to block out what was going on, and, when he couldn't, he'd become enraged. He refused to visit his mother in the hospital. "What good would it do?" he said. "I can't cure her or change her or anything, so why should I visit her? It hurts too much!"

Jon, the youngest of the three, was only six when his mom got sick. He never realized, throughout the entire course of her illness, how grave the situation was. As long as he was able to see his mom, Jon thought everything was fine. There were times, however, when I had to whisk Lizzie off to the hospital, which was a hundred miles away from our home, and was unable to tell Jonny his mother might not be returning that night.

Somehow, Jonny didn't notice the life and death struggle that was taking place around him. Lizzie and I talked to him about death and heaven. Sometimes he had nightmares, but even during the worst of Lizzie's sufferings, Jon remained staunchly content and optimistic.



Lizzie and Jim O'Donnell

It had always been our goal to supply each boy with a normal routine of home, school, family and friends. That wasn't possible with all the medical emergencies that rocked our lives. Because of their varying ages and temperaments, each boy handled this roller coaster in different and individual ways, and each boy required special love and help. The transplant process stretched our family to its limits. But, thanks to the help of our friends and our faith, we made it—so far at least.

Today Nick is 28. He's a stage actor living in Seattle and is married. Andrew is 25, and is living and working in New York City as an investment banker. Jonny is 16 now. He's an honor student, in love with his first girlfriend, and hopes to one day find a cure for cancer, or to do research on making transplant medicines less toxic.

I look back on the last eight years with gratitude for the time we have been given. Miraculously, we have become a closer family. **TC**

See page 4 for more "Family Matters"

A Family Affair

■ By Lara Tashla, LCSW, MSW

WHEN YOU READ A STORY like Lizzie O'Donnell's (pg. 5), it becomes apparent that chronic illness affects the entire family and not just the person with the illness.

Watching a family member go through the roller coaster of chronic illness and transplant is difficult. Family members may experience many feelings including:


- **CONFUSION AND ANGER:** Why is my mom suffering? Why isn't God answering my prayers? Dad said he was coming to my concert and now he is so tired, he can't come.
- **GUILT:** Did I do something to cause my sister to be sick? Can I still have fun with my friends and laugh while my dad is suffering?
- **FEELING LEFT OUT:** My brother gets all the attention now that he is sick. My dad can't come to my games because he is in the hospital again.
- **HELPLESSNESS:** I can't do anything to make my mom better!
- **FEAR AND SADNESS:** What will happen if my dad dies? What will I do without my sister?
- **PRESSURE TO BE MATURE:** I have to help take care of my younger brother while mom and dad go to the doctor's appointment. I have to be strong for my mom.

These feelings and others are normal and are okay. Your sick family member is also experiencing lots of emotions.

Everyone has "coping mechanisms." These are techniques you use without

even thinking about it to get through stressful times. Do you make jokes when you are uncomfortable? You might be using humor to cope with stress. Did you go to the library or search the Internet when you learned that your father needed a new liver? You might be trying to understand what is going on in order not to feel so out of control. Do you change the subject when your parents start talking about the latest test results? You might be trying to avoid talking about things that are scary or hurtful. Are your grades slipping? You might be trying to tell the other people in your family that you need some attention. Everyone uses different coping mechanisms, so we are sometimes confused by the ways other people in the family act!

It is important for everyone in the family to have someone to talk to. Sometimes family members can talk to each other. Other times a teacher, coach, best friend, minister, rabbi or religious leader is the confidante. Sometimes it is helpful for the whole family to see a social worker or professional to help make sure everyone understands each other. If you or someone in your family is having troubling feelings or thoughts, talk to a trusted member of your transplant team. They can help identify counseling resources in your community or provide an opportunity to speak to you as a family.

Editor's note: Future issues of Transplant Chronicles will feature articles by Dr. Bradley, a teen psychologist. 

Making the Most of Your Life:

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DID YOU MISS our telephone discussions? The NKF held a series of telephone discussions, hosted by actor Ken Howard, on "hot topics" for transplant recipients. Access all the information on www.transplantrecipients.org Click on the boxes on the homepage. You will gain access to the audio recording, and written script for each of these topics: *Getting the Most Out of Medicare*; *Understanding Depression*; and *Helping Others While Empowering Ourselves*.

The National Kidney Foundation gratefully acknowledges the unrestricted educational grant received from Roche for these programs.

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Gastric Bypass Surgery... An Answer for Transplant Recipients?

■ By Nancee Vander Pluym, MS, RD



Nancee Vander Pluym, MS, RD

The assessment of weight status of transplant candidates and recipients is now becoming a more-often used tool of comprehensive management. Kidney patients face the same struggles and frustrations as other individuals who need to

control weight. Transplant candidates and recipients deal with issues including increased fatigue, physical limitations, dietary restrictions, side effects of medications and the newfound freedom of non-regulated diet after transplant. Weight loss methods, such as herbal products, over-the-counter diet pills, or severe restriction of certain food groups are not safe. Gastric bypass surgery has recently been considered as a treatment option for select transplant candidates or recipients. Gastric bypass surgery is performed in the upper part of the abdominal cavity, while transplanted kidneys are placed in the lower groin area. As Dr. Alfredo Fabrega from Banner Good Samaritan Transplant Service stated, "These are two separate surgeries. The bypass procedure will not interfere with, or prevent having a kidney transplant."

The number of gastric bypass surgeries in America has increased dramatically in the past few years. These procedures may be an option for people who are more than 100 pounds overweight. The medical name for this is morbid obesity. Obesity presents a significant risk factor for developing Type 2 diabetes, high blood pressure, high cholesterol, sleep apnea, joint disease, heart disease, acid reflux and early death. Many transplant candidates and recipients already have many of these medical problems or are at a greater risk of developing them. It is therefore necessary to determine what gastric surgery is and whether it can be more successful than conventional weight-loss techniques.

There are two categories of gastric bypass surgery for obesity. The first is called malabsorptive. This surgery

shortens the digestive tract and thereby reduces absorption of food. The other type is called restrictive. This surgery reduces how much food the stomach can hold. Some surgical procedures combine both restriction and malabsorption.

Malabsorptive:

This procedure is both restrictive and malabsorptive. With this surgery, most of the stomach and part of the small intestine are bypassed. The natural stomach is reduced to hold only a few ounces and is referred to as a pouch. The pouch is then connected to a lower part of the small intestine. This bypasses part of the digestive tract that absorbs nutrients and calories. The most common type of bypass surgery in the United States is the Roux-en-Y gastric bypass. This operation creates nutrient deficiencies due to malabsorption of nutrients. Protein, iron, calcium and B12 are "at risk" nutrients that require special attention. A complete vitamin and mineral supplement is required daily. Long term follow-up blood tests are needed to avoid malnutrition.

Restrictive:

A restrictive procedure only limits the quantity of food eaten and does not change the normal digestive process. An adjustable gastric band is now used more often than other banding or stapling procedures. The gastric band is placed around the upper part of the stomach. There is no cutting or stapling needed to divide the upper stomach into a pouch. The lower part of the stomach is not affected. This limits how much food can be consumed at each meal. The band can be adjusted

by filling it with normal saline to further limit food intake. Food choices and physical activity are the most important determining factors in success with gastric banding. The body absorbs all the calories eaten, because there is no malabsorption with the gastric band.

Gastric bypass surgery is a specialized procedure that requires a non-transplant surgeon. Consideration for this surgery requires a referral from both the nephrologist and the transplant surgeon. A comprehensive workup and evaluation is performed by the bariatric team. The type of procedure will be determined by the combined medical teams. All surgery carries a risk of complication, and, possibly, death. These risks are increased in the severely obese person.

Gastric bypass surgery requires an absolute life-long commitment to be successful. This commitment starts with changes instituted before the surgery that must continue thereafter. Initially, dietary intake is restricted to a progression of liquids, pureed food, protein drinks and soft foods lasting several months. Food intake is dramatically reduced to only a few ounces per meal at the beginning. Certain foods and beverages must either be eliminated or severely restricted. Physical activity is a vital component. Optimal excess weight loss will not occur if exercise is not a part of the new lifestyle.

Life-long vitamin and mineral supplementation is required for those having a malabsorptive procedure to avoid malnutrition and bone loss. In addition to the routine tests done for the pre-transplant patient or transplant recipient, regular blood tests are required to monitor nutritional status. This monitoring must be jointly provided by

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“The Pharmacy Won’t Fill My Prescription...!”

■ **By Lara Tushla, LCSW, MSW**

THIS IS A COMMON CALL that I get. It is the hardest to resolve when it happens before a weekend or holiday, late in the afternoon, or when the person is almost out of medications.

My first piece of advice is to refill your prescription several days before you are out of medicine. This gives everyone time to figure out if there is a problem and how to resolve it without putting your transplant at risk. Below is a list of possible reasons why the pharmacy may not be refilling your prescription:

| QUESTION TO ASK | LIKELY PROBLEM | SOLUTION |
|---|--|--|
| Is the prescription still good? | Prescriptions can only be written for 12 months at a time. | The doctor’s office will need to provide a new prescription. This can often be done by phone or fax. Ask the pharmacy to call your doctor’s office. |
| Do you take my insurance? | Some prescription plans only work with certain pharmacies. | The pharmacy may know which other pharmacy you should use. If not, contact your insurance company to find out where you need to go for the best coverage. |
| | Does the pharmacy have your current insurance information? | Make sure the pharmacy has your most current insurance information. |
| Is it too soon to refill my prescription? | Most insurance plans will not let you refill a prescription until the week before you run out. | <p>If you run out before your official refill date, the answer depends on why this happened.</p> <ul style="list-style-type: none"> • Did you lose some of your medicine? If so, the pharmacy can try to get approval to fill early. Some insurance plans will deny this and you will have pay for replacements. • Are you going on vacation and need to stock up before you leave? Most insurance plans will allow for early refills for vacations. • Did your prescription change and you are now taking more of the medicine? With an updated prescription, the pharmacy should be able to fill the new prescription without trouble. <p>The pharmacy should be able to handle the first two options with the insurance company directly. The pharmacy will need to talk to your doctor’s office for the last one.</p> |
| Is there a similar medicine that my insurance would cover? | Most insurance companies have lists of preferred drugs. This is called a “formulary.” Your drug may not be “on formulary.” | If a similar drug would be covered, ask the pharmacist to call your doctor’s office to see if that switch can be made safely. If so, the pharmacist can request a prescription. If not, there is a process to “override” the formulary. Ask the pharmacy if they will handle this, or if your doctor’s office has to be involved. |
| Does this drug need “prior approval”? | Some drugs are so expensive, or so rarely used, that the insurance company wants to make sure that you really need it. | Ask the pharmacy if they will handle the prior approval process or if the doctor’s office needs to be involved. Sometimes a letter from the doctor or recent lab tests are required. Ask the pharmacy to call your doctor’s office about what information they need. |
| Do you bill Medicare? | Not all retail pharmacies do Medicare billing. | If your pharmacy does not work with Medicare, contact your transplant team for suggestions about pharmacies that work with Medicare recipients. |

If you are not able to solve the issue with the pharmacy, call your doctor’s office or transplant team. Don’t skip medicines. 

See page 11 for a special factoid.

Transplant News Digest

from the editors of **Transplant News**

■ By **Jim Warren**, editor and publisher



Jim Warren

Transplant News, edited and published by Jim Warren, is a twice-monthly newsletter for the transplant community focusing on developments in organ, tissue, eye and bone marrow procurement and transplantation. *Transplant News Digest* is written exclusively for quarterly publication in *Transplant Chronicles*. For more information about *Transplant News* visit: www.trannews.com

Bipartisan effort to get Organ Recovery and Improvement Act fully funded in the fiscal year of 2006 begun in the House and Senate

MORE THAN 50 MEMBERS of the U.S. House of Representatives and 20 senators signed "Dear Colleague" letters urging full funding in the fiscal year (FY) 2006 for the Organ Recovery and Improvement Act (PL 108-216). Reps. Michael Bilirakis (R-FL), Vice Chairman of the House, Energy and Commerce Committee, and Jay Inslee (D-WA) led the effort in the House while Senate Majority Leader Bill Frist (R-TN) and Chris Dodd (D-CT) provided the leadership in the Senate.

The letter, sent to members of the House Subcommittee on Health, makes the case that increasing the number of organs available for transplantation has the "potential to actually reduce future Medicare expenditures."

Here is the bulk of the text of the House "Dear Colleague" letter:

"There are currently over 88,000 Americans awaiting organ transplantation; over 6,000 this year will die, never having received a potentially life-giving organ. To combat this trend, Congress enacted the Organ Donation Recovery Improvement Act (Public Law 108-216) to reduce organ donation barriers and improve organ donation and recovery rates. We are

asking the Committee to continue this effort by fully funding the initiatives established by this law for Fiscal Year 2006, including expanding public awareness programs, strengthening our organ procurement infrastructure, and reimbursing expenses incurred by living donors.

"The Organ Donation and Recovery Act authorizes \$25 million in FY 2005 and 'such sums necessary' for the fiscal year 2006 and onward. However, the bill was not funded in FY 2005 due, in part, to its enactment late in the appropriations cycle. As a result, FY 2006 is a critical year to achieve funding. We ask that the Committee provide an initial appropriation of \$25 million to immediately begin implementation of the critical programs authorized under the law.

"We are encouraged by the recent news that nearly 27,000 Americans received an organ transplant in 2004, setting a new national record and marking the largest increase in organs from deceased donors in the past 10 years. Fully funding the [Act] will build on the current efforts by the federal government, states, and other entities to promote organ donation, reduce the waiting list, and improve the practice of organ recovery, so that more Americans may receive the gift of life.

"Additionally, by fully funding the [Act], we have potential to actual-

ly reduce future Medicare expenditures. By its own estimate, Medicare would avoid direct dialysis costs, which routinely exceed \$55,000 per patient per year for each patient transplanted. Because of the shortage of donated organs from deceased donors, the current median waiting time from being placed on the waiting list (at the state of a patient's disease where dialysis becomes necessary to sustain life) to transplantation now exceeds four years. Therefore, for every new donor facilitated by this program Medicare would save a minimum of \$220,000 over four years. Four-year savings to Medicare (from patients transplanted in FY 2006 alone) would exceed \$110 million. A similar four-year savings would accrue on a continuing basis for each subsequent year."

Death rates for patients awaiting liver transplants down; use of Extended Criteria Donors kidneys up, HRSA annual report finds

DEATH RATES FOR PATIENTS awaiting livers is down considerably over the past 10 years; the use of expanded criteria donor (ECD) kidneys is growing steadily; and the survival rate for lung transplant recipients is expected to rise in the next few years.

These are just a few examples of information contained in the

Continued on next page

Fourteenth Annual Report on Transplant Data, published by the Health Resources and Services Administration (HRSA) of the US Department of Health and Human Services (HHS). The new report summarizes official and definitive data on solid organ transplantation in the U.S. from 1994 to 2003.

The report, which is prepared jointly by the Scientific Registry of Transplant Recipients (SRTR) and the Organ Procurement and Transplantation Network (OPTN), contains data of interest to the entire transplant community, including medical professionals, patients and researchers.

The full report features 10 chapters written by more than 50 national experts in transplantation, analyzing data and identifying trends in transplantation over the past decade. One of the “special focus” chapters featured in the new report examines various ways to measure organ donation rates by donation service area, which has implications for improving overall rates of organ donation. All 10 chapters, which were coordinated by SRTR, have just been published as a special issue of the *American Journal of Transplantation*.

The OPTN/SRTR *Annual Report* is being published exclusively in electronic formats—on a CD-ROM and on the Web. The full report is available at the SRTR’s and OPTN’s Web sites:

www.ustransplant.org and **www.optn.org** Free CD-ROMs of the report may be ordered at either site.

Here are some examples of the information from the press release announcing the availability of the publication:

✿ Death rates for patients awaiting livers have decreased considerably in the last 10 years, from 225 to 124 deaths per 1,000 patient years. Death

rates following liver transplantation have also shown a declining trend over the decade, dropping from 197 to 156 deaths per 1,000 patient years.

- ✿ The number of people living with a functioning allograft has more than doubled over the past decade, rising from 69,345 to 153,844 in 2003. While most of the recipients have kidney grafts, the prevalence of those living with functioning grafts has been increasing more quickly for most other organs. Compared to 1994, there were three times as many lung recipients living in 2003, as well as six times as many pancreas recipients and eight times as many intestine recipients.
- ✿ The use of expanded criteria donor (ECD) kidneys—those with higher risk of long-term failure due to donor age and medical history—has continued to grow in response to the shortage of organs. ECD kidneys were used in 16 percent of kidney transplants in 2003, up from 11 percent in 1994, and 15 percent in 2003.
- ✿ The number of donors after cardiac death (DCD) has also been growing, from 57 in 1994 to 189 in 2002 and 271 in 2003.
- ✿ A new lung allocation system, approved in June 2004, is expected to maximize the survival benefit of lung transplantation. The new system is not based solely on waiting time, but incorporates a measure of how long patients are expected to live after receiving a transplant (versus remaining on the waiting list).

Coalition study says only one third of Americans understand organ donor process

ONLY ONE THIRD of Americans understand the proper steps for making it known that they want to be an organ and tissue donor, according to a new survey released to coincide with the beginning of April—National Donate Life Month in the U.S.

The survey of 4,500 Americans found that while an overwhelming number of Americans said they support organ and tissue donation—90 percent—only 34 percent know the proper steps for committing to donation, according to the Coalition on Donation, the nonprofit alliance of national organizations and local coalitions, that commissioned the survey.

Not all of the 90 percent were comfortable with donation, however. Only a little more than half (56 percent) indicated they would be willing to donate their own organs and tissue. Another 28 percent said they are undecided and 6 percent indicated they would only be comfortable donating certain organs or tissues.

“The gap between those who support organ and tissue donation in theory and those who actually become donors is colossal and troubling and must be bridged if we are to meet the (growing) need for organs and tissues,” said G. David Fleming, Director of the Coalition. “Just as vital is the need to educate willing donors about the steps they need to take to commit to donation. We hope to utilize this research to find more effective ways for turning this overwhelming public support into practical, life-saving action.”

The survey, the first of its kind in 13 years, unearthed some other interesting findings... 18 percent of the respondents had the impression

that physicians may be less inclined to provide life-saving treatment to prospective donors, and a significantly higher percentage (44 percent) said they “sometimes don’t trust the medical community,” although they have a high degree of confidence in their own personal physicians.

Procedures for becoming an organ and tissue donor vary from state to state. The Coalition on Donation Web site contains information on how to become an organ and tissue donor in each state. Those steps can be found by clicking on the U.S. map on the coalition’s Web site: www.donatelife.net

International standards of care for live donors adopted by The Transplantation Society

ABOUT A YEAR AGO, more than 100 experts in transplantation from all over the world gathered in Amsterdam, the Netherlands, with a goal of developing a consensus on an international standard of care regarding the responsibility of the community for the live kidney donor. The end result was to be a position statement that would be adopted by the Transplantation Society.

The conference report, *A Report of the Amsterdam Forum On the Care of the Live Kidney Donor: Data and Medical Guidelines*, was published as a supplement in the March 27 issue of *Transplantation* (Transplantation 2005; 79: S53-S66).

Here are portions of the international Standard of Care with a position statement adopted by the Council of the Transplantation Society that is included with the full report in Transplantation:

“The international transplant community recognizes that the use of kidneys from the living donor needs to be performed in a manner that will minimize the physical,

psychological and social risk to the individual donor and (that) does not jeopardize the public trust of the health care community. The donation decision should be performed in an environment that enables the potential donor to decide in an autonomous manner.

“Because of the need for more transplantable kidneys, persons with conditions that may increase the health risks for the potential donor and/or recipient (for example, hypertension) are currently being considered and used as donors. The international transplant community recommends that the acceptance of such individuals as kidney donors be conducted in an ethical manner, accounting for the autonomy and safety of the donor and with rigorous attention to clinical outcomes.”

The statement contains a number of detailed recommendations to be followed “in view of the evolving trends in living kidney donor transplantation.”

They include:

- ✱ The donor must receive a complete medical and psychosocial evaluation prior to donation.
- ✱ The donor must be informed of all of the potential risks, including impact on future health care; the risk of death; expected transplant outcomes.
- ✱ The donor must be informed of alternative therapies available.
- ✱ The decision to donate must be voluntary.
- ✱ The transplant center has responsibilities post-transplant.
- ✱ A health care professional advocating the welfare of the potential donor should be provided.
- ✱ Medical evaluation and concurrence by the donor is essential.

- ✱ Minors less than 18 years of age should not be used as donors.

The final recommendation in the consensus statement adopted by the Society calls for the establishment of an international donor registry. “A international registry for ‘sentinel events’ after living kidney donation should be established and maintained (including the recording of donor deaths or the need for dialysis or kidney transplantation by the donor). Appropriate prospective research should address the long-term outcomes of donors considered to be at potentially increased risk for adverse events.”

A two-page summary of the statement can be viewed online at: www.kidney.org/recips/livingdonors/pdf/newsConsAmstershort.pdf

The full statement can be viewed at: www.kidney.org/recips/livingdonors/pdf/newsConsAmsterdamlong.pdf

California finally launches statewide organ/tissue donor registry

AFTER SIX YEARS of unexpected budget problems, exacerbated by the state’s fiscal woes and legal haggling over such things as data privacy, California finally joined 36 other states in the U.S. with donor registries.

With the launch of the new Donate Life California Organ & Tissue Donor Registry on April 4, California joined 24 other states that allow individuals to indicate their wishes to donate their organs and tissues after their death. The new registry even allows the signer to e-mail their intentions to family and friends after they have signed up.

In the first 10 days after the registry opened, more than 160 media

stories statewide “helped to inspire more than 25,000” to register on the Web site.

The registry can be accessed at www.DonateLifeCalifornia.org or the Spanish-language site, www.doneVIDAcalifornia.org. It is operated by Donate Life California, a nonprofit organization that operates the registry for the state’s four designated organ and tissue procurement organizations—Golden State Donor Services in Sacramento, California; Transplant Donor Network in Northern California; Lifesharing in the San Diego area; and OneLegacy in the Greater Los Angeles area.

International Society for Heart and Lung Transplantation to review prioritizing treatments for heart and lung transplant candidates

CITING NEW ADVANCES in heart and lung transplant medicine, such as beta-blockers, ventricular assist devices, and stem cell transplants, the International Society for Heart and Lung Transplantation (ISHLT) has initiated a review of the process for prioritizing heart and lung transplant candidates and determining

the treatments they receive. The review began in early April, ISHLT announced in a press release.

ISHLT has created several task forces to review criteria for placing patients on a waiting list for a donor organ as well as pharmacological, surgical and device-based interventions to successfully bridge patients-to-transplant.

Guidelines will be presented to the ISHLT’s membership on performance, interpretation and use of stress testing to guide patient listings, as well as when and how to use invasive catheterization. The proposed guidelines also expand the limitations of previously established contraindications to transplantation, such as age, diabetes, peripheral vascular disease, renal insufficiency and a history of cancer.

Patients with damaged kidneys also prone to develop heart problems, study finds

PEOPLE WITH DAMAGED KIDNEYS are prone to a chain reaction that increases their risk of heart problems, according to a new study.

Researchers at Washington University in St. Louis used mice in a study which followed the chain reaction: the kidney damage leads to a weakening of the skeleton, which in turn leads to increased phosphorous in the blood. The higher phosphorous levels are linked to vascular calcification—a stiffening of the smooth muscle cells that are in blood vessels.

The study found that vascular calcification leads to enlargement of one of the heart’s four chambers that creates increased risk for congestive heart failure, heart attack and other cardiac problems.

Injection of BMP-7 stopped vascular calcification. In another group, mice were injected with a substance that binds compounds with phosphorous but had no effect on the skeleton. The substance also stopped vascular calcification, indicating that phosphorous was the key link, the researchers wrote. **TC**

NKF's People Like Us Patient Empowerment Initiative Launched

THE NATIONAL KIDNEY FOUNDATION (NKF) has established “People Like Us,” a movement to empower and enable transplant recipients, living donors, donor families and kidney patients to become effective national and grassroots advocates on issues related to their health care.

To kick off the *People Like Us* initiative, the NKF held a series of advocacy and empowerment activi-

ties in Washington, D.C. in May 2005. One hundred advocates were recruited from around the country to learn about the need for and importance of participation in both national and grassroots public policy initiatives, and about the skills required to become persuasive and confident spokespeople.

Who can become a part of *People Like Us*? Kidney patients, transplant recipients of all organs, living

donors, donor family members, and others affected by kidney disease, transplantation and donation. With the energy and input of all, *People Like Us* can become the largest and most influential group of advocates in the transplant, donation and kidney communities. To sign up for NKF's patient empowerment initiative, contact the National Kidney Foundation at peoplelikeus@kidney.org or 800-622-9010. **TC**

My Experience With BK Virus

■ By Joe Belarde

ABOUT TWO YEARS AFTER MY SECOND TRANSPLANT, my kidney biopsy revealed signs of kidney rejection or failure. The results indicated that I had come down with BK virus. I didn't know how serious this virus could be.

My immunosuppression was lowered and I received five infusions, once every other week, along with anti-viral medication to treat the virus. The results of my next biopsy, however, confirmed kidney failure. I was going to lose my kidney because I was curing the virus! I was confused and a little scared. Then I was told I should get back on the kidney transplant list.

I had to go back on kidney dialysis and felt it was the worst thing. Previously, I'd done dialysis for three and a half years and had learned to deal with it. I couldn't accept that my kidney was failing again. I took large amounts of steroids to counteract the

rejection, but the virus was too much for my kidney and eventually I had to go back on dialysis for the third time.

I had to force myself not to despair. About this time two of my close friends came down with very serious illnesses. One had cancer and the other had a failing liver. My friends' struggles with these serious illnesses were enough to show me how lucky I really was to have dialysis to fall back on. My attitude improved, I went back on a regular routine of dialysis and now I'm doing fairly well. I'm holding my own. My wife, Georgene and I go square dancing every week and go RV-ing as much as we can. Yes, I plan to have another kidney transplant. I



Joe Belarde hiking in the Sierra Mountains.

am on the waiting list. Unfortunately, the waiting time increases every year. I estimate I'll have to wait four to five years. Transplantation allows for a more enjoyable, normal and less restricted life than dialysis, so it's worth waiting for.

Joe Belarde has been married 42 years to Georgene. They live together in San Jose, and have three children and five grandchildren. **T_C**

DID YOU KNOW...

Medicare Supplement Plans pay the copays and deductibles after Medicare Supplements pick up the 20 percent of your anti-rejection medications. This includes QMB (Qualified Medicare Beneficiary) which is a Medicaid program for people who have Medicare and meet certain income guidelines (usually more than regular Medicaid guidelines). Not all pharmacies are set up to do this more complicated billing. You may need to switch to a pharmacy that specializes in transplant recipients. Ask your transplant team for recommendations. **T_C**

Gastric Bypass Surgery...

Continued from page 5

bariatric and transplant professionals experienced in the long-term management of gastric bypass procedures.

Existing medical conditions greatly improve, as weight loss occurs. Medications to treat pre-existing diseases can be reduced or even eliminated. If, however, weight loss is not maintained, these conditions will return and require intensive medical treatment. Gastric bypass surgery provides the individual with a tool. How well this tool is used will determine how much weight is lost, and how well the loss is maintained. To maintain life-long success, a commitment to changing and developing new lifestyles and dietary habits is essential.

Nancee Vander Pluym, MS, RD, is a Transplant Nutrition Specialist at Banner Good Samaritan Transplant Service in Arizona. She also works in the Bariatrics Program.

Editor's Note: Our next issue will feature a recipient's experience with gastric bypass. **T_C**

For the Love of Family

Continued from page 1

For five months in 1996, I once again endured the agony of hemodialysis. During this time, my first cousin, Elijah—who I call “my brother,” offered me one of his kidneys. I did not know how to feel because I worried how it would affect his health. I knew I’d be okay because, even though I dreaded dialysis, it had become a part of my life I’d learned to accept. Besides, dialysis was helping me to survive.

We underwent a series of tests to check our compatibility. When Elijah and I found out we were compatible, he did not want to wait a minute longer. Once again, through the miracle of transplantation, I’ve managed to accomplish more, and it’s all thanks to the love of my family!

After this transplant, I followed my heart and obtained certification to become a Certified Hemodialysis Technician. As a Patient Care Technician I administered care at the unit where I was once a patient. Giving back is a big deal for me. My heart fills with joy when I can make a difference to one person like myself. I graduated from college and married my childhood sweetheart. These things helped me to continue to reach for the stars!

I’ve had my share of ups and downs with transplantation, but the way I see

it is: we take chances in life and we have to take the bitter with the sweet, and the good with the bad.

After my second transplant, I had several major surgeries. The surgeon said there was a chance of kidney failure. Fortunately, that did not happen for a long time. I survived seven and a half wonderful years with Elijah’s kidney.



Malik (3rd donor) and Leslie


I believe that success is a state of mind, an attitude obtained through the right combination of setting reasonable goals, taking action and overcoming the fear to take risks!

I lost the kidney in 2004 and I felt horrible about it. I thought Elijah would be upset, but he said “It’s not your

fault. What’s important is that you are alive and well!” My family is amazing! I will never take my family or friends for granted because, without “my support team,” I don’t know if I would have made it this far.

Later in 2004, I underwent my third transplant. This time, another first cousin, Malik, who is also a “brother” to me, stepped up and offered me one of his kidneys. Since Malik is the baby of the family, I was nervous because I was concerned about his health, too. As the eldest, I would never want my loved ones to experience what I have. But the doctors do extensive testing to make sure the donors are physically, mentally and emotionally fit, and they reassured us that the possibility of a donor’s remaining kidney failing is remote.

The enormous support I have gotten from family and friends has been tremendous. They educated themselves about my medical condition.

I am doing extremely well since the third transplant. Undergoing three transplants is a decision I’ve made because transplantation works for me physically, mentally and emotionally. I believe every dialysis patient should consider transplant. It’s worth the experience. “Don’t knock it, unless you’ve tried it!” 

H.R. 2051 Aims to Extend Medicare Coverage of Immunosuppressive Drugs

ON MAY 3, 2005, REPS. DAVE CAMP (R-4TH, MI) AND TED STRICKLAND (D-6th, OH) introduced H.R. 2051, to eliminate the 36-month limitation for coverage of immunosuppressive drugs for Medicare ESRD beneficiaries. The legislation would provide continued entitlement to coverage for immunosuppressive drugs furnished under Medicare Part B, providing the same lifetime immunosuppressive coverage presently available for Medicare aged and Medicare disabled (SSDI) transplant recipients.

Let your Member of the House of Representatives know that this bill is important! To find out who your House Representative is, follow these steps on the Internet:

- 1.) Go to www.kidney.org
- 2.) Click on "Government Relations."
- 3.) Scroll down to "Government Officials."
- 4.) Click on "Find your Member of Congress."
- 5.) Enter your zip code.

Also join NKF's People Like Us (peoplelikeus@kidney.org) to add your voice to the voice of thousands fighting for legislative change.

Preventing Back Injuries Through Body Mechanics

■ By Cynthia Tilley, MS, OTR, CEAS

MOST BACK INJURIES are associated with poor posture, body mechanics and work habits. Body mechanics means the way individuals move their bodies.

Back injuries are also associated with stress. They are also caused by accidents and environmental factors such as poor workstation set-up. Back injuries can either be cumulative or caused by isolated traumatic events, such as a falls and automobile accidents. Back injuries generally affect men and women equally and most frequently occur in people between the ages of 25 to 45.

POSTURE



Posture is an important aspect of body mechanics. In order to understand what good posture is, individuals must first understand the construction and function of the spine. The

spine consists of 29 bones known as vertebrae, which provide support and flexibility to the body. The vertebrae are separated by discs, which help to absorb shock and provide protection to the spinal nerves. The muscles and ligaments provide support, add stability, and control motion of the spine.

The balance between forward bending (cervical and lumbar regions) and backward bending (thoracic and sacral regions) of the spine defines good posture. Well-balanced posture places the least amount of stress to the joints, ligaments, discs and muscles of the spine. Proper body mechanics and posture depend on the alignment of the musculoskeletal structures while sitting, standing or sleeping.

Recommendations for good sitting posture:

- SHOULDERS back
- HEAD over shoulders and chin tucked
- Lower BACK curve maintained with a pillow or towel roll
- HIPS and knees at a 90-degree angle
- FEET resting on a flat or slightly inclined surface



Recommendations for good standing posture:

- HEAD, SHOULDERS, HIPS, KNEES and ANKLES are aligned
- WEIGHT is evenly distributed to each leg
- KNEES are straight or slightly flexed



Recommendations for good sleep posture:

- USE a firm mattress
- SLEEP on side with knees bent and pillow(s) placed between knees
- SLEEP on back with pillow(s) under knees
- DECREASE the amount of pillows used under head



BODY MECHANICS

Attention to body mechanics is important. Through its proper use, individuals can reduce the amount of stress and strain on the musculoskeletal structure of the spine. This also conserves energy, produces safe, efficient and effective movements, and helps to maintain proper balance and control of the body.

Individuals who must lift, reach, push, pull and carry objects should use good

body mechanics. This will help prevent trauma to the spinal structures. Before performing these tasks, all obstacles should be cleared from the work area, and the manipulated objects should be kept close to the body.

Lifting Recommendations

Lower back stress and strain can be reduced by following these steps:

1. INSPECT THE OBJECT and decide the best way to hold it.
2. TEST THE LOAD by lifting the object a couple of inches from the ground or by pushing the object with your feet to ensure that the object can be moved safely.
3. PLAN THE LIFT — Decide where the object is going to be placed.
4. KEEP YOUR FEET at least shoulder-width apart to increase stability and balance.
5. BEND YOUR HIPS and knees in order to be closer to the center of gravity of the object.
6. KEEP YOUR HEAD UP in order to maintain low back curvature.
7. LIFT WITH YOUR LEGS and in a vertical motion.
8. MOVE YOUR FEET to avoid twisting.

Reaching Recommendations

Place frequently used items within close reach. Items should be placed between waist and shoulder height to reduce strain to the spine and upper extremities from bending at the waist or from over-reaching. Use a footstool or a ladder to retrieve/replace items placed above head level. Keep your head up. Avoid reaching and twisting at the same time.

Pushing/Pulling Recommendations

Push rather than pull objects if possible. Square yourself to the object. Use your legs and arms instead of the back to perform the task. Try to keep your arms slightly bent when pushing. Move objects in a straight line and try to keep the pushing/pulling force parallel to the ground.

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Islet Cell Transplantation: New Therapy for Diabetes



Yogish Kudva, MD

■ By Yogish Kudva, MD

Diabetes affects millions of Americans and nearly 1,700 patients are on the waiting list for a pancreas transplant (UNOS 2005). Another 2,400 people are waiting for a combined kidney and pancreas transplant, due to renal failure caused by diabetes. People with diabetes experience progressive organ damage due to an insulin imbalance. Type 1 diabetes (formerly called juvenile onset diabetes) usually strikes early in life. The islet cells that produce insulin are destroyed by the body's own immune system. When this process begins, the body is unable to convert glucose to the energy needed for normal cell function.

Pioneered by Dr. James Shapiro, Dr. Jonathan Lakey, et al. who published in 2000, human islet cell transplantation has been performed at more than twenty medical centers around the world. Nearly two hundred Type 1 diabetics have received this therapy. Islet cell transplants are being performed in adults with otherwise good general health between the ages of 18-60. Candidates for this procedure are those who are unable to manage their diabetes without suffering from severe insulin reactions.

Until now, pancreas transplantation has been the most commonly performed therapy to replace the islet cells that can no longer produce insulin. Although pancreas transplantation is quite successful, it is a major surgery with associated risks that usually require steroid use as part of the anti-rejection therapy. The goal of islet cell transplantation is to replace the non-functioning islet cells without transplanting the whole pancreas. An advantage of this strategy is that it avoids the necessity of steroid use. Steroids can damage islet cells and are therefore contraindicated in the anti-rejection therapy program.

Perfecting the technique needed to transplant islet cells has been a chal-

lenge. Roughly one million cells are needed to successfully transplant islet cells in an average-sized person. In order to harvest so many cells, a minimum of two pancreases from recently deceased donors have to be used. After being extracted from the whole organ, the cells are prepared and then infused into the recipient's liver via the portal vein. Islet Cells adapt to the environment of the liver, but they must mature before they are capable of producing insulin. Thus, the recipient may need to continue using insulin to control blood sugar levels. In some cases a second infusion of islet cells is necessary before insulin can be discontinued completely.

The success of islet cell transplantation depends on the timely extraction of the cells from the deceased donor organ. The recovered islet cells need to be ready for infusion into the recipient within 48 hours from the time of removal from the donor. This requires specialized equipment and laboratory personnel knowledgeable in islet cell management.

Future challenges for implementing islet cell transplantation include finding ways of increasing the number of candidates who qualify for this proce-

dures, increasing the number of surgeons trained to perform it and finding a way of alleviating the continuing national problem caused by a shortage of donor organs from which islet cells can be extracted. Careful selection of donor organs and appropriate recipients are important contributors to the outcomes. Hopefully, this procedure can be offered in the future, either after or in conjunction with kidney transplantation. This will effectively help recipients to avoid diabetic complications of transplantation. To accomplish this, the scientific community must develop improved steroid free anti-rejection medication programs and continue to educate the public on the importance of organ donation.

Dr. Kudva is an Assistant Professor of Medicine and a Consultant in the Department of Internal Medicine at the Mayo Clinic. He is involved with numerous committees and projects with the Kidney/Pancreas Transplant Program and the Division of Endocrinology, Diabetes, Nutrition and Metabolism. TC

Preventing Back Injuries...

Continued from page 13

Carrying Recommendations

Alternate objects from one hand to the other. Balance the load of the object being carried. Long objects should be carried in front for control. Heavy objects can be carried on the shoulder. Whenever possible, use a dolly or a cart to transport objects instead of carrying them.

IN SUMMARY, proper body mechanics assist in providing balance and stability to the spine. Individuals can help reduce the risk of back disorders by exercising,

maintaining flexibility, keeping weight down, and wearing good supportive shoes. To avoid back injury, it is most important to avoid loads that are too heavy.

Cynthia D. Tilley, MS, OTR/L, CEAS, is an Occupational Therapist and Ergonomic Specialist for the University of Maryland Medical Center. She has been practicing occupational therapy for over nine years in the areas of acute care, acute and subacute rehabilitation settings, and ergonomics for over four years. TC

HIV & Transplantation

An HIV and Transplant Study Saved My Life


■ By **George Martinez**

I am a person living with HIV/AIDS (18 years) and Hepatitis B (36 years). After I learned that I had liver decomposition in 1999, I was told that transplantation was not an option. My prospects looked grim. Then in 2000, transplant centers began a study involving transplantation in individuals with HIV. This gave me hope that I would someday be put on a transplant waiting list and in 2002, I was. I underwent liver transplantation in May 2004. Today, I am doing very

well with my anti-rejection and anti-retroviral medications and am optimistic about the future. Organ donation is a selfless and generous gift of life. Transplantation may be a viable option for individuals living with HIV and liver decomposition. I am one of several people in the country who are living examples of how far medical science has advanced in saving the lives of those with co-infections (HIV/ hepatitis or HIV/nephropathy).



George Martinez is an advocate for organ donation.

He is a member of the National Community Advisory Board for the Solid Organ Transplantation in HIV: Multi-Site Study. 

George Martinez

HIV and Transplant

■ By **Rodney Rogers**

PEOPLE WITH HIV DISEASE are at risk for kidney and liver diseases, just like people who do not have HIV.

Increasing numbers of patients with end stage liver and kidney disease are seeking transplantation. People with HIV infection have been considered ineligible for organ transplantation in the past for two important reasons. First, HIV shortened their expected life spans, making them less likely to be viewed as viable candidates by transplant centers who tended to decide which patients received organs, based on how likely they were to survive after the procedure. Secondly, it was thought that the anti-rejection drugs required by post-transplant patients could hasten the progress of HIV and thereby increase the number of deaths.


Poor survival is no longer a reason to deny a transplant to a person with controlled HIV.

Due to advances in treatment, people with HIV/AIDS are living longer, healthier lives. Excluding them from consideration for organ transplantation based only on the length of time they may live can no longer be considered a valid policy.

Small pilot studies are showing good outcomes. Nevertheless, these findings must be duplicated in a larger, longer study in order to determine that solid organ transplantation in HIV-positive people is safe and effective, to find which patients are most likely to benefit from transplantation, and determine who would be at greater risk with transplantation. We need to explore the possibility and extent of interactions between the anti-rejection drugs and the drugs used to treat HIV.

Understanding how these drugs interact in HIV-positive transplant recipients will be essential to improving the management of anti-rejection therapy in these patients.

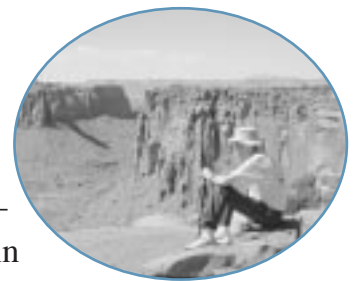
A study evaluating the safety and effectiveness of kidney and liver transplants in a select population of HIV infected individuals is currently underway at 19 transplant centers across the country. Information about HIV and transplant is available at: www.hivtransplant.com

Rodney Rogers is the Project Manager of the Solid Organ Transplantation in HIV: Multi-Site Study at the University of California. 

THEN & NOW: Kidney Transplantation in 1989 vs. Today

■ By Jack Fassnacht

FACED WITH THE PROSPECT of a second kidney transplant, I attended a meeting to learn about kidney transplantation for the second time in my life and realized a lot had changed since 1989.



Jack Fassnacht

THE WAITING LIST IS MUCH LONGER

Back in 1989 there were 16,294 kidney candidates. Today, 15 years later, the kidney waiting list has grown to over 63,600. That's an increase of almost 400 percent! I'm just speculating, but the increase may have something to do with the success of kidney transplantation as well as the increase in the number of persons suffering from diabetes and high blood pressure in the U.S.

WAITING TIMES ARE LONGER

Although the waiting list has grown, the pool of potential donors has not kept pace. Consequently, the average waiting time on the deceased donor kidney waiting list has grown from less than two years to somewhere between six to eight years. While this varies according to the candidate's blood type and where one is listed, the fact remains that waiting times have greatly increased.

LIVING DONATION HAS BECOME MORE COMMON


To my surprise, many of the transplant candidates sitting with me were accompanied by potential living donors. The percentage of kidney donations from living donors has increased, from 32 percent of all kidney donors in 1989 to more than half in 2004. This is because there are not enough deceased donors and that medical advances have helped make donors and recipients more compatible.

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