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Transplant Chronicles

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Are You Ready to Rumble? Training for the 2004 U.S. Transplant Games

■ By Chris L. Wells, PhD, PT, CCS, ATC

This summer thousands of people will gather in Minneapolis - St. Paul, Minnesota, for the 2004 U.S. Transplant Games. We will come together to remember and honor the people who have donated the most precious gift of all, organs and tissues, so others can continue to live.

We will gather to celebrate public awareness of organ and tissue donation by demonstrating the depth of our dedication through competition.



Photo credit Marc Serota

I spent many hours behind the scenes at the 2002 Games, watching people give their all. I evaluated many athletes who had lunged a bit too far or whose muscles complained that they had been overworked during a competitive event. You cannot avoid all injuries, but you can do your share in preventing them by proper training. So lace up those sneakers and let's get ready!

If you think you cannot compete either because you are still recovering, or you have never participated in a sport and do not think you are athletically inclined, please think again. The best place to begin in preparing for the Games is with your cardiopulmonary (heart and lungs) system. This will allow your body to use oxygen efficiently and strengthen your muscles and bones. It is best to select an activity that relates to the sport events that you wish to try at the Games. For example, if



your sport is going to be basketball, tennis or running in track events, you should focus on jogging. Speed walking would be a good training activity for sports like badminton, table tennis, bowling, golf and field events.

Your goal for aerobic training should be to work out for at least 20 minutes, three to four days per week. You should begin exercising at a low to moderate exercise intensity. You can gauge your intensity by either monitoring your heart rate or by using the "Rate of Perceived Exertion Scale" that was described in the previous issue of *Transplant Chronicles* ("How Exercise Can Help You Kick the Habit," page 13 of Volume 11, No. 3).

Whatever your sport, it is important to participate in a strengthening program two to three times per week to prevent injuries. Exercises should focus on the large muscles of your body. These large muscles are the "work horse" for sports and are susceptible to weakening due to the chronic use of steroids and inactivity. Each strengthening exercise should be

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Laurel Williams

RN, MSN, CCTC
Editor-in-Chief

The other day I ran into our staff psychologist, Mark. He always takes the time to say hello and makes the staff feel a bit better about the day because of his positive attitude. Mark has been battling colon cancer. On this day I asked him how he was doing. In his positive manner, Mark explained he was having chemotherapy for an indefinite period of time and that it made him feel sick. He explained that though he lost almost 60 pounds, his oncologist was pleased because he had gained six pounds back! He told me that his cancer had spread and the chemo was just "buying him time." He hoped for another year or two. We talked about how unusual it must seem to him to be going through all the things that he has helped others cope with for over 20 years. He acknowledged it was odd but gave him some real insights that he had never had before. He continues to work two days a week.

The point of this story has to do with the choices we make, and the power of those choices. As Victor Frankl, Auschwitz survivor and author, so eloquently stated, "Everything can be

taken away from you but one thing, the last of human freedoms, to choose one's attitude in any given set of circumstances, to choose one's own way." Or as my mother would say, "It's not so much what happens to us in our lives but how we deal with it."

When we think about people who have the biggest impact on us, it is not about what those people do but how they do it—their attitudes towards life and living. We all have "bad days," and some are worse than others, but despite that we do have choices. As we approach an exciting summer, with the 2004 U.S. Transplant Games and the 50th anniversary of transplantation, let us keep in mind the lesson from Mark and the joy we can bring to others and ourselves by our attitudes. Our choice of attitudes not only affects us, but also has a ripple effect on all of those around us. When you are having a bad day, whether because of rejection, extra lab work, re-hospitalization, more surgeries or maybe just problems with a difficult child, co-worker, person or situation, remember that we do have control, we can make a difference. The choice is up to us. Here's to you Mark! **TC**

Laurel Williams
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let your VOICE be heard!



Q: What types of things have you found helpful if you are feeling down or depressed? Do you think there is a down side to taking medications for depression? Why or why not?



Log onto www.recipientvoices.org to share your answer to this question, and view the responses of others. If you do not have access to the Internet, feel free to write out your response and send it to:

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'Only' Isn't a Bad Thing

■ By Ron Ehrle, RN, CPTC

Recently I was asked to give a presentation on organ donation and transplantation to a group of interns at an area hospital, something I had done many times over the years. In preparation for this presentation, I was updating the "numbers" by reviewing the 2003 Annual Report of the Scientific Registry of Transplant Recipients www.ustransplant.org. In the section on organ donation and transplantation trends I came across this statement: "In 2002, the number of deceased donors increased by only 1.6 percent."

Initially I was saddened and disappointed that the increase was so small, considering the amount of work and dedication that our nation's Organ Procurement Organizations put into increasing donation. As I thought about this 1.6 percent increase, I began to think about what this means to those who are waiting.

Maybe you or someone you know benefited from the additional 195 kidneys, 56 pancreases, 184 livers or 84 lungs recovered from this increase of only 1.6 percent. To these patients and their families, this increase is not "only" 1.6 percent—it is immeasurable. Just think what the 5 percent increase in donation projected by Health and Human Services Secretary Tommy Thompson for 2003 will mean to those waiting. Any increase in donation, no matter how small, is always better than no increase.

If you are a transplant recipient, transplant candidate or if you are from a donor family, you have had a major role in increasing donation, even if you do not realize it. Take a moment to reflect on how many people know of your gracious decision to donate or your struggles before your transplant and how your life has changed since

your transplant. These experiences have had a profound impact on those around you. It is not uncommon, when talking with a family about donation, for them to mention someone they knew who had donated, had received a transplant or was waiting for that second chance. Knowing this helped them make the decision to donate. Just by talking to friends, neighbors and anyone who will listen increases awareness about the critical shortage of donors and the success of transplantation. Certainly, working with your local donor program in helping to open doors to schools, churches and civic groups for formal presentations is also extremely beneficial.

While too many of our friends, family members and patients die every day waiting for that second chance, let's not lose sight of the critical difference just one donor makes. **TC**

About the Author

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Are You Ready to Rumble?...

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done with a resistance or weight that you can complete 10 to 12 repetitions for two to three sets.

Along with strengthening, it is vital to dedicate time to stretching. With your strength training and participation in sports you will develop muscle tightness that can increase your risk of straining a muscle during play or work. Stretch tight muscles—not to the point of pain, but to the point of tension—and hold for 30 to 60 seconds, and repeat three to five times. It is particularly important to stretch muscles around your shoulders, hips, knees and ankles.

As the Games get closer, one good training principle is to practice your sporting event. This is a good technique to get your body used to the specific demands of your sport and to improve your skill level. This could mean driving a bucket of golf balls or practicing your bumping skills in volleyball. This could also include com-

pleting a mile race in 25 minutes when your goal for the Games is to walk the distance in less than 20 minutes, or playing 7-point table tennis games. Slowly work up to your goal for the specific sports event.

One part of training that frequently gets overlooked is getting your body used to the weather conditions, particularly if your sport is outdoors. You need to slowly expose yourself to the sun, rain, humidity and wind and prepare your body to efficiently consume

the extra fluids. (See the article on page 14 of this issue for more information on sun protection.) You need to talk to your transplant coordinator and physician about any fluid restrictions before changing your intake. It is advised to drink about six ounces of fluid every 15 to 20 minutes during competition. It is best that it be mostly water. Sports drinks should only make up about a fourth to a third of the total fluid. You can either alternate sport drinks and water or mix the sport drink and water together.

The U.S. Transplant Games is a special event to celebrate life, make new friends and experience the exhilaration of competition. The preparation you dedicate to getting yourself ready for the Games will only make the experience more pleasurable for you. It will decrease your risk of injury. Although the medical support team would love to meet every one of the athletes and their family members, we would like to keep you off the examining tables and on the playing fields. So get yourself ready properly, and in July, just stop by and say hello. **TC**



Photo credit: Jay LaPrete

Cardinal Essential Rules of Transplantation

■ By Lee E. Downing

As I approached the milestone of 15 years as a liver transplant recipient, the members of a transplant support group asked me, “What are the keys to successful transplantation?”

After thinking about it, I realized the answer was rather simple. Life after transplant can be rewarding and uncomplicated if you follow four Cardinal Essential Rules of Transplantation (CERT):

C—**COMPLIANCE:** One of the leading causes of late organ loss is non-compliance. To have a successful lifelong transplant, you must always take your medications as prescribed and attend your scheduled clinic appointments. As the old adage goes, “Timing is everything,” and this certainly applies to taking your medication at the designated times. If you are required to take a medicine at 6- or 12-hour intervals, there is a good medical reason for this. The same applies to clinic check-ups. Is anyone compliant 100 percent of the time? That is unlikely, but the recipient who is compliant 80-90 percent of the time certainly has a greater opportunity to stay healthy and live a “normal” lifespan.

E—**EXERCISE:** For a transplant recipient it is imperative that you pursue some form of mental, physical and spiritual exercise on a regular basis. A healthy body contributes to a healthy mind and vice-versa. By keeping your brain active—through reading, crossword puzzles or other activities—you might protect yourself against future memory loss. Spiritual expressions can strengthen your resolve to overcome any hurdles pertaining to issues related to your transplant. So go for a walk daily, practice yoga, read a book at your leisure, dance and learn a new dance step, seek spiritual direction/ guidance. Routine involvement in physical, mental and spiritual activities will be critically beneficial to you.



If you are interested in special greeting cards for your donor family, contact transplantchronicles@kidney.org

R—**RESPONSIBLE CORRESPONDENCE:** Regular contact with your donor/donor family is an obligation each transplant recipient should try to fulfill. Send a letter, note or card periodically to let your donor/donor family know how grateful and appreciative you are for the unconditional gift of love you received. I am surprised by the countless numbers of recipients who have never written. Your cards or letters could be sent on your birthday, the anniversary of your second chance at life, holidays or for no particular occasion at all, just to drop a note of appreciation. It need not be elaborate—a simple greeting card can work small miracles.



What do you do if you contact your donor family but never hear back from them? Ten years ago I was speaking at a donor awareness program and I was telling the audience that although I had never received any letters back from my donor family after years of writing (and it seemed more than likely that I would never hear from them), I continued writing out of a sense of obligation and a desire to continually let them know what their gift of life has meant to me. I was frank in stating how I became increasingly frustrated when there was no acknowledgment of receipt of my letters. After my presentation, a gentleman approached me and told me he was a donor father and that I should continue writing to my donor family. He told me that for over six years he had been receiving letters from the recipient of his son’s liver, but never opened them until recently. He said he just kept the unopened letters in a shoebox until he was emotionally pre-

pared to read them. He helped me realize that there is no time limit for bereavement, and I should continue writing despite my personal feelings of frustration. After 12 years of writing to my donor family without a single response, I received my first letter from my donor’s spouse. She indicated that she had received all of my letters and was thankful for them, but she was just now capable of responding. Imagine if I had given up and stopped writing. I would have missed the letters that finally came, an invitation to my donor’s daughter’s high school graduation, and most extraordinarily, our meeting each other.

T—**TRANSMIT:** Transmit your gift of kindness/compassion for mankind to others. Take the gift of life that you have received and practice some act of kindness to others. As transplant recipients we can never hope to repay or pay back our donor and donor family for their ultimate act of selflessness and compassion, but we can “pay it forward” in a way to ensure that the chain of giving to others will continue beyond the span of our lives. Simply think of doing random acts of kindness for others as a means of honoring your donor and donor family.

I am convinced that if transplant recipients incorporate these four simple “rules” into their daily lives, their lives will be enriched and fulfilled tenfold. **T_C**

About the Author

Lee E. Downing received his liver transplant August 12, 1988. He is a Senior Product Specialist for Fujisawa Healthcare, Inc.

Managing the Risk of Chronic Kidney Disease After Solid Organ Transplantation

■ By Silas P. Norman, MD



Silas P. Norman, MD

Solid organ transplantation has been a lifesaver for thousands of recipients. Since 1988, over 95,000 heart and liver transplants have been performed in the United States. The benefits of organ transplantation have not come without new challenges. One of these challenges has been the development of kidney disease following transplantation. Kidney disease is detrimental in several ways.

Individuals with significant kidney disease have an overall lower life expectancy than people without kidney disease. Some individuals will progress to end-stage kidney disease requiring dialysis or a kidney transplant. In addition, kidney disease is a risk factor for cardiovascular disease (heart attack, stroke), which is responsible for 30 percent of all deaths in transplant patients.

In trying to prevent and manage kidney disease in transplant patients we first need to understand some of the many causes of kidney problems. Abnormal kidney function is common in individuals with heart and liver failure. Kidneys suffer from the decreased blood flow and low blood pressures that are common with these diseases. Prolonged exposure of the kidneys to inadequate blood flow may lead to permanent kidney damage that does not improve following a heart or liver transplant. In addition, the medications given to treat heart and liver disease have the potential to cause kidney injury. At the time of organ transplantation, many individuals already have kidney disease.

Many of the diseases that lead to the need for heart or liver transplants may cause kidney damage, and can continue to do so after a transplant. Immunosuppressive medications have dramatically decreased rejection episodes and helped prolong the life of organ transplant recipients. Unfortunately, a number of the drugs

that are mainstays of current immunosuppression can contribute to kidney disease. They can cause increases in blood pressure, which can hasten the progression of kidney failure. In addition, some of the medications are potentially kidney-toxic, since they decrease blood flow to the kidneys and can lead to scarring of the kidneys. Despite these potential complications, these medications continue to be used because other drugs have not matched their beneficial effects on the survival of the transplanted organ.



Kidney disease in transplant patients usually occurs as part of overall increased heart disease risk. In considering the management of kidney disease we must understand the additional factors that contribute and the interrelation of their management. The heart disease risk factors include high blood pressure, diabetes, elevated cholesterol, smoking, obesity, being male, being older and having kidney disease. Each condition increases an individual's risk for developing heart disease. Transplant

medications can not only cause kidney injury, but also typically worsen blood pressure and cholesterol. Five to fifteen percent of recipients will develop diabetes, in part because of the weight gain common after transplant.

High blood pressure is the single most important factor to control in managing kidney disease. Poorly controlled blood pressures will accelerate the decline of kidney function regardless of the cause of kidney disease. Transplant recipients should maintain a blood pressure of less than 130/80 mmHg (to see full guidelines on hypertension and chronic kidney disease, visit www.kdoqi.org). Individuals often require multiple medications to reach their target blood pressure. Achieving a goal blood pressure requires consistent home blood pressure monitoring and regular contact with a physician. The choice of immunosuppressant medications may also have an impact.

The cause of diabetes after transplant is usually medications and weight gain combining to make individuals resistant to the glucose lowering effects of insulin. Medications often increase appetite, which further worsens the weight problems of transplant recipients. Healthy eating goes a long way to minimize this risk. In addition, increasing aerobic activity improves insulin sensitivity,

Continued on page 15

Am I Singing the Blues... or Is This Depression?

■ By Lara Tushla, LCSW, MSW

It is completely normal to have periods of feeling sad, down, out of sorts, in a funk or depressed. Everyone has these feelings at times. The question is: when do these feelings reach the next level and become “major depression”?

Major depression is identified when you have at least five of the symptoms listed below for at least two weeks:

- ✓ Feeling depressed on most days, for most of the day. Sometimes this appears as irritability.
- ✓ Loss of interest in the things you used to enjoy.
- ✓ Significant increase or decrease in appetite, weight or both.
- ✓ Sleep disorders: either the inability to sleep or sleeping more than usual, nearly every day.
- ✓ Feelings of agitation or sense of intense slowness. Sometimes this feels like “nervous energy” or like you are walking through water.
- ✓ Loss of energy and daily sense of tiredness.
- ✓ Sense of guilt or worthlessness nearly all the time.
- ✓ Inability to concentrate, nearly every day.

Many times people will have some of the symptoms of depression because of their transplant, medical history or the medications they are taking. For example, imagine you started a new medication and find that you are tired all the time. If so, you should ask a health care professional if your tiredness might be a side effect of the medicine.

But if you have lost your appetite, are sleeping all the time, can't get interested in your favorite hobby, feel like

your body is moving in slow motion, and you feel depressed... then you may have major depression, and you should talk to someone about it.

When someone comes to a doctor with feelings of depression, the first step is to look for medical causes of the symptoms—medication side effect, thyroid disorders, etc. Once a medical cause has been ruled out, the severity of the depression guides the treatment. There are many levels of depression. It can range from periods of feeling sad, to times when you can't even get out of bed, to thoughts of hurting yourself. Some of the mildest depression can be managed by talking about your feelings with someone you trust. If the symptoms are more disabling, counseling may be recommended and anti-depressants may be prescribed.

Talk with someone you trust, a member of your family, your health care team, a teacher, a minister or a friend. Don't carry this by yourself.

I'm depressed because I am sick.

It is normal to go through periods of feeling depressed when you have a chronic illness. Facing the reality of your new life with a transplant means you have lost a previous life. Depression during periods of loss is natural. It is similar to grieving the loss of a loved one. If the depression lasts a long time and interferes with your ability to live your life, then it is time to ask for help.

I feel guilty that I am sad when I have gotten the Gift of Life.

It is not disrespectful to your donor family to have periods of depression. It does not mean that you do not appreciate the gift. You are going through a transition period. Change brings a lot of emotions.

How does age affect depression?

Studies have identified depression in children as young as six. Children and teens may experience depression differently than adults. In addition to the list above, young people may also experience inability to enjoy favorite activities, persistent sadness, increased irritability, complaints of physical problems, poor performance in school, persistent boredom, feeling burned out and a greater tendency to bully others.

Although aging alone does not increase your risk of depression, the longer you live the more losses you are likely to have experienced, which does increase your risk. Identifying depression in the elderly takes a little more investigation because of the complicating medical history.

Can I take St. John's Wort or other herbal remedies?

Talk with your health care team before taking any herbal medication. St. John's Wort has been proven to interact with transplant

medications and can put your transplant and overall health at risk.

I sometimes feel like giving up.

We all get tired of the challenges life has brought us. It would be unusual if you never thought you had had enough. But if this feeling starts to affect your ability to care for yourself—not taking your medication correctly or thinking about hurting yourself—you should reach out and talk with someone. **TC**



Transplant News Digest

from the editors of **Transplant News**

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

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: <http://www.trannews.com>



Jim Warren

NEW For monthly updates from the *Transplant News* editors, read *Chronicles Xtra* at www.recipientvoices.org

'Organ Donation and Recovery Improvement Act' becomes law

The "Organ Donation and Recovery Improvement Act," first introduced in February of 2002, has finally become a law.

Senate majority leader Bill Frist (R-TN) and Senator Chris Dodd (D-CT) led the effort to gain passage in the Senate. Representative Michael Bilirakis (R-FL) spearheaded the effort in the House.

"I'm thrilled that the president signed my bill into law," Bilirakis said in a press release. "This landmark legislation represents the most significant congressional action in this area since the National Organ Transplant Act of 1984, which established our current organ donation network. My hope is that this new law will help move us closer to the day when no patient is forced to languish on a waiting list due to a shortage of donated organs and tissue. Everyone should have access to the 'Gift of Life.'"

President Bush acknowledged including nearly \$25 million in his 2005 budget proposal for organ procurement and transplantation efforts and noted he had signed the transplant bill.

The legislative provisions to be funded with the \$25 million include:

- ▼ *\$5 million for reimbursing living organ donors for travel and subsistence expenses incurred when making a living donation;*
- ▼ *\$3 million for funding for hospitals and organ procurement organizations to help them establish new organ donor coordinator positions;*
- ▼ *\$15 million for funding public awareness programs and demonstration projects to increase donation; and*
- ▼ *\$2 million to support research efforts to increase organ donation and improve the recovery, preservation, and transportation of organs.*

Number of deceased organ donors in US increased 4.3% in 2003; deaths on waiting lists declined—UNOS

The number of deceased organ donors in the U.S. increased by more than 4 percent in 2003 over 2002; however, the number of live donors once again exceeded deceased donors, according to preliminary data compiled by the Organ Procurement and Transplantation Network (OPTN).

There were 6,455 deceased donors in 2003, an increase of 268 from the previous year and the highest rate of increase in five years, according to the United Network for Organ Sharing (UNOS), the agency which operates the OPTN under contract from the Department of Health and Human Services (HHS).

The number of live organ donors in the U.S. has exceeded the number of deceased donors each of the past three years, UNOS said in a press release.

The combined total of deceased and live donors—13,263—resulted in a total of 25,448 transplants in 2003. A total of 18,648 transplants performed used organs from deceased donors, while 6,800 were from live donors, including 40 percent of kidney transplants.

In addition to the modest increase in deceased donors, UNOS noted that the number of transplant candidates who died waiting for a transplant in 2003 fell to 5,968 after exceeding 6,000 each year since 1999.

The number of deaths among candidates listed for a transplant declined 10.5 percent from 2002 to 2003. This decline was likely due in part to the nearly 550 additional transplants performed in

Continued on next page

2003, UNOS said in the release. However, UNOS cited other factors as possibilities, including better medical management of patients waiting for a transplant and the effects of recently enacted OPTN/UNOS organ allocation policies that give more priority to patients who are medically urgent and/or harder to match with most donated organs.

Here is a breakdown in the number of transplants performed in 2003 by organ and type of donor where applicable:

- **Kidney** – Total: 15,120; Deceased donor: 8,662; Living: 6,458
- **Liver** – Total: 5,671; Deceased donor: 5,351; Living: 320
- **Heart** – Total: 2,055
- **Lung** – Total: 1,085; Deceased donor: 1,070; Living: 15
- **Pancreas** – Total: 502; Deceased donor: 502; Living: 0
- **Heart/Lung** – Total: 29
- **Kidney/Pancreas** – Total: 870; Deceased donor: 867; Living: 3
- **Intestine** – Total: 116; Deceased donor: 112; Living: 4

Explosion of live kidney donors creating a new class of patients to be cared for by transplant community

While the worldwide explosion of live organ donors has certainly benefited those in need of organs, it has also spawned a somewhat unanticipated problem: Those very donors have become a new class of patients who must be cared for and followed by a transplant community not fully equipped to deal with them.

More than 100 experts, representing over 40 countries who met in Amsterdam on April 1-3, struggled to arrive at a consensus on what standards need to be set, and what kind of tracking system would be feasible for the thousands of individ-

uals who become donors each year. “With living donation increasing rapidly worldwide, the transplant community has been challenged to ensure that it is a safe and carefully considered experience for the live donor, including the pre-transplant evaluation, the surgical procedure and post-transplant care,” Francis Delmonico, MD, the chair of the forum told participants. Delmonico is chair of the Ethics Committee of the Transplantation Society and professor of surgery at Harvard Medical School and Medical Director of the New England Organ Bank in Boston.

One of the thorniest questions tackled by the group concerned how to express concern for the donors’ post-operative welfare without “spooking” them with the possibility of an obtrusive lifelong follow-up process.

“It’s very important to keep in mind the sense that the number of donors who experience problems is very low,” said Gabriel Danovitch, MD, director of the division of nephrology at the University of California, Los Angeles. “We need to keep the low number in perspective and not force all donors to undergo an onerous set of follow-up procedures over their lifetime.”

“We have to be careful in making recommendations to government or public health officials so that we don’t throw the baby out with the bath and get nothing,” added Bob Gaston, a nephrologist at the University of Alabama at Birmingham. “It’s important that we don’t overshoot or be impractical.”

However, Faissal A.M. Shaheen, MD, argued forcefully that it is the “obligation and duty” of the transplant community to ensure that the living donor has proper assessment. Faissal emphasized that assessment must include medical and psychological screening before the opera-

tion, proper follow-up covering the immediate period after the operation, and in the long term, be based on the best available medical care and driven by compassion.

As the demand for organs for transplant has grown, so has the use of marginal donors—older donors, less healthy, HIV positive, etc., several forum members observed.

“We have moved from using an ideal donor to more marginal donors in living donation just like we have in using marginal deceased donors,” said Yves F. Ch. Vanrenterghem, MD, of the Catholic University of Leuven University Hospital Gasthuisberg in Leuven, Belgium. “So demand [for donors] has had an impact and we are now stretching the boundaries of which donors we can use. Assessing the risk to the donor by doing so is important.”

“If we’re going to use these donors or a constellation of them, it gives us a much different responsibility if the individual will become a patient if they donate,” Delmonico agreed. “They will have to be followed by their local physician or some other means like a national registry.”

Arthur Matas, MD, director of the world’s most prolific live donor program at the University of Minnesota, argued that the development of standards must be broken into separate categories for patients and follow-up.

“We need to have standards for what the donor should do and separate standards for research should be conducted after the donation,” Matas told participants.

Matas stressed that post-operative follow-up is not easy, adding, "We have only been able to find 50 percent of our donors after 20 years. But we have to attempt to track our donors and get information for our research."

Once the debate over the scope of the recommendations was concluded, forum participants delved into the lengthy, often grueling process of developing standards to recommend to the worldwide transplant community for caring of the live kidney donor, including the evaluation of various medical issues that could affect the potential donor, such as hypertension, body mass index, dyslipidemia, renal function, malignancy and a history or current presence of infectious diseases such as tuberculosis or hepatitis.

Participants agreed that the live kidney donor must receive a complete medical and psychosocial evaluation, receive appropriate informed consent, and be capable of understanding the information presented in the consent process in order to make a voluntary decision to donate.

The importance of live donor programs having a "donor advocate" was also stressed as being an important part of the process to help protect and promote the interests and well being of the donor.

Delmonico said the next step in the process includes developing a position statement addressing the responsibility of the transplant community for the live donor; forging an alliance with the World Health Organization (WHO) to implement the standards; and encouraging forum participants to become emissaries of the standards in their own countries and professional organizations.

The Forum was administered by the U.S. National Kidney Foundation. Sponsorship was provided by

Novartis Transplantation & Immunology; Fujisawa Healthcare, Inc.; Roche Pharmaceuticals; Genzyme Corporation; Wyeth Pharmaceuticals; the International Society of Nephrology; the National Kidney Foundation of Singapore; and The Transplantation Society.

Two rare eight-organ transplant operations performed

An Italian baby and a 36-year-old German secretary both received eight organ transplants at once in the past two months, according to press reports.

Alessia Di Matteo, who is now 7 1/2 months old, received a new liver, stomach, pancreas, small intestine, large intestine, spleen and two kidneys during a 12-hour operation on January 31. The transplant was performed at the University of Miami-Jackson Memorial Medical Center in Miami. The transplant team was led by Andreas Tzakis, MD.

The baby Alessia, of Genoa, Italy, was born with congenital smooth muscle disorder, which prevented normal function of her stomach, intestines and kidneys and left untreated is fatal. "In order to treat the child, one must replace all of these abdominal organs," Tzakis said, the Associated Press reported.

German transplant physicians announced in early February that they had performed Europe's first simultaneous transplant of eight vital organs in November 2003. The transplant was performed at Charite Hospital in Berlin.

The secretary identified only as Stefanie H, received a new liver, pancreas, stomach, duodenum, small intestine, partial large intestine, kidney and adrenal gland during the 12-hour operation.

The woman, who had Crohn's disease for more than 20 years, had been hospitalized since 2001. Andreas Paschner, a member of the four-person surgical team, said all the organs were fully function and Stefanie may be able to go back to work in six months.

FDA approves first heart assist device for children awaiting transplant

The FDA's Center for Devices and Radiological Health (CDRH) on February 25 approved a Humanitarian Device Exemption (HDE) for use of the miniaturized heart pump for children aged 5 to 16. Use of the pump may allow children with severe left ventricle failure to survive long enough to receive a heart transplant.

The approval was based on a review of data from 190 adults worldwide who were implanted with the miniaturized pump, and on extensive mechanical testing performed by MicroMed, the FDA said in a talk paper. The data revealed the device has "reasonable probability" of being safe and effective.

The FDA estimates that fewer than 100 children a year will be candidates for the new pump.

The device, which is a modified version of the Jarvik heart, the first artificial heart ever implanted in a human, in December 1982, has been used to save the lives of more than 200 patients in the U.S. and Europe, according to the *Arizona Daily Star*. Almost 80 percent of those patients survived long enough to get a life saving heart transplant. **TC**

Medicare Prescription Drug Improvement and Modernization Act of 2003

■ **By Dolph Chianchiano, JD, MPH**

On December 8, 2003, President Bush signed into law the Medicare Prescription Drug, Improvement, and Modernization Act of 2003 (Public Law 108-173). The legislation could help kidney patients and transplant recipients pay for many prescription medications. However, **it is important to remember that the various benefits will only be available to kidney patients and transplant recipients who are entitled to Medicare at the time the respective provisions of the law go into effect.**

Beginning May 3, 2004, Medicare beneficiaries were able to enroll in a drug discount card program. For people whose income is less than 135 percent of the federal poverty (in 2004, no more than \$12,569 if you are single, or no more than \$16,862 if you are married), the card is free and entitles the holder to \$600 of prescription drugs per year, before operating as a regular discount card. For others, the cards do not include the \$600 benefit, and they will cost up to \$30 per year. Individuals deciding whether to purchase a card should view the drug prices offered by various cards on the Medicare Web site:

www.medicare.gov

The card program will expire on January 1, 2006. The only people who are not eligible for the drug discount card program are those who have outpatient prescription drug coverage under Medicaid.

On January 1, 2006, a new drug insurance program, Medicare Part D, will become available to Medicare beneficiaries. Enrollment in Part D is voluntary and will require the payment of a premium. This payment is in addition to the premium required for benefits available under Part B of Medicare (e.g., immunosuppressants). Part D will

be administered by private insurance companies which can limit the type of drugs that will be covered in any therapeutic category. **Part D will not provide assistance for immunosuppressants, or other drugs that are covered under Part B.** The Medicare Prescription Drug Act does not extend the length of immunosuppressive drug coverage beyond that provided under the Benefits Improvement and Protection Act of 2000.

Medicare beneficiaries are responsible for substantial deductibles and co-pays under Part D. If a Medicare beneficiary incurs large annual medication costs, Part D will cover 95 percent of the cost of medications. This “catastrophic” benefit does not kick in until after the beneficiary has spent \$3,600, out-of-pocket, for prescription drugs. On the other hand, the legislation provides graduated relief from the deductible and co-payment requirements for beneficiaries whose income approaches the poverty level. There are also asset restrictions on this relief. For Medicare beneficiaries whose income is above 150 percent of the poverty level, it is estimated that, on average, Medicare Part D will cover half the cost of their prescriptions.

Should Transplant Recipients Enroll in Part D?

As noted above, Part D will be available only to individuals who are entitled to Medicare. Therefore **enrollment in Part D will be limited to the following categories of kidney transplant recipients: a) senior citizens, b) individuals who have received SSDI payments for 24 months, or c) ESRD-only Medicare beneficiaries whose 36 month post-transplant Medicare eligibility has not expired.**


Coverage for immunosuppressants will continue to be provided pursuant to Medicare Part B until Congress legislates otherwise.

Under Part B, Medicare pays 80 percent of the cost of medications and the transplant recipient must pay the balance. (The cost to the beneficiary is called a co-payment). While the 20 percent co-payment that is required under Part B is less than the cost sharing required under Part D, **transplant recipients will not be able to count out-of-pocket expenses for Part B drugs in determining whether they have spent \$3,600 for medications and are thereby entitled to “catastrophic coverage” under Part D.**

Based upon their individual financial circumstances and total medication needs, Part D could help Medicare beneficiaries who are transplant recipients if they have substantial prescription drug bills beyond their payments for immunosuppressants. Other self-administered drugs that could be covered under Part D are: oral blood pressure drugs, blood sugar drugs, lipid lowering drugs, oral infection treatments, antiviral agents and intravenous immune globulin.

Other Provisions for Transplant Recipients to Note

- Drugs currently paid for under Part B of Medicare (e.g., immunosuppressants) could move to Part D in the future.
- As of January 1, 2006, no Medigap drug policy can be sold, issued or renewed, except for individuals already enrolled in a Medigap drug plan, who choose not to enroll in Part D.
- “Dual-eligible” kidney patients who are entitled to both Medicare and Medicaid will be enrolled in Part D and will lose the benefits they have received from their state Medicaid program.

For additional information, please see the NKF Web site, **www.kidney.org** 

To My Friends

■ By Flora Solarz



Flora Solarz

We all hope that our transplant experience will be a success. The sad fact is that candidates are so ill that many die while on the waiting list, and others suffer complications after transplant. While the story below is difficult, it is a side of transplantation that needs to be told, so that we are prepared for what could lie ahead (although we all hope it won't), and transplant programs are equipped to help patients address the emotional issues that arise.

When I was waiting for a lung transplant I joined a support group. At the first meeting, during the break, I started chatting with Charly. Afterwards, she introduced me to two other women. By the end of the next monthly meeting, we had dinner plans.

It was comforting to have so much in common, and to find a circle of friends that was warm and welcoming. Over the months, we grew close, shared our difficulties and joys, information and anxieties, and became a source of comfort and encouragement.

Charly had been reluctant to have a transplant. She read everything she could, and interpreted it to mean that she should be cautious. She was on the list the longest, and was called first. Charly never did well. She pulled out of ICU, but didn't perk up. We were filled with dread as we heard the daily reports of her inability to rally. During the third week post-transplant, Charly died.

Our group processed every bit of information we knew about the transplant and grieved, repeatedly describing her wonderful qualities as though they were a mantra. We cried to one another on the phone, and tried to make sense of how this bright, beautiful and capable woman could die.

And at the same time, we wondered what it meant for us. From the beginning, I convinced myself that if I was

strong, and believed that I would do well, I would, no matter what. By contrast, Charly was fearful and had postponed her first offer. She had many complications.

As a group, we began the process of healing, knowing that we had to move forward because our opportunities lay ahead. That summer, Rachel had her transplant. She was off oxygen in a few days and doing remarkably well. She came home, started rehab, and even began to work a few hours a day. Then something went wrong. She was back in the hospital suffering from so many complications. Rachel fought, and made it back home again, but every time we spoke, there were more complications. Then she was re-listed.

Her attitude remained incredibly positive. She knew that without the transplant, she would die. Her husband, however, could not imagine that this transplant would do anything other than restore her life, and so he suffered terribly when she failed to thrive.


Donna's story was different. After two years on the waiting list, she was diagnosed with ALS, Lou Gehrig's Disease, a degenerative disease of the muscles. She was taken off the list, and her fate was sealed.

I was still on the waiting list and attended Rachel's funeral on oxygen. Donna survived many years, most of them in a nursing home. I remained in

contact with her, marveling at her spirit, and trying to be of comfort. Charly, Rachel and Donna touched my life so. I am blessed for having known them. Now, I am alone to write the story.

In support groups, we talk about the medical and sometimes the financial issues, but rarely about the possibility that our friends around the room may not all be there in the months and years to come. As we go through the difficult struggles of being transplant candidates, and later through the healing process as recipients, it is important to know that watching our friends struggle with their illnesses—infections, rejections, side effects or their mortality—can have a profound effect on us. Comfort can be taken in the knowledge that every individual's battle is unique, and that your courage has helped you get this far.

Be sure to get support for the emotional ups and downs. Talk with the social worker at your hospital or seek individual counseling. You can get a recommendation from the social worker, transplant coordinator or your doctor.

The days I wrote about were difficult ones. Now, I'm eight years post-transplant and doing well. I've made new friends who are transplant recipients and are in good health. I plan to know them into my ripe old age! 

About the Author

Flora Solarz is a lung recipient living in New York City. She is a member of the Secretary of Health and Human Services Advisory Council on transplantation.



A Healthy New Beginning

■ By Nancee Vander Pluym, MS, RD

When you receive a kidney transplant, the majority of the restrictions and limitations associated with dialysis and pre-dialysis are no longer the driving force for your food choices. "Eating to live healthy" can now become your motto.

Not everything changes right away, however. For the first six weeks or so after getting your transplant, higher protein intake is desirable because it enhances the healing process and may help control some of the side effects from the steroid medication. This protein intake may be similar to the amount recommended when you were on dialysis. But once you have recovered from the operation, you are ready for the next phase, and you may ask, "What should I be eating now?"

After a successful transplant, it may seem that you have unlimited choices. A heart healthy diet stresses more fruit and vegetable choices without having to worry about "low potassium" versus "high potassium." Selecting whole grains such as wheat breads and cereals, brown rice and a variety of legumes (all those dried beans that were avoided or limited while you were on dialysis!) is encouraged. Several servings of low fat or fat-free dairy products should be included. Milk and cheese provide not only good protein but also essential calcium and vitamin D for bone health. Lean protein

foods are beneficial, but are no longer the main focus. Now your plate can have more variety from the various food groups that also are good sources of fiber. Dietary fiber slows how quickly the stomach empties. This keeps you feeling satisfied longer after eating and may decrease the urge to snack. High fiber foods will also aid the body to lower cholesterol.

transplant. Weight control is the number one priority, as many individuals gain weight after transplant. Controlling your weight makes it easier to control blood pressure, blood sugar and cholesterol.

Side effects from the medications may require some modifications to your diet. For example, your potassium levels may initially be higher than desired. Limiting the frequency of high potassium foods consumed may be necessary for a while. Some weight gain after transplant is to be expected. Replenishing muscle mass is the goal and will increase your strength and vitality. Excessive fatty tissue weight gain is not healthy. Your transplant team is always available to assist you, so do not hesitate to seek their guidance.

Take the extra time and effort to plan your daily eating and then review how well you have done. Any time a change in your typical routine occurs, it requires more focus to accomplish but it can be done with practice. These guidelines are appropriate for most adults and will benefit other family members so everyone can be walking on the same healthy path. **TC**

Initially, it is helpful to write down your daily goal for the specific food groups. Consider the following as a starting point:

- **5-6 servings of Fruit and Vegetables (1/2 cup = one serving)**
- **6 servings of Grains (refer to Nutrition Facts on product label)**
- **2 servings of Low Fat or Fat-Free Dairy Products**
- **2-3 servings of Lean Protein and Legumes**
- **3-4 servings Fats or Oils (1 teaspoon = one serving)**

The key to your dietary choices is selecting heart healthy foods that will enhance heart health and assist in managing diabetes and high blood pressure, as these conditions will still exist after

About the Author

Nancee Vander Pluym, MS, RD, is a Transplant Nutrition Specialist at Banner Good Samaritan Transplant Center in Arizona.

A Study of Non-Melanoma Skin Cancer in Organ Transplant Recipients

THE UNIVERSITY OF CALIFORNIA SAN FRANCISCO is embarking on research funded by the National Institutes of Health to study why organ transplant recipients are so susceptible to skin cancers. In order to begin, the researchers must collect blood and tissue specimens to create a "Tissue Bank." This is a big undertaking that will be key for this study, as well as future studies that will benefit transplant recipients. Needed for this research are blood samples and tumor samples (blocks) from organ transplant recipients with skin cancers. Donors would also fill out a medical history questionnaire and a consent form. There is no cost to participants.

We would be delighted to hear from anyone interested in helping at 866-386-8500; epsteine@derm.ucsf.edu; or Room 269, Bldg 100, San Francisco General Hospital, 1001 Potrero Ave., San Francisco, CA 94110, USA.

Ervin Epstein, Jr. - Boris Bastian - Ryo Hirose, Departments of Dermatology and Surgery, University of California, San Francisco

Our studies are approved by the UCSF Committee on Human Research

Skin Cancer in Transplant Recipients: The Importance of Caring for Your Skin

■ By Leslie J. Christenson, MD

The success of solid organ transplantation is one of the greatest accomplishments of modern day medicine. This great accomplishment, however, is accompanied by secondary complications that result from life-long immunosuppression. One of these complications is the occurrence of skin cancer.

Unfortunately, problems that transplant recipients experience with their skin receive little attention when overshadowed by the more immediate and potentially life threatening medical problems they may be experiencing. But it is important not to let the health of a transplant recipient's skin be overlooked. A transplant recipient's risk of developing squamous cell carcinoma, the most common type of skin cancer in transplant recipients, is 65 times greater than that of the general population. The risk of developing a basal cell carcinoma, the second most common type of skin cancer in transplant recipients, is increased 10 times that over the general population. As many as 40 percent of transplant recipients may develop skin cancer within 20 years of receiving their transplant. There is a subset of transplant recipients who can develop hundreds of skin cancers in their lifetime. Although the majority of skin cancers are easily treated, and may not shorten a transplant recipient's life, they can have a significant effect on one's quality of life.

Prevention of skin cancer is possible and vital for all transplant recipients.

The four key steps for prevention are:

- knowledge of what skin cancer is and how it appears
- understanding one's personal risks
- taking measures to protect oneself from the sun
- having a screening skin examination by a dermatologist and continued follow-up based on their recommendations.

Types of Skin Cancer

Squamous cell carcinoma is the most common type of skin cancer in transplant recipients. It can appear as a red scaly bump on the skin or as an open sore that will not heal. It may be tender to touch. It most often occurs on sun-exposed skin, specifically on the head, neck, or back of the hands.

Basal cell carcinoma is the second most common type of skin cancer in transplant recipients. It may appear as a slightly shiny or red bump. It may be an open sore or a spot that bleeds with minimal trauma. It is often described by patients as a pimple that will not go away, or an irritated mole. It also commonly occurs on the sun-exposed skin of the head and neck. It rarely goes elsewhere in the body, but will not go away without treatment.

Melanoma is a type of mole cancer. It often appears as an irregular, asymmetric, multi-colored (predominantly brown) spot on the skin that may be changing in shape, size or color. This is a very serious type of skin cancer and does require immediate attention.

Characteristics that Put One at Risk for Skin Cancer

1. Skin that easily burns.
2. Blue, green, or hazel eyes.
3. Red or blonde hair.
4. Extensive freckling.
5. Outdoor occupation or history of extensive sun exposure.
6. Family history of skin cancer.
7. Personal history of skin cancer.
8. Older age.
9. Longer duration of immunosuppression.
10. History of warts.
11. Residing in a latitude that is closer to the equator or at a higher altitude.

Sun protection

- ✓ Wear sunscreen. It is recommended that you wear sunscreen with an SPF of 30 or greater blocking UVA

and UVB rays. It is often desirable that this be an oil-free product when applying it to the face. We recommend that you apply this daily even in moderate weather.

- ✓ It is recommended that you wear a protective hat and protective clothing including a long-sleeve shirt and pants.
- ✓ It is recommended that you avoid the noonday sun and concentrate your outdoor activities prior to 10 a.m. and after 4 p.m.

Evaluation by a Dermatologist

It is good for all transplant patients to be seen by a dermatologist for a screening skin examination and baseline risk assessment. If you are at risk, it is then recommended that you be seen on a yearly basis or at an interval recommended by your dermatologist. If you have a history of skin cancer, your dermatologist may recommend that you be seen on a more frequent basis.

The International Transplant-Skin Cancer Collaborative (ITSCC) was developed to integrate and support basic scientific and clinical research to address the special needs of transplant recipients with skin cancer and to educate health care professionals on these unique issues. The ITSCC Web site at www.itccc.org has photos of the different types of skin cancer and more detailed information regarding skin cancer and other skin concerns in transplant recipients. 

About the Author

Leslie J. Christenson, MD, is the assistant professor of Dermatology at the Mayo Clinic in Rochester, Minnesota. She is certified by the American Board of Dermatology and has recently been involved in creating a Web site for patients through the International Transplant Skin Cancer Collaborative.

Preparing for Living Donation: A Psychiatrist's Perspective

■ By Sheila Jowsey, MD

Because of the shortage of deceased donor organs, the national waiting list continues to grow. The United Network for Organ Sharing reported that nearly 60,000 people were listed for a deceased donor kidney transplant at the end of 2003. This includes first time recipients as well as those who have experienced loss of a previously transplanted kidney. Although the rate of re-transplantation for kidney recipients has dramatically improved over the last 10 years, it is still an unfortunate reality for many people. If you know of someone who may be interested in living donation, the following information may assist him or her in understanding some of the issues involved in the donation process.

Living donor kidney transplantation is a unique situation in medicine. Two surgeries in two individuals result in a remedy for one person's illness. Evidence supports improved outcomes with living donor organs. As a result, living donor surgery is increasingly being used for kidney transplantation. Family, friends and even anonymous living donors are expressing their desire to help others in increasing numbers across the nation. Excellent outcomes are now possible even if the donor is not genetically related.

because of a strong desire to help, they likely will have a good experience with the donor surgery. Many people are willing to donate, but may not be able to complete the process for a variety of reasons. Transplant centers have specialists that assist donors in fully understanding the process of donation and help them to understand their feelings regarding this very emotional, and often difficult, decision.

Individuals who have mixed feelings about donating or who are under significant stress at the time of donation may not feel as satisfied after surgery as other donors. It is important for donors to consider their roles and responsibilities and how these will be affected by donor surgery.

Having young children, other family members with health problems, a demanding job or a spouse who is not supportive of the donation can all

It is important for donors to consider their roles and responsibilities and how these will be affected by donor surgery.

A kidney donor must be willing to undergo surgery purely for the psychological benefit of having helped someone else. Donors who are acceptable candidates for this procedure are motivated by their interest in helping someone else. Research suggests that if a person is donating

increase the demands on a potential donor. Some donors report worries about being in a hospital setting or feeling uncomfortable with needles or other tests.

Besides the physical risks of the surgery, and being an acceptable candidate from a medical and psychological point of view, the transplant center specialists help the potential donor to consider other important issues such as:

- ❖ surgical recovery and how it may affect lifestyle and time away from work
- ❖ financial or emotional pressures surrounding the donation process
- ❖ relationship expectations with the recipient during or after the donation
- ❖ motivation for wanting to donate
- ❖ accepting the variable outcome of the transplant procedure and kidney function.

It is important for a donor to feel comfortable proceeding with donor surgery and to let the medical team know if there are any questions or concerns during the donor evaluation. Supportive family and employers will make the surgical recovery time less of a problem and help the donor do well both physically and emotionally after the donation process.

For more information on living donation, visit www.livingdonor.org 

About the Author



Dr. Sheila Jowsey is a practicing psychiatrist at the Mayo Clinic Department of Psychiatry in Rochester, Minnesota.



Organ Donation/Assistance for Living Donors

■ By Troy Zimmerman

President Bush signed **H.R. 3926**, the Organ Donation & Recovery Improvement Act, on April 5, 2004 (Public Law 108-216). The National Kidney Foundation (NKF) worked with the sponsors to help craft the final bill.

A key provision of the legislation establishes a federal grant program to provide assistance to living donors with travel and subsistence expenses and incidental nonmedical expenses incurred by individuals toward making living organ donations. This provision has been an NKF priority. The NKF believes in the principle that living organ donors should not personally bear any financial costs associated with donation. Moreover, the NKF maintains that removing the financial barriers associated with donation could possibly expand access to transplantation for members of lower socio-economic groups who are often precluded from considering living donation.

The legislation also grants money to states for organ donor awareness, public education and outreach activities designed to increase the number of organ donor, awards grants to organ procurement organizations and hospitals to establish programs coordinating organ donation activities and authorizes the Secretary to establish mechanisms to evaluate the long-term effects associated with living organ donations.

The bill also requires the Secretary of Health and Human Services to submit a report to Congress that evaluates the ethical implications of proposals to increase non-living donation, which could include financial incentives. However, it does not authorize demonstration projects to examine

whether financial incentives would increase non-living donation. A previous Senate version of the legislation would have permitted such demonstration projects, but the NKF, which opposes any direct or indirect payments for organs, advocated for the removal of the provision. **TC**

Managing the Risk...

Continued from page 5

the cholesterol profile, blood pressure, and weight loss. Individuals also tend to feel better when they exercise. For diabetic individuals, aggressive glucose control can help to minimize kidney and other organ damage.

High cholesterol is a result of the transplant medications. Recipients of organ transplants are considered to be at high cardiovascular risk and so should target cholesterol values accordingly.

Transplant recipients absolutely must not smoke. Smoking is not only a risk for cardiovascular disease, but also accelerates kidney failure and increases the risk of transplant organ rejection.

Transplant recipients are faced with numerous health challenges following successful organ transplantation. Among these challenges are the increased risks of kidney and cardiovascular disease. The transplant recipient ultimately has control over many of the factors which contribute to kidney disease. The transplant recipient can play an active role in his or her health maintenance through aggressive home monitoring

of blood pressures and blood sugars along with healthy eating and regular exercise. Intervention to prevent and limit complications following organ transplant requires a team approach, and we encourage patients to engage their physicians to help reach health goals which will allow them to maximize the benefits of their organ transplants. **TC**

On the Web

There are a number of patient friendly Web sites readers may find beneficial: United Network for Organ Sharing site for patients:

www.transplantliving.org

The American Diabetes Association:

www.diabetes.org

The National High Blood Pressure Education Program:

www.nhlbi.nih.gov

About the Author

Dr. Silas Norman, MD, is a transplant nephrologist at the University of Michigan, Department of Internal Medicine. He is currently interested in issues of organ allocation and chronic kidney disease in the liver transplant population.

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