

# Transplant Chronicles



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TRANSPLANT CHRONICLES IS A TRANSACTION PROGRAM OF THE NATIONAL KIDNEY FOUNDATION.

## liver recipient *runs her first Marathon*

By Terri Willis, liver transplant recipient (1991)

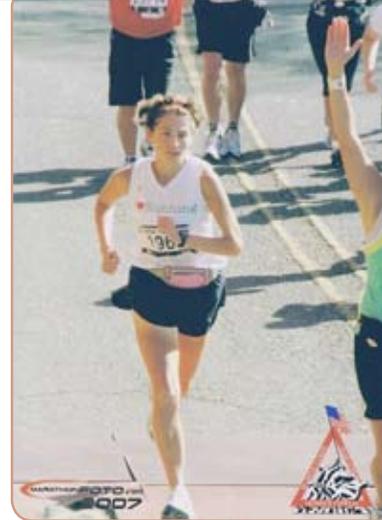
AFTER SEEING A NEWS STORY ABOUT THE U.S. TRANSPLANT GAMES where they showed a girl running, I was moved and knew I had be a part of it. At the time, running 100 meters was hard for me. Before competing in my first U.S. Transplant Games in 2000, I had never been competitive or into anything athletically challenging.

I was encouraged by a friend to also run the 200 meter race and ended up winning the silver medal! On the back of that medal it said "Going the Distance." I look back at that now and think it was a sign of what was to come. In September 2006, I ran my first mile ever. I was originally just trying to increase my stamina and improve my times at the U.S. Transplant Games, but then I couldn't stop. Over the course of a year, I kept running enough to where I entered the Marine Corps Marathon.

I had many reasons for wanting to run the marathon, mainly I just wanted to find out if this same girl who couldn't run a lap around the track had it in her. I also wanted to be an example to other transplant recipients—to not to think of yourself as sick, to take your gift and use it for all it's worth.

### Marine Corps Marathon, Race Day—October 28, 2007:

I had already attached my bib to my shirt the night before so I could just throw it on and go. I had two bibs, one was my number and the other one was to write whatever I wanted on. One of my other friends from the Transplant Games, Janet, had been waiting for a kidney transplant for over three years and got the call four days before the race. Her brother Tom's words to me were "When you're running it, don't think about the miles ahead. Once you're half way, think about the miles you put behind you and that should drive you to finish and not quit. Each mile can represent a transplant that has saved someone's life." I wrote on that bib "TERRI 4 JANET." The back of my running shirt said "Liver Transplant Survivor—July 2, 1991," and I put on my Arkansas Razorback Hog pin. I always wear it during a race, in honor of my donor who is from Arkansas.



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## editor's desk...

Laurel Williams, RN, MSN, CCTC  
Editor-in-Chief



### A message from our "guest editor":

#### Being Thankful...

By Josh Goldberg

**D**URING THE HOLIDAYS I TEND TO BECOME VERY SENTIMENTAL AND REFLECTIVE. I take stock of the love of my family, the stable health of my mom and the good fortune that has been bestowed on me. This past holiday season was no exception.

I was reminded that many of my friends' families were not so lucky. For some, this was the last time they could all sit around the table sharing a turkey dinner, due to a profound illness.

I am liked. I am loved. I am extraordinarily thankful.

I am thankful that my mom believes that every day is Thanksgiving. She has taught me that nothing is to be taken for granted. Each moment we are given on this earth is something for which to be grateful. By making each day count, we remain thankful for life. We all experience challenges. Some make us stronger, others cause us to question our beliefs. But, how splendid

it is to be able to make choices that only strengthen and enrich our lives.

I am thankful to have the opportunity to share my thoughts with a community of individuals who are heroic in their battles to stay strong and focused every day. Renal disease is terrible. It strikes young, old, men and women, and crosses every ethnic and racial line. I am thankful to all the doctors and nurses who are helping to fight this battle to find a cure.

As I sat around my family holiday table this year, I was thankful for all the support *Transplant Chronicles* has given me. Inasmuch as I would like to contribute more, my junior year in high school has been brutal. I will really be thankful when school ends in June and I get to revel in those warm lazy days of summer...

*On behalf of the Editorial Board, thank you to Josh for being the guest writer for the editor's message.* **TC**

—Laurel Williams, Editor-in-Chief

[transplantchronicles@kidney.org](mailto:transplantchronicles@kidney.org)

Let your **VOICE** be **HEARD**

Log on to tell us what you think! Read others' responses...  
[www.recipientvoices.org](http://www.recipientvoices.org)

Last issue we asked: "What helps you maintain a healthy weight?"

[Click here to read the responses on page 5](#)

# THE U.S. TRANSPLANT GAMES:

## Not Just for Transplant Athletes

While the NKF U.S. Transplant Games is the only national athletic competition for recipients of all life-saving organ transplants, the Games aren't just for athletes. The Games is the largest gathering of transplant recipients and donor families (those with a family member or friend who donated organs or tissues after their death) in the world and serves to promote the health and fitness of its participants while showcasing the success of transplantation, highlighting the tremendous need for more organ and tissue donors, and honoring the thousands of selfless acts of love from donors and their families all over the world.

At the U.S. Transplant Games, there are many events and activities designed for you. You are given many opportunities to meet other transplant recipients from around the country, share your transplant story, honor your donor, improve your health and fitness and support the thousands of other patients who are still waiting for their second chance at life.

If your most recent life-saving solid organ transplant (including allogenic bone marrow/stem cell) has been functioning for at least nine months, you, as a transplant recipient, are eligible to compete in the sports competitions. Medals will be awarded to the top finishers in each of seven age categories to balance the competition.

### The National Registration Deadline is June 5, 2008.

You may register and reserve your housing online at [www.transplantgames.org](http://www.transplantgames.org). Registration forms and housing reservations will be processed on a first-come, first-served basis.



Sponsored by  NOVARTIS

Registration Dates	Athlete*	Non-Athlete**
Now – March 15	\$90	\$30
March 16 – April 30	\$120	\$35
May 1 – June 5	\$150	\$40
On-site	N/A	\$45

\* *Athlete: A transplant recipient who is competing in the Games.*

\*\* *Non-Athlete: Donor Family, Living Donor, Transplanted Spectator, Professional, General Supporter/Other Spectator.*

Visit the U.S. Transplant Games Web site to see what is included in the registration fee, as well as what additional registration upgrades are available. Visit [www.transplantgames.org](http://www.transplantgames.org) for more information.



photo credit Eric Miller



National Kidney  
Foundation

# Honor

*"To give anything less than your best is to sacrifice the gift."*

Stephen Prefontaine



## Padriac McCole, 20, Kidney Recipient

Athletes participate in the NKF U.S. Transplant Games because they have received a new start through a life-saving organ transplant. But nearly 100,000 men, women and children are still waiting for their second chance at life. There are many ways that you can help. To learn how, visit [www.transplantgames.org](http://www.transplantgames.org) or call 866-TX-GAMES.

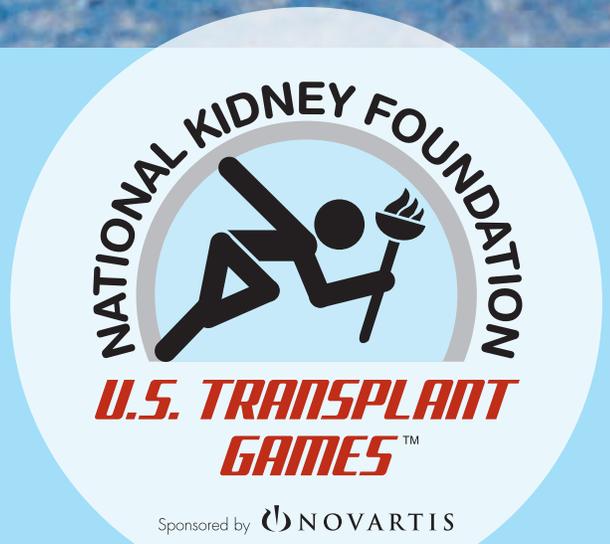
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## let your VOICE be HEARD

### Recipient Voices Responses

Our last question was:

**“What Helps You Maintain a Healthy Weight?”**

*And you said:*

“I have always been physically active and worked outdoors all my adult life. In the last 10 years or so, bicycling has become one of my favorite things to do. After starting dialysis and having recovered from a double nephrectomy, I got the bike out and decided to take a little spin. What a great day that turned out to be! That summer I rode 3500 miles, without kidneys and while on dialysis. That fall, a neighbor called with the offer of a kidney, and since the transplant I haven’t looked back. What do I do to keep the weight off? 1.) Eat healthy. 2.) Get lots

of sleep. 3.) Lift weights and do sit-ups. At this point (November 2007), I’m just a little shy of bicycling 5000 miles. YOU CAN MAKE IT WORK!”

—Dale B. Hopkins

“Simply: by eating a healthy diet, exercising three times a week and enjoying all the sinful items I love in moderation. My motto: ‘cut down, not out and enjoy life.’ That’s what the gift of life is all about—LIVING LIFE!”

—Karen Weddick

*Our next question:*

**“Have you ever used your voice and experience to educate members of congress and help influence public policy and legislation?”**

Tell us by logging onto

[www.recipientvoices.org](http://www.recipientvoices.org)

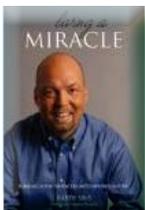
## Read, Review and Share

If you like to read, you may be interested in the Book Review section of the transAction Council Web site. This section is devoted to both fiction and nonfiction books about organ donation and transplantation, and reviews from transplant recipients like you. Visit the Web site today to

learn about books you might like to read or to post your very own review on a book you have read!

[www.kidney.org/transplantation/transAction/shareBookReviews.cfm](http://www.kidney.org/transplantation/transAction/shareBookReviews.cfm)

Read these new book reviews online today:



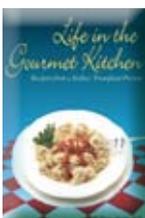
*Living a Miracle*  
By Randy Sims



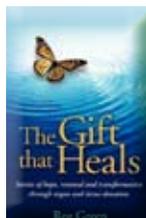
*Field Notes on the Compassionate Life: A Search for the Soul of Kindness*  
By Marc Ian Barasch



*Glamour, Interrupted: How I Became the Best Dressed Patient in Hollywood*  
By Steven Cojocar



*Life in the Gourmet Kitchen—Recipes from a Kidney Transplant Patient*  
By William Austin, O.D.



*The Gift that Heals*  
By Reg Green



*Dying was the Best Thing that Ever Happened to Me*  
By William E. Hablitzel, MD

# PUBLIC POLICY 2007

## *Lots of Promise, Little To Fruition*

By Troy Zimmerman, National Kidney Foundation Vice President for Government Relations

When Congress left town on December 20, 2007, it felt like we had an exciting first half with lots of plays, but too many fumbles. Through mid-December, there was a real possibility that several kidney provisions would be added to the Medicare bill and become law. But as the clock ticked away, Congress scaled back bills to ensure passage and avoid presidential vetoes, so extras, like the End Stage Renal Disease improvements, were not added.

Congress returned in mid-January to resume the second half of the 110th Congress. We are pushing them to enact a range of legislation to help people with kidney disease, including expanding coverage for immunosuppressive drugs, providing pre-dialysis education for people with advanced kidney disease, and promoting programs that improve identification, treatment and outcomes of kidney patients.

Our legislative accomplishments in 2007 include:

- Passing legislation clarifying that paired kidney donations are legal, which will allow for a national registry for paired kidney living donations.
- Gathering nearly 150 co-sponsors for the Kidney Care Quality and Education Act (HR 1193). Parts of this bill were passed in the House Medicare bill.
- Gathering nearly 50 co-sponsors for legislation that would extend immunosuppressive drug coverage for the life of the transplant (HR 3282).
- Increasing support for a congressional medal for organ donors or their families.
- Maintaining funding for living donor assistance and programs to encourage early identification of kidney patients and educate primary care physicians on early intervention and care of kidney disease.

In April 2007, we launched the **Take Action Network** and you have been a huge part of our initial success this year. Together—

- We sent over 7200 messages to Congress in eight months.
- We have nearly 3000 volunteers in all 50 states and 97 percent of congressional districts ready to contact their Members of Congress when asked.

We are looking forward to a busy year, and with your help, we can make lives of kidney patients better in 2008. Thank you again for your support, and please join the Take Action Network [ [www.kidney.org/takeaction](http://www.kidney.org/takeaction) ] if you have not already done so. **TC**



## 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: [www.trannews.com](http://www.trannews.com)



Jim Warren

### *The Highlights from 2007*

- The International Pediatric Transplant Organization announced it has launched a new outreach program initiative to bring pediatric transplantation to under-served areas of the world.
- A study found that losing post-transplant Medicare coverage can be fatal for young organ transplant recipients. The study, conducted by St. Louis University researchers, suggested that once Medicare coverage is halted, such patients are more likely to stop taking necessary immunosuppressive drugs. "Kids with transplanted kidneys who lose their insurance have a nine times greater chance of dying than those who don't," according to Mark Schnitzler, PhD, the lead author of the study.
- The U.S. General Accounting Office (GAO) issued a much-anticipated study containing evidence that providing kidney transplant recipients with lifetime immunosuppressive drug coverage is good medicine, good public policy and very cost-effective. The report found that the percentage of transplant recipients who experience a transplant failure varies by age group, as do the percentages who experience dialysis, retransplantation or death. In addition, the GAO found that the median annual Medicare cost for a beneficiary whose transplant failed was \$50,938 a year, 500 percent more than the median annual Medicare cost for a beneficiary with a functioning transplant, estimated to be \$8,550.
- The OPTN / UNOS Board of Directors adopted a resolution urging physicians to treat individuals who receive an organ through "transplant tourism" or to provide an alternative physician who will. The Board also adopted an Ethics Committee resolution denouncing the use of organs from executed prisoners and reaffirmed the rights of patients with disabilities to be transplanted.
- Surgeons in Romania reported they had successfully performed the world's first half-kidney transplant, allowing a three-year-old boy suffering from kidney failure to receive part of his mother's kidney. The entire kidney was taken from the mother but could not be used intact.
- A poll conducted by the Gallup Organization found that 53 percent of Americans have signed their license or organ donor card, almost double the 28 percent who did so in 1993 when the last Gallup Poll was conducted. The poll also found that the concept of brain death is still a mystery to many people, with more than 22 percent agreeing with the statement: "It is possible for a brain-dead person to recover from his or her injuries." To understand the definition of brain death, read the NKF's National Donor Family Council booklet *Brain Death: A Simple Explanation*. A free sample copy can be obtained by calling 800.622.9010 or viewed online at: [www.kidney.org/transplantation/donorFamilies/infoBooksBrain.cfm](http://www.kidney.org/transplantation/donorFamilies/infoBooksBrain.cfm) NKF's National Donor Family Council Web site is located at: [www.donorfamilies.org](http://www.donorfamilies.org)
- The Food and Drug Administration approved a license supplement for the first fully automated West Nile Virus test to be used to screen deceased donors. For the government brochure *West Nile Virus and Transplant Recipients* go to NKF's online *A to Z Health Guide* at [www.kidney.org/atoz/atozTopic.cfm?topic=3](http://www.kidney.org/atoz/atozTopic.cfm?topic=3)

# Yoga and Tai Chi: what are they all about?

By Martha Walker, DPT, CSCS

Exercise can be defined as any type of physical activity that is performed to improve health. After your transplant surgery, incorporating exercise into your daily routine is of utmost importance to improve your strength, endurance, health and overall quality of life.

Fortunately, this doesn't mean you need to "pump iron" or spend hours on a treadmill. There are many alternatives to the traditional gym workouts, such as practicing yoga or tai chi, that are equally effective in your journey back to health.

Yoga, developed in India thousands of years ago, is a form of exercise that can be practiced by anyone, regardless of age, exercise experience or physical ability. The five key elements of yoga include: proper relaxation, exercise, breathing, diet and positive thinking.

Based on the principles listed above, your practice of yoga will center around breathing. The "yoga breath" focuses on breathing slowly and deeply while exhaling completely. The slow, complete exhalation allows you to clear the lungs of air and promotes a proper inhalation. It is suggested that the "yoga breath" improves metabolism, utilizes muscles that improve posture, keeps lung tissue elastic, tones abdominal muscles, strengthens the immune system and reduces anxiety.

Yoga also consists of asanas, or postures, that are performed as slow,

fluid movements. It is the belief of yoga practitioners that these postures promote a state of physical and mental well-being by increasing overall flexibility, massaging glands and organs and improving circulation.

For more information about yoga you can go to: <http://exercise.about.com/library/morningyoga.htm> or <http://yoga.about.com/>

Examples of a couple of yoga poses:



## THE YOGA BREATH

Lie on your back with legs and arms out from the body. Let your feet flop out and relax, including your fingers. Close your eyes and relax your muscles, while you begin to quietly and deeply breathe in and out. You will feel your abdomen swell as you fill the bottom of your lungs. Then let your ribs expand, and finally

fill the lungs by raising your collar-bones. You should breathe slowly and silently, allowing air to go in and out with one continuous flow. After you have breath control, focus on relaxing your muscles by starting at your feet, and consciously relax each part of your body, letting all your tension go as you breathe. Focus on your breathing as you work your way up your body relaxing each body part until you are completely relaxed. This breathing and relaxation exercise can be progressed to sitting, standing, and finally with basic movements or activities.

## WARRIOR I

Step forward with the right foot into a lunge, keeping the back leg straight and the left toes pointed out at about 45 degrees, heel down on the floor. Keep the right knee directly above the ankle and the hips squared to the front. Sweep the arms up and overhead, palms together, and look up as you slide the shoulders down and away from the ears. Stretch and hold for 3 to 5 breaths.



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Tai chi is another form of exercise that focuses on slow, smooth movements and coordinated

breathing. This form of exercise, originally derived from Chinese martial arts, consists of a series of forms performed in a slow, graceful manner as each form flows into the next without pausing.

Tai chi is also safe for people of all fitness levels because the movements are low impact and, therefore, put minimal stress on muscles and joints. Because tai chi is performed slowly and meticulously, it can easily be started and modified to fit a wide

range of functional levels and at all stages of your transplant journey. As you add tai chi to your daily routine, you will begin to notice improvements in your balance, flexibility, strength, breathing, and energy.

For a short video example of Tai chi for beginners and seniors go to [www.taichiforseniorsvideo.com](http://www.taichiforseniorsvideo.com)

*When starting any exercise program, it is important to discuss your plans with your physician.* It will be beneficial for you to enroll in a yoga or tai chi class initially in order to understand the basics of each before performing the exercises independently. Many of your local gyms and YMCAs generally offer these types of classes

for all levels of fitness. The smaller the class size, the more attention you will get as a beginner. Many places also offer chair yoga and tai chi classes for those who do not have the balance, strength or endurance to stand throughout the session.

Remember, it's important to stay focused and take each day one at a time. Your journey to health doesn't have to be a struggle, and certainly doesn't have to be painful. Just a few minutes daily, and tai chi and yoga can greatly improve your overall health and well-being. **TC**

*Martha Walker is a physical therapy student at University of Maryland Medical Center, Department of Rehabilitation Services, in Baltimore.*

Continued from page 1

I looked at myself in the mirror and that's when what was about to happening hit me. My Team Manager, Alison, dropped me off at the shuttle that was taking us to the starting line. I walked over, found my corral and stood there for what felt like hours. I was amazed at how many people were registered. It kind of reminded me of being at the Transplant Games, except I was probably the only transplant recipient there.

When they turned us loose, it took me 20 minutes to cross the start. I had spent six months training for this and I told myself to run hard and not let up until I saw the bridge, the cutoff point to determine if I could remain in the race. I felt like I wasn't moving fast enough and started worrying about not making it, but I wasn't aware of how fast I

was actually going. At the end of the half-way point, I looked up at the clock and saw that I had beaten my "half marathon" time from that May.

I had read somewhere that in a marathon, you run the first 20 miles with your legs and the last six with your heart. That is where the real race happens.

I purposefully slowed down while running across the bridge, taking it all in. By the time I got to mile 25, my back was killing me and legs were cramping. I was in so much pain that I started talking to myself saying "That's it. I'm not running another step. This hurts. I am going to stop now!" I wanted to stop, but couldn't make myself do it. All I kept thinking about was my donor and Janet. Near the end, I was running alongside another girl for a little bit

and we were both complaining about the pain. I noticed the hill leading to the finish. I congratulated the girl and said I can't take this anymore. I took off as hard as I could. After I crossed the finish, I was greeted by a very cute marine. He congratulated me and placed the medal around my neck. That's when I broke down and lost it. I'm sure he appreciated me crying all over his uniform. I left the finishing area thinking "ME... marathon...RAN...not dead!"

Even though the training was more than I had bargained for, and the race left me very sore for a week, I don't regret any of it. It's like what my friend Tom has always said, "It's all in your mind and heart; you have to really want it." If I can do it, then it proves it isn't *that* impossible. **TC**

## “BUT THEY ONLY DO KIDNEYS, RIGHT?”

By Jim Gleason, heart transplant recipient

Not so. Despite what most people may think, I discovered several years ago through the U.S. Transplant Games that the National Kidney Foundation is a support resource for transplant patients of all types. This includes their well-known biennial Games. I honestly don't remember what prompted me to look into the NKF but when I did, I found a wealth of resources on their Web site, [www.kidney.org](http://www.kidney.org)

Upon reaching out to the transplant network within NKF, I found open arms welcoming my participation, even as a heart transplant recipient. I accepted an opportunity to serve on their transAction Council Executive Committee that provides a guiding light for transplant support initiatives. With my technical/computer background, there were additional opportunities to consult on the effectiveness of their Web site. This was coming full circle from my discovering them on the Web, to making a contribution back to that resource with book reviews and other support. Since rotating off that committee, I remain involved with several recent initiatives, such as the patient and nursing audio training meetings that cover several topics, for which I have been sharing personal experiences and contributing to the content.

As an athletic participant in the U.S. Transplant Games since 1996, I have also been involved in

numerous volunteer activities, such as hosting the popular open forum Coffeehouse where recipients and donor families share insights, feelings and even music. When the NKF directors held a national meeting here in Philadelphia, PA, my wife and I gave a presentation to them on what it was like to participate in the Games. My wife is a “donor mom” who now also volunteers at the Games for the NKF. I was invited to present a workshop entitled “The Long and Winding Road” at yet another national NKF event, sharing what it was like to be a heart transplant recipient. It was a really fun

opportunity to touch many hearts. In Florida, my wife and I offered a NKF-sponsored workshop on the subject of volunteering. For the past few years, I have also served on the editorial board of their donor family newsletter *For Those Who Give and Grieve*, contributing both articles and editorial direction for this very special resource.

As you can see, the National Kidney Foundation serves much more than “just” kidney patients. Working with their very professional staff has been a rewarding partnership. I hope that you, too, might find personal fulfillment by offering your own time and skills to this very worthwhile and broad support organization.

*Jim Gleason received his heart transplant in October 1994.*

[www.rjwitte.com/changeofheart/GiftFromTheHeart/Section2/chp-29-CANCER.pdf](http://www.rjwitte.com/changeofheart/GiftFromTheHeart/Section2/chp-29-CANCER.pdf)



*Jim and Pam HeartHug*

**NEW**

## **FINANCIAL ASSISTANCE FOR POTENTIAL LIVING DONORS**

If you know someone who is considering becoming a living organ donor (kidney, lung, liver) the National Living Donor Assistance Center (NLDAC) may be able to pay for up to \$6,000 of the living donor's (and his or her companion's) travel and lodging expenses.



**[www.livingdonorassistance.org](http://www.livingdonorassistance.org)**

National Living Donor Assistance Center (NLDAC)  
2461 S. Clark Street, Suite 640  
Arlington, VA 22202  
Phone: 703.414.1600 | Fax: 703.414.7874  
E-mail: **[NLDAC@livingdonorassistance.org](mailto:NLDAC@livingdonorassistance.org)**

The transplant center where the recipient is waiting will apply on the living donor's behalf. Visit the NLDAC Web site at **[www.livingdonorassistance.org](http://www.livingdonorassistance.org)** for more details and to read about general eligibility requirements and how the program works. For example:

Eligibility Requirements include:

1. Donor and recipient of the organ are U.S. citizens or lawfully admitted residents of the U.S.
2. Donor and recipient have primary residences in the U.S. or its territories.
3. Travel is originating from the donor's primary residence.

This National Living Donor Assistance program is administered by the United States Health and Resources and Services Administration, United States Health and Human Services, Division of Transplantation **<http://www.organdonor.gov>** in partnership with the University of Michigan (UM) and the American Society of Transplant Surgeons (ASTS).

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Immunosuppression  
Medicines*



**FEATURED PANELISTS:**

DEAN COLLIER, Pharmacist | DR. SCHLESSINGER, Kidney Transplant Doctor | DEBRA WASHINGTON, Kidney Recipient of Ten Years

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**TIME: 8:00 AM Pacific Time | 10:00 AM Central Time | 11:00 AM Eastern Time**

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