

KIDNEY CONNECTION

Summer 2008

Your Kidney Transplant: Finding the Best Match and the Best Outcome

Kidney transplantation is one treatment choice for end stage renal disease, also known as ESRD or kidney failure. A successful transplant can improve both quality of life and overall health for many people.

There are many factors that can shape the outcome of a kidney transplant. As anti-rejection (immunosuppressive) medications have gotten better over the years, so have transplant outcomes, allowing for excellent long-term survival of the kidney transplant even if a "perfect match" is not available. Some of the factors related to long-term outcome can be controlled by either you or your transplant team. Other factors may be beyond control.

Living Donor vs. Deceased Donor

Kidneys for transplantation come from two sources: kidneys from living donors—family members, spouses, friends or others who wish to donate—or kidneys from deceased or non-living donors—people who have died and donated their organs for transplant. Most transplant centers encourage living donor transplants for many reasons. A blood relative may give a closer genetic match, which can have a lot to do with the success of the transplant. Over the long term, most living donor kidney transplants do better as compared with deceased donor transplants. Also, a living donor's kidney will be removed in a scheduled surgery, thus eliminating the wait for a deceased donor. Finally, the chance that the kidney will work immediately after surgery is much greater with a living donor transplant because of the short length of time the donor kidney is without blood supply. Many people feel uncomfortable asking family members or friends to donate a kidney. Although the subject may be difficult to talk about, family and friends are often very interested in being evaluated as living donors. (cont. on pg. 3)



Message from the Executive Director
Lisa Allgood

The NKFK is preparing to offer a Chronic Kidney Disease Education class for people with stages 1-4 of kidney disease. Participants will learn about CKD, prevention measures, and treatment options. Participants from the KEEP program or an individual with a referral from a Primary Care Physician may attend.

TOPS EDUCATION PROGRAM

TOPS is an educational program for patients who are about to begin dialysis treatment. The program emphasizes treatment options including transplantation, hemodialysis, and peritoneal dialysis. Participants will attend one two-hour class. A referral from a nephrologist is required.

DATES:

May 28th	August 28
June 26th	Sept. 25
July 24th	Oct. 23

TIME: 10:00 a.m.

Location: Breckenridge Inn

For more information or to RSVP, please contact Beth Moran at 1-800-737-5433.

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Mark your Calendar! 2008 Events

Program Events

KEEP Screening

May 21 & 22
Cynthiana
Harrison Co. Extension Office

May 29
Madisonville
Covenant Community Church

July 29
Owensboro
Daviess Co. Health Center



Special Events

Gift of Life Gala
May 16

**Dean Kutz 5K Race for
Organ & Tissue Donation**
June 14

NKF Golf Classic—Louisville
June 23

**Ride Out Loud Bike Event—
Bowling Green**
August 16

**NKF Golf Classic—
Lexington**
September 8

Kidney Walk
September 20

Your Used Clubs Can Help Fight Kidney Disease!



Donate your gently used golf clubs, and the value of the clubs, in dollars, will benefit the **NKFK**.

For more information, please contact Leann Wiley at 502-585-5433 or lwiley@nkfk.org or visit www.kidneyclubs.org!

Due to inclement weather,
the NKFK Gift of Life Gala

has been
Rescheduled for

Friday, May 16th
Hyatt Regency Hotel
7 p.m.-12 p.m.

Tickets are still available for
\$75 per seat

Open Bar/Food Stations
Silent & Live Auction
Music by Beatles Tribute Band
Eight Days a Week

For more information, please contact [Lisa Allgood](mailto:Lisa.Allgood)
At 502-585-5433 or lallgood@nkfk.org

Team Kentucky Calendar of Events



Comedy Caravan Fundraising Event
May 11, 2008
Doors open at 7 pm
Tickets \$10 each
Contact: Carroll Williams 502-367-4284
proceeds benefit Team Kentucky

Team Kentucky Meeting
June 29th, 2:00 pm
KBA Building
101 Enterprise Drive, Frankfort
Contact: Lisa Allgood 1-800-737-5433

NKFK Chapter News

Lexington

The next Chapter meeting will be June 27, 2008 at 11:30am at the Kentucky Clinic Room J005. Lunch is provided. Anyone interested in learning more about the NKFK programs and services is welcome to attend. For more information, please contact Lisa Allgood at 800-737-5433.

Your Kidney Transplant (cont. from pg. 1)

If someone has been approved for a transplant and does not have any living donors, then he or she will be placed on the deceased donor national waiting list. Overall, the national one-year survival rate after deceased donor kidney transplantation is 94.2 percent; the national one-year kidney survival rate is 88.4 percent. These numbers improve to 97.6 percent and 94.5 percent for living donor kidney transplants.

Tissue or Human Leukocyte Antigen Matching

Tissue or human leukocyte antigen (HLA) matching relates to genetic matching between donors and recipients. Genes occur in pairs and are inherited, one set from each parent, and have features that makes each of us an individual. Some of these features are blood proteins, called antigens, that play an important role in the immune system—the way our bodies fight off germs and disease. Kidney transplant professionals define six antigens, known as HLA, in each donor and recipient. The best compatibility is a six-antigen match between a donor and a recipient. This match, which occurs 25 percent of the time between siblings, also occurs from time to time by chance in the general population.

As might be expected, the long-term outcomes in kidney transplantation relate to tissue matching. The best long-term outcomes are between people who match all six antigens. Over the last several years, however, because immunosuppressive medications have gotten so much better, less perfectly matched organs now function almost as well. This means that living donors who are not matched for any antigens may still confidently donate, knowing that the long-term outcomes for recipients of a zero-antigen-matched organ appear quite good. Similarly, poorly tissue-matched deceased organs do well in many recipients.

Donor Factors: Age, Size, "Extended Criteria"

Other factors that seem to play a role in long-term outcomes include the age of the donor and size of the donor, with kidneys from older (age 60 or above) or smaller-sized donors (especially when transplanted into large-sized recipients) having slightly worse long-term function.

Your transplant center may also discuss "extended criteria donor kidneys" with you. These organs come from donors who would not have been considered in the donor pool in the past, because of their age (older than 60 years) or other medical conditions, such as a history of stroke or high blood pressure. However, outcomes with these "less than perfect" organs have still been generally excellent and may be preferable to remaining on dialysis for some people.

Cold Ischemia Time, Delayed Graft Function, or Early Rejection Episodes

Cold ischemia time refers to the amount of time the donated organ is in iced storage between the donor and recipient (usually minutes for a living donor transplant, hours for a deceased donor transplant). As cold ischemia time increases, particularly greater than 24 hours, the risk of slower initial kidney function increases. Your transplant surgeon works hard to ensure that kidney transplants take priority over other surgeries to try to reduce the amount of time the kidney is without blood flow. It has also been shown that kidneys that do not function well right away (a condition known as delayed graft function) have worse long-term function. Similarly, people who suffer from early acute rejection episodes have shorter half-lives of their kidney transplants than those who get through the first year of transplant without any signs of rejection. (cont. on pg. 4)

Your Kidney Transplant (cont. from pg. 3)

Adherence with Medications and Health Care Follow-Up

The last major factor that affects long-term outcomes in kidney transplantation is the involvement of the person who gets the transplant. In almost all cases, the recipient's immune system will recognize the transplant as "foreign" and will require immunosuppressive medications to prevent rejection for as long as the kidney transplant functions. Missing medication doses is unfortunately still the most common cause of rejection that can lead to failure of a kidney transplant. Making sure that you follow your transplant team's instructions and seeing your doctor for regular office visits is the key to transplant success.

*Written by Dr. Gopa G. Green, transplant nephrologist
Article from Family Focus, Vol. 16, No. 1, Winter 2007*

"I am thinking about becoming a living donor. What do I need to consider before I decide to donate?"

Becoming a living donor is a big decision and you should make sure you feel comfortable with your decision. Many people find it helpful to speak about your consideration to your family, a social worker or psychiatrist, or your spiritual advisor. It may be beneficial for you to speak with other living donors about the donation process and what to expect (see resources next page). Remember, it is *your* decision and you should never feel pressured to donate. It is also important to gain as much information as possible about the donation process so you can make an informed decision on whether living donation is right for you. Below are some tips that will help you make an informed decision.

- **Educate Yourself:** If you are thinking about being a living donor, you should first read everything you can about donation. Listed under the Resources section on the next page are websites that can help inform you. You can also contact the NKFK for an information packet at 1-800-737-5433.
 - **Consider Your Reasons:** Make sure you understand the risks and benefits of donation. Think about your reasons for wanting to donate, and the impact of donation on you and your family—emotionally, physically, and financially. Here are some questions to consider:
 - How do I feel about organ donation in general? What are the benefits and risks of donation to me personally?
 - How would living donation affect me financially? Would you lose wages during your recovery or are you able to get paid leave from your employer?
 - How is your relationship with the recipient? (If the donor and recipient have a difficult relationship, some donors may have unrealistic expectations that the relationship might improve)
 - Do you live near the recipient and the transplant center where the donation would take place? Living near the transplant center will help reduce expenses for travel and lodging.
 - Do you smoke? Are you overweight? If so, you may need to quit smoking and/or lose weight prior to the donation.
 - Who can support you (both in emotional and practical ways) during this process?
 - **Request Information from a Transplant Center:** If you decide to pursue donation, you will need to contact transplant centers in your area about the possibility of being a living donor. You can also request information from your local Transplant Center. Below is the contact information for the Transplant Centers in Kentucky:
 - *Jewish Hospital Transplant Center: 1-800-866-7539*
 - *UK Healthcare Transplant Center: 1-866-474-6544*
- As a potential donor, you will undergo rigorous physical and psychological testing to ensure that you are a suitable candidate for donation. (cont. on next pg.)

Dean Kutz 5K Run and Walk

There have been many advances in the science of transplantation, but the need for organs remains critically high. 98,000 Americans are on the waiting list for life saving organs and 17 die each day waiting. 630 are in Kentucky. On Saturday June 16, 2008 hundreds of organ recipients, donor families and the community at large will walk and run to support the National Kidney Foundation of Kentucky in its mission to increase the availability of all organs for transplantation.

Pat Day, world renowned jockey is the Honorary Chair. He was the best friend of jockey, Dean Kutz who was a kidney recipient and supporter of the National Kidney Foundation of Kentucky.

June 14, 2008 8:30am

Start/Finish: Jefferson Square Park

Registration Fee: \$20

USATF Certified Race Course

Top finishers overall will receive a prize!

This process is not easy, and does take time. The evaluation process will include several different components to ensure that donation is right for you. Evaluation processes differ for each transplant center and it is important to contact your local transplant center for specific information.

Although you may not be able to be a living donor or decide against becoming one, you can still help those awaiting life-saving organ transplants. You can make a difference by:

1. signing the Kentucky Organ Donor Registry by visiting www.donatelifeky.org and designating that you'd like to become a donor at the time of your death.
2. donating blood or bone marrow. Call the American Red Cross at 1-800-GIVE LIFE or visit www.redcross.org or the Kentucky Blood Center at www.ckbc.org.
3. Volunteer or make a donation: to continue our work of serving those affected by kidney disease and organ donation, please consider making a donation or check out the volunteer opportunities on pg. 7!

NKF Golf Classic

The National Kidney Foundation Golf Classic will enter it's fourth year in Louisville and it's third in Lexington. The event is schedule for June 23, 2008 at the Lake Forest Country Club In Louisville. The first flight will begin at 7:45 a.m. and the second at 1:30 p.m. The Lexington NKF Golf Classic will be held later in the year on September 8, 2008 with one flight starting at 9:30 a.m. Teams at both events will compete for a chance to compete in the Pebble Beach Tournament and 2nd and 6th placement prizes will also be awarded. Teams must have a combined handicap score of 42 to compete for Pebble Beach.

The Louisville Golf Event will feature a raffle drawing for two Ryder Cup passes for the entire week. Tickets currently are on sale and can be purchased for \$10 each. *Please contact the NKFK at 1-800-737-5433 to purchase raffle tickets.*

The Lexington Golf Event will host a "Toast to Tee Off" Cocktail event at Sal's Chophouse on September 7th. The event will feature an open Calcutta with auctioneer Brett Setzer.

Resources for Potential Organ Donors and Recipients

- **NKF Living Donors:** dedicated to providing education and support for living donors, potential donors, professionals, and family and friends www.livingdonors.org
- **Transplant Living:** provides information on pre and post transplantation and statistics www.transplantliving.org/livingdonation
- **www.organdonor.gov:** provides general information on organ donation
- **Jewish Hospital Transplant Center:** www.jewishhospital.com/carecenters/organtransplant.asp
- **UK Healthcare Transplant Center:** ukhealthcare.uky.edu/transplant/
- **National Living Donor Assistance Center** provides up to \$6,000 in financial assistance for potential living donors in need of reimbursement for travel and other non-medical expenses www.livingdonorassistance.org



Volunteer Spotlight: Kaori Tashiro

Kaori Tashiro has been a dedicated volunteer for the NKFK for two years and has been a tremendous help at the Dean Kutz 5K, Gift of Life Gala, NKF Golf Classic, and the Louisville KEEP screenings. Thank you Kaori for being a dependable volunteer!

Occupation: Social worker at Fresenius Medical Care NA dialysis clinics.

Why did you become involved with the NKFK?

My first volunteer experience was when I was asked to volunteer for a local kidney disease screening held by NKFK.

Why do you volunteer for the NKFK?

I work with dialysis patients every day and realize how much support they need to be able to live a fulfilling life. I also realize how important it is to prevent kidney disease. I believe NKFK has an important mission to help kidney patients, their family, and to influence the society about prevention. I enjoy volunteering for NKFK and hope to continue to be part of their good work!

Wanted

TIME, TREASURE, AND TALENT (and that means you!!)

The NKFK is a growing organization and has ample opportunity for its supporters to be actively involved. Here are some of our upcoming summer events that we can use your special talents and time!

- ü KEEP Screenings
- ü NKFK Golf Events
- ü Dean Kutz 5K
- ü CKD Education Program
- ü Health Fairs

To find out more about NKFK volunteer opportunities, please contact Laura Temple at 1-800-737-5433 or ltemple@nkfk.org.

Going for the Gold: Team Kentucky Athlete Paula Caudill



Paula and the Second Chance at Life held a Candlelight Vigil in Central Park, Ashland

Paula Caudill received the gift of life in 2002 when her liver failed, requiring immediate transplantation. During the early 1980's, Paula contracted Hepatitis C during a blood transfusion that gradually destroyed her liver. In July 2002, Paula experience cognitive confusion, a symptom of liver failure. Her family became concerned and Paula checked into the hospital where she was added to the transplant waiting list and received a liver three short weeks later.

Paula is an active member of the Second Chance at Life Ashland chapter, a group dedicated to raising awareness about organ and tissue donation. Paula is very passionate about educating young people for she says they "are the future of organ donation and they need to be educated and not be afraid [of transplantation]." The group has also raised over \$1,500 for Team Kentucky to participate in the U.S. Transplant Games in July, in Pittsburgh, Pennsylvania.

Paula first participated in the U.S. Transplant Games in Louisville in 2006 and will be attending the games in July. For Paula, the games presents an opportunity to "honor my donor and his family for saving my life. Many people think that transplantation means it's the end of your life but it's the beginning of life." She will be competing in the bowling, basketball, volleyball, and 5K Run in Pittsburgh.

Transplant Success! Kerri and Amy's Story



Kerri (L) & Amy attend the Kidney Day at the Capitol in support of the Gift of Life Act.

Kerri Cope and Amy Covert are more than just friends, they are linked together for a lifetime. Kerri was in need of a kidney after her first transplant of 13 years failed from long-term chronic rejection. Seven of Kerri's closest friends and relatives were willing to be tested and give Kerri a kidney.

From the very beginning, both Amy and Kerrie's intuition told them that Amy would be the best match to donate. Kerri always made the

point that if Amy decided to say no, she would respect her decision and love her as much as she had before. Despite the Amy's indecisiveness to go through with the surgery, she never felt comfortable with the decision of saying "no." Two months after the initial testing period, Amy donated her kidney to Kerri after Kerri's 34th birthday.

Kerri and Amy have taken their shared experience to encourage others to become living donors. Kerri drafted a bill—now known as the Gift of Life Act (see side column)—sponsored by Senator Julian Carroll .

Legislative Updates

State Legislation

- *Gift of Life Act (SB35)*: stipulates a \$10,000 tax credit for individuals who donate live organs and a 30 day paid leave for state employees. Is currently in the Senate Appropriations & Revenue Committee.
- *CKD Task Force Resolution (HJR74)*: calls for a state plan to address the growing problem of chronic kidney disease in the state. Is currently in the Senate Health & Welfare Committee.

Contact your state representatives and show your support by calling the Legislative Message Line at 1-800-372-7181.

Federal Legislation

- *Comprehensive Immunosuppressive Drug Coverage (S2320)*: This legislation would extend Medicare payments for immunosuppressive medications past the current 36 month limit for those who received a kidney transplant.

Show your support for organ donation by contacting your congressman via the *Take Action! Homepage* www.capwiz.com/kidney/home.

Team Kentucky on the Road to U.S. Transplant Games

They haven't hit the court or track yet and already this group of athletes has performed death-defying feats. They all carry an inner trophy – a new organ that qualifies them for the dream team in the game of life.

From the Kentucky area alone, more than 35 athletes will celebrate their second chance at life in the largest sports event in the world for people with life-saving organ transplants: the National Kidney Foundation U.S. Transplant Games.

The 2008 U.S. Transplant Games, to be held July 11-15 in Pittsburgh, Pennsylvania, will attract athletes from all 50 states to compete for gold, silver and bronze medals in 12 different sports, including track and field, swimming, cycling and basketball. The five-day event, presented by the National Kidney Foundation and sponsored by Novartis Pharmaceuticals Corporation, also features educational programs and workshops for families of living and non-living organ donors.

The Games visually demonstrate the success of transplantation and call attention to the dramatic national organ shortage. Nearly 100,000 Americans are currently on the national transplant waiting list for every type of life-saving organ transplant and 18 people die each day while waiting. In Kentucky alone, the waiting list numbers 630. Information from NKF and UNOS.

If you would like to support Team Kentucky by pledging a sponsorship or making a gift, please contact Lisa Allgood at 1-800-737-5433. Proceeds benefit Team Kentucky at the U.S. Transplant Games.

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FIFTY LIVES!
Sign the Kentucky Organ Donor
Registry at www.donatelifeky.org!

Kidney Connection
is now on the web!
Please visit us at
www.nckfk.org!

4 Reasons Why You Should Donate Your Old Car to Kidney Cars

- Save Lives
- No Hassle
- Free Pickup
- Tax Deduction*

*FOR THOSE WHO ITEMIZE THEIR TAXES

There are a number of good reasons to donate your old car to the National Kidney Foundation, in addition to the good feeling of helping to save lives.

You'll eliminate all the hassles of putting your car up for sale and the pain that goes with it. We'll even pick up your car if you wish. And, if you itemize your taxes, we'll furnish you with a receipt after we process it. So pick your favorite reason and call or visit us now!



National Kidney Foundation

Contact the National Kidney Foundation in your area, donate online at www.kidneycars.org or call us at **800.488.CARS**

Yes! I would like to receive the ***Kidney Connection***

Name _____

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Please complete and send to:

National Kidney Foundation of KY
250 East Liberty Street, Ste. 710
Louisville, KY 40202

Or email Johanna Clapp at jclapp@nckfk.org