PEOPLE LIKE US AND END THE WAIT!

People Like Us

*People Like Us (PLU)* is a growing movement to empower, educate and encourage people to become effective advocates. It includes: The Patient and Family Council (PFC), which works to ensure that kidney patients receive the best care possible and supports family members and caregivers; the National Donor Family Council (NDFC), which supports donor families and works to increase the sensitivity and effectiveness of the organ recovery process; the transAction Council, which promotes a better quality of life for transplant recipients; and Living Donor Council and potential living donors, for whom the NKF is a leading source of information and support.

How can YOU get involved?

There are many ways to get involved with PLU. The easiest and most informative way is to go to your local meetings. Currently, the NKFK holds meetings in Louisville at the Clifton Center on Frankfort Avenue every third Thursday of every month. To attend these meetings, please call Lisa Allgood at lallgood@nkfk.org or 502.585.5433. If you’re interested in meeting in the Lexington area, please contact Charissa Cook at ccook@nkfk.org or 859.533.6575.

PLU also offers an email program, *People Like Us: Messages of Hope*, which shares personal stories of those on the Patient and Family Council Executive Committee. These messages tell how they faced challenges related to life with CKD, transplantation and donation. To read sample stories, go to www.kidney.org/patients/pfc/messages_hope.cfm. To receive the PLU: Messages of Hope, you can join any of the below listed councils by visiting their websites:

- Patient and Family Council, www.nkfkidneypatients.org;
- Living Donor Council, www.LivingDonors.org

**END THE WAIT!**

The goal of NKF’s END THE WAIT! Campaign, launched in January of 2009, is to eliminate the waiting list for kidney transplants in 10 years.

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**Mark your Calendar! Upcoming Events**

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<td><strong>KEEP Screening</strong>&lt;br&gt;January 30 - Paris&lt;br&gt;February 24 - Owensboro&lt;br&gt;March - Louisville&lt;br&gt;Call to set up your appt!</td>
<td><strong>Gift of Life Gala</strong>&lt;br&gt;Henry Clay, Louisville&lt;br&gt;March 20, 2010</td>
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<td><strong>Treatment Options Class:</strong>&lt;br&gt;<em>Stage 4 Kidney Patients</em>&lt;br&gt;4th Thursday every month&lt;br&gt;Louisville&lt;br&gt;Breckinridge Inn</td>
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**Save The Date!**

You’re invited! The Gift of Life Gala has been set for **March 20th, 2010** at the Henry Clay on 3rd Street in Louisville. For more information, please call the NKFK at 502.585.5433 or email Abby Johnston at ajohnston@nkfk.org.

For more information on the Henry Clay, please visit their website: [www.thehenryclay.com](http://www.thehenryclay.com).

**NKFK Chapter News**

♦ **Bowling Green**

The Bowling Green Chapter held their 3rd Annual Ride Out Loud Bike Ride at Chaney’s Dairy Barn on August 16th. The event was a great success with over 130 riders coming out to support the NKFK. The chapter and presenting sponsor, The Medical Center, provided great volunteers and services to this year’s event. Well done!

♦ **Lexington**

The Lexington Chapter held a NKFK fundraising event, WineFest of the Bluegrass on August 8th at Gainesway Farm. Guests enjoyed wine, liquor and beer from eight local vendors, while the presenting sponsor, Porsche of Lexington, gave away a ‘Porsche for the Weekend,’ among other auction items.

The Chapter met on Friday, October 23 for its last meeting of the year. We discussed End the Wait, KEEP Screenings, Living Donation and the UK Transplant Center, Team Kentucky and the US Transplant Games. We also discussed the TAKE ACTION NETWORK (www.kidney.org/takeaction) and encouraged people to sign up to become an advocate. The next meeting will be on January 22, 2010.
Common Questions & Misconceptions About Organ & Tissue Donation

What do I need to do to become an organ donor?
The first step is to talk with your family. If your family is aware of your choice, the decision will be much easier when the time comes. Next you should sign the National Donor Registry. This is a nationwide list of donors and ensures that your wishes to help others will be carried out through Kentucky’s First Person Consent law.

I signed my drivers license, do I need to sign the National Donor Registry too?
YES! If you have not renewed your license since the summer of 2008, you may not be on the National Registry. Unlike other states, Kentucky did not add names to a national list to ensure credibility and first person consent. Signing the registry will only re-affirm your desire for organ donation.

Will my quality of care be less if the nurse or medical team knows I am an organ donor?
NO! All patients will receive equal care regardless of their decision to become an organ donor. Organ donation becomes a concern with the medical team when death occurs, and not before. Also, the transplant team is separate from the medical team who administers your care.

Will I still be able to have an open viewing funeral if I am an organ donor?
YES! Removal of organs and tissues will not interfere with customary funeral arrangements. No alteration in the donor’s appearance will occur and this includes all organ and tissue donation.
Welcome New NKFK Board Members!

**Dominick D’Urso**
Aircraft Division Maintenance Division Manager, UPS

I chose NKFK because my father was a kidney transplant recipient. I know the struggles that patients and their families have to endure to deal with CKD.

A goal of being a part of the NKFK BOD is to assist in the efforts to help people in our community make the most of the resources that are available to them in dealing with kidney disease.

The NKFK is an important part of the community. The support that was provided by the Kidney Foundation to my father and family where we lived helped us a great deal, and I look forward to being able to provide help to others any way I can through the Foundation.

My wife Candee and I have been married for 22 years and have three children; Nickalas 20, Amelia 17, and Maria 12.

**Dominick volunteered for our 2009 Dean Kutz 5k Race for Organ & Tissue Donation Awareness.**

**Daniel Haddix**
Director of Quality Assurance, UPS Airlines

I chose to join the NKFK to support the organization’s goal to increase tissue and organ donation and awareness. I received a liver transplant on April 10, 2006 at Jewish Hospital in Louisville.

Looking forward to joining the board members in fundraising and meeting its mission and goals.

*Dan has already volunteered and participated in our 2009 Dean Kutz 5k Race for Organ & Tissue Donation Awareness.*

**Dominick D’Urso**
Aircraft Division Maintenance Division Manager, UPS

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**Dominick volunteered for our 2009 Dean Kutz 5k Race.**

**Stephanie Lanham**
Director, Norton Physician Services

I chose to become a part of the NKFK because my grandfather battled with Kidney Disease before he passed away a number of years ago, so I have experienced it first hand.

I hope to be able to raise awareness about Kidney disease and educate the public about its prevalence. I think far too many people are unaware of kidney disease and how many are affected by it. I also want to encourage the public to consider organ donation and giving the gift of life, which truly makes a difference!

I have been married to my husband, Todd, for 5 years and have two children; Makena, 4 and Sawyer, 2.

*Stephanie also served on our Walk Committee where she recruited sponsors and gifts for the 2009 Walk.*

**Robert “Rusty” Wells**
Senior Account Executive, Neace Lukens

I chose NKFK to help educate as well as personally help those needing assistance with kidney diseases.

My hope is that others will benefit from our service.

The NKFK means there is hope for the future for anyone suffering or who may suffer any kidney ailment.

I am married to my best friend and beautiful wife Mary Ann for 18-years with two equally beautiful children William Harrison Wells (son) and Meredith Hunter Wells (daughter).
People Like Us and END THE WAIT! Con’t from cover story….  

There are four components to this initiative, and public policy advocacy is vital in accomplishing each of them:

1. **Improve Outcomes of First Transplants**  
   Improved Medicare coverage of antirejection medications is an important step towards reaching this goal. Therefore NKF is advocating for legislation to provide continued Medicare entitlement for these drugs for kidney transplant recipients beyond 36 months post-transplant.

2. **Increase Deceased Donation**  
   While NKF is opposed to providing financial incentives for organ donation, we want to be sure that organ procurement organizations have the discretion and funding to assist donor families with expenses directly related to the donation, which may include some funeral expenses.

3. **Increase Living Donation**  
   NKF has maintained that living donors should not personally bear any costs associated with donation. In addition, NKF believes that living donation can be increased by removing disincentives that living donors face. Members of Congress have been working on three types of legislative proposals that address these concerns: A. increasing ability to obtain health insurance post-donation; B. the Living Organ Donor Tax Credit Act which would provide a nonrefundable federal income tax credit of up to $5,000 for expenses incurred in connection with living organ donation that have not been reimbursed; C. amendment to the Family and Medical Leave Act to allow time off from work for individuals who provide living organ donations.

4. **Improve the Donation & Transplant System**  
   The NKFK strives to improve this system by eliminating regional variations in access to transplantation and follow-up care (more efficient) and eliminating racial disparities in donation (equitable).

**People Like Us Advocating for END THE WAIT!**  
Among the most vitally important components needed to accomplish NKF’s goal to END THE WAIT! for a transplant in this country are NKF’s *People Like Us* advocacy activities. By sharing their personal stories of kidney disease, waiting for a transplant, or donation, PLU members demonstrate the reason why NKF launched this campaign - so that we can do our absolute best to support the patients we serve, as well as the living donors and donor families who make transplantation possible. Since the launch in almost a year ago, more than 2,000 People Like Us advocates have sent letters and met with Members of Congress asking for support for legislation, including a federal income tax credit for direct expenses incurred by living donors and Medicare coverage of needed immunosuppressive medications for the life of a transplant. These are essential legislative components of END THE WAIT!  

Please visit www.kidney.org/endthewait to learn how you can become a People Like Us advocate to help END THE WAIT! through the public policy goals described in this article.

Information retrieved from RenaLink, Fall 2009, Vol. 10, No. 3
Team Kentucky News

Join Team Kentucky!

The National Kidney Foundation U.S. Transplant Games will be held in Madison, Wisconsin July 30-August 4, 2010.

Team Kentucky is looking for new recruits age 18 months and up. There is a sport/activity for everyone.

Team Kentucky membership is open to organ transplant recipients, donor families and living donors.

To learn more, attend our Team Meeting on December 6, 2010 at 3:00pm
Kentucky Broadcasting Association
101 Enterprise Drive
Frankfort, KY

Contact Team Manager:
Lisa Allgood
800-737-5433 or lallgood@nkfk.org

This is a great opportunity to meet fellow recipients, donor families, living donors, and supporters and learn about being a part of a very special Team.

If you thought it was too late to get involved in Team Kentucky, just read on about a Louisville native who has inspired us all.

Kim Estep-Lampley won 5 gold medals and set 4 world records at the 2009 World Transplant Games in Australia in the 50-59 age group. She won all medals in swimming categories (freestyle, backstroke, and individual medley).


Commemorate your loved ones

Honor your loved one who has kidney disease or is a recipient of an organ transplant by making a donation to the National Kidney Foundation of Kentucky in his/her name. You may also commemorate your loved one who has passed by donating in memory of him/her. All donations will be announced in our quarterly newsletter, Kidney Connection (see page 10). Your kind donation will continue to help those who are affected by kidney disease and end the wait for organ donation.

If you are interested in making a donation, please send your name, address, honoree's name, announcement, and donation to the following address:

National Kidney Foundation of Kentucky
250 East Liberty Street
Suite # 710
Louisville, KY 40202

With organ donation you can give someone a gift they can really use. Life.
What can I donate?
Donors can choose to donate all or some of the following organs: kidneys, heart, lungs, liver and pancreas. Donors can also donate tissues including corneas, skin, heart valves, bones, saphenous veins, and tendons. You can save and enhance up to 50 lives by becoming an organ donor.

Will my family have to pay for my organ and tissue donation?
NO! All costs related to organ & tissue donation are paid by the organ procurement organizations (OPO) in each state. Kentucky’s OPO is known as the Kentucky Organ Donor Affiliates.

What if I change my mind after I become an organ and tissue donor?
By creating a profile online (www.donatelifeky.org), you can specify which organs and tissues you would like to donate. If you change your mind about any, you can go online and update your profile. You may also contact KODA at 1.800.525.3456.

For more information on organ donation or to sign up, please visit www.nkfk.org, www.donatelifeky.org, or www.kyorgandonor.org.
2009 Walk Re-Cap!

Another Walk has passed us by and this year we raised almost $25,000 through team and individual donations alone! We had over 300 Walkers come out to support the NKFK and its mission to prevent kidney disease and to spread awareness. Thank you to those Walkers who went far and above their personal fundraising goals and to the Team Captains who led their team through months of fundraising!

LOVE YOUR KIDNEYS

Thank you to all our Sneaker Sponsors!

Recipient

Top Dialysis Team Fundraiser
South Central Kidney Beans

Top Team Fundraiser
Miles for Zoey Jade

Top Individual Fundraiser
Donna Bothur

Largest Dialysis Team
DSI

Largest Team
Miles for Zoey Jade

Pictures by: Traci Gould with Team Miles for Zoey Jade
DEAN KUTZ 5K RACE
FOR ORGAN & TISSUE
DONATION AWARENESS

2009 RACE WINNERS

Men
Overall 1. Drew Knott
        2. Kevin Finnegan
        3. Michael Mudd
20-24  Drew Knott
25-29  Shaun Cowherd
30-34  Jeramy Kazlauskas
35-39  Michael Mudd
40-44  Joe Hinkle
45-49  Will Ashlock
50-54  Kevin Finnegan
55-59  Clarence Jordan
60-64  Jeff Sherman
65&Over Chris Brodehl

Women
Overall 1. Katie Prince
        2. Andrea Rouse
        3. Nancy Burgess
14&Under Erica Shuler
15-19  Rikako Nakano
20-24  Nicole Alderson
25-29  Katie Prince
30-34  Dana Brawner
35-39  Nancy Burgess
40-44  Stacie Kutz
45-49  Jeanne Padilla
50-54  Debra Harper
55-59  Beth Hensley
60-64  Beverly Leslie

SPECIAL THANKS to all the volunteers who helped tirelessly for the Kidney Walk, Dean Kutz 5k Race, Winefest of the Bluegrass and Ride Out Loud Bike Ride. Huge thanks to the Committees for the extra hours of work and many times entertainment! As said before, our organization would not exist if it weren’t for our amazing volunteers and we greatly appreciate each of you!
In Loving Memory

The following individuals donated to the National Kidney Foundation of Kentucky in memory of loved ones from June 24, 2009 through October 31, 2009. We are very grateful for these thoughtful contributions and wish to express our sympathy to the family and friends of the deceased.

In Memory of Patricia Aldrich
Janet Connell

In Memory of Carl Boles
David Sinclair

In Memory of Willie Brown
Renal Advantage, Inc.

In Memory of James "Jim" Cecil
R.L. & Judy Allender
Leon & Jane Bennett
Amy Bickett
Bruce & Martha Blair
Doug & Sue Borders
Gamie Brown
Patrick & Judith Bullock
Philip Bullock
Carol Carlisle
Loretto Casper
Carole Clifford
Jesse & Mary Pat Cole
Philip & Patricia Davis
Edward & Norma Delmenhorst
Frank & Terri Desensi
Ron & Margaret Dischinger
Michael & Helen Feeney
George & Mary Ann Feger
Patricia Ferrell
Michelle Frisbie
Mary Gleason
Lane & Mary Josette Goulet
Kenny & Gail Hagan
Louis & Dorothy Hall
Mike Hasselbring
Kevin Hayes
James & Mary Ann Higdon
Roger & Barbara Howard
Edward & Agnes Jury
Arthur & Catherine Kopp
Raymond & Sharon Kuhn
Susan Law
Jack & Joan Luckett
Katherine Lyons
Steve & Allison McCombs
Michael & Pamela Minter
Dana Paglina
Donald & Ann Ransdell
Janet Reddington
Lana Riley
Olivia Sleadd
Nina Stack
Raleigh Swift
Stanley Talesnick
L.H. Toebbe
William & Janice Wiedandt
Royce & Linda Bailey

In Memory of Betty Collins
Margaret & Edward Pohlegers

In Memory of Joyce Doeker
Donald & Alma Hans
Claire Merman

In Memory of Roena Earles
Jennie Patterson

In Memory of Norma Eberle
Mike & Sue Lutz

In Memory of Duddie Eleerle
Margaret Fleck

In Memory of Emily Gaddie
Lori Poole

In Memory of Harman
Aaron Montgomery

In Memory of Donald King
Joel & Julita Jones
John & Betty Williams

In Memory of Norma Kircher
Eugene & Dorothy Byron

In Memory of Dominick LaVera
Joseph & Anne French
Mary French
Shelli Koestner
David & Patricia Peterson

In Memory of Mildred Lukas
Jane Eppich
Gail Martinko
Laura Zanewicz

In Memory of Ruby Mangold
Doris Harrison

In Memory of John Markham
Mattie Sanders
Southern States

In Memory of Stan Marszalek
Marilyn Bland

In Memory of VeJbai Champaíi Maru
Judith Alender
Dr. R. Wathen Medley
Ohio Valley Nephrology Associates, PSC
Ohio Valley Nephrology Office Staff
Joann Risner
Randy Spaw & Kimberly Johnson
Mike & Karen Thompson

In Memory of Egene Morgan
Curtis & Rebecca Cunningham
Jeffrey & Arlene Klinker
Dorothy Morgan

In Memory of Lula Nalley
Diana Britton

In Memory of Charles Nonweiler
Baptist Healthcare System, Inc.

In Memory of Dennis Pearl
Joseph & Suzanne Thornton

In Memory of William Peck
SuZanne Troske

In Memory of Clarke Potter
Dana & Richard Roby

In Memory of John "Jock" Rueger
Janet Scott

In Memory of Roger Shepherd
George & Beth Blandford
Brian Brohman
Ronald Butt
Matt Campbell
Creative Alliance
Susan Dallas
Stephen & Sara Deetsch
Phyllis Dries
DecAnna Esslinger
Robert & Sandy Glasford
Eric Gregory
Michael Grisanti
Kenton & Rhu Hayes
Melanie Henry
James & Mary Jo Heppner
Debbie Hudson
Antoinette Linville
Nancy Stephen
The Vimar Group

In Memory of Virginia Tighe
Anthony & Marie Roche

In Memory of Beulah VanArsdall
Eckler-McDaniel Funeral Home

In Memory of Laura Vestal
Brett Beaversor

In Memory of Bobby Willoughby
Wanda Hobbs

In Memory of W.T. Young
Hoy & Beverly Blackburn

In Memory of Edith Zedonek
Virginia Berry
**What:** DONORAMA
*American Red Cross Blood Drive*

**When:** December 29 & 30
12-7pm

**Where:** Crowne Plaza, Louisville

In need of volunteers to work the NKFK table at this event. There will be two shifts, 12:00 - 3:30 and 3:30 - 7:00. We are hoping to have 2-3 volunteers per shift.

Volunteers will be signing people up for the Donor Registry and promoting the NKFK. Each volunteer will receive a tee shirt for helping!

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**Attention Volunteers!**

The NKFK is in need of volunteer assistance with database entry. If you’re interested, please contact our office at 585-5433 or ajohnston@nkfk.org.

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Our organization could not function without our faithful and motivated volunteers. Volunteer for upcoming NKF opportunities to help spread awareness:

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For more information on how to volunteer at the NKFK, please call 502.585.5433 or email ajohnston@nkfk.org.
Yes! I would like to receive the
Kidney Connection

Name _______________________________
Address _____________________________
City ________________________________
State _______________ Zip _____________
Email ______________________________

Please complete and send to:
National Kidney Foundation of KY
250 East Liberty, Ste. 710
Louisville, KY 40202
Or email Lisa Allgood at lallgood@nkfk.org

OR
Visit us online at www.nkfk.org!

National Kidney Foundation
The Number One Vehicle Donation
Program in America

KIDNEY CARS

DONATE YOUR GOOD USED CAR. GIVE SOMEONE A NEW LIFE.

Contact the National Kidney Foundation in
your area, donate online at www.kidneycars.org
or call us at 1.800.488.CARS

250 E. Liberty Street
Suite 710
Louisville, KY 40202
(502) 585-5433
(502) 585-1445 (fax)
www.nkfk.org