

# KIDNEY CONNECTION

Winter 2008

## Time Well Spent on Hemodialysis

**C**hildren who receive hemodialysis usually spend 12 to 16 hours each week at the dialysis center. Only a few units specialize and cater to the needs of children, and these units are not often available to many children with chronic kidney disease (CKD). As a result, most children dialyze in centers that mainly serve adults. Because of this situation, this article describes how children's needs may be met in centers that treat both adults and children.

### The Benefits of Recreational Activities During Dialysis Treatment

Children often complain of boredom while on dialysis and pass the time by sleeping. For many children, a daytime nap can disrupt their nighttime sleep and consequently their ability to function optimally during the day. A backpack or activity bag with some of your child's favorite card or board games, arts, and crafts supplies, books and books on tape, hand held video games and approved snacks (if the unit allows eating during dialysis) may be very useful in preventing the "boredom" nap (*cont. on pg. 3*).

## Being Overweight: A Growing Problem for Kids, Too

Much attention has been given to the ballooning waistlines of Americans over the last several years, and many refer to this trend as an "epidemic." Statistics back this claim. The number of obese adults older than 20 years of age doubled between 1980 and 2002. During that same period, the number of overweight children aged 6 to 19 tripled. A recent study found that 17 percent of U.S. children and adolescents were overweight and 32 percent of U.S. adults were obese (*cont. on pg. 6*).



Message from the Executive Director  
Lisa Allgood

### UK-UL Gift of Life Challenge

The UK-UL Gift of Life Challenge is sponsored by the Donate Life Kentucky Coalition, a group of 14 organizations invested in organ and tissue donation and transplantation awareness. The mission of the Coalition is to increase organ, eye, tissue and blood donation in Kentucky with public education, marketing, networking and advertising. The coalition also encourages all Kentuckians to place their name on the Kentucky Organ Donor Registry at [www.DonateLifeKY.org](http://www.DonateLifeKY.org).

The UK-UL Gift of Life Challenge is a fan based competition between the two schools. The school that registers the most new donors on the Kentucky Organ Donor Registry is presented the Team Cup at half time of the UK-UL Basketball Game being held at Freedom Hall on January 4, 2009. The Team Cup is presented to the President of the winning university.

Watch for the UK-UL Gift of Life Challenge at all the home games in December, 2008. Visit the Registry table or go to [www.DonateLifeKY.org](http://www.DonateLifeKY.org) and indicate which team you support.

Say "Yes" to Organ and Tissue  
Donation

## Mark your Calendar! 2008-09 Events

### Program Events

#### KEEP Screening

**November 15**  
Richmond  
First Christian Church

**February**  
Lexington  
TBA

### Special Events

**Gift of Life Gala**  
*Celebrate Life in Paradise*  
**March 21**  
Galt House, Louisville

### Become empowered for your healthcare needs!

**The Patient Empowerment Program** is for people living with kidney disease, transplant recipients, and their families that work together to educate and empower themselves and others to address issues related to their healthcare needs.

#### Join the First Meeting!

**January 15, 2009**  
**6:00pm**  
**Clifton Center, Louisville**  
**Dinner provided**

*For more information and to RSVP by January 8th, contact Leif Morgan at 1-800-737-5433 or [office@nkfk.org](mailto:office@nkfk.org).*

**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 visit  
[www.kidneyclubs.org](http://www.kidneyclubs.org)!

## NKFK Chapter News

### Bowling Green

#### 2nd Annual Ride Out Loud Bike Event

The Bowling Green Chapter of the National Kidney Foundation of Kentucky joined with The Medical Center to present the 2nd Annual Ride Out Loud Bike event held at Chaney's Dairy Barn. The event was a great success with 175 riders coming out to support the NKFK. The cyclists had the opportunity to learn about prevention of kidney disease and sign up to be an organ donor with the Kentucky organ donor registry. Thanks to our contributing sponsors: The Medical Center, Hughes and Coleman, and the Bowling Green Bike Club, The event raised \$3,000.00 to benefit programs and services of the NKFK. Thanks to all the volunteers for your time and talent.

### Lexington

The next Chapter meeting will be February 27, 2009 at 11:30am at the Kentucky Clinic Room J005. Lunch is provided. Anyone interested in learning more about the NKFK's programs and services is welcome to attend. For more information, please contact Lisa Allgood at 800-737-5433 or [lallgood@nkfk.org](mailto:lallgood@nkfk.org).

## VOLUNTEER OPPORTUNITIES

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

- ü KEEP Screenings
- ü CKD Education Program
- ü Patient Empowerment Program
- ü NKFK Golf Classic
- ü Health Fairs
- ü Kidney Walk

*To find out more about NKFK volunteer opportunities, please contact Laura Temple at 1-800-737-5433 or [ltemple@nkfk.org](mailto:ltemple@nkfk.org).*



## **Time Well Spent on Hemodialysis** (cont. from pg. 1)

Change the contents of the activity bag every few weeks and let your child help decide what to pack.

### **The benefits of Education About CKD and Dialysis During Dialysis Treatment**

Most people have heard the expression, “knowledge is power.” This is especially true in the management of kidney disease and there is a lot to know. Children need to understand how and why hemodialysis works, the importance of taking their medicine, how they can stay healthy in between treatments, the importance of protecting their graft and keeping the graft area clean, the importance of eating the right foods and consuming the correct amount of fluid and alternatives to hemodialysis. This information should be given in language that the child will understand, a little at a time and with frequent review and opportunity for questions. Many dialysis units have books, pamphlets and videotapes with drawings and charts that can be used and there may also be educational materials that are designed specifically for children.

### **The Benefits of Optimism During Dialysis Treatment**

Keeping a positive attitude in the face of continued and frequent hemodialysis is sometimes a very difficult thing to do. It is important for children and parents to get emotional support, especially if emotions or attitudes get in the way of full treatment. Emotional support helps in keeping a hopeful attitude about the future. Schedule an appointment with your unit’s social worker to discuss your child’s adjustment to dialysis. Try to get connected with other patients and families in the unit in order to increase your social support network. Your child might also benefit from talking with other children who have CKD. If you cannot find the support you need in your center, ask a health care team member for a referral to a health professional who specializes in working with chronically ill children.

### **The Benefits of Focusing on Education During Dialysis Treatment**

Children of all ages on hemodialysis can take advantage of their time on dialysis by working on educational and school assignments. For many children, missed school is an unfortunate result of chronic hemodialysis. It is important that parents and health care team members advocate for the child to get educational and vocational services suitable to their level of need. In fact, it is required under Federal Public Law that all children receive a fair and appropriate education in keeping with their medical needs. Talk to the unit manager and counselors at your child’s school to find out if tutoring or academic instruction can be set up at the dialysis unit by the school system. If formal instruction is not available in the dialysis unit, parents and unit staff should create an atmosphere to encourage studying and homework at the clinic. It is important to praise your child for academic and vocational interests. Older teens can use dialysis run time to study for standardized tests (GED, SAT, GRE), to search the Internet (if the Internet is available) for educational and vocational opportunities and/or to work on college coursework  
*(cont. on pg. 5).*



## Volunteer Spotlight: Karen Waddell



*Karen and her husband, Rob, with their four children.*

### **What led you to become involved with the NKFK?**

My friend Keisha Hagan invited me to participate in the 2008 Kidney Walk and I said "yes" without hesitation. This is a cause that is very important to me. It was after the first meeting at the NKFK that I realized I was actually a coordinator for the walk. My role was bigger than I had expected. However, I knew if I could bring attention to kidney disease and raise funds for the NKFK, doing so now was better than ever because of the heightened awareness kidney disease in my community due to my husband, Rob, being in end-stage renal disease. However, we are very fortunate to have a living donor and are in the process of scheduling his transplant. So, I started emailing family and friends and "The Kidney Beans" were formed. Soon my team started

growing, as did the donations.

### **What is the importance of the NKFK mission to you?**

It is extremely important to me because my husband's family has the genetic kidney disease known as Polycystic Kidney Disease (PKD). It has affected his mom's family for a long time now. She has undergone two transplants with the second coming from her oldest daughter. They are both doing very well. He also has a sister with PKD. This disease will be with our family until a cure is found. If our family needs any support we know we can turn to the NKFK. I am pleased to support the NKFK and their mission and to bring awareness that there are so many people living with kidney disease and the need for organ donation.

### **What do you enjoy most about participating in the Kidney Walk?**

This was my first year participating in the Kidney Walk. It was rewarding to me to be the captain for "The Kidney Beans" team because my team consisted of my family and friends. My team made it so easy and enjoyable because they all put some much of their own efforts into the walk. Our team was recognized for having the largest number of walkers and being the top fund-raiser. I belong to Our Lady of Lourdes church and support from the church community has been overwhelming. The Walk was over and one of my team members was still getting donations. The children at Our Lady of Lourdes are continuing to raise money by doing their own walk and collecting donations. This is what makes it enjoyable. Being surrounded by a supportive family and a community who truly cares about this cause that means so much to me, made my involvement personally satisfying and somewhat effortless.

**Thank you Karen for your excitement and commitment to our efforts in raising awareness about kidney disease!**

## Time Well Spent on Dialysis (cont. from pg. 3)

### The Benefits of Advocacy During Dialysis Treatment

Parents, as well as the child, are important members of the health care team and can positively influence their child's treatment experience. One of the most important things you can do for yourself and your child is to be an advocate for your child's needs within the hemodialysis center.

Learning about hemodialysis, nutrition and medication can help parents be good advocates for their child. Hemodialysis is a major commitment and will be a big part of your child's life. Encouraging a child friendly atmosphere in the dialysis unit will help make runs more pleasant. Consider talking to the nurse manager, social worker or doctor about creative ways to better meet the needs of your child in the unit. This can range from asking the center for videos or pamphlets about kidney disease that are targeted to children, to helping the child be more comfortable in the clinic, through decorations, activities, and music. Your help can make all the difference in creating a pleasant dialysis experience for your child.

*Written by Beth Bounds, LCSW-C & Arlene C. Gerson, PhD. Published in Family Focus, Volume 13, Number 1. Available from [http://www.kidney.org/patients/pdf/ff\\_wi04.pdf](http://www.kidney.org/patients/pdf/ff_wi04.pdf)*

### Going for the Gold: Team Kentucky Athlete Jessica Owen



*Jessica, with her father, James, wearing her Sportsmanship Medal.*

Jessica Owen received her first gift of life on January 25<sup>th</sup>, 2004 when she received a liver transplant. She was born with biliary atresia, a rare condition in newborn infants that affects liver function. Due to this condition, Jessica's kidneys failed and she and her family were faced with yet another challenging situation; to initiate dialysis treatment or hope to find a compatible kidney donor. Jessica's mother was tested and was a perfect match. On September, 2006, Jessica received one of her mother's kidneys.

Jessica competed in her first U.S. Transplant Games in Pittsburgh and participated in the softball toss, bowling, and swimming events. For Jessica the games presented a chance for her to meet similar kids who understand it's about the interaction and making of new friends. Jessica loved the fact that the games were "not about winning, but about playing for fun and realizing their common bond." Whether winning or losing a game, Jessica was always very respectful and congratulatory to other athletes. Jessica was awarded the Team Manager Gold Medal for Sportsmanship in recognition of her positive attitude at the games.

Despite the challenges Jessica and her family have faced, she is a spirited, fourteen year old charmer who will have you laughing within minutes of meeting her. Jessica will bring her encouragement and spirit to the 2010 U.S. Transplant Games in Madison, Wisconsin.

## Being Overweight (cont. from pg. 1)



### What is the definition?

Terms such as overweight and obese are generally used to describe people with too much body fat. The most common measurement for defining these terms is the body mass index (BMI). BMI, a measure of weight adjusted for height, is favored because it is much easier to determine than the amount of fat in your body. Just like height and weight, BMI varies by age and sex of a child. Therefore, BMI percentiles are used in children. The percentile indicates how the child's BMI number compares to other children of the same age and sex. Children with a BMI greater than the 95th percentile are considered overweight, and children between the 85th and 95th percentile are "at risk." A health care provider can help determine your child's BMI percentile, or you can calculate it yourself if you have your child's recent height and weight. A BMI calculator can be found at the Centers for Disease Control and Prevention (CDC) Web site: <http://apps.nccd.cdc.gov/dnpabmi/Calculator.aspx>.

### Why is it dangerous for children to be overweight?

Many studies show that being overweight is linked to multiple health problems in both children and adults. Those who are overweight are more likely to have diabetes, high blood pressure, high cholesterol, stroke, heart disease, asthma, sleep problems, gallbladder disease, joint problems and some cancers. Children who are overweight may also be the target of social discrimination (i.e., they get mocked). The stress connected with this may cause low self-esteem, which can disrupt many aspects of a child's life. Overweight children and teenagers are also more likely to become overweight adults. For many of the health problems described above, longer exposure to the risk factor (being overweight) makes developing the problem more likely.

### Can being overweight affect the kidneys?

Yes! The leading causes of kidney disease in adults are diabetes and high blood pressure. Being overweight increases the chances of developing these diseases and makes the problems resulting from them more severe.

### Why are children overweight?

In adults and children, being overweight results from an imbalance between calories taken in and calories used. The CDC explains that although this is a simple concept, a number of factors, including genetic, behavioral and environmental, add to the problem. Finding and "fixing" these is a big challenge. Some examples of "behavioral" factors listed by the CDC include: larger portion sizes, frequent snacks, drinking beverages with added sugar (juices, soda), less participation in physical activity during school and more time spent with media (DVDs, TV, and video games), which in turn leads to sedentary (inactive) behavior (cont. next page).

## Being Overweight (cont. from previous page)

### Learn More about the Problem!

Your child's health care provider will help determine if your child is overweight, and if so, he or she will help come up with a plan for achieving a more healthy weight for your child. But you need not wait for your next appointment to learn about healthy choices! Given the scope of the problem, there is a lot of excellent information available regarding overweight children. A few Web sites are mentioned below. Children are much more successful at keeping a healthy weight if the whole family joins in healthy eating and lifestyle choices. What is good for your child will be good for you!

*Article by Jeffrey J. Fadrowski, MD, MHS. Originally published in Family Focus, Volume 16, Number 2. Available from [www.kidney.org/patients/pdf/ff\\_wi08.pdf](http://www.kidney.org/patients/pdf/ff_wi08.pdf)*

### Resources on Childhood Obesity

**Center for Disease Control**—provides information and additional resources on preventing childhood obesity  
[www.cdc.gov/nccdphp/dnpa/obesity/childhood/index.htm](http://www.cdc.gov/nccdphp/dnpa/obesity/childhood/index.htm)

**National Kidney Foundation**—provides information on obesity and how to lose weight  
[www.kidney.org/atoz/atozItem.cfm?id=131](http://www.kidney.org/atoz/atozItem.cfm?id=131)

**American Academy of Pediatrics**  
[www.aap.org/healthtopics/overweight.cfm](http://www.aap.org/healthtopics/overweight.cfm)

### CALLING ALL MOMS AND DADS!

The NKF offers an educational program called **Kidneys in the Classroom** that teaches children the importance of healthy living to prevent kidney disease and its causes—diabetes, high blood pressure, and obesity. The free program is offered to children and youth in grades 3—12. If you would like for Kidneys in the Classroom to be presented in your child's class, please contact Laura Temple at 502-585-5433 or [ltemple@nkfk.org](mailto:ltemple@nkfk.org).

### Help Build the Congressional Kidney Caucus!

The purpose of the Kidney Caucus is to increase awareness among Congressmen about issues related to kidney disease and transplantation and garner their support for pressing legislative issues. 1 in 10 Kentuckians live with chronic kidney disease and most don't even know it. We need your help in encouraging our Kentucky Congressman to make lives better for those living with kidney disease.

You can help by sending a message to your Congressman through the NKF Take Action Network. By joining the Network, you can e-mail a customizable letter of support to your Congressmen. The more letters our political leaders receive from their constituents, the more likely they will listen and take action to support our concerns.

Show Your Support and Make a Difference!  
Join the NKF Take Action Network by visiting  
[www.kidney.org/takeaction](http://www.kidney.org/takeaction)

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The NKF is offering a series of FREE monthly interactive telephone discussions called Coffee House Conversations. These calls are being held to educate and empower you to become your own best advocate by giving you valuable information on different topics related to chronic kidney disease, donation, or transplantation.

**Join the next call!**

**"Your Safety on Dialysis Treatment:  
In-Center and at Home"  
Tuesday, December 9  
3:00pm-4:30pm**

*Space is limited! Be sure to register by calling the National Kidney Foundation at 1-888-564-6653.*

***Kidney Connection  
is now on the web!***  
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www.nkfk.org!**

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