



Heartland Headlines

A Newsletter for ESRD Patients

July 2008

Who Are We? What Do We Do?

Do you know who we are and what we do? Heartland Kidney Network is a nonprofit organization that contracts with Center for Medicaid & Medicare Services (CMS) for End Stage Renal Disease (ESRD). Heartland Kidney Network is part of a national system of ESRD Networks established by Congress in 1976 to help dialysis and kidney transplant centers achieve high standards of care for kidney patients. Heartland Kidney Network serves the dialysis and kidney transplant Medicare population in Iowa, Kansas, Missouri, and Nebraska.

Heartland Kidney Network focuses on the Six Aims from Institute of Management (IOM, 2001) and promotes the following goals of patient care:

- Patient Centered
- Efficient
- Effective
- Equity
- Safe
- Timeliness

Heartland Kidney Network's mission is to promote and facilitate high quality care standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri and Nebraska. We are able to fulfill our mission daily by assisting patients and facilities in the following areas:

Quality Improvement (QI): The team helps your dialysis facility with continuous quality improvement (CQI) activities. This is done by providing education to the staff, monitoring your facility's quality outcomes, collecting data and examining trends. We watch specific measures to ensure your facility delivers quality care.

Information Management (IM): The team works with your healthcare provider in the collection and filing of Medicare eligibility forms. The IM staff are responsible for supplying forms, providing instruction, editing data, entering data, transmitting information to CMS, and monitoring facilities for compliance.

Patient Services (PS): The team provides technical assistance to both patients and staff, handles complaints and grievances, and identifies and develops educational resources. This department also facilitates the Patient Advisory Committee, which acts as an advisory group and helps to promote issues of patients' rights and responsibilities. The Network is available to help patients who have complaints regarding the quality of care provided in their dialysis unit.

Promoting and facilitating high quality standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.

Inside This Issue:

2. Your AVF Fistula & Organ Donation
3. Patient Perspectives- Ardy's Transplant Story
4. Emergency Preparedness
5. A Patient Perspectives Continued...
6. Fluid Intake and Dialysis
7. Medicare Drug Coverage & Dialysis Facility Compare
8. Voc Rehab & Patient Advisory Committee
9. Calendar of Upcoming Events
10. Adherence to Dialysis treatment, Immunizations & Network contact



What Does an Arterial Venous Fistula (AVF) Mean to You?

Here are some good reasons to consider an arterial venous fistula (AVF)

- Improved quality of life
- Better blood flow for better treatment
- Lifespan is usually longer
- Dramatically reduced chance of infections
- Fewer trips to the hospital
- Usually last years, compared to weeks or months for other access types

For more information visit the FistulaFirst website at: <http://www.fistulafirst.org>

Organ Donation Saves Lives

Hemodialysis, peritoneal dialysis, and kidney transplant are the three main treatment options when an individual's kidneys fail. Each dialysis unit is expected to offer you the option of transplant evaluation. However, not every patient is a candidate for a transplant.

In making a decision about whether this is the best treatment for you, talking to people who already have had a kidney transplant may be helpful. You also need to speak to your doctor, nurse, and family members. Weight adherence, support systems, dental hygiene, and your blood work are important factors during transplant evaluation.

The Network has a comprehensive transplant booklet that covers all the phases of a kidney transplant, from lab tests to drugs, pretransplant, to life after transplantation. For more information, please contact us or go to our website: www.heartlandkidney.org

Promoting and facilitating high quality standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.

Patient Perspectives

Deceased & Living Donor Kidney Recipient



Ardy and her living brother donor Stuart

When I was 15 years old my parents were told, after 3 weeks of agonizing waiting, that I had glomerulonephritis. The prognosis was that I wouldn't live past the age of 18 or 19. Although my sisters were too young to understand my 12 year old brother understood as well as a 12 year old could. But then, who can really understand a chronic disease and why it happens or to who it happens. This would later lead my brother to make one of the biggest decisions of his life.

After being stabilized, at the age of 15, and put in a research group at the University of Iowa, (I fortunately got to take medication in my group), life in the Boley family went on. I attended 9th grade over an intercom and only went to school half days in 10th grade. But, I completed high school on schedule and got married at the age of 19. When I was 20 my husband and I adopted a beautiful baby daughter. We brought her home from the hospital when she was four days old. At age 23 my blood pressure skyrocketed

(290/190) and as a result, I was declared an End Stage Renal Disease (ESRD) patient. I began Hemodialysis in July of 1972. In April of 1973 my mother began testing for living related donation. She, unfortunately, didn't pass her angiogram and my father began testing. He, like my mother did not pass the angiogram. My sisters were too young to be tested and my brother, just 20 years old with a wife and new baby was not an option, in my opinion. In September 1973 I was placed on the deceased donor waiting list. At the same time my husband left because my illness was too much for him to handle. If it hadn't been for the grace of God and the emotional and moral support of my family, I'm not sure I would have survived. On October 9, 1973 at 3:00pm, I received that wonderful, yet sad, call from the hospital stating "we have a kidney for you." I was the 100th kidney transplant performed at the University of Iowa. The kidney worked immediately and I went home two weeks to the day after my transplant.

Continued on next page

Promoting and facilitating high quality standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.

Story Continued from previous page...

Life, again, went on. I gained a whopping 60 pounds in the first 6 months after my transplant and knew I had to remedy this. In August of 1974 I vowed to a girlfriend that I would be at least 30 pounds lighter, have a job, and either be engaged or married. By December 1974 I had lost 40 pounds. In February of 1975 I began working at Mercy Hospital in Des Moines and in June I married my current husband, Jim. Jim adopted my daughter, Tammy and in 1980 we adopted another beautiful baby girl, Maryanna. Life was wonderful and through it all my parents, sisters, and my brother were there. No one could have asked for a more loving and supportive family.

In June, 1983 in a “freaky accident” my kidney failed and I was airlifted to the University of Iowa. I had a fistula created to prepare for dialysis. My two sisters and my brother were all tested as potential donors. My brother, Stuart, seemed the best match (3 antigen) and on December 1, 1983 we found ourselves in surgery. The recovery room staff told us that our first questions after waking were “How is my sister?” and “How is my brother.” I had always been close to my sisters and brother, but when Stuart gave me this precious “Gift of Life” I knew I could never do or say anything that would ever come close to expressing how I felt toward him for giving me that renewed life. After receiving this gift from Stuart I began thinking when you receive a deceased donor gift, you grieve for the family who lost a loved one and at the same time you thank them for giving you the “Gift of Life.” When you receive a living donation you have so many things going through your head such as: What about their financial well being?; What will this do to their family?; What if they do this for me and it doesn't work?; Do they understand they are going into the hospital healthy and strong and will be waking up feeling awful while I on the other hand am sick and will feel much better than they when I wake up?”

Anyway, here we are 25 years later and I am doing well and working in at Fresenius Medical Care as a dialysis unit office manager and my brother is fantastic. Thanks to my experiences I have had the great pleasure of working in dialysis for 23 years, I have served on the Medical Review Board and am currently serving on the Executive Committee for Heartland Kidney Network, currently a member of the PAC (Patient Advisory Committee), currently board president of National Kidney Foundation of Iowa, have been a member of Community Health Charities, and an active member of First Church of The Open Bible in Des Moines.

I've never had the opportunity to meet my deceased donor family but thank them everyday for donating their loved ones organs, even though they were grieving their loss, it gave me 10 precious years. I also want to thank my brother (my friend) whose kidney has given me another 25 years and counting.

One last thought.... If you have renal failure or any chronic disease, I can't stress enough how important emotional and moral support from friends and family can be and don't give up on yourself – as you can see I have lived well beyond the 19 years I was expected to live. If it hadn't been for my faith in God, love of life, and encouragement from my family and friends I'm not sure I would have survived this long. I have said it many times but would like to say, again, thanks to my wonderful husband Jim, Maryanna, my dad, Karen, Erma, and all my other family members for being there when I need you. I love you all with all my heart!!! And to my brother...you gave me this new life (even though I am now old) and hope for the future. Thank you and I love you!!

**Promoting and facilitating high quality standards for dialysis
and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.**



Be Safe! Be Prepared!

While nobody likes to think about being involved in an emergency situation, it is important in the light of the major disasters of recent years, to know how to prepare for and act in one, especially if you are a dialysis patient. Most emergencies are minor and pass without incident (such as a brief power outage), but as a dialysis patient it could be life saving to know what to do in an emergency lasting long enough to affect your health. The following tips are just a few of the precautionary measures you should do in order to prepare for an emergency or a life-threatening situation. Heartland Kidney Network has Emergency Preparedness resources for dialysis patients. These resources can be obtained by calling the Network at [1-800-444-9965](tel:1-800-444-9965), or by visiting our website at www.heartlandkidney.org

EMERGENCY TIPS

- Provide your dialysis unit with current telephone numbers in case they need to contact you.
- Maintain a week's worth of your current medications at all times and instructions for administration.
- Wait at home for instructions and details from TV, radio, messages or phone. But if you must seek shelter, take your week's worth of medication, emergency supplies, personal items, blanket and Medic Alert ID information.
- Know how to care for your access.
- Know your dietary guidelines for emergency preparedness and maintain appropriate dietary supplies.
- Begin the survival diet: 2 cups of fluid per 24 hours, no fresh fruit or vegetables.
- If you go to a shelter, tell the person in charge about your special needs.

Remember: Hospitals may not be equipped to provide maintenance dialysis treatments.

Frequently Asked Questions...

Q: I don't drive. How do I get to another clinic?

A: Pre-plan emergency transportation with your family, friends, church members or your neighbors. Utilize the diets provided by your dietitian in order to stay within your eating guidelines in case dialysis treatment is not available for several days.

Q: I dialyze at home. What about my utilities?

A: Most companies already have a system in place for restoring services. Let them know that you are a dialysis patient receiving treatment at home so they can add you to their priority list.

Other Patient Resources can be found at: <http://www.kcercoalition.com/resources.htm>

Promoting and facilitating high quality standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.



Just the Facts: Fluid and Dialysis

The following is an extract from Life Options Rehabilitation Program supported by Amgen Inc. They can be contacted at: 603 Science Drive, Madison, WI 53711, (800)-468-7777, and www.lifeoptions.org

Why Are My Fluids Limited?

One of the jobs of healthy kidneys is to remove extra fluid from the body. When the kidneys fail, dialysis can remove some of the fluid, but you also need to drink or eat less fluid.

What Happens if I Have Too Much Fluid?

If you come to dialysis with too much fluid, your treatment will make you feel bad. Your blood pressure may drop, so you feel dizzy or faint. Your muscles may cramp. You may have headaches, nausea, or pass out. Over time, too much fluid can harm your body. Too much fluid can cause a type of heart failure. Your feet or legs may swell up with fluid. This is called *edema* (a-dee'-ma). You may feel short of breath if extra fluid goes to your lungs.

What Counts as a Fluid?

Anything you drink is a fluid. This includes water, coffee, tea, soda pop, milk, beer, wine, and so forth. Some foods can count as fluids, too. Any food that is liquid at room temperature, like ice cream or popsicles, is a fluid. Soups, thin stews, and watery foods like watermelon count as fluids too.

How Much Fluid Can I Have?

How much fluid you can have depends on how much urine you make. If you make a lot of urine, you can have more fluid. If you make no urine, you can have less fluid. Measuring your fluids for a while will help you get used to your limit.

What Does Salt Have to do With Fluid?

Salt makes you thirsty. It also makes your body keep more water. Healthy kidneys remove extra salt. When the kidneys fail, most people must limit salt and fluid. Ask your **dietitian** how to make foods taste good without adding salt.

What is Dry Weight?

Dry weight is your weight without extra fluid. It is used as a target for each treatment. At your dry weight, you should feel good after dialysis. This is often measured in Kg (kilograms). Each Kg equals 2.2 pounds.



Basics of Medicare Drug Coverage

Medicare Part D is a drug coverage plan available for anyone who has Medicare Part A and/or Part B. This plan may help you pay for the prescriptions you need. If you have other drug coverage, you may not need Medicare Part D.

When can you join a Medicare Part D plan?

You are encouraged to speak with your social worker and/or financial counselor before making any decisions.

You may enroll during the following times:

- Initial enrollment – 3 months before and 3 months after the month you are first eligible for Medicare.
- If you are notified in a letter that your Medicare was “backdated,” you can sign up the following two months after receiving the letter.
- Open enrollment November 15 through December 31 each year.

Important! If you do not sign up during your initial enrollment period, you could have to wait for open enrollment.

Do you have limited income and assets?

You may qualify for a low-income subsidy, also known as “extra help.” Extra help will pay all or part of your Medicare Part D plan premium, deductibles, and coinsurance. You may only have to pay small co-pays for prescriptions. Call Social Security at 1.800.772.1213 or apply online at www.socialsecurity.gov/prescriptionhelp.

Need help choosing a plan?

You can use the online Medicare Prescription Drug Plan Finder on www.medicare.gov or call 1.800.MEDICARE for help.

Source: “Medicare Part D 2008 Update” – Kidney Medicare Drugs Awareness and Education Initiative. www.kidneydrugcoverage.org

Dialysis Facility Compare

The Center for Medicare & Medicaid Services is interested in the quality of care you receive at your dialysis facility and want to share quality indicators and information with you. They therefore host a website called “Dialysis Facility Compare”, which allows all individuals the ability to compare quality, search for other facility’s in the area and see what options each facility has to offer. Shifts at the facility are displayed, as well as patient tool section and other useful information. Please visit the website at: www.medicare.gov/dialysis or contact us for more information at 1-800-444-9965 or visit our website at www.heartlandkidney.org

Promoting and facilitating high quality standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.

Vocational Rehabilitation

Here are resources to encourage you live life to the fullest. Rehabilitation encompasses more than just returning to work, although that can provide a more stable and fulfilling life. Rehabilitation is getting back to the activities and experiences that brought you joy and satisfaction in your life. It also includes exploring new activities and experiences.

Iowa:

Vocational Rehabilitation Services
1-800-532-1486 V/TDD
www.ivrs.iowa.gov

Kansas:

Rehabilitation Services (RS)
1-888-369-4777
www.srskansas.org/rehab/text/VR/htm

Missouri:

Vocational Rehabilitation
1-877-222-8963
www.vr.dese.mo.gov

Nebraska:

Vocational Rehabilitation services
1-800-472-3382
www.vocrehab.state.ne.us

Patient Advisory Committee

The Heartland Kidney Network's Patient Advisory Committee (PAC) was established in 2007. The PAC is comprised of End Stage Renal Disease (ESRD) patients that represent the ethnic diversity, geographic distribution and treatment modalities of the ESRD population in Missouri, Kansas, Nebraska and Iowa . The PAC encourages patients to become more involved in their care and treatment options. Any patient interested in learning more about their treatment options should discuss this with their nephrologist or treatment team at the dialysis facility.

The PAC has established a mission and vision statement and focuses on three main goals.

Mission Statement: To educate and provide patients with perspective for dialysis and transplant.

Vision Statement: To Improve the quality of life for those living with Chronic Kidney Disease (CKD) and End Stage Renal Disease (ESRD).

GOALS:

- Develop informational and educational resources related to renal disease.
- Identify and address needs and concerns of renal patients.
- Provide information and feedback to the Patient Services Department.

Promoting and facilitating high quality standards for dialysis and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.

CALENDAR OF UPCOMING EVENTS

Iowa:

See Upcoming National Events

Kansas:

See Upcoming National Events

Missouri:

June 6, 2008 --- National Kidney Foundation. Kidney Walk Event. St Louis, MO.

June 14, 2008 --- National Kidney Foundation. Kidney Walk Event. Springfield, MO

July 12-13, 2008 ---Missouri Kidney Program. Patient Education Program. Kansas City, MO

August 3-7, 2008--- National Kidney Foundation. Camp Chimer. Excelsior Springs, MO

September 13-14, 2008--Missouri Kidney Program. Patient Education Program. Kansas City, MO

September 2008 --- National Kidney Foundation. Joplin Ride for Life. Joplin, MO

October 4, 2008--- National Kidney Foundation. Kidney Walk Event. Independence, MO

For more information, contact the NKF's Division Special Events Manager, Jennifer Storms at 913-262-1551 x17

Nebraska:

See Upcoming National Events

Upcoming National Events:

June 25, 2008 ---American Association of Kidney Patients.

Conference call topic: Understanding Your Kidney Treatment Options.

Please call (800) 749-AAKP to register or go to the website at:<http://www.aakp.org/events>

July 15, 2008 ---American Association of Kidney Patients.

Conference call topic: Understanding the Connection: Anemia & Iron Deficiency.

July 11-16, 2008--- National Kidney Foundation. Transplant Games. National Event. Pittsburg, PA

August 28-31, 2008. American Association of Kidney Patients.(AAKP) 35th Annual Convention. Washington, DC. Please visit www.aakp.org or call the National office at (800)-749-2257.

Promoting and facilitating high quality standards for dialysis
and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.

Compliance & Adherence to Dialysis Treatment

A shortened or missed treatment means more toxins in your body. Here are just a few side effects:

- Dizziness
- Vomiting- which is mainly caused by a build up of poisons in your system and directly related to not having enough dialysis
- Phosphorous levels affect bone density when they go up thus causing weakened brittle bones
- Fluid build up which causes increased pressure on the heart and may lead to congestive heart failure.
- Irregular heartbeat and possible stopping of the heart function as a result of high potassium levels

Protect Yourself



Influenza, pneumococcal disease, and hepatitis B can be prevented using available vaccines. As a dialysis patient, several conditions weaken your immune system making your body have a harder time fighting infections. The vaccines help to boost your immune system. Remember to always keep a record of your immunizations. If you have had your immunizations given elsewhere, please tell the staff at your facility.

For more information on immunization please talk to your care provider or visit the website below.

Immunization and vaccine information:
<http://www.immunize.org>

Stay in Touch

Heartland Kidney Network maintains a nation wide toll free number for patients and their families.

Our Contact Information:

Toll free: 1-800-444-9965

or

1-816-880-9990

Heartland Kidney Network
7505 NW Tiffany Springs Pkwy, Suite 230
Kansas City, MO 64153

www.heartlandkidney.org

This Newsletter was developed while under contract with the Center for Medicare & Medicaid Services (CMS), Baltimore, Maryland.
Contract # HHSM-500-2006-NW012C. The contents reflected do not necessarily reflect CMS policy.

**Promoting and facilitating high quality standards for dialysis
and kidney transplant patients in Iowa, Kansas, Missouri, and Nebraska.**