

# Renal Outreach

The Renal Network, Inc.  
ESRD Networks 4, 9 & 10

**Working to facilitate the  
achievement of optimal wellness for  
renal disease patients.**

ESRD Network 9 & 10

October 2011/Vol.20, No.2

## Complaints and Grievances

During 2010, The Renal Network, Inc., ESRD Network 9/10 received 115 complaints primarily from people with chronic kidney disease (CKD) and family members. The complaints mainly involved quality of care issues and staff-related issues. The Network also received two grievances, both of which were reviewed by the Network's Medical Review Board Patient Relation Subcommittee. There were 62 patients involuntarily discharged from facilities primarily for disruptive, threatening and abusive behaviors and many of them were also non-compliant to treatment.

- If you are frustrated with your care, work with your facility staff or contact the Network to resolve your concern.
- If you find that you are not going to treatment on a regular basis, work with your staff to resolve the issues that prevent you from receiving your needed treatment.

Of the 40 patients who were having a difficult time finding placement in a facility, over half of them were described as having behavior-related concerns, primarily non-compliant to treatment and verbally abusive. More information about the Network trends is on our Web site at [www.therenalnetwork.org/data/grievance.php](http://www.therenalnetwork.org/data/grievance.php).

When you have a complaint about your care or your patient care provider, the Network encourages you to talk to your staff to resolve the issue. You also can file a written complaint at your facility. Ask your staff for a copy of its **Facility Complaint and Grievance Process** and follow the steps listed. Provide as much information about your concern as possible and meet with the staff to find a solution. If you are not satisfied with how your facility handled your complaint, or you do not want to go through your facility first, you may contact The Renal Network for assistance with your complaint or grievance.

Continued on page 2

The Network can help you solve your complaint by providing suggestions on how to work with the staff, can contact the facility with your permission to investigate your concern and intervene on your behalf, and can provide other agency resources that may be of assistance. The Network toll-free patient line is 1-800-456-6919. More information about the Network's complaint and grievance process can be found on our Web site at [www.therenalnetwork.org/about/grievance.php](http://www.therenalnetwork.org/about/grievance.php).

## Exercise for LIFE!

By Martinlow Spaulding, weKAN Patient Activist, PEPP Speaker pictured below with exercise buddy, Joe seated on exercise bike.



I find it funny when people say, “You look good! Why do you exercise?” I respond, “Maybe it’s because I exercise that I look good.”

When I encourage people to exercise, they often say, “I don’t have time in my busy life.” I then ask, “How is your life so busy?” The usual answer is, “I work nine hours a day with an hour commute.” That’s when I share that I’m a daddy of six active children, an arts administrator, and a religion teacher at church. And oh, by the way, I also have kidney disease. But I’ve made a commitment to myself to exercise at least three times a week. Life is about choices, and I choose to “Exercise for LIFE!”

For me, learning about the benefits of exercise was my “ah-ha” moment. The possible benefits of regular exercise, especially for those who are living with kidney disease, include lower blood pressure, more energy, greater endurance and flexibility, less stress, less risk of heart disease, an active sex life, a better self-image, and a positive outlook.

Everyone has a different capacity for exercise and should discuss any proposed exercise program with a doctor. A person should stop exercising immediately if any of the following occur: shortness of breath, chest pain, severe headache, or a racing heart rate.

Continued from page 2

There are so many ways to exercise. My wife, Elaine, and I alternate between water aerobics, weight lifting, and the treadmill. Exercising with a “buddy” provides companionship, encouragement, and accountability. I enjoy weight lifting, which keeps my muscles healthy and my body fit. The treadmill is a great way to burn calories (from my weakness for cheesecake). Water aerobics has proven to be beneficial for me too: It raises my heart rate, and my annual bone density test has shown that I have little bone disease. I also enjoy my conversations with the ladies in the class—there are advantages to being the only man!

I’ve made a lot of friends at the YMCA, where my family has had a membership for many years. My water aerobics class celebrates milestones with monthly lunches, and it was during my regular workouts that I met Joe, my role model. Sometimes I find myself trying to keep up with him, not only in exercising but also in sharing jokes. I’m blessed to have such an extraordinary man in my life. Did I mention that he’s twice my age? As Joe says, “I’m 84 years young. What’s your problem?”

Most YMCAs offer discount programs based on ability to pay. Other fitness centers may also offer discounts to

seniors, students, and families. My family membership costs about \$400 a year, which is a little more than a dollar a day. Most people spend that much on a drink or snack. Why not invest the money in your health instead? It’s priceless!

(This article was reprinted with Permission from the Renal Support Network *Live&Give Newsletter* Summer 2008.)

## Not All Health Care Is Created Equal

The quality of health care professionals, services, facilities and plans can greatly impact a patient’s health. Medicare beneficiaries have choices when it comes to the quality of their providers. That’s why the Centers for Medicare & Medicaid Services just launched the Quality Care Finder designed to help beneficiaries and their caregivers find better health care options.

Patients and their caregivers can get started by going to [www.Medicare.gov/QualityCareFinder](http://www.Medicare.gov/QualityCareFinder) to find health care providers, facilities, health and drug plans, and equipment suppliers, and make “apples-to-apples” comparisons of their quality.

Continued on page 4

**Available resources for beneficiaries include:**

- **Hospital Compare:** Compare Medicare-certified hospitals locally and throughout the country based on the quality of their care.
- **Nursing Home Compare:** Find Medicare-certified nursing homes and the special services each nursing home offers, like dementia care, ventilators or rehabilitation. Then compare their star ratings and the quality of care they give.
- **Home Health Compare:** Find Medicare-certified home health agencies based on services like skilled nursing care, physical therapy, speech therapy and home health aides. Then, compare each home health agency based on the quality of their care.
- **Medicare Plan Finder:** Get detailed, personalized information about the cost and benefits of available Medicare health and drug plans, and compare the quality of the services they provide.
- **Dialysis Facility Compare:** Find Medicare-certified dialysis facilities and their services. Then, compare each facility based on quality of care.
- **Physician Compare:** Find doctors based on medical specialty, clinical training, foreign languages spoken, and more. Check to see if a doctor accepts the Medicare-approved amount as full payment.

## Get Your Flu Shot

**The Centers for Disease Control (CDC) recommend that EVERYONE, 6 months of age and older get an annual flu vaccine.**

Vaccines are one of the simplest, most convenient preventive care measures available. A flu vaccine reduces your risk of illness, hospitalization, or even death and can prevent you from spreading the virus to your loved ones.

People infected with the flu may be able to infect others beginning 1 day BEFORE symptoms develop and up to 5-7 days AFTER becoming sick. That means you may be able to spread the flu to someone else before you know you are sick as well as while you are sick. Protect your family from flu: GET VACCINATED.

Everyday, preventive actions may slow the spread of germs that cause illnesses like the flu.

- Wash your hands often
- Cover your nose and mouth with a tissue or sneeze and cough into your elbow.
- Avoid touching your eyes, nose and mouth
- Let your dialysis unit know if you are symptomatic. They may want to use extra precautions such as wearing a mask.

## 2011 AAKP Convention

By Julie Boatwright



I have been on dialysis since the age of 15. I have had three kidney transplants and been through every modality of dialysis. I am currently on

hemodialysis in Columbus, OH. I am also the recipient of the Robert Felter Award. With this award I was given the opportunity to attend the AAKP convention in Little Rock, AK on the weekend of August 26<sup>th</sup>. I want to share some of the things I learned and experienced while there.

The morning started off with a trip though the Exhibit Hall where companies from dialysis treatment facilities to patient care organizations had tons of information, not to mention free stuff, to distribute. Some of the exhibits I found most helpful were NxStage, a company that offers home hemodialysis information ([Nxstage.com](http://Nxstage.com)); and a nonprofit organization called Caring Bridges, which offers patients an opportunity to set up their own health care web page. This way friends and

family can go securely to the web page for a daily update on a love one's health ([CaringBridge.org](http://CaringBridge.org)).

I then attended a seminar called "Research and Development; The Future of Kidney Disease" where I learned some startling statistics, like that in the 1960s dialysis was not an option but you had to be approved by a committee to receive treatment. I also learned of some of the treatment options that are only now in development, a Wearable Artificial Kidney, or AWAK. It is a device that can be work 24/7 for continuous dialysis. The presenters also spoke of more centers starting to offer Nocturnal dialysis. This would consist of dialyzing for eight hours while sleeping at the center. They have found that, with this slower treatment, often patient can stop blood pressure medications, reduce the need of binders and increase diet and fluid options.

Next I attended a session called "Creating a Meal Plan Right for Me – The Dialysis Diet." Here dietitian Nadiya Lakhani from Dallas, Texas spoke of the three P's – Protein – patients need a lot and it can be found in eggs and meat; Phosphorous – stay away from processed foods, dairy and brown foods, especially dark colas; and Potassium, did you know it is best to double boil your potatoes? The most interesting fact I took away from this

Continued on page 6

session was that when you drink dark colas the phosphorous actually starts entering the bloodstream through your mouth (cheeks and gums) and that taking a binder will not even help (I will miss you, Pepsi ☹️).

The session I found most interesting was “Home Dialysis Options – Is it Right for Me?” Dr. Christopher Blagg presented some interesting facts regarding home hemodialysis and the short daily cleansing vs. longer less clinic treatments. Two current dialysis patients spoke, one being on CAPD, the other on home hemo. This gave me some real insight to the advantages that may fit my particular situation. I would encourage you to talk with your dialysis team and research all the options.

The final session I attended on Saturday was “Effective Ways to Communicate with your Healthcare Team.” Dr. Stephen Fadem from Baylor University in Houston, TX, spoke of using your healthcare team to take care of your health. Don’t be afraid to ask questions, do your research and most importantly be involved. Know what each member of your healthcare team does and that they are there to help you.

On Sunday, I attended two more informative sessions, the first being “Medicare Bundling; How Will It Affect

Me?” In this session, Dr. Jay Wish from Case Western Reserve in Cleveland, OH, told of the new Medicare bundling rules and how they affect dialysis patients. One of the things I took away from it is that in 2014 binders and dialysis medications will be included in the bundling, meaning that the patient will receive these as part of treatment. Now patients will still have to pay their 20% coinsurance on the bundling but it will still be lower out of pocket cost to patients who are paying entirely for their medications or even a co-pay. I also learned that in 2012 anemia medications will be affected and that patient should be aware of their hemoglobin (HGB) lab values and certainly let your clinic or doctor know if you are feeling tired or anemic.

The final session I attended was on Social Security and a benefit they offer called “Ticket to Work.” If you are receiving Social Security Disability (SSDI) or Social Security (SSI) and want to return to work, be sure to talk to your local Vocational Rehab office and they will work individually with you to meet your return to work goals. They have great incentives and programs to assist your in returning to work while on dialysis. For more information on your local office, visit <http://www.ssa.gov/work>.

Continued from page 6

Lastly I would just like to say that this was a wonderful opportunity that I would not have been afforded without a nomination from my social worker and the great people at The Renal Network that made this opportunity available.

I hope this information I have shared has helped you in your journey with kidney disease and if you ever get the opportunity to attend one of these conferences I cannot stress enough the importance of all the information I received, not to mention the wonderful people I was able to meet: doctors, nurses and the families affected by kidney disease.

## **The Patient Leadership Committee**

The Renal Network has a Patient Leadership Committee (PLC) that acts as an advisory group to the Patient Services Department. This group gives ideas for patient education, shares their opinions, and discusses issues such as not coming to treatment and how to help patients and staff work together. This group of volunteers is made up of patients and staff in Indiana, Ohio, Kentucky, and Illinois. There are two meetings a year and conference calls by phone as needed.

If you are interested in learning more about becoming a member of this group, please visit the Network Web site at <http://www.therenalnetwork.org/about/patientlead.php>.

## **National Kidney Foundation Peer Support Program**

The PEERS Program is a national, telephone-based peer support program from the National Kidney Foundation that connects people who want support with someone who has been there.

Participants call a toll-free, automated telephone system to connect to each other. They do not disclose personal phone numbers or incur long-distance charges. If you are interested in becoming a mentor or in receiving support please call 855-653-7337 or email National Kidney Foundation at [nkfpeers@kidney.org](mailto:nkfpeers@kidney.org). Please also visit the National Kidney Foundation website for access to educational resources at [www.nkfcares.org](http://www.nkfcares.org).

### **Remembering A Patient Advocate**

The Renal Network, Inc. mourns the death of John Newmann, a patient advocate and national champion for quality treatment and care for all kidney patients. John Newmann was a positive force, a role-model and inspiration for all members of the ESRD community – patients, family members, renal professionals and staff alike.

# RENAL OUTREACH

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## The Robert Felter Memorial Award Winners

The Renal Network, Inc. is pleased to announce that the Robert Felter Memorial Award winners are Julie Boatwright, from Network 9, and Jim McFarlin, from Network 10.

The Award was established in 2002 to honor Robert Lee Felter, a man who was a mentor, leader, and advocate for dialysis and transplant patients. Each year, interested patients are encouraged to complete an application that focuses on "their unique story;" how they adjusted to living with kidney disease, and what they have done to help other patients diagnosed with chronic kidney disease. The winners are awarded the prize of attendance at a kidney-related conference of their choice.

The Renal Network provides funds for registration, hotel accommodations, travel expenses and miscellaneous costs associated with attending the conference. The award winner is then asked to share his or her experiences in an article for the ***Renal Outreach***.

Both Award winners chose to attend the August, 2011, American Association of Kidney Patients conference in Little Rock, Arkansas as their prize. Read Julie Boatwright's article starting on page 5 in this issue. We look forward to learning about Jim McFarlin's experiences in a future issue of the ***Renal Outreach***.

The Renal Network wishes to express its thanks to all of the Robert Felter Memorial Award applicants for their courage and positive attitude and for their ongoing efforts to reach out to their fellow patients.

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