



RENAL OUTREACH

ESRD Network 9/10

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Need Some PEPP?

Martinlow Spaulding (pictured above left) is a long-time patient volunteer with The Renal Network, Inc. (TRN). He has *Some PEPP* and then some.

Currently he is a member of TRN's Medical Review Board (MRB) and its Patient Leadership Committee (PLC). He has been a member of the national RISE rehabilitation pilot program and is a trained volunteer in TRN's Patient-to-Patient program where he meets with newly diagnosed Chronic Kidney Disease (CKD) patients. Martinlow was the first recipient of The Renal Network's Robert Felter Memorial Award for Patient Service. And you can see why - service to patients is his middle name.

Martinlow has been a CKD patient since 1992. He has been on peritoneal dialysis and has received two kidney transplants, first in 1993 and the second in 2004, both from his siblings. He is married to Elaine, a renal/oncology RN and they have six children.

Martinlow is also a speaker with the Renal Support Network's (RSN) Patients Educating Patients and Professionals (PEPP) program out of California.

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Robert Felter Award



From June 23rd to June 25th of this year I was in Washington, D. C. to participate in the 17th annual conference on PKD. I (Barb Gronefeld, pictured above right) was able to attend this conference because I received the Bob Felter award for patients. And what a wonderful award this was!

I was thrilled to be able to meet with other people like myself who have polycystic kidney disease: Many of them have a family history of this disease but some do not, as this disease can be the result of a mutation of the genes. Some were just beginning to learn the implications of this disease and some had transplants like I did.

Among other things, we learned that PKD is the most common of all life-threatening diseases that are genetic. It affects 600,000 Americans alone and 12.5 million adults and children worldwide.

The name "polycystic" means that there are many cysts on the kidney. Diagnosis of PKD is done with ultrasound, magnetic resonance therapy (MRI) or computed tomography (CT) after age 30. Before then, it may require genetic testing.

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There are two hereditary forms: autosomal dominant (ADPKD) and autosomal recessive (ARPKD). ARPKD is relatively rare but it often causes children to die in the first year of life. People with ADPKD have a 50 percent chance of passing this disease on to each of their children.

More than half of those with PKD go into kidney failure by age 60. Dialysis and transplantation are the only available treatments for this disease at present, but there is ongoing research to find ways to stop the cysts from growing.

Some promising research in treating polycystic kidney disease includes:

1. Use of Tolvaptan. Phase III clinical trials are about to start. It has been considered safe in treatment of congestive heart failure and cirrhosis of the liver. It is now being evaluated as a possible way to stop or slow cyst growth in patients with PKD. The FDA has granted Tolvaptan designation as a "Fast Track" treatment for ADPKD.
2. "Halt PKD" Clinical Trials are beginning. These trials are trying to determine whether aggressive blood pressure control will slow the growth of the cysts by using a combination of blood pressure medications.
3. There is a possibility that the immunosuppressant drug Rapamycin (also called Sirolimus) will go into clinical trials to see if the drug is effective on PKD. We know that this drug helps prevent rejection of a newly transplanted kidney by blocking cell growth. Rapamycin has been found to shrink the patient's polycystic kidneys (after a kidney transplant) by about 25 percent over two years.

4. Scientists have found a genetic source that could lead to treatments for PKD. They have found that kidney cells have small cilia in them which send signals to the tubules. Losing cilia function leads to PKD because the cell tubules think that there is an injury that they have to repair and they do this by forming many cysts. To find out more about these clinical trials, go to **www.pkdcure.org/clinicaltrials**.

So as you see it is an exciting time for people who have PKD. I am hoping that the seriousness of this disease will be eliminated in my lifetime, so that my children and grandchildren will not have to suffer its devastating effects.

Most of the money that the Polycystic Kidney Foundation receives goes to research. It was the hope of the organizers of this conference that by having it in Washington, D. C. it would make Congressmen more aware of the disease and the need for further research to halt this disease.

The conference was well organized with the names of the people attending, the presenters and their affiliations, copious notes and information, definitions of common terms, not to mention the many opportunities to ask questions and meet with the presenters and other attendees at the conference. There were two tracks: one for ARPKD and one for ADPKD. The tracks contained personal stories, the basics, transplantation, nutrition, controlling high blood pressure, and insurance issues. To find out more about PKD, the Web site is **www.pkdcure.org**.

Next year the conference will be in Orlando, Florida. My brother, who has polycystic kidney disease and also has a kidney transplant, is planning to attend. Thank you again for allowing me this very special opportunity.

It was all in the SMILE!

(A successful rehabilitation story from a facility in Chicago, Illinois and submitted by a Patient Leadership Committee member.)

Another successful intervention by a group of healthcare providers, who found the right resources, brought a more productive future for a young man named RT with “the cutest smile!”

When RT was first admitted to the unit, he was wheelchair bound with scoliosis. During a multidisciplinary care conference, one team member casually mentioned that RT had “the cutest smile” (an international mode of non-verbal communications). His smile was his only way to communicate.

The social worker had documentation that stated that RT had been diagnosed with severe developmental disabilities in his native country. A meeting was called to discuss these issues with the family. RT’s family members were all non-English speaking. So a staff interpreter had to be present.

His family was happy to learn that there were opportunities for REHABILITATION in this country. Few services were available to RT in his native country. He was isolated there. This was one of the reasons his family moved here. Soon the mounting financial burdens forced the parents into long workdays and again RT was left in seclusion.

Fortunately for RT, he was brought to the attention of these particular caseworkers who worked diligently to re-evaluate him. Ultimately, the reassessment proved that this young man was only moderately retarded and definitely trainable.

The social worker placed him in day care where he works. He not only spends the entire day there but receives vocational training also. He speaks some basic English, is out of the wheelchair and walks with a cane despite cerebral palsy.

And, it all started with what was “the cutest smile” noticed by a health care provider and someone willing to find the right vocational rehabilitation resources!

(NOTE: Vocational rehabilitation strengthens and enriches the individual - in his/her work, social and family life. Talk to your social worker today about a vocational rehabilitation referral and evaluation.)

That’s The Ticket!



Wesley Crawford (*pictured above*), a dialysis patient from Toledo, Ohio, won tickets to the Final Four NCAA Championships in Indianapolis last spring. The tickets were donated to The Renal Network by a basketball fan who was unable to attend the championships and wanted to give them to a basketball-loving renal patient. The tickets were raffled during the 2006 Nephrology Conference.



Audrey Chengelis, Member
Patient Leadership Committee

Is There a New Normal?

Suddenly one day, as a spouse of a “soon to be dialysis patient,” I found myself deep in a world of many unknowns, frightening decisions to be made, and a husband who had decided that when he was released from the hospital, he would just leave dialysis behind!

While I tried to grasp the facts, I realized that our “normals” in everyday life had just been drastically changed forever. Chris continued to ignore the fact that dialysis for him was a lifetime diagnosis. The doctors had spoken; he wasn’t listening.

Mind you, we are talking about a retired naval commander, test pilot and successful business man. There he sat in his hospital bed clicking from one TV channel to another not facing the important fact that his kidneys were no longer functioning properly.

The nephrologists and vascular surgeon discussed the placement for dialysis access. When they announced that surgery was in two days, he tuned in with “what surgery?”

Well, Chris, as most of us, never really thought about his kidneys, what they were, and how they functioned. The doctors simplified their explanation... the kidneys were a pair of glandular organs that removed waste products from the blood and secreted urine. Chris was still missing the importance of his diagnosis. Given the life that he had lived for 84 years, he announced to the doctors that he would think about dialysis. He knew the basics. He was going to the bathroom and eliminating fluids.

He wasn’t certain about eliminating waste products.

He assured the doctors that I, his wife, would carefully monitor things and he didn’t need dialysis! And, okay he said, he would limit his fluid intake to 48oz or six cups a day. Just tell Audrey and we’ll get things organized before our next doctor’s appointment.

As the doctors continued talking he became more agitated as well as more puzzled by the news that he would be connected to a machine which would now take over functioning for his one remaining kidney. Eight years ago he lost one kidney to cancer.

The discussion went on. The doctors decided that he would not be eligible for a fistula now because his vascular system was so compromised. The lights began to go on. Chris realized that his vascular access was one of many things to come over which he could exercise only a limited choice. Until now, Chris had called all the shots. Now, he listened as others determined what would be best for his survival. There was NO CURE for his problem – only ever changing plans of medical treatment and challenges that his body would react to each day.

Our journey began.

And, as I listened to all these new and varied do and don’t rules, I realized that Chris wouldn’t acknowledge them. I would need to be the one to implement them, to make his new life as a renal patient as successful as possible.

Obviously, it would be up to me to create a new “normal.”

Without question, compliance is the biggest obstacle a patient faces. It’s not an easy sell to anyone on the verge of dialysis. Not only

Is There a New Normal?(cont'd)

do you need to change your lifestyle but your attitude and food intake. There are physical, psychological, social, sanitary and culinary problems. These do not come one at a time: They're a package deal.

I, too, was relatively ignorant. I was certain that if I followed all the rules, everything would be fine. WRONG! Very quickly I learned that as I solved one problem, three more waited my attention. And, Chris still believed somehow this would all go away and what didn't go away, I could certainly handle.

As a caretaker of a dialysis patient, I urge you to understand that you will have many periods when you feel ignorant and lost. But, as you begin this journey you find many resources, helpful staff and other patients willing to share. Our renal experience lasted five years – and the trip was never smooth. Sometimes it was really, really rocky. But, always remember that patients/caretakers can overcome problems with help.

Don't be afraid to talk to the facility's social worker, your clergy, and trusted, supportive friends.

Is There a New Normal?

This is the first in a series of articles to be written from a caregiver's point of view. Each article will focus on one part of the journey that patients and their family members must face as they cope with the challenges of chronic kidney disease. We are interested in hearing your reactions and responses. Send us your story. Give us your suggestions about topics for the future. Contact Network social worker, Kalisha Nance, with your comments or suggestions (Email: knance@nw10.esrd.net or mail or fax comments using the Network's contact information on the back of the newsletter.)

A Patient Viewpoint



My name is Michael France (*pictured above*). I am a 28-year-old male on hemodialysis at the Muncie, Indiana Outpatient Dialysis Unit. In August of 2005 I started hemodialysis after being diagnosed with kidney failure and having a catheter placed.

There were several concerns related to the catheter use: family, work and hygiene. I am married with an active two-year-old son. While playing with my son I was constantly concerned about the catheter being pulled out.

My doctor advised me not to work with the catheter in place, due to risk for infection and dislocation. Being a mechanic, my work environment is not clean and my arms are frequently over my head. Hygiene was a major concern since showering is not permitted with a catheter.

A fistula was placed in September and cannulation started in December. Initially, I had some concerns about the pain and discomfort with the needle sticks, etc. However, use of the *Emla* cream relieved most of the pain.

The fistula is more convenient, less stressful, and safer. I would recommend a fistula to anyone needing to start hemodialysis or currently receiving hemodialysis treatment.

Patients Voice Concerns to The Renal Network

Patients can call, write, or email The Renal Network if they have concerns about their care at their dialysis or transplant center.

Although patients are encouraged to try to resolve their concerns with the facility staff first, they may contact the Network if they do not think the issue was resolved well or if they are uncomfortable discussing their concern with the facility.

The main reasons people contacted the Network during the first nine months of 2006 involved quality of care concerns and staff relationships. The Network staff can assist patients with their concerns and can help them find accurate information as well as coach them on ways to meet with the staff to discuss their needs.

The Network also can intervene and help resolve issues between the patient and the facility.

In addition, the Network can refer patients to other resources that can assist them, such as the Department of Health, if there are concerns regarding issues such as cleanliness or adequate staffing.

Patients also contacted the Network when they were involuntarily discharged from a facility. The federal guidelines state that patients “are transferred or discharged only for medical reasons or for the patient’s welfare or that of other patients, or for nonpayment of fees (except as prohibited by title XVIII of the Social Security Act) and are given advance notice to ensure orderly transfer or discharge.”

Patients also contacted the Network when they were unable to find a dialysis facility to accept them. Although the Network cannot make any facility accept a patient, the Network can make suggestions and can provide a list of facilities in the area.

Dialysis Facility Compare (DFC), which is a Medicare internet site (www.medicare.gov/dialysis), also provides facility information, including where facilities are located, hours of operation, type of treatment provided, and compares the quality of services provided at facilities, to the extent it can.

The Network is available to assist patients with many types of concerns and complaints and helps to locate the resources that patients or caregivers may need. The Network also provides free educational resources and has created a patient-focused Web site at www.kidneypatientnews.org. The Network’s contact information is available on the back of the newsletter.

To Manage Conflict:

Address concerns regarding treatment or quality of care with the facility staff as soon as they happen. Bottled-up anger or frustration can lead to words, actions, or behaviors that may cause others to be afraid and may affect the welfare of others at the unit.

When bringing concerns to staff, present them as clearly and objectively as possible. Issues have a better chance of being resolved if approached in a calm manner, are stated specifically, and include all parties involved.

Stay positive. Yelling or pointing fingers at people, does not produce productive results or change. Remember YELLING, HITTING, SLAPPING, OR SHOVING are some of the behaviors most likely to cause a patient to be discharged from a facility - regardless of the original issue.

Need Some PEPP? (cont'd)

PEPP is a series of educational programs led by patient-speakers who have been specifically trained to present these programs at meetings of renal patients and healthcare professionals.

The PEPP program, which is funded by Amgen, has three educational talks available for patient and professional meetings. The program topics are:

1. Energize Yourself: What you need to know about anemia
2. Your Achy Breaky Heart: What you need to know about Secondary Hyperparathyroidism (HPT)
3. Promoting Patient Participation in the Dialysis Setting

Thanks to Amgen, the RSN PEPP program is available at no cost to the participant or hosting organization. TRN is collaborating with RSN to make these educational programs available in TRN's four-state area (Illinois, Indiana, Kentucky and Ohio). For more information about RSN and the PEPP program go to www.RSNhope.org.

Everyone needs a little PEPP every now and then.

PEPP Program in Indianapolis

“Energize Yourself: What you need to know about anemia.”

Speaker: Martinlow Spaulding

Date: December 4 or 5th.

Time: 10:00am to 2:00pm
(lunch included)

Location: Executive Offices Park North
911 E. 86th Street
Suite 40 (Lower Level)
Indianapolis, IN 46240

Register by: November 22nd
(Registration is free.)

To register for the program call 317-257-8265 and ask for Katie (outside of Indianapolis call 1-800-456-6919).

If you are interested in hosting a PEPP program, ask your Social Worker to call Kalisha Nance with TRN Patient Services at (317) 257-8265.

New Resource For Patients

Taking Control: Money Matters for People with Chronic Kidney Disease was published in 2005 by the National Endowment for Financial Education and the National Kidney Foundation. People affected by CKD and their family members encounter many financial challenges associated with having a chronic illness. This booklet is designed to provide individuals with stage 5 CKD (dialysis and transplant) the information they need to help them negotiate financial matters, such as paying for treatment for kidney failure, understanding what Medicare pays for, employer group health plans, prescription drug coverage and other relevant money matters. You can obtain a copy of it by calling 1-800-622-9010 or get it online at www.kidney.org/patients/pfc/control.cfm.

Protect Yourself and Other Patients from the FLU!

Talk to your doctor today about getting a flu shot.



Because influenza can result in serious illness for people with chronic kidney disease, kidney patients are recommended to get a flu shot. Influenza is a contagious disease. When a person with influenza sneezes, coughs, or even talks, the influenza virus is released into the air and may be inhaled by anyone close by. By getting a flu shot, kidney patients protect not only themselves but other patients and dialysis center staff from possible virus infection.

It takes about two weeks after vaccination for antibodies to develop and provide protection against influenza virus infection. So it's important to get your flu shot early. Also it's necessary to get a flu shot every year because flu viruses are always changing. Each year the shot is updated for the most current flu viruses. People with kidney disease are not recommended to receive the live influenza vaccine known as "FluMist" which is approved for healthy people between the ages of five and 49.

The best time for flu vaccination is October and November; Centers for Disease Control (CDC) recommends the vaccine be offered throughout the flu season, which does not peak until February or later.

So don't delay; call for an appointment today!

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