



# RENAL OUTREACH

*ESRD Network 9/10*

*Winter 2005/Vol. XV, No.1*

## Robert Felter Memorial Award



My name is Tracee Bauer (Patient Leadership Committee member, pictured left) and I was chosen to be the 2004 patient recipient of the Robert Felter Memorial Award.

When I was given this news, I felt very honored. This allowed me to attend this year's national conference for Polycystic Kidney Disease (PKD), which is genetic and more common than people realize. It has also been a part of my life for more than fourteen years.

PKD causes cysts to form, grow and multiply in the kidneys until they take over the healthy tissue, then they continue to do so until the kidneys can reach the size of footballs and take over the abdomen. But thanks to the PKD Foundation, research has made many amazing discoveries and there is hope that one day a cure may be won.

The conference was held in Washington D.C., which was an added bonus for me because I had never been there. The purpose for holding the conference in the Nation's capital was to be able to meet with our congressional representatives to make them more aware of PKD and the need for more research.

*Continued on page 2*

## Meaningful Employment is Possible!

Leslie DeBaun  
Patient Leadership Committee,  
Board of Trustees

My diagnosis of renal disease was made only 3 months before I went into End Stage Renal Disease. Just 4 years prior to that diagnosis my husband and I had bought our dream home and had plans for helping our teenage and young adult children complete school.

Professionally, I was at the peak of my career both in income and national recognition. However, the company I worked for had been sold and during the months between my diagnosis and ESRD this newly re-invented "dotcom" was failing.

My adjustment to the illness and rapid decline kept me from seeking another job. As was expected, a week after starting on dialysis, my employer informed the staff we had one day of employment left. It was an extremely difficult time for our whole family.

The adjustments to living with chronic illness, an uncertain future, loss of income and new medical bills affected each of us profoundly. For the first six weeks I was depressed and did little more than focus on my illness and concern for family members. As I adjusted to my new life, the need for employment became a priority.

*Continued on page 3*

were a number of things I learned at the conference that I found quite exciting. For example:

1) There is now a genetic test to look for the actual gene for PKD in someone who is at risk. Before, the test could only search for genetic markers and required two or more family members who already had the disease. Once identified, then it was possible to look for these identical markers in the at-risk family member.

Now, even if there is only one member in the family with the disease, the test can identify the actual gene that is affected and then test to see if the at-risk member has that same exact gene.

This test can benefit my family because I am the only member in the family who has PKD. The only drawback is that the test is quite expensive and most insurance policies aren't covering it yet.

2) There is now an experimental kidney transplant program at John Hopkins University Hospital that holds a lot of promise. It will help patients who produce too many antibodies against foreign tissue to still be candidates for transplantation.

3) There is a study that will soon begin that will test a medicine that may slow down cyst production in patients who haven't lost the use of their kidney function yet. This study is called HALT.

You can find more information about PKD, research studies, and educational opportunities by visiting the web site [www.pkdcure.org](http://www.pkdcure.org).

During my free time I was able to see some of the sights, such as the Washington Cathedral, whose outside architecture is very impressive but the inside is breathtakingly beautiful.

I also saw most of the monuments when I went on a tour. While seen during the day, you can tell how beautiful and grand they are but when you see them at night, all lit up, their true beauty is revealed.

I had an enlightening and rewarding weekend which I thank The Renal Network and the Robert Felter Memorial Award for giving me the ability to go.

###

## A Note on the Robert Felter Memorial Award

Patients who participate on one of The Renal Network's committees (Patient Leadership Committee, Medical Review Board or Board of Trustees), can apply for the Robert Felter Memorial Award which is given each Spring. Nominations are accepted at the beginning of each year. Robert Felter was a long-term patient who advocated for patient education throughout much of his life.

Examples of upcoming conferences/ activities in 2005 for patients:

- May 25 & 26: The Renal Network's Annual Nephrology Conference (Indianapolis, IN)
- September 1 – 4: AAKP Annual Convention (Las Vegas, NV)
- September 29 – October 1: The Renal Support Network's National Patient Meeting (Chicago, IL)

###

I felt strongly that I had to help pay my medical costs and wanted to continue to help our children with education.

I applied for unemployment compensation and began the work of finding a job. The right job for me had to be close to home to allow me time to rest and time for dialysis. One job for which I interviewed, not only fit the criteria but was in an area for which I had achieved recognition and had references from some of the top people in the country.

I had always done well in interviews and was used to receiving positive feedback. However, I had decided to share with the potential employer that I was on dialysis and going to be on a transplant list.

Immediately after giving that information, I knew they did not want me. In fact, I felt they could not wait to get me out of the office. I would like to share that I bounced back after that interview, but I was feeling down and did not take any action for a few weeks. The medical bills kept coming. I felt insecure about approaching potential employers.

Because I knew of an employment agency in the area that took a personal interest in others, I made an appointment with them. In addition to taking the usual information for a job search, they recommended I speak with one of their temporary personnel people, Carole<sup>1</sup>.

Carole's good friend was on a transplant list; she understood the challenges of chronic illness. Carole arranged for a temporary job at a local hospital under the supervision of a nurse.

Through that temporary job I was able to demonstrate that I was a productive and valuable worker. The hospital hired me after

5 months of temp work. They sent me on two trips with other employees as I lugged my peritoneal dialysis machine through airports and set up my nightly regimen.

Accommodations were made during the time of my transplant surgery and healing process. It has not always been easy. To get time off for post-transplant clinic visits out-of-town I've worked 10 hour days for 4 days to get the 5<sup>th</sup> day off.

Our lifestyle has been simplified; no longer is it important to have "executive clothing" or a meal in a fancy restaurant. The trade-off is that I have more time at home and am closer to my family. I am in a new profession and am enjoying education towards certification in my new field.

<sup>1</sup> Fictitious name

###

## Dear Marci: A helpful Internet resource for Medicare

Dear Marci is a service of Medicare Rights Center (MRC) ([www.medicarerights.org](http://www.medicarerights.org)) an independent source for providing Medicare information and questions and answers.

Dear Marci also offers a free weekly newsletter for patients. To sign up, e-mail [DearMarci@medicarerights.org](mailto:DearMarci@medicarerights.org) with the words "subscribe consumer" in the subject line.

There is a new topic each month and there are links to other sites relating to the weekly topic if more information is desired. If you have a question for Marci, simply click on the appropriate link or e-mail your question.

###

---

# Health, Happiness and Hope

Kathy Kirk-Franklyn  
Patient Leadership Committee

From September 30<sup>th</sup> to October 3, 2004, I had the pleasure of attending the Renal Support Network Inaugural National Patient Meeting that was held in Denver, Colorado. This meeting was the first of its kind.

The Renal Support Network president, Lori Hartwell, outdid herself. This meeting was geared for patients and administration. The meeting consisted of 45-minute sessions. Everything ran smoothly, was straight to the point and was very informal. If you asked questions, you were given very supportive information and everything was geared to empower patients for health, happiness and hope.

When I arrived in Denver, I was greeted with much love. Everyone made me feel special. When I checked in at the hotel, I felt like I was a star. The hotel staff and setting was very unique. At the registration table, Ms. Hartwell seemed as if she knew me personally. Everything was well organized with special badges, nice bags and notebooks to aid with notes for every meeting.

On Thursday, I attended several workshops. The first one featured Sandra Wilson presenting the "Seven Secrets to Success" for dialysis patients. The next meeting I attended was "Know Your Life Line" which was about your access. We discussed the different types of access such as fistula, grafts, button-holes, ports, and catheter, as well as peritoneal dialysis and transplants.

It was great to see other people who live with other types of access besides fistulas

and catheters. I really liked the button-hole for myself personally.

The next meeting I attended was with the "Big Boys" from Centers for Medicare/Medicaid (CMS) which is the Federal agency charged with ESRD Medicare oversight. He talked about major changes in quality health care services for patients such as the AV fistula initiatives that are taking place nation-wide.

The most important meeting to me was the Mystery of the Dialysis Machine. We saw the first dialysis machine and met a man who used to dialyze on the first machine. The evolution of dialysis machines was fascinating to me. Thank God for new technology because I might not have made it on dialysis using the first machines.

I attended lots of meetings, each was unique and interesting. I learned quite a bit from each session. But the thing I enjoyed the most was meeting other patients from around the world and listening to them talk about dialysis and how they are taking care of their own healthcare. They are really educated about their bodies, medications, centers and health solutions. There are lots of materials out there and plenty of places that will help you learn to live successfully on dialysis.

I also had an opportunity to see Denver, but it was rainy so I did not go out much. We had a lovely dinner that was delicious. They also held raffles after each session with nice prizes donated by speakers and various organizations. We had lunches with the experts which allowed for personal time to ask questions one-on-one.

We also had a casino night that was great, but I lost all of my play money.

I wish that more patients would pay attention to articles, newsletters, and everything available to them at their dialysis centers and in particular take advantage of the educational materials that are out there for us.

I'd also like to thank Diane Wish and the CDC Staff for making it possible for me to attend this great meeting and letting me represent CDC patients at this level.

Listed below are some excellent educational resources on renal disease:

- The Renal Network (800-456-6919) [www.kidneypatientnews.org](http://www.kidneypatientnews.org)
- Renal Support Network (818-543-0896) [www.renalnetwork.org](http://www.renalnetwork.org)
- IKidney [www.iKidney.com](http://www.iKidney.com)
- Dialysis Patient's Health Guide [www.nephron.com/dialysishg.html](http://www.nephron.com/dialysishg.html)
- American Association of Kidney Patients (800-749-2257) [www.aakp.org](http://www.aakp.org)
- National Kidney Foundation of Illinois [www.nkfi.org](http://www.nkfi.org)
- National Kidney Foundation of Indiana [www.kidneyindiana.org](http://www.kidneyindiana.org)
- National Kidney Foundation of Kentucky [www.nkfk.org](http://www.nkfk.org)
- National Kidney Foundation of Ohio [www.nkfofohio.org](http://www.nkfofohio.org)
- Life Options Rehabilitation Program (800-468-7777) [www.lifeoptions.org](http://www.lifeoptions.org)
- Kidney School [www.kidneyschool.org](http://www.kidneyschool.org)
- TransWeb [www.transweb.org](http://www.transweb.org)

###

## The Choice of Dialysis at Home

When you learn that your kidneys are no longer working and that you have chronic renal failure, a number of decisions have to be made.

One major decision is choosing a treatment that is best for you. This choice is not necessarily forever. You may later choose the choice of transplant or if you are receiving incenter dialysis you may later choose to do home dialysis or vice versa.

It is important to talk to your doctor about your method of treatment and to discuss together the best option for you. There are advantages and disadvantages to each choice.

Although most people go to a dialysis center for treatment for kidney failure, home dialysis may be an option you want to explore.

According to Home Dialysis Central ([www.homedialysis.org](http://www.homedialysis.org)), the benefits of home dialysis include living longer, having a better quality of life, more convenience as to when treatment is done, and more control of your own care.

There are five different ways to do dialysis at home, and one of them might be a good fit for your lifestyle and needs—either right now, or in the future.

With new equipment and technology breakthroughs, it's easier than ever to get high quality dialysis at home.

---

## Number 11712

Debbie Shaffer

I would like to tell you a story about my friend, 11712. He is someone very special to me and has been my best friend and live in partner. A few years ago, I was introduced to 11712 and he is really a big part of my life now.

To some people they would think of him as a little strange in his looks and dress. I would really like to explain why. But before I go any further, I would like to tell you 11712 now has a name, it is George. I just couldn't go through life calling him 11712.

Anyway, George's body is odd shaped, and he wears the same shirt of gray and cream day and night. On the front of his shirt are three round buttons, one of green, one of red and one of blue. There are also two triangles of blue with white triangles in the middle. These triangles point, one up and one down. I suppose George is trying to start a new trend in men's clothing.

Anyway, we have about an hour at night before George goes to work and about the same in the mornings before George goes to bed. You see, George works nights and that is about all the time we can see each other.

One evening I asked George what he did at work. He explained he made soft sounds on his job. So, I asked George to show me, he began to puff softly, creak and squeak. He also has a pocket, which holds a cassette, this plays without music, I really was amazed. George has this amazing way to keep time. George told me his face glows green while making these sounds.

George has really been very helpful to me these past few years, and has given me much support in my illness.

I now have a problem and since George is such a special friend, I really don't know how to break the news to him. I must tell George our relationship, may have to end soon.

If things keep going the way they are, then George may have to move out soon. I'm sure George can find someone else that would make him happy and that he could make happy too.

George was born with a silver shield on his shirt that reads Serial Number 11712. If you haven't figured out who George is, he is George Dialysis Machine. If things go well and the tests are good, I will soon have a kidney transplant and I won't need George, 11712 as my nighttime companion. That's George's job at night, to cycle all night with soft sounds of creaking, squeaking and purring softly.

###

## Transplant Resources for Children

Resources for children with kidney disease to learn about transplantation:

***The Inside Story, A Kid's Guide to Kidney and Liver Transplants*** by Karen Crowe. Published in 2001 by Fujisawa Healthcare, Inc., it is available free from [www.fujisawa.com](http://www.fujisawa.com) or by calling (800) 727-7003, Option #4.

***Kids Kare***, an internet site developed by kids for kids about organ donation and transplantation. It includes a coloring book, scrap book, recipes, net pals, and other "cool" links at [www.kidskare.org](http://www.kidskare.org).

---

## Data Support Renagel Use in New Dialysis Patients

(News Release Dated: October 29, 2004)

Genzyme Corporation announced that investigators have new preliminary data supporting the use of Renagel (sevelamer hydrochloride) in patients who are new to hemodialysis. The data, drawn from the recently completed Renagel in New Dialysis (RIND) study, compare the clinical experiences of new dialysis patients on Renagel with those on calcium-based phosphate binders for a period of 18 months.

Investigators reported during a symposium at the American Society of Nephrology meeting in St. Louis that the RIND study data show a significant difference in the amount of coronary artery calcification over 18 months -between patients using calcium-based phosphate binders and those using Renagel. Results show that the artery calcification scores were significantly greater in the calcium-based phosphate binder group than in the Renagel group.

The RIND data also show that patients using both types of phosphate binders were able to achieve target levels for phosphorus and calcium-phosphorus product as outlined in the National Kidney Foundation's Kidney Disease Outcomes Quality Initiative (K/DOQI) guidelines.

Genzyme, through the **Renagel REACH Program**, is partnering with many of the Medicare-approved Drug Discount Cards to offer Renagel at a reduced rate. Patients must sign up for a participating Medicare-approved Drug Discount Card to be eligible.

To find out which cards offer the Renagel discount, talk to your Social worker or call

the Renagel REACH Program toll-free at (800) 847-0069 for more information.

Genzyme also supports the **Renagel Patient Assistance Program (RPAP)** which helps qualified dialysis patients obtain a free, six-month supply of Renagel product each year. RPAP is administered by the American Kidney Fund.

For application materials or more information about the Renagel Patient Assistance Program, contact the American Kidney Fund's RPAP Department at (800) 638-8299, ext. 1773 or visit [www.kidneyfund.org](http://www.kidneyfund.org). To learn more about Renagel ask your healthcare staff or visit [www.renagel.com](http://www.renagel.com).

###

## A Note on Binders

Different binders bind different amounts of phosphorus. The most widely used binders include Renagel and PhosLo. They are very different. Renagel is a calcium-free and aluminum-free binder and PhosLo is a calcium acetate-based binder.

If you are taking a calcium-based binder you can substitute over the counter Tums until you get your prescription filled. This is not recommended if you have been prescribed Renagel because of the risk of developing high calcium levels. Always check with your nephrologist and renal dietitian before making any substitutions on your binders.

Aside from taking binders, phosphorus can be controlled by watching what you eat. AAKP's "Na-K-Phos Counter" is a 14-page pocket-size brochure that provides the amounts of sodium (Na), potassium (K) and phosphorus (Phos) in the standard sizes of various types of food. Available in both English and Spanish, this brochure provides an excellent guide for dialysis patients ([www.aakp.org](http://www.aakp.org)).

###

The five types of home dialysis are:

- CAPD – Four manual exchanges of peritoneal dialysis fluid everyday
- CCPD (APD) – A form of peritoneal dialysis using a cycler machine nightly
- Conventional home hemodialysis – Three times a week hemodialysis, 3-4 hours at home
- Daily home hemodialysis – Short (2-3 hour) treatments
- Nocturnal home hemodialysis – Nightly 6-8 hour treatments

The Network's patient Web site ([www.kidneypatientnews.org](http://www.kidneypatientnews.org)) has linked to Lynchburg Nephrology Web site which created a series of video clips featuring patients responding to questions about their experiences on the nightly home hemodialysis program.

You can go to Dialysis Facility Compare (a link can be found on the CMS home page at [www.medicare.gov](http://www.medicare.gov)) and compare the different treatment options and services found at local dialysis facilities.

You also may want to review the Network's material on treatment choices at [www.kidneypatientnews.org](http://www.kidneypatientnews.org). Also be sure to ask your dialysis team for more information on each of the choices and what is best for you.

If you are considering home dialysis, keep in mind the following:

- It isn't the answer for everyone.
- It requires, among other things, a suitable place in the home for setting up the equipment.
- It requires that someone be comfortable working with technology and troubleshooting problems.

There's a lot to consider and prepare for when doing home dialysis.

- Do your research.
- Ask lots of questions.
- And find out what is covered under Medicare and/or your personal insurance.

###

---

## RENAL OUTREACH

**Address Service Requested**

**The Renal Network, Inc**  
911 E. 86th Street, Suite 202  
Indianapolis, IN 46240  
Phone: 317-257-8265  
Patient line: 800-456-6919

**Jay Wish, M.D.**, President  
**Susan A. Stark**, Executive Director  
**Kathi Niccum, Ed.D.**, Editor  
Patient Services Director

**Patient Web site:** [www.kidneypatientnews.org](http://www.kidneypatientnews.org)  
**Email:** [info@nw10.esrd.net](mailto:info@nw10.esrd.net)

Non Profit Org. U.S. Postage <b>PAID</b> Indianapolis, IN Permit No. 8606
---