



RENAL OUTREACH

ESRD Network 9/10

Summer 2004/Vol XIV, No.3

Robert Felter Memorial Award Winner

This year's patient award winner is Tracee Bauer of Wadsworth, Ohio.

Tracee is a newly appointed member to the Network's Patient Leadership Committee. She has been a kidney patient for 13 years. Tracee started on peritoneal dialysis and then had a transplant for 6 years. Currently she is on hemodialysis at the Greater Akron Dialysis Center.

In 1991, Tracee was trained as a Patient-to-Patient Volunteer and likes to do peer support as well as volunteer in her local community as a make-up artist in a dinner theater group and as an officer in a local chapter of the fraternal and service organization, *Women of the Moose*.

Maintaining her goals and independence are very important to Tracee, so much so, that she finished college while on dialysis.

Tracee is very interested in helping other patients learn about new issues, trends and accomplishments in the renal field.

As the recipient of this award, Tracee will attend the PKD Foundation's Annual Conference in Washington, DC in June.

Tracee is a single parent with a 14-year old son named Ian.

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Achieving in Life

By Barbara Gronefeld

In September of 1999, I started feeling awful. I couldn't even stand the smell of food cooking on the stove, especially vegetables and fish, and I had to walk to the other end of our house whenever my husband cooked food. I felt nauseated a lot.

I was (and still am) lucky that he likes to cook and was willing to take over this job. I slept a lot and was still tired, and I was very cold—probably for the first time in my life. I thought I was going crazy, but my husband feared that I was going into kidney failure.

Our cat, *Face*, had exhibited some of these same symptoms (such as the nausea) the summer before, and she had take Epogen shots and had also experienced kidney failure, which she eventually died of.

In January of 2000, I couldn't even lift my purse or my preschool things, and when I tried to walk into preschool, I was so short of breath that I had to keep stopping and resting. The other teachers were very helpful and carried my things for me. Soon I was put on Epogen shots and I started to feel a lot less tired.

In June of 2000, my worst fears came true. I had to go on hemodialysis. My father had been on dialysis for seven years. He suffered from the same disease I have: polycystic kidney disease.

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Achieving in Life cont'd

Hemodialysis did not work very well for me, and in August Dr. Premanandan, my nephrologist, told me about peritoneal dialysis. After some initial training sessions, I was able to do this successfully for two and a half years.

I felt very well on this type of dialysis. I could give myself the treatments at home and at times to match my busy schedule. I was (and still am) teaching preschool, and I could schedule my dialysis around this and also do the peritoneal treatments while I was watching my grandson, William.

My husband offered to be tested to see if he could donate his kidney to me (he is the same blood type I am) but he didn't pass one of the tests and they would not let him be a donor. It meant a lot to me that he was willing to go through all of the tests for me and even give me his kidney to make my life better.

Dialysis had always been like work to me whereas teaching preschool was my fun. Teaching helped me get through a lot of difficult times, and kept me from focusing so much on myself and on my health problems.

In January of this year I got very sick with diverticulitis and peritonitis, and I had surgery to remove part of my colon. I was no longer able to do peritoneal dialysis and I had to switch to hemodialysis. I didn't feel very well on hemodialysis and my nephrologist suggested that I should make an appointment with my surgeon to see if I could go back on peritoneal dialysis.

It was during this time that I found out that I was chosen as teacher of the year by the Dayton Association for the Education of Young Children. Some of the teachers at the preschool where I work had nominated me for this honor. I was both shocked and surprised to receive this award.

Before I could see the surgeon about going back on peritoneal dialysis, I got the call I was waiting for: A cadaver kidney was available for me. When I received the kidney transplant I was euphoric: No more dialysis, no more foods tasting bad, no more nausea.

Although I have had to work through some side effects of the transplant and the ensuing medication—diarrhea, high cholesterol, blurred vision, hair loss, diabetes, and the beginning of cataracts, I am still thrilled to have my new kidney. It has given me a more normal life. I can walk more, and I am back at preschool, doing what I love best: teaching. Foods finally taste good to me—maybe too good.

I appreciate all the support my family and friends have given me, and all that life has to offer me. I realize that I may still have some hurdles to get over, but I feel confident that I will be able to do almost anything that I set my mind to do.

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Starting a Patient Group

Many facilities have offered patient support groups only to find that very few people attend.

If you would like your facility to start offering support group meetings, you may want to talk to your social worker or head nurse and express an interest in helping to get patient meetings started.

These meetings can be fun, informative, and provide a means for more communication between staff and patients.

The article on page 4 shares the the story of one facility that started a patient group and how it helped to bring the unit together.

Medicare Prescription Discount Card Program

Health and Human Services announced that older and disabled Americans receiving Medicare benefits, including End-Stage Renal Disease (ESRD) patients, would be eligible for the Medicare Prescription Drug Discount Card Program beginning in May 2004. This is a voluntary program.

Some of the drugs that are expected to be covered by the discount card programs include:

- Anti-infective agents, including hepatitis
- Cardiovascular therapy agents (calcium channel blockers, diuretics, and angiotensin converting enzyme (ACE) inhibitors)
- Antidepressants
- Estrogens
- Diabetic therapy
- Immunosuppressive agents
- Impotence agents

Make sure you get all of the facts. Cards will vary, offering discounts on only certain drugs or using only specific pharmacies. It is important to compare programs for what drugs they cover, what discount they will provide and how much they will cost. If you have a limited income and you do not have drug coverage, you may be eligible for a credit up to \$600 on the Medicare-approved drug discount card.

Check other programs. If you are currently receiving medications under an existing pharmaceutical patient services program, check to see how these companies are planning to coordinate their services with Medicare-approved drug discount card programs. Also check other programs or agencies for help with prescriptions (e.g. Veterans Association).

Choose wisely. Once you chose a program, you will not be able to change to another Medicare-approved drug discount card until 2005 (applications to change programs must be submitted from mid-November to end of December 2004).

A list of Medicare-endorsed cards is now available at <http://www.medicare.gov/AssistancePrograms/home.asp?>

To learn more about the drug discount cards CMS has several publications available. Call 1-800-MEDICARE to order a copy or use the Web addresses provided to access these booklets online.

- **Introducing Medicare-Approved Drug Discount Cards - 11060** This brochure gives a brief introductory overview of the new Medicare-approved drug discount cards and \$600 credit. (4 pages)
<http://www.medicare.gov/Publications/Pubs/pdf/11060.pdf>
- **Medicare-Approved Drug Discount Card Tip Sheet - 11071** This tip sheet provides guidance for counselors, caregivers, and intermediaries who help people with Medicare compare and choose drug discount cards. (2 pages)
<http://www.medicare.gov/Publications/Pubs/pdf/11071.pdf>
- **Guide to Choosing a Medicare-Approved Drug Discount Card - 11062** This booklet provides information about the new Medicare-approved drug discount cards including who can get a card, how they work, and how to choose the best card for you. (36 pages)
<http://www.medicare.gov/Publications/Pubs/pdf/11062.pdf>

Patient Advocacy Groups: They Really Do Work

Patient advocate groups really work! By facilitating communication between patients and the management team, a much more positive culture can be achieved in the dialysis clinic. Compliance with the rules of the clinic can, in turn, be fostered. Patients are more willing to “buy in” to the company’s policies when they are allowed some input.

At one facility in which I worked, I observed a group of patients who formed a patient advocate group themselves. They planned parties and social activities for the patients at their facility thus relieving the staff of doing all of the planning. Whether the intention was to provide a 4th of July cookout or a Thanksgiving Day dinner, the patients came out of it with so much more. The patient advocate group meetings also provided an opportunity for the patients to receive new educational materials and to address problems that were occurring in the clinic. It seemed it could be done in a positive, friendly manner.

Upon my transfer to another facility, I met with staff and patients who were insecure with the change in management. They reacted to the change in different ways (some more subtle than others). Some patients were very positive and supportive, while others were not so sure. No one was more unsure than a young man who had transferred into this clinic (after having been asked to leave other clinics in the area). He greeted me in a very positive manner, but began talking negatively with other patients regarding recent changes. As we began to enforce policies in the unit, he began to have informal “meetings” in the lobby.

He complained, (and the other patients listened), as he had a captive audience.

In order to promote the patients’ confidence and security with me as a manager, I tried to let them get to know me. I worked on the floor as a staff nurse, and spent time talking with each patient and their family. I tried to become a “fixture.” I was hoping they would all just get use to my existence, and with the support of my staff, would get used to me being in charge. While we were enforcing company policies, the patients were acting like I was doing something new. They felt they had never heard of these policies before, with one patient fueling the dissention of many.

The disgruntled patient asked the social worker for a copy of our company’s grievance policy and procedure. The social worker talked at length with him regarding recent changes, and offered him a copy of the Network’s *Policy & Procedure for Complaints and Grievances*. The Network’s grievance packet which can be used to file a grievance is available on their patient Web site (www.kidneypatientnews.org).

I discussed with the patient the procedure for notifying the Network of any problems that could not be resolved within our clinic. In addition he was given another of our Company Policy & Procedure for Grievances along with Patient Rights and Responsibilities that the social worker reviewed with him. Different staff members tried to talk with him about his concerns but overall he seemed unhappy.

This patient did not like our facility’s food and drink policy and he continued to eat and drink while on dialysis. Again we tried talking to him and again, it didn’t seem to have made a difference. The patient was frustrated with us and we were frustrated with him. At this point we needed to try another approach.

Patient Advocacy cont'd

He was asked to attend a meeting to discuss what was happening. Since he agreed to have a meeting, I suggested he set up a "Patient Advocate Meeting" and include all the patients in the unit. He set the date and time. I made invitations and typed the agenda (which was reviewed and approved by this patient). He invited all the patients. The general patient response seemed very negative, until an hour before the meeting. I did not know if anyone would show up.

Kathi Niccum, Ed.D., the Director of Patient Services for Network 9/10, called me just before the meeting was to occur, and I reviewed everything I had done in order to resolve the problems with the patient. She was very encouraging, and offered me suggestions for the meeting. By the meeting time, (to my amazed surprise), a roomful of patients and family members had gathered.

I passed out the agenda, and explained the purpose of establishing a patient advocate group. I told them I was only there to help them get started. I mentioned the social worker and dietician would be at the next meeting, and they were free to invite anyone else they wanted to. I offered to help in any way they chose, but I would basically let them run the show. I then introduced the patient who had caused this meeting to come about, and allowed him to speak.

To my surprise, he was extremely positive as he spoke of his intentions for the group and upcoming meetings. He wanted to use the meetings as a forum in which to make suggestions for improvement to the facility and for educational and support purposes. The patients all interacted and made several very positive suggestions, which ranged from getting a game table, to getting a suggestion box and an electric door opener for the front door.

They discussed diet and where to get replacements for discontinued dietary supplements. They brought up the policy regarding drinks and one patient proposed they limit their drinks to one drink while on the machine. The group voted to restrict the amount of the drink to 6 ounces. They thanked me for causing them to think about doing something they should have done for themselves. They decided to meet at least quarterly and planned to have fun activities as well as just serious meetings.

The biggest surprise to me is the positive and drastic change in the behavior of the patient who started all of this. The disruptive patient is now the patient advocate leader. He has stopped complaining and speaks to all the other patients in a positive, encouraging way. He offers to present any of their suggestions or concerns at the next meeting, and has been distributing Internet information to the patients, in order to form a local patient support group online. He is in the process of forming his own Web site. There is no more complaining. The patients on the whole are content, and most follow their own fluid restrictions while on dialysis.

It is my opinion that patient advocate groups are an extremely valuable tool to be used in providing patient care. It helps the patient feel more a part of something important. It helps him/her to feel that he/she matters. It creates the feeling that his/her influence is felt by other patients – and by the company where he/she dialyzes. It causes him/her to behave in a more responsible manner, as he/she knows that others are looking to him for guidance. From what I have experienced first hand, "Patient Advocate Groups Really Do Work!"

This article was submitted by a nurse manager in a Network facility. Identification has been removed to protect confidentiality.

Vascular Access - Making Your Lifeline Choice

A kidney patient's choice of vascular access is one of the most important choices he or she will make while on dialysis. More and more evidence has emerged that the AV fistula is the most effective and complication free access choice. Yet data shows that not all patients who could benefit from an AV fistula have chosen this access option.

Please help us to understand why you do not have an AV fistula by taking a few moment to complete the following form and returning it to: **Patient Services, The Renal Network, Inc., 911 E. 86th Street, Indianapolis, IN 46240 or Fax to 317-257-8291.**

Has your nephrologist/staff talked to you about having an AV fistula placement? (Please circle your answer.) Yes No

Have you ever refused AV fistula placement? (Please circle your answer.) Yes No

If you have refused AV fistula placement, what factors affected your decision to refuse an AV fistula placement? (Please check all that apply.).

Afraid of the big needles

I'm too old

Potential fistula problems – like excessive bleeding after treatment

Don't trust staff to stick me

Don't want another surgery

Don't have time to stay and hold site after treatment

Can get on/off treatment easily with catheter

Doctor told me I can't have one because (please specify)

My access is my choice

Scared of pain

Patients with fistula don't recommend it

Won't make a big difference in my outcomes, numbers

Staff hasn't encouraged it

Catheter is less noticeable

Other (please explain) _____

AV fistula takes too much care

Catheter is easier to maintain

Don't know enough about AV fistula to make a decision

Don't want a scar

Don't want to be stuck

Generally afraid of having any surgery

Know patients with AV fistulas that have problems

Not experiencing a problem with my (please specify)

PD is my treatment choice

Tried AV fistula but it didn't work

Want to wait until it is necessary

On the transplant list – dialysis is temporary

Afraid of blood, bleeding

Don't like the way fistula looks

Diabetic Retinopathy

Diabetic retinopathy is one of the complications of diabetes. There are no early warning signals for diabetic retinopathy. Having a comprehensive dilated eye exam at least once a year is the best way to identify problems before they become too severe to respond to treatment or cause permanent vision loss. ***For more information contact:***

American Academy of Ophthalmology

P.O. Box 7424
San Francisco, CA 94120-7424
415-561-8500
www.aao.org

American Diabetes Association

1701 North Beauregard Street
Alexandria, VA 22311-1717
800-342-2383 (National Headquarters)
1-888-342-2383 (Local Offices)
703-549-1500
E-mail: AskADA@diabetes.org
www.diabetes.org

Juvenile Diabetes Research Foundation International

120 Wall Street
New York, NY 10005-4001
800-533-CURE (2873)
E-mail: info@jdrf.org
www.jdrf.org

National Diabetes Information Clearinghouse

1 Information Way
Bethesda, MD 20892-3560
800-860-8747
301-654-3327
E-mail: ndic@info.niddk.nih.gov
www.diabetes.niddk.nih.gov

National Eye Institute

National Institutes of Health
2020 Vision Place
Bethesda, MD 20892-3655
301-496-5248
E-mail: 2020@nei.nih.gov
www.nei.nih.gov

For more information on services for people with low vision:

American Foundation for the Blind

11 Penn Plaza, Suite 300
New York, NY 10011-2006
800-232-5463
212-502-7600
E-mail: afbinfo@afb.net
www.afb.org

Lighthouse International

111 East 59th Street
New York, NY 10022-1202
800-334-5497
800-829-0500
212-821-9200
212-821-9713 (TDD)
E-mail: info@lighthouse.org
www.lighthouse.org

National Association for Visually Handicapped

22 West 21st Street, 6th Floor
New York, NY 10010-6943
212-889-3141
www.navh.org

For more information about the diagnosis and treatment of kidney failure, visit:

Kidney Patient News

<http://www.kidneypatientnews.org>

NIDDK National Kidney and Urological Diseases Information Clearinghouse

<http://www.niddk.nih.gov/health/kidney/pubs/kdd/kdd.htm>

Ready for Something Different?

Coping with chronic kidney disease takes time. How long it takes will vary from one person to another. People also respond differently to treatment and the different methods of treatment so the time it takes to feel better also varies. Once you have accepted your kidney disease, have a system established for your treatment and you are feeling better, you may decide you are ready to add another dimension to your life. The story, *Achieving in Life*, on p.1 shows one person's success approach to returning to work.

If you are employed and have taken a leave of absence, it may be time to return to work. If you had to quit or retire from your job, you may want to pursue a career move. Or, you may be interested in a retraining program or getting a college degree to further your work and income options.

This may be the time to approach your social worker about a referral to your local vocational rehabilitation office. You also can find a listing of state vocational rehabilitation offices by visiting our patient website at www.kidneypatientnews.org.

The Life Options Rehabilitation Program (LORAC) has updated its patient guide on employment options.

Employment: A Kidney Patient's Guide to Working and Paying for Treatment now has information for people with kidney disease and people on dialysis or with transplants. Topics include employment and vocational rehabilitation; Medicare, Medicaid, and health insurance; disability programs, including SSDI and SSI; and federal legislation affecting kidney patients.

Visit the Life Options Web site at www.lifeoptions.org to download a copy of the booklet or contact them at 1-800-468-7777.

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Address Service Requested

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