



# RENAL OUTREACH

ESRD Network 9/10

Winter 2004/Vol XIV, No.2

## Take Action...Take Charge...Live Well!



Hi, my name is Kathy Kirk-Franklin and I have been a dialysis patient for the last five years.

I have been a member of The Renal Network's Patient Leadership Committee (PLC) for almost as long.

The PLC is a group of patients, dialysis staff and family members brought together by the Network's Patient Services Department to work on educational projects and materials and to give feedback on issues and concerns that affect us all. Right now my sub-committee is working on a vascular access project that supports the national *Fistula First* initiative (see article on p.1).

It is because of my work on this group and the contributions of the late Bob Felter that I had the wonderful opportunity to attend this year's American Association of Kidney Patients (AAKP) Annual Convention.

This convention was a very unique experience because everything was geared for patients. It certainly reflects AAKP's goal to empower patients about their own care, sharing experiences with other kidney patients, and learning to live well with kidney disease.

Continued on page 6

## Fistula First

*Fistula First* is a national quality improvement project. It was started by the Centers for Medicare and Medicaid Services (CMS). All of the End-Stage Renal Disease (ESRD) Networks, as part of their contract with CMS, will be working with dialysis facilities in their areas to put the project into action.

The principal goal of the project is to have everyone working together to improve the management of vascular access. The objective is to increase the number of patients using an AV fistula as their primary hemodialysis access.

***Why promote AV fistulas for hemodialysis patients?*** Kidney experts agree that the AV fistula is the first choice for vascular access for hemodialysis. Research shows that the AV fistula has fewer complications (such as infections), lasts longer, and over time costs less. The benefits to the patient include better adequacy of dialysis, fewer hospitalizations and as a result a longer, better quality of life.

Yet most hemodialysis patients in the United States do not have a functioning fistula. Some patients may have a medical or physical condition which makes having an AV fistula difficult. But, for the most part, this is not the case. Other factors, such as, education on vascular access, availability of vascular access surgeons and timely referrals are just a few of the causes for patients not having an AV fistula.

Continued on page 2

Fistula First - cont'd

*Fistula First* hopes to raise the national patient vascular access rate to the levels recommended in the Kidney Disease Outcomes Quality Initiative (K/DOQI) guidelines. This would include 50% of all new hemodialysis patients (prevalence rate) and 40% of existing hemodialysis patients (incidence rate).

**How are we doing?** The Renal Network's current prevalence and incidence rates reflect the national average (see table below.).

<b>Current Prevalent Fistula Rates</b>	
(New hemodialysis patients - <i>Fistula First</i> goal 50%)	
Illinois	34%
Indiana	32%
Kentucky	33%
Ohio	32%
<b>U.S.</b>	<b>31%</b>
<b>Current Incident Fistula Rates</b>	
(Current hemodialysis patients - <i>Fistula First</i> goal 40%)	
Illinois	29%
Indiana	28%
Kentucky	27%
Ohio	28%
<b>U.S.</b>	<b>29%</b>

Obviously reaching the recommended prevalence and incidence rates will take some time. The Renal Network is conducting a series of *Learning Sessions*. It's an opportunity for nephrologists and vascular access surgeons who have successful AV fistula placement and management programs to educate others on what works and why.

To learn more about the AV fistula logon to [www.kidneypatientnews.org](http://www.kidneypatientnews.org) and download a copy of *Access Care: Your Lifeline*. For more information about the *Fistula First* logon to [www.therenalnetwork.org](http://www.therenalnetwork.org).

## Dialysis – The Unfriendly Companion

Dialysis sparks a feeling of intense despair; I want to run away and forget that I need to be there.

It makes my body change so much I forget how to feel;

It makes me feel like I am on a roller coaster going up and down a hill.

Most of the time I can handle it with manners and grace;

But most of the time I wish it were human so I could punch it in the face.

Nine years of needles, operations and loss;

I feel like I am an abused worker with a relentless boss.

I want to do karate, roller skate and run;

But with kidney failure taking my leg I have little or no fun.

Someday I hope to help someone go through this life changing game;

They will not go through being a number or by their disease, but being known by their name.

Bonnie Berry  
11/19/2003

Bonnie is a patient at the Kidney Center of Terre Haute, IN. She is 30 years and has been on dialysis for 9 years. Bonnie lost her leg last August due to a tumor.

If you have a personal success story about returning to work or school, or doing volunteer work after starting dialysis, and would like to share it with our readers, please submit it to the ***Renal Outreach*** for review.

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## Would've, Should've, Could've: Do Not Leave Your Unit In A Huff!

Some of you love your dialysis facility: the staff seems like family; you have a good experience with your treatment and you are satisfied with your care.

Others are dissatisfied and frustrated to the point you are thinking about transferring to another facility. Occasionally patients have been so angry that they just up and leave their facility. Please do not do that.



If you fall into the first group, count your blessings. If you are part of the second group, talk to the staff about your concerns and work with the staff to address them.

Talk about your concerns as they come up, it will keep them from multiplying. If talking through the issues does not seem to resolve the problems, you can file a grievance with your facility.

If that still does not seem to help or you are uncomfortable with filing a grievance at your facility, you can call **The Renal Network (800-456-6919)**. We will assist you with your complaint, discuss your options, or tell you how you can file a formal grievance.

Another option would be to dialyze at a different facility. You can talk to the social worker or your nephrologist about transferring to another facility. The social worker will let you know what other facilities are in the area, can check if they have any openings and on what shifts, and can start the paperwork process for you.

The new facility staff may want to meet with you ahead of time or review your medical records, as part of the admission process. Your nephrologist will need to determine if he/she has privileges to treat you at the new facility or if you will need to switch nephrologists as well. A facility cannot accept you as a patient if you do not have an associated nephrologist to oversee your care.

Or you can search for a new facility online using **Dialysis Facility Compare**. This website has information about the dialysis facilities that Medicare has certified. Dialysis Facility Compare has information about Dialysis Facility Characteristics such as number of treatment stations and type of dialysis offered. In addition, it provides information on selected Quality Measures including number of patients on EPO and patient survival rates. Dialysis Facility Compare is on the internet at [www.medicare.gov/dialysis/home.asp](http://www.medicare.gov/dialysis/home.asp)

Try to handle any problem before it gets to the point of your leaving without having another dialysis facility to go to for treatment. Once you end your care at a facility, you may have difficulty finding a new facility on your own.

Without a dialysis facility, you would have to go to the hospital emergency room for treatment until you could find a new center. Some patients have had to move or drive a long distance to find a new facility for their care.

A decision made quickly or in anger may later be regretted. Even in the best of facilities, there can be misunderstandings and concerns. Please talk to the staff when you have concerns. Good communication between patients and staff is key to a good dialysis experience.

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## Diet – What Me Worry?

By Janet Schueller, M.S., R.D., L.D.

Is maintaining a diet stressful? In response to a questionnaire by The Renal Network, family members of kidney patients responded that coping with the renal diet was a major stressor especially during the first year of dialysis. Now remember, this was a survey of family members, those individuals trying to provide the best care and support for their loved one who is now requiring dialysis treatments. As support people, family members are usually involved in planning the family diet and in actual meal preparation.

In my experience, their major concern is that they will accidentally do something wrong with diet planning and end up harming the patient. In fact, the renal diet has become easier to follow in the past few years due to improvements in dialysis procedure and the removal of more toxins during treatment. Very few patients are harmed solely by diet choices. Such patients are in denial about their disease and are really ignoring their diet restrictions in a big way.

Most patients achieve good results with the renal diet and are still able to enjoy mealtimes with family and friends. You really do not need to be perfect in planning the diet! Right from the start, in the first months on treatment, good results can be achieved with help from the health care team and with normal efforts. In fact, in that same questionnaire, family members reported that the renal diet becomes only a minor stressor after time.

There are several things that you can do in the first weeks to help you get to this less stressful state. As a practicing renal dietitian, I will share some of those tips with you in this article.

will meet with the dietitian and receive information on the renal diet in the first couple of weeks on dialysis. Try to be there for this instruction. Or review the materials later with the dietitian.

Remember the renal dietitian is there to help your family to “live” with the diet plan. Let her/him know about your family’s eating habits, favorite recipes and traditions so that they can be worked into the diet as much as possible. When the diet plan is followed regularly, there is usually room for that special holiday recipe.

I especially like to work with the person who does the grocery shopping and cooking for the household to make the diet acceptable for the patient. Encourage the whole family to learn this new diet and to offer creative suggestions



for adapting it for your lifestyle. The new diet will be much easier to follow if everyone helps, especially in the first few weeks and months!

So, you have had your first instructions on the renal diet. Now you are home with your family and have a whole new plan to follow.

How do you start?

Take it slow at first. Get used to the new diet. It is common for family members to take over meal planning for the patient in the first few weeks as the patient regains their strength and appetite. However, the dialysis patient should be feeling better soon and should take control of their own meal planning then. The patient needs to understand why they need to follow this plan.

It is not healthy for the family or the patient if you become the “enforcer” of the diet. Especially when the patient is capable of handling it.

4 The first step in reducing the stress for you, the family member, is education. The new patient

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Continued on page 5

If the patient does not follow the diet and medical advice given, you should continue to offer your support but do not accept the responsibility for their actions. After all, we are able to make long-term changes best when they are accepted and not forced upon us. The commitment is an individual choice. Give the patient the chance to make the right choices for him/herself while providing lots of love and support!

You may find the first weeks of following the renal diet to be stressful since changing old habits require a determined effort. Change does not happen overnight for anyone! Grocery trips may take more time because you need to read the food labels of familiar foods. You may find that some convenience foods can no longer be used due to high sodium content. You will also be surprised to discover that potassium and phosphorus are not even listed on most food labels.

Questions will come up right and left as you learn this new diet. You may find yourself preparing “safe” meals of broiled or baked meats, plain vegetables and soaked potatoes because you are afraid to try anything else. Neither the patient nor family members will be happy with this situation for long!

This is the time to visit your dietitian again to find creative approaches to the diet. Now is the time to adapt the diet for the “long haul” of dialysis. The most successful and contented families will look for renal cookbooks, advice on shopping and help in changing favorite recipes.

Ask your dietitian for a “refresher course” if you have forgotten some of the diet guidelines. Write down any questions you have about diet and bring them to treatments to be answered. Please remember that all dialysis staff are not equally qualified to answer diet questions.

So be sure to ask for the registered dietitian who cares for your family member. If you are still overwhelmed by the diet, ask the dietitian to teach it “in pieces” so that you can understand each restriction that is needed and the reasons for it. Your dietitian will be happy to help you care for your loved one!

Experienced dialysis patients will tell you that it is very hard to change your diet habits for months and years. Think how hard it is to follow a diet for just a week! It becomes much easier if the patient and family have a lot of social support. Research shows that the most important factor related to good compliance is the positive support of others.

You and the patient should surround yourselves with persons with encouraging attitudes. I have found that many young patients do not want to admit that they are ill and so they will act like they are “invincible.” They often do not follow their diet, take their medications or come to treatment because they want to “fit into their crowd”. However, these patients may listen to people other than their family like teachers, coaches, co-workers or friends. On the other hand, older patients may not want to burden their family and friends with their illness but will talk to dialysis staff who care for them. Find more support people for your loved ones so that you don't carry the burden alone! Some other options for encouragement include church leaders, club members or neighbors. Support groups at your dialysis unit may also prove helpful.

Just remember that your family member is an individual unlike any other in the waiting room at the dialysis unit. Do not allow other patients and family members who are angry or discouraged to change your own approach to the diet and dialysis. The right attitude is a large part of the whole equation!

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*Take Action... - cont'd*

The convention took place from August 28-31, 2003 in New Orleans, Louisiana.

The speakers talked about every aspect of dialysis that we, as patients, deal with including high blood pressure, being diabetic, accesses, exercise and nutrition. They also discussed the types of dialysis available to patients such as home hemodialysis, peritoneal dialysis, in-center hemodialysis, nocturnal hemodialysis, and herbal treatment. I was so excited when I got the brochure about the convention that I could hardly wait to get there, as I was eager to learn about everything.

I attended several workshops on Friday, one of which was *Controlling High Blood Pressure*. Many of us say we have high blood pressure or low blood pressure but we really don't know what that means.

Dr Blagg, who gave the lecture, broke it down into plain terms that anyone could understand. He defined blood pressure as "*a way in which the muscles contract in order to circulate the blood through out the body and how much pressure it takes to make the blood circulate.*"

He also talked about the systolic vs diastolic. He gave numbers by which anyone could monitor their pressure and know when things are at a danger point. I attended lunch with this expert that day and had a chance to talk more one-on-one with him.

"*Lunch With The Experts*" is a feature of the convention that is most helpful to patients. It's not often that patients have the opportunity to talk to experts.

I also attended a workshop called *Lightening Up With Laughter*. This was a very interesting workshop because I wanted to know what could be funny about dialysis.

Instead the workshop turned out to be a way to teach yourself how to enjoy your time while receiving your treatment. The antidote was making humor a part of your therapy. Dr. Leslie Gibson, the instructor said, "*humor would make you healthier.*" The convention day ended with an awards ceremony and presentation.

On Saturday, I got to experience being a transient patient. I was really scared because when you go somewhere new and have never had treatment outside your home base it's like starting all over again.

It was just like the first day at CDC in Cleveland. My eyes got really big, the tears started flowing and I wondered if I was going to make it out alive. It was not what I was used to; but I got my treatment, I lived and I was glad it was over. When you go away from home it makes you appreciate what you have at home. I think that was the best lesson I learned while being a transient patient.

As a transient patient, you need to learn everything about the dialysis center before going. Remember to always ask questions about the center before you go so that you know what to expect when you arrive.

Later that day, I also attended workshops on nutrition and exercise; each was very informative. It served to remind me of what I should and should not be eating. It made me look at and rethink some of my eating habits. I also learned ways to maintain and regain mobility. The night ended with a Mardi Gras Ball that was exciting and colorful; our patients and health care advocates were dressed for the occasion and their costumes were marvelous to see.

On Sunday we ended with a breakfast that was delicious. It was a heartbreaking time because it was over.

*Continued on page 7*

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Take Action... - cont'd

I met lots of patients who were taking charge of their health. I made new friends. The vendors were very informative; they gave out great promotional literature and items for keepsakes. I wished it could have lasted another week or so.

I would like to thank the late Bob Felter for paving the way for patients and The Renal Network for making it possible for patients to experience a convention that is geared just for us; one that empowers us to TAKE CHARGE AND LIVE WELL.



Diet - What Me Worry?... - cont'd

Veteran dialysis patients have suggestions for dealing with your diet and social life also. Your family member may feel like an outcast at social events if there are many restricted foods on the menu. This may cause them to turn down invitations and just stay home.

Do not pass up these events which will boost patient morale and help them accept their new life! Plan ahead by preparing an appropriate potluck dish, or checking with the dietitian if some "careful cheating" could be tolerated. Patients who follow their diet closely most of the time may have room in their diet plan for some "special foods" in moderate amounts.



Ask your dietitian for "Eating Out" guidelines and portion sizes. It is also helpful to offer a small meal or snack before going

to the event to prevent poor choices due to extreme hunger!

As in many things, moderation is essential.

Successful dialysis patients have shared other hints with me over my years of practice. They suggest finding hobbies which distract the mind from food.

Exercise can also serve this purpose. Perhaps you can even join your family member in a new pursuit! Also, enough time should be allowed to plan appropriate meals, especially if they must be taken regularly to work or to school.

Unfortunately, there is not yet a "renal fast food" chain of restaurants available for meals on the run!

Patients who are successful also do not punish themselves with negative feelings when they do make poor choices. The entire diet plan need not collapse because you made a couple of mistakes! You just need to "get back on the horse and try again."

Finally, both patients and family members should remember that although the behavior may not be good, that does not mean that the person who made the mistake is also not good. If you find yourself or your loved one with that attitude, take time to talk to your social worker about the "whole picture."

You too can be one of the family members who finds stress from the renal diet lessening with time! You can find yourself enjoying a good meal with your loved one and discussing current events, rather than the amount of vegetable allowed for dinner in the diet plan. Your family will have found new favorite dishes to share together at the holidays.

Social occasions will again become the time to visit with friends that you don't see often enough.

Your renal team and your dietitian are there to make this vision become a reality for you!

For more information on diet and renal cookbooks, logon to our patient and family website: [www.kidneypatientnews.org](http://www.kidneypatientnews.org).

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# National Patient Safety Awareness Week

March 7 - 13, 2004

## How Well Do You Know Your Medications?

As part of patient safety awareness week, review all of your medications and make sure you know all of the following about each one:

- What did your physician tell you the medication was for?
- Know the “Brand Name” —the name given to a medication by the manufacturer.
- Know the “Generic Name”—the chemical name of the medication.
- What will the medicine do?
- How did your physician tell you to take the medication?
- How many times a day?
- How much to take at one time?
- How long to take the medicine?
- When to take the medication (before or after meals)?
- What did the physician tell you to expect from the medication?
- What results to look for?
- What to do about possible side effects?
- What monitoring will need to be done?
- How should you store the medication?
- How do you refill the medication if necessary?



Keep your medications organized. Maintain a list of all your medications and the times of day you take each medication. Make sure it is up to date. Ask your pharmacist to review your medication list especially when using “over the counter medications” for colds, stomach upset and the flu.

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## RENAL OUTREACH

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Non Profit Org. U.S. Postage <b>PAID</b> Indianapolis, IN Permit No. 8606
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This newsletter is published under CMS Contracts 500-03-NW09 & 500-03-NW10

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