



# RENAL OUTREACH

ESRD Network 9/10

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## **The Flu Shot, Who needs it?**

**If you have kidney  
disease, you do!**

Flu season generally starts early in November, and often continues through late April.

Influenza is a potentially serious condition that can often be prevented. All it takes is a simple shot - a vaccination.

Having chronic kidney disease places you at risk for complications from influenza. Why take that chance?

Although it is best to get your flu shot before the flu season starts, it is never too late.

Check with your dialysis healthcare team to find out where you can get a flu shot.

Don't wait; act today!

## **Robert Felter Memorial Award**

*2002 Patient Award Recipient -  
Martinlow Spaulding and his wife, Elaine.*

### **What an Experience!**

I was blessed by receiving the first Robert Felter Memorial Award from The Renal Network. By receiving this honorary award, I was allowed to attend the American Association of Kidney Patients 2002 National Convention in Orlando, Florida. Bob was a member of AAKP and a long-time patient advocate just as he was with The Renal Network. My wife, Elaine, who has been a renal/oncology nurse since 1991, attended the conference with me.

AAKP was founded in 1969 by kidney patients; the purpose is to help patients and their families cope with emotional, physical and the social impact of

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## Robert Felter Memorial Award (cont'd)

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kidney disease - leading to more normal, productive and satisfying lives. The theme for this year's convention was "Patient-to-Patient...Sharing Our Experiences." The convention included three full days of educational sessions, sharing with fellow kidney patients and providers and attending social events. As you can imagine, the sessions covered the whole spectrum of chronic kidney disease from treatment options to the role of herbal medicines to financial issues.

I will highlight some of the more interesting things I learned.

In "Peritoneal Dialysis: Is It An Option For Me?" with Dr. Tom Golper and panel members George Brown and Debbie Sacchi, I learned that in the United States, only 12% of kidney patients who need dialysis use peritoneal dialysis (PD), while, in New Zealand, 59% of dialysis patients use PD. Few kidney patients have medical contraindications for one dialysis option over the other. In fact, cardiovascular problems are 40% less in patients who choose PD. Furthermore it has been shown that PD patients tend to be more compliant. Could that be because they have more diet choices? PD is a good option choice that maybe more patients should explore. But it is not for everyone.

After this session, a young lady approached me. I was very impressed with her spirit. I learned that she was only 16, a Southern Belle from Mississippi and on peritoneal dialysis. A very supportive mother accompanied her. Needless to say, we became friends. We both attended the welcoming ceremonies and entered the "tacky tourists" dress-up contest. My wife, Elaine, and I were finalist in the contest. We all enjoyed the evening and we were the last ones to leave the dance. The young lady was a true inspiration. She shares her kidney stories with her fellow classmates hoping to educate others about kidney disease. We have now become pen pals and are sharing our hopes and dreams with each other. Kidney disease may confront us with challenges but we can still live a quality of life!

Dr. Jay Wish, Board President of The Renal Network, Inc. and Dr. Amy Friedman led a talk on "Anemia Management: Secrets To Keeping Your Hematocrit High." It is important to know the symptoms of anemia. They are fatigue, exercise intolerance, decreased mental capacity and decreased sexual function. Looking at anemia management, some studies show that a shot of EPO is 30% more effective than in an IV, which remains treatment of choice for many.

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Drs. Wish and Friedman also stressed that patients must have “iron stores” replaced in their body to have EPO work effectively to reach target Hgb and Hct levels.

The session “Bone Connection: Building A Healthy Foundation” was led by Dr. Jack Waterman. Up to 99% of our calcium and 85% of our phosphorus are stored in our bones. Calcium and phosphorus together in blood can form crystals. Parathyroid (PTH) hormone maintains calcium level. Increased calcium absorption is from bones and kidney(s). Increased PTH can cause bone problems, neuropathy, and anemia. Kidney patients may need to take phosphate and/or calcium binders for bone control. Most kidney patients need to take calcium for long-term care and participate in a regular exercise program.

Finally, the session, “All You Wanted To Know About Transplants, But Were Afraid to Ask” included Dr. Tom Peters and panel members Jess Arceneaux, Eileen Kenney (RN) and Karen Scott. Attendees were provided with some very personal and professional insights about transplant. A recurrent theme of “humor” was prevalent in all responses. Panel members shared challenges they had to overcome but focused mostly on their personal choice to live a quality of life.

For many years, Bob Felter kept telling me about his experiences with the AAKP folk. I was interested but - with working, being married with six children and my volunteer work with The Renal Network (TRN) – I just couldn’t see how. Yet, this convention goes beyond information to connection. Much of the information may not be “new” to long-term kidney patients. It is the human quality of kidney and transplant patients, family, friends, and staff all coming together that makes this meeting unique.

Now after attending this AAKP convention, I realize that I should have listened to Bob years ago. I have an interest in forming an AAKP chapter for patients in TRN area. If you would be interested in belonging to an AAKP chapter, please share this with me at [kidneyme@cs.com](mailto:kidneyme@cs.com) or by writing me, Martinlow Spaulding, at 23191 Vote Road, Batesville, IN 47006.

In closing, I would like to thank the Robert Felter Memorial Award Committee for honoring me with this award and allowing me to attend the 2002 AAKP convention.

This opportunity will allow me to continue to “carry on” with my personal commitment of living a better quality of life each and every day. Thanks for the experience!

*Martinlow Spaulding is a member of The Renal Network’s Medical Review Board and the Patient Leadership Committee.*

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# Patient Leadership Committee

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## I'M NOT THE PATIENT! SO WHY DO I FEEL SO BAD?

*Fonda Setters, MSW  
Renal Social Worker*

We — the doctors, unit staff, billing office employees and the patients themselves — all expect a lot from the family of a patient. You also expect a lot from yourself and you do not cut yourself much slack when you feel that you have not performed up to expectation. You may be a husband or wife, son or daughter, best friend or maybe you are an ex-spouse who stepped back into the patient's life when illness came to call. Whoever you are, you are the person who has stepped up to help the patient carry the burden of living with chronic kidney disease (CKD). You want your loved one to live well and that is exactly what the rest of us are counting on. Your involvement makes providing treatment and living with treatment easier.

But what are you doing to make sure you also live as well as possible? Numerous times I have heard family members say things like, "I need a medical procedure done but I just cannot take the time because my wife needs me" or "I could really use a vacation but who would take care of

Dad?" No, you are not the patient but your life has probably changed almost as much as theirs.

Dialysis patients are very susceptible to depression so it should come as no surprise that the people closest to them would be more vulnerable as well. Let's take a look at what depression is, at what you, the families, are dealing with and ways that you can take care of yourself.

According to the Diagnostic and Statistical Manual IV, depression is a mood disorder. Common symptoms of depression are: 1) depressed mood nearly every day, 2) lack of interest and/or pleasure in most activities, 3) changes in appetite/significant weight loss, 4) insomnia or excessive sleep, 5) psychomotor agitation or retardation, 6) fatigue or loss of energy, 7) feelings of worthlessness or inappropriate guilt, 8) lack of concentration and 9) recurrent thoughts of death (not just fear of dying). A major depressive episode might be diagnosed for someone who presents with five or more of these symptoms, including number one or two, during the same two-week period.

Other non-involved family members, friends and acquaintances might wonder why you would be at risk for

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## *Family Focus Series*

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depression when, as noted previously, you are not the one who is ill. If those people had any idea what you are coping with, they would not have to ask that question. You may have experienced any number of life changes, such as financial hardship (due to employment changes), role changes (children caring for parents), relationship problems (emotional distance/loss of intimacy) or just the large amount of time you spend transporting your family member to hemo or helping them with their PD treatments at home.

From an emotional standpoint, you may wrestle with the same feelings as your family member. You also experience fear due to loss and change and an uncertain future. You may also have periods of anger. Anger at the patient for “getting sick.” Anger at God for “allowing it to happen.” Anger at the rest of the world for going on with its normal routine while your world has been turned upside down.

You may also be suffering physically. You are tired all the time because you have to keep working, be a caregiver, raise children, run the home, just plain do EVERYTHING! You may also be more susceptible to illness because your physical reserves are so depleted. Or you may be putting off medical care for yourself until “a better time.”

You jeopardize your own health because you feel like you just do not have any other option.

Then there is the fact that everyone, including you, puts all the focus on the patient. The patient may be self-absorbed as he or she tries to cope. The dialysis staff is busy providing direct care services to the patient. Family and friends want to know how the patient is doing. Sometimes we all forget that helping you take care of yourself IS taking care of the patient.

So what can you do to take care of yourself considering the situation you are in?

1) Express your emotions to someone you feel comfortable with. Even the anger, fear, guilt and worry. There are no “bad” feelings, just feelings.

2) Take some time for yourself by asking other family members or friends to assist you with concrete duties. A retired friend might be able to transport the patient to hemo one day a week. One of your children could stay with grandma while you go for a doctor appointment. If someone in your life says “let me know how I can help,” look them in the eye and tell them what you need. Too many times I have had people say to me “I just couldn’t ask my family or friends to help me.”

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Well, why not? You may be doing such a good job acting like everything is fine that the rest of us may not realize, for a time, that you are struggling also. The people who care cannot read your mind and by the time we pick up on the clues you have probably already suffered far too much.

3) Reconnect with your place of worship. Perhaps you have not attended services for many years or maybe your recent attendance has become sporadic due to the illness of your family member. Regardless of the time that has passed, this can be an important source of hope, help and support. Even if you can no longer attend services, your church can still minister to you. Providing spiritual care to shut-ins is a common practice at many churches. Also, it is not unusual for the people of a congregation to offer assistance, as well as emotional support.

4) Take time for your physical needs. Go to your doctor when you are sick or hurt. Do not ignore symptoms hoping they will magically “go away.” When you need a rest, make arrangements for someone to cover your responsibilities for a few hours, or if possible, for a few days.

5) Talk to the social worker at your dialysis unit. We are not just here for the patients. We realize that the well-being of the patient is tied to your well-

being and vice versa. The social worker can be a source of support, counseling, information, referral, comfort, tissues, etc...

Social services vary from state-to-state, county-to-county, and even city-to-city. For this reason it is best to discuss your needs with the social worker. He or she will know, or can find out, about services available in your area. Most services are part of an umbrella of programs administered by agencies, such as the Area Agency on Aging, Department of Job and Family Services, Community Service Organizations, etc...

The majority of agencies are administering government funds and charitable contributions. Do not assume that you do not qualify for services. Programs have different guidelines and some have a sliding fee schedule for people who do not meet the qualifications for free services.

Services potentially available to assist patients and families (depending on where they live) include transportation, nursing/aide services, home delivered meals, personal emergency response systems, respite care and homemaker services. Some agencies provide adult daycare, chore services, counseling, support groups and friendly visitors. Depending on your situation, you might benefit from employment placement and counseling, energy bill credits,

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veterans services or prescription drug assistance programs.

Sharing your concerns and needs with the social worker will allow you to determine what assistance might be available from your community. However, please remember that “the government” is not going to meet all our needs. Families have the primary responsibility to take care of their own. Once you have established what your family, friends, church, etc., can assist you with, you can investigate how community services might fill in the gaps.

6) When necessary, medication and counseling can make a world of difference in how you feel and your ability to cope. You are important and you should not suffer needlessly. Depression is a treatable condition and that is why we want you to be aware of your risk and the things to look for.

But no matter where you are on the continuum of feeling and emotion, from occasional sadness to an actual depressive episode, there is help and hope. It is up to you to take that crucial first step and ask for help.

*Your comments on this and other articles in this series are always welcomed.*

*Please write the Family Sub-committee of the Patient Leadership Committee  
c/o The Renal Network, 911 E. 86th  
Street, Suite 202, Indianapolis IN 46240.*

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## ONE-SITE-ITIS

*By Mary Ann Webb, M.S.N., C.N.N.  
Quality Improvement Coordinator,  
The Renal Network, Inc.*

Who wants to get stuck with two big needles? Do you answer with “I do, I do”? “No way,” you say. Nobody likes to have needles stuck into his or her arm.

Unfortunately, hemodialysis patients usually have to have this done three times a week. The needles have to be quite large in order for the blood flow to be adequate for a good dialysis treatment.

Some accesses are easier to stick than others. Inserting needles into a fistula or graft is trickier than drawing blood for lab work out of a vein in your arm. The needle must be placed exactly in the center of the vessel or graft for the best blood flow.

Sometimes the vessel cannot be seen or felt very well due to swelling, bruising, poor development, or placement deeper into the tissues. Usually, the larger the blood vessel, the easier it will be to stick. The easier it is to stick, the less pain and discomfort you will experience.

Some patients get comfortable with the needles going into the same place every time because they did not hurt as

much when placed there and good blood flow was obtained.

Sticking new sites can be scary.

There is always a risk that the needles will not work there and you may have to get re-stuck. It may hurt a little more also because your skin hasn't toughened up yet with scar tissue.

However, as scary as it may be, it is extremely important to allow and encourage your dialysis staff to stick new sites and use as much of your fistula or graft as possible.

Each new stick should be a couple of centimeters away from the last stick to allow the first one to heal completely before returning to that site. Repeat sticking of the same site over and over again (one-site-itis)

can cause a thinning of the vessel wall, which eventually may pop out like a balloon (aneurysm). This aneurysm can be dangerous. It could burst and cause a large amount of bleeding. It also may make it more difficult to find other places to stick. Needles should never be placed directly into an aneurysm. Your vascular surgeon may want to take you to surgery to remove the aneurysm to prevent further complications.

Also, repeat sticking of the same sites can cause you to bleed longer after the needles are pulled out. Rotating needle sites directly affects the long-term survival of your access. Protecting your access from complications is your responsibility!

So, even though it may be scary, be sure to rotate your needle stick sites. Don't let ONE-SITE-ITIS happen to you!

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