

ESRD NETWORK

6600 North Meridian Avenue, Suite 155
Oklahoma City, OK 73116-1411

**KIDNEY
CONCERNS**

FALL/OCTOBER 2001

ISSUE 38

Network 13 PAC Members at AAKP Convention

I recently had the pleasure of attending the 2001 AAKP (American Association of Kidney Patients) Convention. It was held at the nationally famous Peabody Hotel in Memphis, Tennessee. This was a very informative conference, and if you ever get the opportunity, please go and experience it for yourself! There were many dialysis and transplant patients in attendance. There were also doctors, nurses, social workers, dieticians, and technicians who took advantage of this event as well. Doctors and patients alike spoke on a wide range of topics. These topics included "Your Access, Your Lifeline: Knowing Your Options", "Straight Talk: Effective Communication with Your Healthcare Team", "Optimizing Dialysis: A Plan for Success", and the current hot topic "Daily Hemo Vs. Three Times Per Week".

One common thread seemed to emerge during the meeting. This single desire was for kidney patients to learn the best way to live well and live long with their current physical condition. We all must do our part and work as a team in order to accomplish this. The healthcare team is an important part of that goal. However, as it was pointed out time and time again, **the final responsibility in realizing this goal remains with you! You are the key, the one with the final choices, and the main player on your healthcare team.**

Doctors can prescribe treatment, nurses can offer care, social workers can give guidance and encouragement, and dieticians can recommend diet, but you must provide the final performance. **You have the ultimate responsibility for your care.**

Educating yourself about your disease is extremely important, and can be the deciding factor in feeling good or feeling poorly. To accomplish this education requires a commitment to read and study materials that are available from many sources. Educating yourself will lead you to taking an active role in your healthcare. This was really stressed during the convention – taking an active role in your personal care. Get involved, get educated and ask questions of your healthcare team. No question is stupid or any concern trivial.

One important step in getting your questions answered is in communication. In order to make information you learn fit you as an individual, you need to discuss it with your doctor. In the session about "Straight Talk: Effective Communication with Your Healthcare Team", we were given some helpful tips to follow.

1. Look up as much information as you can on the issue/question at hand.
2. Think about what you really want to know or ask.
3. Make a list of your issues/questions.
4. List your issues/questions in order of importance to you.
5. Practice stating your issues/questions with someone, make sure they understand you.
6. Take someone along for your doctor's appointment, two sets of eyes are better than one.
7. Bring the literature where your information came from to your doctor's appointment.
8. Speak in a polite though clear and firm language.
9. Be honest and persistent, if you don't understand his/her answer say so.
10. State the answer back to the doctor so you both know you understand.

Remember that your healthcare team can't work well if you don't work together. Your doctor brings knowledge regarding the disease, how it affects the body, and what treatment choices are (Cont. on page 4)

FIGHT FLU and PNEUMONIA

Influenza, also called the “flu,” is a highly contagious respiratory infection. Flu can cause fever, chills, headache, dry cough, runny or stuffy nose, sore throat, and muscle aches. Unlike other common respiratory infections such as the common cold, influenza can cause extreme fatigue lasting several days to more than a week. Although nausea, vomiting and diarrhea can sometimes accompany influenza infection, especially in children, gastrointestinal symptoms are rarely prominent. The illness that people often call “stomach flu” is not influenza.

The “flu” is spread easily from person to person primarily when an infected person coughs or sneezes. After a person has been infected with the virus, symptoms usually appear within 2 to 4 days. The infection is often considered contagious for another 3 to 4 days after symptoms appear. Each year, an estimated 10 to 20 percent of the population contracts influenza.

Who should get a flu shot?

The following groups are at higher risk for having medical complications from influenza and should receive the flu shot:

- **People 65 years of age and older;**
- **Residents of nursing homes and other long-term care facilities housing anyone of any age with chronic medical conditions;**
- People with chronic disorders of the lungs or heart, such as asthma, emphysema, chronic bronchitis, or cystic fibrosis;
- People who are less able to fight infections because of a disease they are born with; infection with the Human Immunodeficiency Virus (HIV); **treatment with drugs such as long-term steroids;** and/or treatment for cancer with x-rays or drugs;
- People who have required regular medical follow-up or hospitalization during the preceding year because of **chronic metabolic diseases (including diabetes mellitus), kidney diseases** and blood cell diseases such as sickle cell anemia;
- Children and teenagers 6 months to 18 years of age on long-term aspirin treatment, who, if they catch influenza, could develop Reye’s Syndrome which causes coma, liver damage, and death; and
- Women who will be 6 or more months pregnant or who will have just delivered during the influenza season;
- In addition, to help protect high-risk people from exposure to influenza, these two groups should receive influenza vaccinations as well:
- **Health care workers** (doctors, nurses, hospital and medical office staff, personnel of nursing homes or chronic care facilities) in contact with people in high-risk groups
- **People—including children—who live with persons in high-risk groups for flu (household contacts)**

Your flu shot is free if you are enrolled in Medicare Part B and your health care provider accepts Medicare assignment. The Medicare program covers the flu shot and the cost of administration for beneficiaries. Medicare recipients do not have to pay coinsurance or a deductible under the flu shot benefit. For HMO members, most must get their flu shot from their HMO. Check with your HMO first. For those covered under Medicaid, check first with your local social services or health department. Many private health insurance plans also cover flu vaccine.

You can get a flu shot at your doctor’s office. You may also be able to get a flu shot from your dialysis unit, your local health department or from other health-care providers. Medicare Part B will pay for the shot no matter where you get it, as long as the health care provider agrees not to charge you more than Medicare pays. To find local health care providers who accept Medicare as payment in full for the flu shot, you can also contact your Medicare Carrier (Arkansas 1-800-xxx-xxxx, Louisiana 1-800-xxx-xxxx, Oklahoma 1-800-xxx-xxxx. Ask the person giving the shot if there will be any cost to you.

(cont. page 3)

FIGHT FLU and PNEUMONIA

(Continued from Page 2)

Here are 5 reasons why:

1. The flu is serious business. Influenza (commonly called the flu) is not just a runny nose or upset stomach. It is a serious illness that can lead to pneumonia. At least 45,000 Americans die each year from influenza and pneumonia, the sixth leading cause of death in the United States. 90% of these deaths are among people 65 years of age or over.
2. The flu can be very dangerous for people 65 and older. People 65 years of age or over should get a flu shot, unless they are allergic to eggs. It's also important for those with a chronic illness, and for those who spend a lot of time around sick or elderly people.
3. **A flu shot is safe and helps you protect others.** Flu shots are safe and effective. And when you get a flu shot, you help yourself and those around you. By avoiding the flu, you avoid giving it to friends and family.
4. **The flu can make you "blue."** Even if you don't develop serious problems, the flu can make you feel bad for days. It can cause fever, chills, headache, cough and sore muscles.
5. **Medicare Part B pays for it.** When you have Medicare Part B and you get your flu shot from a Medicare provider, you pay no "coinsurance or deductible." Also, if the person giving the shot agrees not to charge more than the amount Medicare pays, you pay nothing. Medicare Part B also pays for the pneumococcal vaccination. Ask your health care provider about both of these vaccines. (Note: HMO members may be required to get shots from their HMO. Ask your HMO for more information.)

Influenza is most common in the U.S. from December to April, so it's best to get the flu shot from October through mid-November. The vaccine begins to protect you after 1 to 2 weeks.

Do I need a flu shot every year? **YES.** Although only a few different influenza viruses circulate at any given time, people continue to become ill with the flu throughout their lives. The reason for this continuing susceptibility is that influenza viruses are continually changing, usually as a result of mutations in the viral genes. Each year the vaccine is updated to include the most current influenza virus strains. The fact that influenza viruses continually change is one of the reasons vaccine must be taken every year. Another reason is that antibody produced by the person in response to the vaccine declines over time, and antibody levels are often low one year after vaccination.

PNEUMONIA: Some of these same groups of people should receive one-time vaccination for pneumococcal pneumonia. The groups at higher risk for invasive pneumococcal disease include those over 64 years old and others with increased susceptibility to this infection, such as patients with HIV, splenectomy, sickle cell disease, **diabetes mellitus**, chronic disorders of the lungs or heart, and cirrhosis. You can receive this vaccination on the same day that you get the flu shot. For those covered under Medicare Part B, it is also free when ordered by a physician. However, the pneumococcal vaccine can be given at any time of year and is a once-in-a-lifetime vaccination for most people. If you don't have a spleen, or if you have **chronic renal failure**, HIV, cancer, or other diseases that compromise your immune system, **ask your health care provider if a second pneumococcal vaccination is necessary.**

ASSISTANCE WITH RENAGEL®

The AKF and Genzyme Corporation have launched the Renagel® Patient Assistance Program (RPAP). The program is designed to assist patients who have no alternative way to pay for Renagel® by any other source. Referrals must be made by application by your nephrologist and through your social worker. For more information contact the AKF's Patient Services Department at 1-800-638-8299 extension 6674 or go to the AKF's website at www.kidneyfund.org.

EMERGENCY PREPAREDNESS

All patients should review and be familiar with their facility's disaster plan. It will be important that your facility has contact with the local Emergency Management Authority to be informed of what to do in the case of any bio-terrorist activities that could occur in the community. You need to request that the staff review and have a drill for any disaster that could affect power and/or water. It will be important to know how the facility plans to have needed supplies if the transportation system is shut down or air travel is suspended again. The HCFA publication 10150, Preparing for Emergencies: A Guide to Patients on Dialysis should be reviewed. If your facility needs copies, the social worker can contact HCFA by fax at 410-786-1905 to place an order. The better prepared you and your facility are, the less disruption will occur in the event of a disaster.

WARNING: Many people are attempting to get the antibiotic CIPRO due to the ANTHRAX scare. Precautions must be taken as the misuse of CIPRO can lead to kidney disease or kidney failure. Always consult your doctor before taking any medicine. Let your family and loved ones know the risk of the misuse of this antibiotic. Never take any antibiotic without a prescription. (American Kidney Fund)

Network 13 PAC Members (continued from page 1)

available. You are the one that possesses the unique information about how you are experiencing the illness, and how it affects your body and daily life. The combination of these two facets working together equals your individual healthcare plan for living long and well with this disease!

Heather Powell, PAC Member

Another PAC member attended the AAKP Convention. She attended programs that covered kidney transplant and diabetes.

Diabetes is a newly -diagnosed condition for Edna and she attended a lunch with the experts, "Living Well with Diabetes", to discuss this topic. She learned new and useful information that she had not received since her diagnosis last year.

Dr. Friedman addressed such issues as the need for annual eye exams to detect, monitor and treat any condition caused by the diabetes that affect the vision of the patient. Blindness can occur if such monitoring is not done. Another area discussed is the importance of monitoring your blood sugar as instructed by your treating physician. This will allow the patient to take the necessary action, either oral medication, insulin shots and/or dietary modifications to ensure their blood sugar level remains in a "safe zone". Dr. Friedman pointed out the need for regular foot exams as diabetes affects the circulatory system and you can lose the sense of feeling in your extremities. This could result in getting a cut or other injury to your feet that you are unable to feel that, left untreated, could result in infection. These types of infections can lead to gangrene and the need for amputations. It is up to the patient to be involved and to monitor their blood sugar, adhere to their diet and to get regular eye and feet exams to avoid the complications of diabetes.

"Focusing on Your Transplant Medications" was another session attended. Participants in this session learned the importance of their immunosuppressive medications in maintaining their transplant. The importance of taking your medication as ordered was stressed to avoid complication and rejection. Resources for immunosuppressive medications were discussed with participants.

Edna Whitehead, PAC Member



KIDNEY KONCERNS NEEDS YOU!

Kidney Koncerns is published quarterly by the Patient Advisory Committee of ESRD Network 13. The next edition is scheduled for WINTER/JANUARY. To make this newsletter a success, we need your assistance. If you are interested in contributing to this newsletter, please send any articles, materials and/or ideas to:

Kidney Koncerns
ESRD Network 13
6600 N. Meridian Suite 155
Oklahoma City, OK 73116-1411
1-800-472-8664
<http://www.network13.org>

This newsletter is developed while under contract with the Centers for Medicare and Medicaid Services, Baltimore, Maryland. CMS Contract #500-00-NW13.