



RENAL OUTREACH

ESRD Network 9/10

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Quality First – Patients Driving Excellence

By Lorraine Edmond – 2005 Robert Felter Patient Award Winner



Lorraine Edmond (l.) pictured with Susie Stark, The Renal Network, Inc. Executive Director at 2005 Nephrology Conference Award Luncheon.

My name is Lorraine Edmond. We met in the last issue of Renal Outreach when I was presented the 2005 Robert Felter Memorial Award! This award gave me a chance to attend The American Association of Kidney Patients (AAKP) Annual Conference that was held this year in Las Vegas, Nevada, September 1st – 4th. This was a well-attended event for kidney patients and their families. It featured educational sessions with top-notch healthcare professionals and social activities.

AAKP's mission is to improve the lives of fellow kidney patients and their families by helping them to deal with the social, emotional, and physical impact of kidney

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Playing Hide and Seek with Phosphorus: a Serious Game

By Beth Fry, RD, LD

Phosphorus control is a very important factor in your long term health. You try hard to keep your phosphorus levels down. You limit your high phosphorus foods. You avoid many of them completely—you've even kicked the cola habit! You take your phosphorus binding medication faithfully at each meal and snack. You remember to carry your binders with you when you eat away from home. You watch your dialysis adequacy numbers each month (Kt/V or %URR) to make sure you are well dialyzed. Still, your phosphorus won't stay down in the recommended range of 3.5—5.5 mgs%.

What's wrong? It is no longer enough to just avoid naturally occurring phosphorus, and take phosphorus binding medication when you eat. Phosphorus may be hiding in foods you thought were "safe"—foods that are not on your high phosphorus food list. The general public is demanding an increasing variety of convenience foods for home use. In addition, fast food menus have expanded, and entertainment centers (malls, movie theaters, etc.) offer many quick meals and snacks.

To meet the public demand, the food manufacturers have increased their reliance on phosphorus containing additives to enhance

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Pneumonia Knows No Season!

Unlike the flu, pneumonia is not a seasonal disease – it can strike at any time. For this reason, the vaccine can be given any time during the year.

What is Pneumococcal Polysaccharide Vaccine (PPV)?

PPV is a recommended vaccine for adults and offers protection against 23 types of pneumococcal bacteria.

Adults in fairly good health who receive the vaccine will develop protection within two to three weeks of receiving the shot.

Pneumococcal bacteria can cause serious, life-threatening health problems, such as infections of the lungs (pneumonia), the blood (bacteremia), and the covering of the brain (meningitis).

Although the vaccine does not completely prevent the disease, it does reduce the likelihood of contracting the illness and its serious complications.

Who needs the PPV shot?

All adults 65 years of age or older.

Anyone with the following health problems: kidney failure and organ transplant recipients, anyone taking long-term steroids or radiation therapy, heart disease, diabetes, HIV or AIDS, cancer, damaged or no spleen, lung disease, liver disease, residents of nursing homes or other chronic care facilities.

When, where and how do I get this important vaccine?

Unlike the flu shot, this vaccine is not needed every year. For most adults 65 years or age or older, it may only be needed once in a lifetime.

For adults aged 64 years or younger, a second dose is recommended after age 65 if it has been five or more years since the last shot.



Discuss the pneumonia vaccine with your doctor and make sure your vaccine is current.

Medicare pays for the initial shot and revaccination in five years, if recommended.

Your doctor may recommend you have more than one vaccination if you have serious health problems that put you at greater risk for pneumonia.

The vaccine can be given throughout the year, not just in the fall like the flu shot. You can receive a PPV from most doctors, dialysis clinics, or your local health department. Many health care providers offer the pneumonia vaccine at the same time they offer the flu vaccine, but it is not necessary to wait until the fall to get the PPV.

If your doctor has not recommended the PPV for you and you are in one of the categories in the list of “Who needs the PPV,” ask your doctor or pharmacist about it.

For more information, ask your nephrologist or dialysis nurses, or call your state or local health department or the Centers for Disease Control and Prevention (CDC) at 1-800-232-7468 (English) or 1-800-232-0233 (Español), or Medicare at 1-800-633-4227.

If you do not know if you have received a pneumonia vaccine, check with your doctor or nurse.

Source: Centers for Disease Control and Prevention.

Phosphorus: a Serious Game (cont'd)

shelf life, decrease cooking or preparation time, enhance food texture, or improve flavor acceptability. The forms of phosphorus used in processing are very absorbable—even more absorbable than the phosphorus found in milk or cheese. Reading the package nutrition labeling will NOT alert you to the phosphorus content of foods. The government requires processed foods to be labeled with specific nutrients. Unfortunately, phosphorus (as well as potassium) content is not required to be labeled. It is estimated that you can unknowingly consume up to 1000 mg. of phosphorus with the use of processed foods. This alone likely exceeds your diet guidelines for phosphorus!

How can you find the hidden sources of phosphorus in your diet? You must read the ingredient listing to identify phosphorus additives. Look for words such as:

- Phosphoric acid (in carbonated beverages)
- Monocalcium phosphate
- Poly phosphates
- Pyrophosphates
- Sodium phosphate
- Sodium polyphosphate
- Sodium triphosphate
- Tricalcium phosphate
- Trisodium phosphate

Processed foods with high phosphorus levels include foods such as:

- Canned refrigerated bakery products
- Hot chocolate mix
- Chicken nuggets, breaded meat items
- Biscuit mix
- Any variety of bologna or hot dogs
- Breakfast bars
- Cheese flavored snack foods, such as:
 - Cheese peanut butter crackers
 - Cheese and crackers
 - Cheese filled pretzels
 - Cheese puffs
 - Cheese crackers
- Instant pudding
- Instant sauces
- Pancake mix
- Processed cheese
- Processed spreadable cheese
- Granola bars

Take time to **read the labels on your beverages** to make sure they don't have phosphorus added. Suspect items include:

- Bottled iced tea
- Sports drinks
- Non-cola carbonated beverages
- Flavored water
- Fruit punch
- Fruit drinks
- Flavored cola (cherry, vanilla, etc.)

What's left? The best strategy is "back to basics". Avoiding processed foods will also likely lower your sodium intake. Use fresh meats that you must season and prepare yourself. Use cornmeal or seasoned flour to coat meats, fish, or chicken. Make your "back to basic" meals in bulk, and freeze the unused portions for a quick meal on another day.

disease. The patient members of AAKP provide mutual support to one another and educate new patients about the disease.

I arrived at the J.W. Marriott Convention Center on Thursday, September 1st. I received a warm welcome at the registration desk for attendees. I was given a briefcase containing all materials needed for the convention. My name badge identified me as a very important person and a first time attendee. GEE Whiz!

I made many new acquaintances and friends all evening, which had begun the moment I stepped onto the hotel shuttle from the airport! I met Dr. Stephen Z. Fadem, the AAKP Vice President, when he asked if he could join my family and me for lunch.

My first day of sessions began Friday, September 2nd at 7:45 a.m. The day started with a continental breakfast, visiting exhibits, meeting vendors, receiving samples, and educational materials. There was a game booth where a twenty-dollar donation for Hurricane Katrina relief fund was given each time a participant played "Slinko". Each participant received a nice gift such as a blanket or key lights. Friday's sessions were filled with six workshops, all of which were excellent!

One workshop was "Your Options, Your Choice": Treating Kidney Failure, presented by Dr. Amy Friedman and Keith Norris M.D. They presented an overview of ESRD and the role of renal replacement therapies. They discussed nephrons (the working units in the kidney), how your body system is affected by uremia, and how very important it is for patients to receive early patient education and learn steps for renal replacement.

They talked about choice of dialysis modality, specifically : 1) In-center hemodialysis,

2) Peritoneal Dialysis (PD), and 3) Home Dialysis.

They also discussed physical and social barriers affecting the delivery of adequate dialysis. All points at this workshop were excellent. At the end of all workshop sessions, there was open mike time for patient's questions and comments. Many patients shared that they were never given an option or a choice of modality and how much they appreciated the information gained from the session. There continues to be increasing incidents of ESRD with diabetes and hypertension remaining the leading factors. Friday's workshop sessions ended at 5:30 p.m.

On with the social event - We attended a fun filled "Welcoming Ceremonies and CKD Awards Presentation" Friday night from 7-10 p.m. The theme was "Viva Las Vegas". We were asked to come dressed in Vegas style attire. There was a costume contest and prizes were given. We were greeted in the Valencia Ballroom by hostesses dressed as Black Jack dealers. The dining experience was excellent.

There were twelve contestants who opted for Best Costume, including yours truly! I was dressed as a 1st time tourist gambler equipped with a money belt, maps, money T-shirt, sun visor, glasses, camera, binoculars, dime earrings and even more! I did not stand a chance. The first prizewinner had the same idea. Oh well, maybe next year I'll return a winner!

Our own Dr. Jay Wish, The Renal Network president, was presented with the prestigious "AAKP Visionary Award" which was created to pay tribute to a physician for his or her outstanding performance on CKD education.

Edmond (cont'd)

All cares were cast away as patients spun around the dance floor “Tripping the Light Fantastic” to the sounds of the DJ.

Saturday, September 3rd, started out the same as Friday. There were a total of five sessions that day and we could choose between topics for each session. This proved to be a difficult decision because each topic seemed to be promising and inspiring.

On Saturday I chose to have “Lunch with Experts” and the topic I chose was the “Emotions of Kidney Disease”. The expert was Dr. Mary Heisick, MSW. We had a very nourishing lunch and discussion. We discussed how CKD is catastrophic and our losses are great. Thus, we have to learn to grieve them. Acknowledging them is an important part of grieving. Sharing our feelings with another CKD patient and our families can help us to heal and get on with life.

There are many things we see as losses when first diagnosed. A few of them include: Loss of physical or mental well being, time, freedom, libido, control, income, and “I can’t do what I use to do.” There also are many emotions of loss we experience:

- Denial
- Anger
- Bargaining
- Depression
- Acceptance

We discussed many things to help resolve these issues. Everyone at our table shared their emotions, both new patients as well as veteran patients. The three main emotions many felt were:

- Anger
- Depression
- Suicidal thoughts

Please remember there is *LIFE* after kidney failure! Take charge and play the hand you’ve been dealt!

Saturday night was the Awards Banquet. It was an elegant affair. We began the evening with cocktails served on the beautiful terrace. Dinner was served at 8 o’clock followed by the awards ceremony.

All too soon it was Sunday and time for the President’s Breakfast and Special Presentations. Patients shared addresses, phone numbers, hugs, kisses, best wishes, and parting words of “see ya soon” as they departed and vowing to remember to continue to live by the conference’s theme of “Quality First and Driving Excellence.”

I stayed over an extra day at my own expense to experience Las Vegas. Oh yes, I played the nickel slots and won 2,700 nickels! I played five dollars and won \$134.00. What? Of course I brought it home!

Smile!

To learn more about AAKP’s programs, activities and resources:

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Kris Robinson, Executive Director

D-I-A-L-Y-S-I-S Poems

At the Centers for Dialysis Care (CDC) in NE Ohio, patients recently were encouraged to show off their creative side and share their ideas, hope and fears with others in their same struggle. CDC Activity Specialists, in charge of all things festive, put together an acrostic poetry contest for all the patients. In an acrostic poem, the first letter of each line spells a work vertically down the page, which is the theme of the poem. Of course, this contest used the word 'DIALYSIS'.

Among the eight facilities that participated, there were over one hundred entries. The Activity Specialists were charged with the difficult task of judging them. The smaller units picked one winner while the larger units chose a first and second place winner. Poems were judged for creativity, theme, and style. First place winners received a \$20.00 Wal-Mart gift card. But, the biggest reward here is: *the sharing of ideas*. Many patients who, after reading the poems, felt encouraged, entertained, or just relieved that they are not alone in their worries. CDC patients and staff sincerely hope they have the same effect on you. Here are the winning entries.

Mentor

Day to day changes in my lifestyle
Initially it can be scary
Acceptance is reachable
Life sustaining
Yes it is tedious
Sacrifices are many
I can do this
Striving to make my life better



George Wilson, 1st Place

Dialysis day is here again
I'll soon be talking with my friends
All of us patients have joys and sorrows
Let us live for each new tomorrow
Yesterday has come and gone away
Sun rises to a bright new day
I'm grateful for the time I have to share
So much family to love and care

Marge Cianfaglione, 2nd Place

Shaker

Do you feel down and out?
In a bad mood most of the time?
At CDC Shaker
Let them ease your mind
You see they treat you so special
Staying focused on your every need
Insisting on helping and attending
Standing by you – yes indeed.

Joyce Dayse, 1st Place

Daily I sit and thank God
Initially for my health, which is odd
Actually many people don't do that
Luckily I see a different fact
You know if it wasn't for this I wouldn't be able to
Successfully say that with prayer every day is "A" new
Instantly things will change for you
Simply by staying prayed up

Carolyn S. Hayden, 2nd Place

Warren

Dialysis at first brought me fear
I was reassured by kind words.
And grateful for the hard work of my team
Lying here is so hard some days.
You can't think about it.
Sleep if you can.
If I just stay, I'll live.
So hook me up and get that pump moving.

Eleanor Davis

Warrensville-Heights

Dialysis the extension of your life and dreams
Imitating your kidneys for endless hours it seems
Although it seems to take up valuable time
Lets face it without it we wouldn't be fine
Yes it's a chore to plan each day
Schedule this, do that, find time for the kids to play
Instead of feeling bad about your situation
Smile and make a new friend sitting at the next
station

Scott Tuma

Canfield

Donors are generous, thoughtful and kind
I know they're in heaven in a long line
Angels are donors of every kind
Lives are happier you will find
You may need a kidney, lung or heart
Someone is willing to give you that part
I know it's a blessing for those that care
So lets say a prayer for donors everywhere



Sylvia Riley, 1st Place

Did you every wonder
If the day will finally come
After all you've hoped and prayed for
Life's battles so troublesome
You try to keep your spirits high
Sometimes it tears you up inside
Is your faith enough to keep you strong
Still you sometimes feel so denied

Michael L. Yarnell, 2nd Place

Euclid

During my treatments
I sit and think, there is
Always a kind
Loving, caring someone
Yearning to care for me and
So many others, so now
I want to
Say thank you, for all you do to take care
of me God Bless!

Carol "CJ" Palladino, 1st Place

Do all you can to help yourself and others
Ideas to make your life better
Always be there for others
Love will get you through
Yesterday is gone, live for today and
tomorrow
Smile and make the best of it
Is this making your life better and longer
Stand up and be counted, and live life to
its fullest

Betty Perry, 2nd Place

*Poems submitted by Jessica Abbott ,
CDC Activity Specialist , and reprinted with
permission.*

Phosphorus: a Serious Game (cont'd)

A homemade leftover meal can be quick, convenient, and lower in cost than the high sodium, high phosphorus meal you buy pre-prepared.

Remember that in most cases, tap water is a beverage alternative. Well water may contain high levels of phosphorus and calcium—check with your doctor. Do NOT use softened water if at all possible, due to the normally high sodium content. Heavy reliance on pop, fruit punch, sports drinks, etc. may be adding quite a bit of hidden phosphorus to your diet.

It may not be possible to avoid all processed foods completely. If this is the case, use caution, be selective, and pace yourself. Eating a lot of processed food at one time will have a bigger impact than a small portion eaten infrequently. When ever you can avoid a processed food or beverage, you are taking a big step towards reaching your phosphorus goal!

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