Lexi’s Story

Fun In The Sun
With History As Her Guide
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Features

Cover Story

Lexi’s Story

Lexi Martinez is an active, outgoing 7-year-old. At the age of 5, she was diagnosed with fibromuscular dysplasia (FMD). FMD causes abnormal cellular development or growth in the walls of arteries, and is usually found in the arteries that supply the kidneys with blood. We will learn more about FMD, and about this remarkable young patient who does not let her diagnosis slow her down.

Feature Article

Fun In the Sun

By Amy L. Friedman, MD

Amy Friedman, MD, discusses the importance of limiting sun exposure and provides tips on protecting ourselves against the effects of the sun.

Patient Profile

With History As Her Guide

In 1968, Andrea Zislen was a candy striper at Kings County Hospital in New York. Andrea recalls the now-famous dialysis patients she interacted with as a volunteer. Andrea is now a kidney patient as well, and tells her remarkable story.

Food For Thought

Enjoy the Outdoors for a Springtime Barbeque!

By Mansi Mehta, RD, LDN

There is the smell of fresh air and the feel of wet grass beneath our toes that lets us know spring is here again! Some patients trying to stay loyal to a strict renal diet may find this time of the year difficult. Mansi Mehta helps us answer the question, “Can I have fun without these foods?”

Columns

President’s Message

Executive Director’s Note

Dear Doctor

Kidney Kids

Feature Article

Patient Profile

Washington Report

Food for Thought

Departments

AAKP News

Life Membership

AAKP Chapters
president’s message

I hope this message finds you all in good health. I would like to introduce myself. I am Bobbi Wager. I am a transplant patient and the new AAKP president. I am so pleased to be a part of this wonderful organization helping patients like you remain as active and healthy as possible.

This month AAKP hosted the 12th Annual Medal of Excellence Award Dinner in Baltimore, MD. The Medal of Excellence Award is AAKP’s most prestigious honor, and this year AAKP honored Robert Fennell, MD as the recipient. For more than 30 years, Dr. Fennell has exemplified the best in the field of pediatric nephrology. As Professor and Chief of the Pediatric Nephrology Division of the University of Florida College of Medicine, he is known by his fellow colleagues as the “consummate hands-on clinician” who is regarded as one of the most outstanding teachers, scholars and healers.

AAKP is also working very hard to plan for its 34th Annual Convention. Mark your calendar now! The Convention will be in St. Louis, MO, from Aug. 30 – Sept. 2. Whether you’re a CKD patient, a long-term dialysis patient or a transplant recipient, you’ll want to join us in St. Louis to learn all you can about a variety of important topics. Of course, the Convention will feature exciting social events as well. I hope to see you there!

Once again AAKP has partnered with Ortho Biotech, L.P. to host the popular Kidney Beginnings: Live program for 2007. Kidney Beginnings: Live is a FREE, educational program developed for those who have recently been diagnosed with reduced kidney function, those with risk factors for chronic kidney disease (CKD) such as diabetes and/or hypertension, or those who have a family history of kidney disease. AAKP has added dates to the program, and you can find a list of locations across the country in this magazine (Page #15).

Best wishes to you all, and may your Spring 2007 be safe and healthy!

Bobbi Wager, RN, MSN

executive director’s note

Isn’t the picture on the cover of this issue just too adorable? Every time we spotlight a child’s story I am truly moved and amazed by the incredible strength children have. Lexi has a tremendous spirit that outshines the challenges of kidney disease and is an inspiration to all of us as adults.

There’s something different about being a child with kidney disease. I was diagnosed when I was 5 years old with a single small kidney. I never really thought anything of the doctor visits and tests. I can only imagine how my parents worried. All I really knew was that Monkey Bars, Dodge Ball and other contact sports were not a part of my life. I really don’t think Dodge Ball would have been one of those sports I would have taken up, anyhow!

Lexi reminds me of the importance of not taking life too seriously. She is a strong young lady who has not made her kidney disease the focus of her life. It is a lesson from which we can all learn. For all of us, fun should come first; laughter should ring often and life should be lived.

Kris Robinson
**Why does salt cause high blood pressure?**

**Answer:** When we look at our modern way of life, we must admit we have come a long way. Yet, while we have developed a culture based on fast foods and supermarkets, our kidneys have not really changed. They were originally designed to enable ancient ancestors to concentrate urine in order to become more mobile on land, i.e. to wander away from the lake or pond to forage for food. The kidneys also adapted to climate - becoming more efficient at retaining sodium (a component of salt) in hot, dry climates. In summary, the kidney was designed to balance the salt intake naturally occurring in foods with body needs. Travel throughout Africa and visit the archeological sites where Robert Leaky did his excavations. You will never find a salt shaker there!

*Why salt?*

Refrigeration is a novel convenience. Historically, food was salted to preserve it. Fish not salted would spoil before it was brought to market. Milk was always a vital nutritive staple, and the making of cheese, the process to preserve it, requires salt. Hence, prior to refrigeration, salt was a necessary commodity enabling agriculture to develop.

*The physiology of salt*

Eating as we do, many people accumulate more salt and water than their kidneys can handle. Some people have genes that control cellular channels, enzymes and hormones at various sites in the kidney, conserving salt to enable adaptation to the hot, dry savannah. In order to remain active, one had to control body temperature. If water and salt were scarce, the kidney would conserve salt to retain fluid used to coat the body with sweat during activity. As sweat evaporated from the skin, it would cool the skin and keep body temperature normal. Without sweating, the body would quickly overheat during activity. However, those genes necessary in our early development mistakenly conserve salt regardless of the environment. As long as excessive salt is ingested, it will be disproportionately reabsorbed in about 20 percent of the population. Through a process known as osmosis, salt retains water. It also promotes thirst, as every bartender and movie theater proprietor knows. Excessive
Alexandra “Lexi” Martinez, of Burlington County, NJ, is an active, outgoing 7-year-old. Doctors diagnosed Lexi with fibromuscular dysplasia (FMD) at the age of 5. She was in kindergarten.

In people with FMD, the dysplasia, or abnormal cellular development or growth, involves the walls of one or more arteries in the body. FMD is usually found in the arteries that supply the kidneys with blood, or renal arteries, although it can also be found in arteries that supply the liver, spleen and intestines as well as arteries in the extremities. Usually in FMD, the arteries appear as a “string of beads.”

Kevin Meyers, MD, a nephrologist at the Children’s Hospital of Philadelphia, and a member of the Medical Advisory Board of the Fibromuscular Dysplasia Society of America, says, “FMD in children affects the renal vessels far more commonly than the head and neck vessels. And this is a different pattern than what is seen in adults.”

FMD in the renal arteries may cause high blood pressure. Progression of the disease can also lead to the death of kidney tissue over time, or ischemic renal atrophy. This can eventually lead to kidney failure.

During a routine wellness check at school, the nurse discovered Lexi’s blood pressure to be unusually high for her age. The nurse called Lexi’s mother, Jennifer Martinez, and discussed the results. Jennifer is also a nurse, and immediately came to the school to check Lexi’s blood pressure herself. Jennifer then took Lexi straight to the pediatrician, and Lexi was then admitted to the emergency room. Within a week, the pediatrician and the nephrology team had their diagnosis: FMD.

“To make matters worse, at the time of Lexi’s hospitalization in May of 2005, my husband was four months into his 12 month deployment in Iraq,” said Jennifer. “I think if someone had taken my blood pressure, it would have been high, too! As they say, when it rains it pours!”

Jennifer credits her supportive and loving family with helping her get through that difficult time. “Our families stepped up to the plate when he was away. My parents and sister were at the hospital within two hours from the time I arrived at the emergency room with Lexi.”

Lexi understood she had high blood pressure, though because of her young age, did not necessarily understand that it was due to a problem in her kidneys. There is no standard procedure for treating FMD, and no cure, so Lexi
remained a strong patient while enduring a battery of tests and procedures, including many IVs, various ultrasounds, lots of blood work, many pills and an angiogram.

Jennifer reports that Lexi was a remarkable patient for being so young. “The nurse couldn’t get over the fact that she was 5 years old. Lexi just went with the flow and even said she was having a good time and couldn’t wait to pick her next meal and have it served on a tray. At the hospital, she walked around in her gown and Hello Kitty slippers as if she were at the Hilton.”

Friends and family members admired Lexi for her strength and courage, noting she never once appeared to be afraid. Now that Lexi is a little older, she understands FMD and kidney disease and what it means for her. She has been on medication to regulate her blood pressure since her hospitalization in 2005.

Lexi sees her nephrologist every three to four months. She takes an ACE inhibitor and a diuretic twice daily. Jennifer monitors her blood pressure at home every two to three days. Lexi’s condition has been stable on these medications.

Also, her kidney enzymes have remained stable. She has had two angiograms, the first during her initial hospitalization in 2005 and another in January of 2006. The second angiogram showed no significant change.

A blood test to check her kidney function is done with every visit to the nephrologist.

Lexi says one of the negatives of having FMD is “being thirsty and drinking lots of water.” She is very active, and thinks she could be a better runner if she didn’t have FMD. Lexi maintains a positive attitude, saying, “I feel like a regular person!”

Lexi and her sister, 6-year-old Abrielle, attend Southampton Township School Number One. Abrielle is a kindergartner.

Lexi loves to take dance lessons. This year she is studying Jazz. She plays soccer in the fall, basketball in the winter, softball in the spring and swims in the pool all summer long. She even plans to be on a swim team this year. Her swim teacher says she is a natural swimmer. When asked if FMD has ever held her back, Lexi said, “No!”

The Martinez family understands Lexi’s FMD and how they must all cope with it. Says Jennifer, “We all know what she has and even her little sister somewhat understands but never has it interfered with anything we do or say as a family. Abrielle can tell you what medications Lexi is taking. Abrielle even has me check her own blood pressure to make sure it is normal. I don’t think Abrielle and Lexi see it as a bad thing, just as a small issue that we all deal with as a family.”

As a nurse, Jennifer understands what FMD is and the potential of the disease. She is aware of what kidney disease is and knows the different types of
What is the ideal outside physical activity? Some patients have significant skin changes and are subject to peeling of skin and easy bruising. A more long-term problem with your skin is the occurrence of lesions related to sun exposure. All people should be very conscious about sun exposure. If untreated, these skin lesions can become cancerous. Sun blocks are available, and for those of you who cannot go without a little color, there is always sunless tanner.

Because skin malignancy is both dangerous and unsightly, all patients should avoid purposeful overexposure to the sun. Transplant surgeon and AAKP Board Member Amy L. Friedman, MD, shares with us how to have “Fun In The Sun.”

Sunlight is a vital part of the human environment that must be respected for both the wonderful advantages it brings to our health, and the dangerous consequences it may cause. As with most healthcare threats, it is safest to develop an approach to the sun that is well informed, incorporates moderation, and when needed, seeks assistance to manage negative outcomes. To do this well, you must understand both your individualized level of risk from sun exposure and the generalized amount of exposure to which you subject yourself.

Why worry about the sun? The sun is the earth’s central source of heat and light. Too much exposure to the sun will damage your skin. The long term affects of the sun’s rays include wrinkles, sagging and pigmentation, which may result in an unwanted appearance of premature aging. These affects are not dangerous. More serious damage, including burning of the skin, has both immediate and long term consequences.

Your skin is the largest organ in your body and serves as a barrier between you and the microscopic organisms (bacteria, viruses and funguses) that can cause infections. When the skin becomes burned, this protective layer is no longer intact. Your most important defense mechanism has been damaged and serious infection can result. (In fact, this is the cause of illness and even death in individuals with other types of burns). The other key function of this barrier is to help retain moisture. Burned skin causes fluid in your body to drain (the damaged area appears to weep), and if the area is large enough, may make it difficult for your body to regulate temperature.

Preventing skin cancer is the primary reason for limiting sun exposure and damage. In the United States, more than one million new sun-related skin cancers are diagnosed each year. Most of these develop in the sun bathed areas of the body which suggests that they can be prevented by avoiding their exposure. The most common locations are on the face, ear, neck, lips and backs of the hand. Several factors contribute to
your individualized risk of developing one of the skin cancers.

**What is your own risk?**

Most important is the lightness (or darkness) of your natural skin color. Melanin, the pigment that is responsible for skin color, protects against the sun’s ultraviolet rays. To classify your own skin type, answer three questions:

1. Do you easily get a sunburn?
2. Do you easily get a sun tan?
3. What are your natural skin, hair and eye colors?

Your responses determine which of six skin types you have. Those individuals with the lowest numbered categories have the least amount of pigmentation and natural sun defenses, and have the greatest risk for damage and skin cancer. Accordingly, they will require relatively more aggressive use of auxiliary protective measures.

**How strong is the sunlight?**

Another key factor to consider is the intensity of the sunlight to which your skin will be exposed. Those areas on the earth’s surface that are physically closest to the sun are exposed to the most intense rays. It is generally easiest to become sunburned in geographic regions that are hot, than those that are cool. As the earth tilts throughout the year, the location of the hottest (and closest to the sun) spots on the globe vary. It is important to recognize the impact of how elevated the specific location is, since significant heights will also shorten the distance to the sun, and increase the intensity of its rays. Standing on top of a high mountain in a very warm area will cause a greater amount of sun exposure than would be found in a cool region at sea level. The amount of sunlight is also effected by environmental factors such as surfaces that reflect light (such as sand particles at the beach), thereby increasing the amount of exposure. Finally, the factor that you are most able to alter is the length of time you spend in the sun. To understand the collective impact of these factors consider two examples. A very light skinned, blue eyed blonde individual with many freckles who spends one hour sitting on the top of Mount Kilimanjaro (located near the equator and at 5,885 meters, the highest peak in Africa) in the summer is likely to rapidly become seriously sunburned. A dark skinned, brown eyed person who spends the same amount of time in Central Park (New York City is 10 meters above sea level) during the winter is at much lower risk of becoming sunburned.

**Moderation is the key**

None of us can or should entirely avoid sun exposure. We need the effects of sunlight for adequate calcium metabolism, and for the normal processing of bilirubin, a by-product of normal red blood cell cycles. Moderation is the key. There are simple, inexpensive and effective strategies to limit these risks. Advance planning to ensure availability of the required materials should always be considered.

Which clothing you wear, what it is made of, and how much skin it covers are all factors within your control. Thus, light colors (because they reflect instead of absorbing light) and dense materials offer the most protection to skin. And uncovered skin is unprotected skin. Use of a hat to cover the vulnerable scalp, face and ears provides the dual benefit of limiting heat transfer and light exposure. The use of auxiliary devices, such as an umbrella should also be considered.
Although Andrea Zislen began being tested for polycystic kidney disease (PKD) when she was 18 years-old, her personal connection to kidney disease and the kidney community began much earlier. The day after Andrea was born in 1954, her mother had a kidney removed. By the time Andrea was 13, her mother had started peritoneal dialysis. Later, Andrea was told that her mother had likely inherited kidney disease as her grandmother also had kidney disease.

Andrea and her father would visit her mother in the hospital after school. “I was allowed to visit with the patients in the dialysis ward, and was inspired to learn more about kidney disease and what can be done for it,” says Andrea.

Because it was determined kidney disease ran in Andrea’s family she began being tested, even though there were no signs of the disease.

In the summer of 1968, after Andrea had graduated middle school, her mother was put on home hemodialysis, which her father helped administer. The head nurse at Elmhurst General Hospital had taken care of Andrea’s mother while her father was learning how to manage his wife’s dialysis at home. The nurse at Elmhurst had recently left the Kings County Hospital’s Dialysis Unit.

On one of her many after-school visits to the hospital to visit her mother, Andrea decided she wanted to become a “candy striper,” or hospital volunteer. Andrea applied to work in the dialysis unit at Kings County, but they turned her down since she was too young to work in a designated “blood-bourn area.” However, within the year, the Elmhurst nurse had been in touch with the dialysis unit at Kings County. She said it would not be a bad thing for Andrea to volunteer to work with those patients since she had become so familiar with the unit and had an understanding of hemodialysis.

Andrea can still remember the names of many of those patients: “There was Peter Lundin, studying to become a doctor; Bill Blackton, conversing with other patients; June Crowley and Jo Berman joking with each other; Edna Thornton; Sam Orenstein asking questions; Dennis Mitchell urging me to read ‘Nicholas and Alexander,’ and trying to understand the requests of Natalia Petrianyk.”

These are the same kidney patients who would one day form a group called the National Association of Patients on Hemodialysis (NAPH), which would later be called the American Association of Kidney Patients (AAKP).

In her role as candy striper, Andrea set up the bed stands with the betadine and saline solutions. She made sure that the bed stands had been cleaned and “sanitized.” She put out the cotton swabs and other important materials so the patients could get their cannulas – grafts and AV fistulas were not being used yet – ready for the nurses. After the
patients were setup, she kept them company with conversation.

And then it was time to deliver their dinners. “You see those were the days of at least 12 hours of dialysis and the patients were allowed to eat while being dialyzed,” says Andrea. “What a difference in today’s dialysis units!”

One day Sam Orenstein asked Andrea if she knew how to type and if she owned a typewriter; she did. Thus began the Kings County grass roots grievance committee.

“How did they know that years later, it would be known as AAKP and be a national organization for education and support on kidney disease?” Andrea asks.

In her junior year of college, she was hospitalized for passing a kidney stone, and that is when symptoms of kidney disease first began to surface. After years of progressing symptoms, in December of 1980, the disease had progressed in Andrea. In January of 1981, she started on hemodialysis at Elmhurst General Hospital, where years earlier her mother started.

In March of 1982, Andrea received her first kidney transplant. But overtime, she developed a number of rejection symptoms and her nephrologist decided it best to have the kidney removed. Worse, from the surgery of having the kidney removed, Andrea contracted what was known then as Non A-Non B Hepatitis, and subsequently Epstein-Barr virus. She was called for her second transplant during that time, but because of her illness she could not be considered for surgery. So she waited until 1991 when she was finally called again; a matching kidney was ready for her. Andrea rejected this transplant as well, and remained on dialysis. In 1992, Andrea moved to Florida and kept her name on the transplant lists in New York. After some time, she added her name to the transplant waiting list in Florida, too. The wait paid off for Andrea in 1997 when a transplant team in Orlando performed her third kidney transplant. After nearly 10 years, Andrea considers this transplant a success.

But Andrea again reminds us of the early leaders in the kidney community she worked with as a candy striper in the dialysis unit of Kings County Hospital.

“Oh, how we must thank Shep Glazer for having the guts to go dialyze on the floor of the House of Representatives! How else would we have had Medicare and Social Security Disability support for this disease?”

Andrea has had joint problems, needing both knees replaced. She has fractured numerous bones from falling. Andrea is also a breast cancer survivor, and she has peripheral neuropathy in her feet. Despite this, Andrea maintains a positive attitude toward her life.

“One of the most important things I constantly tell patients is that each must be their own advocate. They must be the squeaky wheel that gets the oil. They must voice their discontent; they need to keep their own records of chemistries and nutritional diets; they need to ask questions as well as demand answers.”

"Oh, how we must thank Shep Glazer for having the guts to go dialyze on the floor of the House of Representatives! How else would we have had Medicare and Social Security Disability support for this disease?"
A New Congress Takes a New Look at Kidney Care

By John A. Schall

Certainly one of the most important stories in Washington in 2007 is the Democratic takeover of both Houses of Congress for the first time in 12 years.

A new Congress means a new direction for many areas of healthcare policy. For instance, we will see legislation to allow the reimportation of drugs into the United States, and to lift the ban on government negotiation of prices for prescription drugs under Medicare.

The New Lineup

The new players assuming power in the 110th Congress will have an important impact on renal care as well. With the new Democratic control of Congress comes a slate of new Democratic chairmen of congressional committees. Fortunately, many of these new committee chairs are familiar with and supportive of critical kidney care issues.

In the House of Representatives, Rep. Charlie Rangel (D-NY) takes over as Chairman of the powerful Ways and Means Committee. Many years ago Congressman Rangel served as an honorary chairman of AAKP and he remains an important ally on our issues.

Rep. Pete Stark (D-CA) now chairs the Ways and Means Health Subcommittee. Congressman Stark and his staff have already indicated to AAKP that he wants to push ESRD legislation in this Congress, possibly to have Medicare coverage kick in earlier in the process of chronic kidney disease (CKD). Rep. Dave Camp (R-MI) has been named the ranking Republican on the health subcommittee – good news considering Rep. Camp’s sponsorship of bills to extend immunosuppressive drug coverage and improve quality of care in previous years.

On the Senate side, Senator Max Baucus (D-MT) has become...
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Food For Thought

Enjoy the Outdoors for a Springtime Barbeque!

By Mansi Mahta, RD, LDN

The sun is shining brighter, the air is getting warmer and tiny colorful tulips have begun to bloom. Spring, one of our favorite seasons, is here again. Happy memories come to mind with the smell of the fresh air and feel of the wet grass beneath our toes. So let’s load our grilling gear and get ready for some barbeque-entertaining with our loved ones!

Some of us trying to stay loyal to our renal diet may find this time of the year rather demanding. Potato salads, baked beans, melons, pickles, relishes and hotdogs – they can all be high in phosphorus, sodium and potassium. Hence, the million-dollar question is: Can I have fun without these foods?

Here are a few helpful suggestions to take the burden off that crucial question:

• Cut back on what you eat at other meals during the day so you can eat a little extra at the barbeque event.

• Choose lower sodium foods, such as chicken and lean hamburgers versus sausages or hotdogs. Go ‘easy’ on sauces like barbeque sauce or steak sauce and instead use mustard, light or reduced-sodium sauces.

• Use smaller cup sizes (4-ounce) and drink ONLY when you are thirsty. Try sugar-free sour candy, sugar-free gum and frozen grapes or blueberries to help moisten your mouth. If your physician has approved alcohol usage, drink in moderate amounts and remember to include it in your fluid allowance. Stay away from high potassium (tomato juice, orange juice) and high phosphorus mixers (colas). Clear and club sodas serve as good alternatives.

• Don’t forget to review the list of ‘high potassium’ foods and ‘allowed’ potassium fruits and vegetables. Be careful with portion sizes.

Food safety takes a priority during cookouts:

• Proper hand washing (for at least 20 seconds) with soap and water. Moist towelettes and hand sanitizers (with more than 60 percent ethyl alcohol) can prove to be handy.

• Keep cold foods cold (40 degrees Fahrenheit). Stock-up coolers with plenty of ice and ice packs. Compared to the hot car-trunks, an air-conditioned back seat may be a better choice for transporting those coolers. Limit the number of times the coolers are opened.

• Pack perishables and non-perishables separately. Raw meat, poultry and seafood should be securely wrapped to keep their juices from cross contaminating other foods.

• Marinate foods in the refrigerator. Avoid re-using marinades unless it is boiled first to destroy bacteria.

• Keep everything clean. Make sure your grill is clean and sanitized before you start. Use separate platters and utensils for raw and cooked foods.

• Use a meat thermometer to ensure the meats are cooked to a safe internal temperature. For example, cook whole poultry to 180 degrees Fahrenheit; cook chicken breasts to 170 degrees Fahrenheit; cook ground meat to 160 degrees Fahrenheit; cook beef, veal, lamb steaks, roasts and chops to 145 degrees Fahrenheit; cook pork (all cuts) to 160 degrees Fahrenheit; always reheat to 165 degrees Fahrenheit.

• Last but not the least; remember to limit your cheese and dairy food intake, and take your phosphorus binders. Check with your renal dietitian if they need to be adjusted for quantity of food.

For springtime recipes, see next page.

References:

Mansi Mehta, RD, LDN, has 10 years experience as a dietitian. She is working as a renal dietitian with Fresenius Medical Care in Chicago.
For great recipes anytime of year, log onto www.aakp.org to order your free copy.
Hamburger Cajun Style

Servings: Hamburger, serves 4 / BBQ sauce, serves 8
Serving size: 1 burger takes 2 tablespoons of BBQ sauce

**Hamburgers:**
- 1/4 cup Low cholesterol egg
- 1/4 cup White breadcrumbs
- 1 tsp. Tabasco® sauce
- 2 tbsp. Chopped onion
- 1/2 tsp. Chili powder
- 7 oz. Lean ground beef
- 2 tbsp. Low-sodium BBQ sauce
- 2 (in number) Lettuce leaves
- 2 (in number) Hamburger buns

**BBQ Sauce:**
- 1 tsp. Packed brown sugar
- 1/4 tsp. Ground cumin seed
- 1 tsp. Margarine
- 1/4 cup No-salt added catsup
- 1/4 cup Regular catsup
- 1 tsp. Prepared mustard
- 1/4 cup Minced onion
- 1 tsp. Ground coriander
- 1/2 cup Water
- 1/2 tsp. Black pepper
- 1 tbsp. Liquid smoke
- 2 tbsp. Cider vinegar

Burger preparation:
- Mix egg product, ground beef, breadcrumbs, onions and chili powder in a bowl.
- Form into patties and cook 3-4 inches from heat until done.
- Mix Tabasco® sauce with low sodium BBQ sauce for a Cajun style taste. Spread on broiled hamburgers.
- Serve hamburger on a bun with sauce and lettuce.

**BBQ sauce preparation:** Melt margarine in a heated non-stick pan. Sauté minced onion. Add rest of the ingredients and simmer for 5 minutes, stirring occasionally. Makes 1 cup. (Prepare in advance).

Now on [www.aakp.org](http://www.aakp.org), *Kidney Friendly Comfort Foods: A Collection of Recipes for Eating Well with Chronic Kidney Disease*. The cookbook focuses on preparing meals low in phosphorus, while offering healthy tips, and delicious and easy to make recipes for patients and their families to enjoy. Celebrity Chef Katie Lee Joel contributed six recipes to the cookbook. They include:

- Spiced Zucchini Pineapple Bread
- Breakfast Burritos
- Turkey Meatloaf
- Crispy Cornflake-Crusted Fish
- Apple Cobbler
- Strawberry Pie

You can log onto [www.aakp.org](http://www.aakp.org) to order your free copy.

**BBQ sauce preparation (prepare in advance):**
Spray non-stick pan with cooking spray and sauté the onion and garlic. Remove from heat and stir in remaining ingredients. Return pan to heat and bring mixture to a boil. Lower heat and simmer for 3 minutes. Stir frequently to prevent sticking.

**Potato Salad**

Servings: 4
Serving size: 1/2 cup

- 2 tbsp. Sweet pickle relish
- 1 tsp. Celery seed
- 1/3 cup Chopped onion
- 2 cups Leached potatoes (see instructions)
- 1/3 cup Diced raw celery
- Paprika for garnish
- 1/4 cup Reduced fat mayonnaise

Preparation:
- Boil leached potatoes (use 5 cups water for each cup of potatoes), until tender but not mushy.
- In a bowl, mix together relish onions, celery, mayo and celery seed. Toss in potatoes.
- Sprinkle with paprika. Refrigerate to blend flavors for at least one hour.

Leaching instructions: Peel, cut into small pieces, exposing as much surface area as possible. Rinse in warm water for a few seconds. Place potatoes in a large container and add large amount of tap water (use 10 cups water for each cup of potatoes). Soak for 2-4 hours at room temperature. Drain and rinse the leached potatoes.

Hamburger Cajun Style

Servings: 4
Serving size: 1 piece

**Chicken Thighs:**
- 1/4 cup All-purpose flour
- 1 tsp. Mrs. Dash® extra spicy herb seasoning
- 4 skinless Chicken thighs
- 2 tsp. Melted margarine

Cooking spray

**Preparation:**
- Combine flour and Mrs. Dash® herb seasoning in a paper bag. Add chicken thighs and shake to coat.
- Place chicken thighs on grill and drizzle with margarine. Broil 3-4 inches from heat until almost done.
- Make the BBQ sauce and pour over chicken (after about 25 minutes) and continue grilling until done.

**BBQ sauce preparation (prepare in advance):**
- Spray non-stick pan with cooking spray and sauté the onion and garlic. Remove from heat and stir in remaining ingredients. Return pan to heat and bring mixture to a boil. Lower heat and simmer for 3 minutes. Stir frequently to prevent sticking.

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Servings: 4
Serving size: 1/2 cup

- 2 tbsp. Sweet pickle relish
- 1 tsp. Celery seed
- 1/3 cup Chopped onion
- 2 cups Leached potatoes (see instructions)
- 1/3 cup Diced raw celery
- Paprika for garnish
- 1/4 cup Reduced fat mayonnaise

Preparation:
- Boil leached potatoes (use 5 cups water for each cup of potatoes), until tender but not mushy.
- In a bowl, mix together relish onions, celery, mayo and celery seed. Toss in potatoes.
- Sprinkle with paprika. Refrigerate to blend flavors for at least one hour.

Leaching instructions: Peel, cut into small pieces, exposing as much surface area as possible. Rinse in warm water for a few seconds. Place potatoes in a large container and add large amount of tap water (use 10 cups water for each cup of potatoes). Soak for 2-4 hours at room temperature. Drain and rinse the leached potatoes.
Kidney Beginnings: Live

Did you know that family members of end-stage renal disease (ESRD) patients tend to be at a higher risk for chronic kidney disease (CKD)? ESRD patients should encourage their family members to attend Kidney Beginnings: Live, a FREE educational program that educates individuals about the basics of kidney disease and proper kidney care. Programs last approximately three hours and feature presentations given by healthcare professionals. In addition, attendees have the opportunity to ask questions in an open forum setting.

AAKP is pleased to offer the Kidney Beginnings: Live program as an extension of our Kidney Beginnings educational series which includes Kidney Beginnings: The Magazine, Kidney Beginnings: A Patient’s Guide to Living with Reduced Kidney Function and Kidney Beginnings: The Electronic Newsletter.

For more information about Kidney Beginnings: Live or if you would like us to consider your area for a future location, please contact Diana Clynes at (800) 749-AAKP or dclynes@aakp.org.

Take Charge of Your Healthcare with AAKP My Health™

Your healthcare information is a valuable tool for you, your family and your healthcare team. AAKP My Health™ is a free, unique section of the AAKP Web site (ww.aakp.org) that provides you with the online tools to be a leader in your healthcare.

The tests and charts within AAKP My Health™ are specific to your stage of kidney disease or risk for kidney disease. This Web site allows you to track and store:
- your doctor visits
- your medical history
- the names/contact information of your healthcare team
- the medications you are taking and what they treat
- your laboratory test results
- your activity status
- your overall knowledge of kidney disease and its side effects

This complete history of your healthcare is stored in a safe and secure location. It is accessible anywhere there is an Internet connection and there is NO COST to you. A username and password (which is provided at the time of registration) are required to access your information.

Upcoming Kidney Beginnings: Live Locations

- Ft. Lauderdale, FL - March 24
- Chicago - April 15
- St. Louis - April 29
- Cleveland, OH - May 13
  - San Francisco
  - San Antonio, TX
  - Detroit
  - Nashville, TN
  - Charlotte, NC
  - Baton Rouge, LA
Dear Doctor, continued from page 5

salt keeps the circulatory volume higher than it should be, exerting excess fluid pressure on blood vessel walls. These walls react to this stress by thickening and narrowing, leaving less space for the fluid already cramped in the blood compartment, raising “resistance” and requiring higher pressure to move blood to the organs. The heart has to pump against this high pressure system. Lifting free weights in the athletic center causes muscles to become harder and larger. This same phenomenon happens to the heart with one notable exception, there is no break. This 24/7 activity can cause the heart to enlarge dramatically, and dangerously. The kidney contains around one million tiny, delicate filters comprised of blood vessels. The increase in pressure transmitted to the kidneys damages its vascular system leading to a disorder known as “hypertensive nephrosclerosis,” a major cause of kidney disease.

Measuring Blood Pressure
Blood pressure measurements consist of two numbers, the top or systolic reflects pressure developed by the heart when it pumps. In diastole, the large chamber of the heart expands, resting a fraction of a second to fill with blood. The “diastolic” pressure at rest is a function of resistance, analogous to the pressure that still remains in a garden hose when shutting off the water valve.

Essential Hypertension
This genetic disorder, essential hypertension, is present in approximately 65 million Americans, and while characterized by measurements over 140/90, cardiovascular risks are already associated with blood pressures greater than 115/75. (8) It is controlled by restricting salt or using a diuretic, and more common in those whose ancestral origins are equatorial. Clinical trials reveal that diuretics (9) are the most successful medications controlling hypertension. Frequently, additional medications are necessary to achieve control. (10,11)

We consider a normal blood pressure to be 130/80 for patients with CKD. (12) But, studies such as the large MDRD trial, suggest lowering the pressure to 125/75 when proteinuria is present. (13)

A healthy diet with salt reduction to roughly less than five grams (100 mmols sodium) substantially lowers blood pressure. (14) Tribes in remote areas that ingest little salt in their diet have lower blood pressures. Around the world, lower salt usage is associated with lower pressure. (15,16) Restricting salt is difficult because it is as much a preservative as a flavoring condiment. Adding salt preserves shelf life, making economic sense for the food industry, even if less healthy. Longer shelf life increases the likelihood it will be sold before it spoils. Discarded, spoiled food is a liability for the grocer, and to compete for the grocer’s business, food packagers extend the shelf life of their products with salt. The alternative, refrigeration, is a more costly but healthier choice.

We hardly live in a salt-free culture, and must therefore read labels, and cut our salt intake to less than five grams per day. In addition, measuring blood pressure regularly and using medications when necessary are vital to reducing the incidence of CKD. (17)
For the control of your high phosphorus levels

Think simple.

Think FOSRENOL®.

Simple and effective in the treatment of high phosphorus levels, with as few as 3 chewable tablets per day.†

Important Safety Information—During clinical trials, the most common side effects of FOSRENOL® were gastrointestinal, and included nausea, vomiting, and diarrhea. Nausea and vomiting generally lessened over time as patients continued with their treatment. Patients who stopped treatment usually reported gastrointestinal side effects as the reason for stopping. Other side effects reported in trials included dialysis graft complications, headache, abdominal pain, and low blood pressure. Although studies were not designed to detect differences in risk of bone fracture and mortality, there were no differences demonstrated in patients treated with FOSRENOL® compared to alternative therapy for up to 3 years. The duration of treatment exposure and time of observation in the clinical program were too short to conclude that FOSRENOL® does not affect the risk of bone fracture or mortality beyond 3 years. While lanthanum has been shown to accumulate in the GI tract, liver, and bone in animals, the clinical significance in humans is unknown. If you suffer from acute stomach ulcer, colon inflammation and colon ulcers, Crohn’s disease, or bowel obstruction, it is important to know that patients with these conditions were not included in FOSRENOL® clinical studies—please discuss with your doctor. Don’t take FOSRENOL® if you are nursing or pregnant, or if you are under 18 years of age.

* Tablet above shown to actual size.
† Dosing based on three meals per day. Number of meals per day and dose may vary. FOSRENOL® is available in 250-mg, 500-mg, 750-mg, and 1-g tablets.

To achieve certain doses, additional tablets may be required.
BRIEF SUMMARY: Consult the Full Prescribing Information for complete product information.

FOSRENOL®
(Lanthanum Carbonate)
(Foss-wren-all)
(Lanthanum Carbonate) 250, 500, 750, and 1000 mg Chewable Tablets.

INDICATIONS AND USAGE
FOSRENOL® is indicated to reduce serum phosphate in patients with end stage renal disease.

CONTRAINDICATIONS
None known.

PRECAUTIONS

General:
Patients with acute peptic ulcer, ulcerative colitis, Crohn’s disease or bowel obstruction were not included in FOSRENOL® clinical studies. Caution should be used in patients with these conditions.

Diagnostic Tests:
Abdominal x-rays of patients taking lanthanum carbonate may have a radio-opaque appearance typical of an imaging agent.

Long-term Effects:
There were no differences in the rates of fracture or mortality in patients treated with FOSRENOL® compared to alternative therapy for up to 3 years. The duration of treatment exposure and time of observation in the clinical program are too short to conclude that FOSRENOL® does not affect the risk of fracture or mortality beyond 3 years.

Information for the Patient:
FOSRENOL® tablets should be taken with or immediately after meals. Tablets should be chewed completely before swallowing. Intact tablets should not be swallowed.

Notify your physician that you are taking FOSRENOL® prior to an abdominal x-ray (see PRECAUTIONS, Diagnostic Tests).

Drug Interactions:
FOSRENOL® is not metabolized.

Studies in healthy subjects have shown that FOSRENOL® does not adversely affect the pharmacokinetics of warfarin, digoxin or metoprolol. The absorption and pharmacokinetics of FOSRENOL® are unaffected by co-administration with citrate-containing compounds (see CLINICAL PHARMACOLOGY: In Vitro/In Vivo Drug Interactions).

An in vitro study showed no evidence that FOSRENOL® forms insoluble complexes with warfarin, digoxin, furosemide, phenytoin, metoprolol and enalapril in simulated gastric fluid. However, it is recommended that compounds known to interact with antacids should not be taken within 2 hours of dosing with FOSRENOL®.

Carcinogenesis, Mutagenesis, Impairment of Fertility:
Oral administration of lanthanum carbonate to rats for up to 104 weeks, at doses up to 65 mg/kg/day (5 times the MRHD), did not show any evidence of carcinogenic potential. In the mouse, oral administration of lanthanum carbonate for up to 99 weeks, at a dose of 1500 mg/kg/day (1.3 times the MRHD) was associated with an increased incidence of glandular stomach adenomas in male mice.

Lanthanum carbonate tested negative for mutagenicity in an in vitro Ames assay using Salmonella typhimurium and Escherichia coli strains and in vivo Hprt gene mutation and chromosomal aberration assays in Chinese hamster ovary cells. Lanthanum carbonate also tested negative in an oral mouse micronucleus assay at doses up to 2000 mg/kg (1.7 times the MRHD), and in micronucleus and unscheduled DNA synthesis assays in rats given iv lanthanum chloride at doses up to 0.1 mg/kg, a dose that produced plasma lanthanum concentrations >2000 times the peak human plasma concentration.

Lanthanum carbonate, at doses up to 2000 mg/kg/day (3.4 times the MRHD), did not affect fertility or mating performance of male or female rats.

Pregnancy:
Pregnancy Category C. No adequate and well-controlled studies have been conducted in pregnant women. FOSRENOL® is not recommended for use during pregnancy.

In pregnant rats, oral administration of lanthanum carbonate at doses as high as 2000 mg/kg/day (3.4 times the MRHD) resulted in no evidence of harm to the fetus. In pregnant rabbits, oral administration of lanthanum carbonate at 1500 mg/kg/day (5 times the MRHD) was associated with a reduction in maternal body weight gain and food consumption, increased post-implantation loss, reduced fetal weights, and delayed fetal ossification. Lanthanum carbonate administered to rats from implantation through lactation at 2000 mg/kg/day (3.4 times the MRHD) caused delayed eye opening, reduction in body weight gain, and delayed sexual development (preputial separation and vaginal opening) of the offspring.

Labor and Delivery
No lanthanum carbonate treatment-related effects on labor and delivery were seen in animal studies. The effects of lanthanum carbonate on labor and delivery in humans is unknown.

Nursing Mothers:
It is not known whether lanthanum carbonate is excreted in human milk. Because many drugs are excreted in human milk, caution should be exercised when FOSRENOL® is administered to a nursing woman.

Geriatric Use:
Of the total number of patients in clinical studies of FOSRENOL®, 32% (538) were ≥ 65, while 9.3% (159) were ≥ 75. No overall differences in safety or effectiveness were observed between patients ≥65 years of age and younger patients.

Pediatric Use:
While growth abnormalities were not identified in long-term animal studies, lanthanum was deposited into developing bone including growth plate. The consequences of such deposition in developing bone in pediatric patients are unknown. Therefore, the use of FOSRENOL® in this population is not recommended.

ADVERSE REACTIONS
The most common adverse events for FOSRENOL® were gastrointestinal events, such as nausea and vomiting and they generally abated over time with continued dosing.

In double-blind, placebo-controlled studies where a total of 180 and 95 ESRD patients were randomized to FOSRENOL® and placebo, respectively, for 4-6 weeks of treatment, the most common events that were more frequent (≥5% difference) in the FOSRENOL® group were nausea, vomiting, dialysis graft occlusion, and abdominal pain (Table 1).

Table 1. Adverse Events That Were More Common on FOSRENOL® in Placebo-Controlled, Double-Blind Studies with Treatment Periods of 4-6 Weeks.

<table>
<thead>
<tr>
<th>Event</th>
<th>FOSRENOL® %</th>
<th>Placebo %</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N=180)</td>
<td>(N=95)</td>
<td></td>
</tr>
<tr>
<td>Nausea</td>
<td>11</td>
<td>5</td>
</tr>
<tr>
<td>Vomiting</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Dialysis graft occlusion</td>
<td>8</td>
<td>1</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>5</td>
<td>0</td>
</tr>
</tbody>
</table>

The safety of FOSRENOL® was studied in two long-term clinical trials that included 1215 patients treated with FOSRENOL® and 943 with alternative therapy. Fourteen percent (14%) of patients in these comparative, open-label studies discontinued in the FOSRENOL®-treated group due to adverse events. Gastrointestinal adverse events, such as nausea, diarrhea and vomiting, were the most common type of event leading to discontinuation.

The most common adverse events (≥5% in either treatment group) in both the long-term (2 year), open-label, active controlled, study of FOSRENOL® vs. alternative therapy (Study A) and the 6-month, comparative study of FOSRENOL® vs. calcium carbonate (Study B) are shown in Table 2. In Table 2, Study A events have been adjusted for mean exposure differences between treatment groups (with a mean exposure of 0.9 years on lanthanum and 1.3 years on alternative therapy). The adjustment for mean exposure was achieved by multiplying the observed adverse event rates in the alternative therapy group by 0.71.

Table 2. Incidence of Treatment-Emergent Adverse Events That Occurred in ≥5% of Patients in Either Treatment Group and in Both Comparative Studies A and B

<table>
<thead>
<tr>
<th>Event</th>
<th>Study A %</th>
<th>Study B %</th>
</tr>
</thead>
<tbody>
<tr>
<td>(N = 682)</td>
<td>(N=533)</td>
<td>(N=267)</td>
</tr>
<tr>
<td>Nausea</td>
<td>36%</td>
<td>28%</td>
</tr>
<tr>
<td>Vomiting</td>
<td>26%</td>
<td>21%</td>
</tr>
<tr>
<td>Dialysis graft complication</td>
<td>26%</td>
<td>25%</td>
</tr>
<tr>
<td>Diarrhea</td>
<td>23%</td>
<td>22%</td>
</tr>
<tr>
<td>Headache</td>
<td>21%</td>
<td>20%</td>
</tr>
<tr>
<td>Dialysis graft occlusion</td>
<td>21%</td>
<td>20%</td>
</tr>
<tr>
<td>Abdominal pain</td>
<td>17%</td>
<td>17%</td>
</tr>
<tr>
<td>Hypertension</td>
<td>16%</td>
<td>17%</td>
</tr>
<tr>
<td>Constipation</td>
<td>14%</td>
<td>13%</td>
</tr>
<tr>
<td>Bronchitis</td>
<td>5%</td>
<td>6%</td>
</tr>
<tr>
<td>Rhinitis</td>
<td>7%</td>
<td>5%</td>
</tr>
<tr>
<td>Hypercalcaemia</td>
<td>4%</td>
<td>8%</td>
</tr>
</tbody>
</table>

OVERDOSAGE
There is no experience with FOSRENOL® overdose. Lanthanum carbonate was not acutely toxic in animals by the oral route. No deaths and no adverse effects occurred in mice, rats or dogs after single oral doses of 2000 mg/kg. In clinical trials, daily doses up to 4718 mg/day of lanthanum were well tolerated in healthy adults when administered with food, with the exception of symptoms. Given the topical activity of lanthanum in the gut, and the excretion in feces of the majority of the dose, supportive therapy is recommended for overdose.

DOSEAGE AND ADMINISTRATION
The total daily dose of FOSRENOL® should be divided and taken with meals. The recommended initial daily dose of FOSRENOL® is 750-1500 mg/day. The dose should be titrated every 2-3 weeks until an acceptable serum phosphate level is reached. The recommended initial total daily dose of FOSRENOL® is 750-1500 mg/day. The dose should be titrated every 2-3 weeks until an acceptable serum phosphate level is reached. Serum phosphate levels should be monitored as needed during dose titration and on a regular basis thereafter.

In clinical studies of ESRD patients, FOSRENOL® doses up to 3750 mg/day were evaluated. Most patients required a total daily dose between 1500 mg and 3000 mg to reduce plasma phosphate levels to less than 6.0 mg/dL. Doses were generally titrated in increments of 750 mg/day.

Tablets should be chewed completely before swallowing. Intact tablets should not be swallowed.

Storage
Store at 25°C (77°F); excursions permitted to 15-30°C (59-86°F).

Rx only
Manufactured for Shire US Inc.
Wayne, PA 19067, USA
1-800-828-2088
Rev: 11/05
251 0107 001
FOSBFS3
kidney diseases. Jennifer has seen both chronic kidney disease (CKD) patients and end-stage renal disease (ESRD) patients in hospitals, but she had never heard of FMD until Lexi was diagnosed.

Jennifer says, “I find myself always educating people about this rare and unknown disease. When Lexi was first diagnosed, I did research online and came across the Fibromuscular Dysplasia Society of America (FMDSA) and other online articles, but there were few. We were once given pens and pads by FMDSA Chairperson Pam Mace to distribute to get people asking about the disease. Lexi proudly took them to school and handed them to her teachers and still gives them to all her other doctors.”

Very little is known about FMD. Says Dr. Meyers, “Although there are many theories about the cause of FMD, the actual cause or causes of FMD are unknown. I predict that FMD is not going to be a single disease entity and that a number of possibly overlapping or intersecting causes will eventually be discovered.”

Although not enough is known about FMD, Jennifer and her family stay hopeful. “It’s a wait and see kind of disease,” she says. Jennifer, Lexi and the Martinez family insist on approaching FMD with a positive outlook. Lexi says that she is doing fine, and her attitude toward her family is “very loving.” And the Martinez family will continue to count their blessings – they are expecting another baby in June.

To learn more about FMD, visit the FMDSA Web site: http://www.fmdsa.org, or call (330) 653-8416.
Lotions, creams and makeup commonly contain products that offer some protection. The SPF (sun protection factor) of these products indicates its ability to block sun rays, when measured in a laboratory. The higher the number, the more protection it offers. Thus, skin that would burn in 10 minutes, will take four times as long (40 minutes) to burn if protected with an SPF of four. Remember, even though such a product is applied, caution is still required, because it may be removed by rubbing, sweating or water. Additional product should be applied liberally and frequently in order to obtain maximum benefit.

Some medications cause sun sensitivity
A variety of medications can increase skin sensitivity to the sun. As with all drugs, it is important to read the label and other information provided with your prescription, to anticipate this type of danger, and plan your behavior accordingly. Be an informed patient!

When you seek help
The indications of important skin changes that should receive attention are a mole that is changing shape or color, any lesion that is painful or bleeds, and virtually any lump or bump that is rapidly changing. The most important advice is to seek help if you find any of these signs. Do not delay! Most skin cancers can be well treated and/or cured if found early. Your job is not to interpret whether or not a particular spot is cancerous, but rather to alert your healthcare provider to a worrisome change. Their job is to distinguish which spots may represent cancers and should be tested (biopsied). But they cannot do so, if you do not seek medical help! You should also have someone else intermittently look at the areas on your skin which are not visible to you.

Put it all together
Safely spending time in the sun requires anticipation of the specific risk to your skin, the intensity and duration of sun exposure to be encountered, and intentional use of the protective measures described before. By choosing to embrace, not deny these simple strategies you can optimize your own safety and still enjoy reasonable time in the outdoors.

Take Home Message
1. Seek shade (avoid sun between 10 a.m. and 4 p.m.)
2. Wear protective gear (clothing, hat, sunglasses)
3. Use sunscreen
4. Keep kids out of the sun
5. Self exam (have someone else look at the skin you cannot see)
6. Medical follow up for skin changes

Amy L. Friedman, MD, is an associate professor at Yale University School of Medicine, Department of Surgery in New Haven, Conn., and serves as Secretary on the AAKP National Board of Directors and the AAKP Medical Advisory Board.

<table>
<thead>
<tr>
<th>SKIN TYPE</th>
<th>SUNBURN TENDENCY</th>
<th>TAN TENDENCY</th>
<th>SKIN, HAIR, AND EYE COLOR</th>
</tr>
</thead>
<tbody>
<tr>
<td>I</td>
<td>I always get a sunburn</td>
<td>I never get a tan</td>
<td>White skin, freckles, blonde or red hair, blue or green eyes</td>
</tr>
<tr>
<td>II</td>
<td>I usually get a sunburn</td>
<td>I sometimes get a tan</td>
<td>White skin, blonde hair, blue or green eyes</td>
</tr>
<tr>
<td>III</td>
<td>I seldom get a sunburn</td>
<td>I usually get a tan</td>
<td>White skin, usually dark hair and brown eyes</td>
</tr>
<tr>
<td>IV - VI</td>
<td>I never get a sunburn</td>
<td>I always get a dark tan</td>
<td>Brown to dark skin, brown or black hair, brown eyes</td>
</tr>
</tbody>
</table>
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AAKP’s 34th Annual Convention is scheduled for August 30 – September 2, 2007 at the Adam’s Mark® Hotel St. Louis in St. Louis, Missouri.

Mark your calendars now for what promises to be another exciting and informative AAKP Convention! This Convention is the largest national meeting where kidney patients can interact on a person-to-person basis with fellow patients and healthcare professionals.

This year’s Convention will offer educational sessions on the latest advances in kidney healthcare, covering topics for chronic kidney disease, dialysis and transplant patients, as well as caregivers. This is a unique opportunity to participate in sessions led by some of the nation’s top healthcare professionals. The Convention also provides fun social events, including dinner and dancing, for attendees.

Watch your mailbox for further details*. An official agenda and registration form will be available in mid-2007.

Make your hotel reservations NOW by calling the Adam’s Mark® Hotel St. Louis at (800) 444-2326 and identify yourself as an AAKP Convention attendee to receive the preferred rate of $105 per night. Please book early, as the Convention hotel has sold out in past years.

*The official Convention brochure is mailed to all AAKP members. If you are not a member and would like to receive a brochure call 800-749-AAKP or visit www.aakp.org.
Dear Doctor, continued from page 18

References:

Dear Doctor, continued on next page
Dear Doctor, continued from previous page


Stephen Z. Fadem, MD, FASN, FACP, serves as a member of the AAKP Medical Advisory Board and a Vice President of the AAKP Board of Directors. Dr. Fadem is a practicing nephrologist in Houston.

The Dear Doctor column provides readers with an opportunity to submit renal related health questions to healthcare professionals who specialize in the area of concern. The answers are not to be construed as a diagnosis and therefore, altercations in current healthcare should not occur until the patient’s physician is consulted.

William Blackton
James Call
Prudence Cohen
Keenan & Isabella Dowe
Mildred (Barry) Friedman
Michael Gahr
Muriel Glickman
Jean B. Golper
Marvin N. Golper, MD
Amos Hanks
Michael Holben
Lawrence Kahme
Elie Katz, PhD, DSC
Sydney Lewis
Martin T. Lublin
A. Peter Lundin, MD
Maureen Lundin
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Kirby Rodriguez
Louis Sand
Morton Sand
John Sawvel, Jr.
Joyce Thwaits
Brenda Burnham-Uhler
Mia Verona
Michael Waite
Jim Ward
Max Weintraub
Bonny Wilburn
Louis Wyrsch
Hy Yuda
Lt. Col. (Dr.) & Mrs. Robert F. Houck
As Life Membership Chair, I want to encourage your participation in AAKP and ask that you consider becoming a Life Member. AAKP provides educational support for thousands of patients through its publications and works to provide valuable input on a variety of public programs addressing the needs of kidney disease patients. This only scratches the surface of what AAKP does. With your help, it can do even more. As a patient, family member or friend, you are part of a team that makes a difference in the quality of care you receive when you join the voice of AAKP. Being a Life Member gives you the opportunity to help sustain an organization dedicated to working with you to help better patients’ lives. For more information on Life Membership, please call AAKP at (800) 749-2257.

Stephen Z. Fadem, MD, FACP
AAKP Life Membership Chair

* Indicates New Life Member
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• Opportunity to subscribe to AAKP’s four FREE electronic newsletters.
• Access to AAKP My Health™ (an online resource for patients who want to be more proactive in managing their healthcare).
• Automatic membership in the AAKP local chapter nearest you (where applicable).
• Advanced updates of upcoming programs and events.
• Access to relevant and updated public policy information.
• Affiliation with an organization that shares your commitment to making a difference.
• Assurance that your voice is heard and your interests are represented in Washington, DC.

3 Easy Ways to Become a Member…

2. Mail: Complete the membership application below and mail it to us at the address on the bottom of the application.
3. Phone: Give us a call at (800)749-AAKP.

Please allow 4 to 6 weeks to receive your membership packet.

Membership Application

☐ I am not interested in membership at this time, but please send me a complimentary package of information.

☐ I am already a member of AAKP but I would like to make a donation of $__________.

Member Information

Name:___________________________________________
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City:_____________________________ State:__________
ZIP: ___________________ Phone: ( )_______________
Email:__________________________________________

Choose a Membership Category:

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Name on Card:____________________________________
3 or 4-Digit Security Code:___________________________
Expiration Date:__________________________________

Mail completed form & payment to: American Association of Kidney Patients, 3505 E. Frontage Rd, Ste. 315, Tampa, FL 33607

www.aakp.org
the new chair of the Senate Finance Committee. In the last Congress, Senator Baucus introduced the Medicare Value Purchasing Act (S. 1356) to create financial incentives that would promote quality care and better value in the Medicare payment system. He worked closely with Senator Chuck Grassley (R-IA), now the ranking Republican on the Finance Committee.

All but one of the House members of the Congressional Kidney Caucus who sought reelection returned to Congress. Senator Mike DeWine (R-OH), a strong supporter of kidney care issues, was defeated for reelection. If your district is represented by a new Member of Congress or if your state elected a new U.S. Senator, make sure they hear your voice on matters of importance to kidney patients!

Last Year’s Last-Minute Flurries

In the very last days of the 109th Congress, there was significant activity related to the ESRD program that may set the stage for action this year.

An Increase for Dialysis Providers:

Just before Congress adjourned in December, legislation was enacted to give providers an increase in the reimbursement rate for ESRD services. Dialysis services under Medicare will receive 1.6 percent more than the year before and will increase an additional 1.6 percent on April 1, 2007. Let’s hope providers use the payment increases wisely in ways that enhance the quality of dialysis services. And with the provider update issue resolved at last – at least for the time being – more attention can be paid to other important issues.

Home Dialysis:

In the same last-minute legislation in December, Congress called for the U.S. Government Accountability Office (GAO) to conduct a study of home dialysis. The GAO report, due by Jan. 1, 2009, will look at the costs of home hemodialysis treatment and patient training for both home hemodialysis and peritoneal dialysis. It will also make recommendations for payment under Medicare for home dialysis.

One of AAKP’s top policy priorities is to ensure Medicare coverage for home dialysis for those patients who want to use that option. Requiring a GAO study is an important first step forward in that process.

Hearing on ESRD:

On Dec. 6, the House Ways and Means Committee held a hearing on the ESRD program. AAKP submitted written testimony for the record and Acting CMS Administrator Leslie Norwalk identified AAKP as “the patient association.”

The hearing demonstrated tremendous concern over what is seen as possible overdosing of patients with Epogen, and whether such overdosing is costing the Medicare program too much money. It was suggested several times that the use of subcutaneous (by injection) dosing of Epogen (as opposed to intravenous administration) could save millions of dollars.

AAKP surveyed more than 3,000 patients in the late 1990s to see how patients felt about subcutaneous administration. Perhaps surprisingly, the vast majority of patients were fine with subcutaneous administration – noting that, for example, “it really didn’t hurt too much,” they were “used to needles,” or they understood the reasons why the drug had to be given in such a manner. Patients in the veteran’s health system are already dosed by subcutaneous administration.

The major outcome of the hearing was to push CMS to move forward on a bundling demonstration project in which all facility administered drug payments would be bundled into the facility reimbursement. CMS currently has a board developing the demonstration project – called the Advisory
AAKP is pushing hard for legislation to eliminate the 36-month cap on immunosuppressive drug coverage for those eligible for the ESRD program. Many lawmakers now see the need to do so. Some have suggested starting first with pediatric patients if extending coverage for all patients is too costly.

**Paired Kidney Donations:**
History was made last November when doctors at Johns Hopkins performed the first-ever quintuple kidney transplant. Twelve individual surgeons simultaneously operated for 10 hours on 10 different people – successfully transplanting organs into five patients in need of a new kidney.

This dramatic life-saving event helps explain the tremendous benefits that can result from such procedures. Senator Carl Levin (D-MI) and others are pushing strongly for legislation to ensure these “paired” kidney donations do not violate current federal law prohibiting compensation for organ donations.

It is estimated that paired kidney donations could increase the number of organ transplants by 1,500 to 2,000 each year!

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