Fibromuscular Dysplasia, An Often Unrecognized Vascular Disease

Going the Extra Mile: AAKP National Convention

Medicines that Help Slow the Progression of CKD

My, how time flies. This has been a very exciting and busy year for AAKP. We’ve had several successful AAKP HealthLine conference calls and still more to come. Our Kidney Beginnings: Live programs have been big hits in cities across the United States. We honored a great renal physician, Robert Schrier, MD, during the Medal of Excellence Award reception in Baltimore, MD. I would like to thank all of the reception sponsors for their generous support. And now we’re gearing up for the 36th Annual AAKP National Convention.

This year’s Convention takes place at the Hyatt Regency Denver in Denver, Colo. Denver is an exciting city and the AAKP Annual Convention is well worth the trip. The Annual Convention allows you to interact with some of the world’s top health care professionals, meet other patients and families who are experiencing some of the same health concerns as you and your family, and it gives you the opportunity to see some of the latest kidney health care products on the market. I highly recommend you read the article on the AAKP Convention and make your reservations to attend today!

Also in this issue, Dr. Stephen Fadem tells you about some of the medicines your doctor may prescribe to help slow the progression of your chronic kidney disease. And Dr. Frederick Kaskel and registered dietitian Lauren Graf discuss kidney friendly vitamin products.

Roberta Wager, RN, MSN
AAKP President
Two-time Kidney Transplant Recipient

American Association of Kidney Patients Honors Representatives Camp and Stark for Their Commitment to Kidney Patients

From left, Kim Buettner, AAKP Executive Director; Rep. Pete Stark (D-CA); AAKP President Roberta Wager, RN, MSN; Rep. Dave Camp (R-MI); AAKP Vice President Stephen Z. Fadem, MD; AAKP Board Member Alice McCall, RN; AAKP Board Member Richard Knight.

On Wednesday, April 22, 2009, the American Association of Kidney Patients (AAKP) honored Representatives Dave Camp (R-MI) and Pete Stark (D-CA) with the Congressional Leadership Medal for their continued commitment to kidney patients and their work with the passage of the Stephanie Tubbs-Jones Congressional Gift of Life Medal Act. The awards were presented to the Congressmen during a special meeting in Washington, D.C. The Congressional Leadership Medal recognizes the outstanding commitment and efforts of those who influence and pass legislative policy benefiting kidney patients.

The Stephanie Tubbs-Jones Act creates a commemorative medal for organ donors and their families. The bill is named after Congresswoman Stephanie Tubbs-Jones, an organ donation advocate, who had her organs donated after suffering a brain aneurysm last summer.
Fibromuscular Dysplasia, An Often Unrecognized Vascular Disease

By Pamela Mace, RN, & Jeffrey W. Olin, DO

Fibromuscular dysplasia (FMD) is thought of as a rare disease and is difficult to detect. It is often seen in young women, but men are not exempt from the disease. In this article, you’ll learn the causes, symptoms and treatment options available to patients suffering from FMD.

Going the Extra Mile: AAKP National Convention

The American Association of Kidney Patients (AAKP) is hosting its 36th Annual National Convention in Denver. Inside this issue of Kidney Beginnings: The Magazine, you’ll find information about Convention registration, hotel accommodations, educational opportunities and Annual Awards nominations.

Medicines that Help Slow the Progression of CKD

By Stephen Z. Fadem, MD, FACP, FASN

As a chronic kidney disease (CKD) patient, there are many options to slow the progression of the disease including, diet, exercise and as this article explains, medications. Dr. Stephen Z. Fadem shows how medications are used to help slow the progression of CKD and its side effects.
What is Fibromuscular Dysplasia?

Fibromuscular dysplasia (FMD) is a non-inflammatory vascular disease that most commonly affects the renal (kidney) arteries (1). While the carotid arteries are the second most common artery affected, FMD may affect any artery in the body (2, 3). FMD is often underdiagnosed and undertreated leading to the misconception that it is a rare disease. FMD causes narrowing (stenosis) and dilation (with possible aneurysm formation) (4) in the affected artery.

Up to 75 percent of all patients with FMD will have the disease in the renal arteries (Figure 1). The most common presentation of renal artery FMD is high blood pressure in a young woman or, less commonly, man. Renal FMD may also cause abnormal kidney function, flank pain and shrinkage (atrophy) of the kidney.

The second most common artery affected is the carotid artery, the main artery in the neck supplying blood to the brain. This is often detected when a doctor hears a noise in the patient’s neck (a bruit) when listening with a stethoscope. Patients may also complain of a swishing sound in the ears. Other symptoms include dizziness, temporary loss of vision, ringing in the ears, vertigo, neck pain, headaches, transient ischemic attack (blood supply to brain briefly interrupted). Other arteries less commonly, but also, affected include the arteries in the abdomen (supplying the liver, spleen and intestines) which may cause abdominal pain after eating and unintended weight loss. FMD in the extremities may cause exertional limb discomfort and rarely FMD may occur in the arteries of the heart causing a heart attack or chest pain. Nearly one-third of all patients with FMD have involvement of more than one artery (2).

What Causes FMD

The cause of FMD is not known, although genetic, hormonal and mechanical factors have all been suggested. FMD may be more than a single condition with more than one cause and investigation is underway to try and identify genetic factors that may cause FMD. Since FMD is more commonly seen in women than in men, some have suggested hormones may play a role in disease development.

How is FMD Diagnosed

There are a number of methods that can be used to detect FMD. These include computed tomographic angiography (CTA) and magnetic resonance angiography (MRA), ultrasound and catheter based angiography. In the most common form of FMD (medial fibroplasia), a characteristic “string of beads” appearance is seen in the affected artery (Figure 1). This appearance is due to changes in the cellular tissue of the artery wall that causes the arteries to alternatively become narrow and dilated. In medial fibroplasia, there are fine webs of tissue in the arteries causing the
narrowing. A less common, but more aggressive form of FMD may cause an area of severe concentric narrowing of the blood vessel (intimal fibroplasia) or long smooth narrowing. Intimal fibroplasia is the most common form of FMD in children but may also occur in adults (Figure 2).

**How is FMD Treated**

There is no cure for FMD; however, FMD can be adequately managed in most cases. The treatment used for FMD depends upon which arteries are affected and the presence and severity of the signs or symptoms.

Medical therapy for renal FMD consists of blood pressure lowering medication to control blood pressure. It is recommended that most patients take aspirin 81 mg daily which acts to prevent platelets from sticking together. Before starting any medication, patients should discuss treatment options with their physician.

Percutaneous transluminal angioplasty (PTA) is the preferred treatment for patients with FMD who require therapy due to narrowing of an artery. Indications for renal artery PTA include recent or rapid onset of high blood pressure and difficulty in controlling high blood pressure with medications. Often, the blood pressure can be cured with angioplasty, if performed properly. During angioplasty, a catheter is inserted into the affected artery and a small balloon is inflated to open the blood vessel in the area of narrowing. A recent study demonstrated improvement or cure in three-quarters of the patients undergoing PTA for renal artery FMD and these excellent results were maintained for up to five years in most patients (5). A metal stent is typically not recommended in FMD and should only be used if angioplasty alone was not successful or to treat a dissection (tear) of the artery (3). Surgical reconstruction is reserved with FMD and aneurysms or complex FMD within the kidney itself.

**Prognosis**

There are no specific studies on the long term prognosis and outcome of FMD. The causes, natural history, management and long-term outcome require further research. The International Registry for FMD is currently underway and will provide much needed information about this poorly understood condition.

**How can I find out more about FMD**

For more information on fibromuscular dysplasia please visit the Fibromuscular Dysplasia Society of America (FMDSA) at [www.fmdsa.org](http://www.fmdsa.org).

**Reference List**


\[ Figure 2 \]

Pam Mace, RN, is a registered nurse and President of the of Fibromuscular Dysplasia Society of America.

Jeffrey W. Olin, DO, is Professor of Medicine and Director of Vascular Medicine at the Zena and Michael A. Wiener Cardiovascular Institute and Marie-Jose and Henry R. Kravis Center for Cardiovascular Health Mount Sinai School of Medicine in New York.
The American Association of Kidney Patients (AAKP) is Going the Extra Mile to bring you its best National Convention yet! The 36th Annual AAKP Annual Convention takes place September 3-5 at the Hyatt Regency Denver in Denver, Colo. The Annual Convention provides kidney disease patients, as well as their friends and family members, with the opportunity to discuss their concerns and share their experiences while learning about important issues affecting their health care. In addition to exciting social events, it is the largest national convention where kidney patients can interact on a person-to-person basis with fellow patients and health care professionals. During this three-day event, attendees participate in educational sessions for those with chronic kidney disease (CKD) to long-term dialysis and transplant patients. Participants also learn about various treatments for each stage of kidney disease.

**Convention Packages**
The Convention packages include three days of educational sessions, a souvenir t-shirt, tote bag and tickets to the First Time Attendees’ Luncheon, Welcoming Reception, Welcoming Ceremonies and Annual Banquet and Awards Ceremony. AAKP offers discount packages to AAKP Life Members and current AAKP Premiere Members.

**Cost:**
- **Patient/Family Member Registration**
  - AAKP Life Member: $90
  - AAKP Premiere Member: $95
  - AAKP Principal Member: $99
  - Non-member: $99
- **Professional Registration**
  - AAKP Life Member: $190
  - AAKP Member: $195
  - Non-member: $199

One-day registrations are also available and include educational sessions only.

**Cost:**
- Patient/Family Member Registration: $25
- Professional Registration: $50

**Educational Sessions**
This year’s Convention offers educational sessions on the latest advances in kidney health care, covering topics for CKD, dialysis and transplant patients and caregivers. This is a unique opportunity to participate in sessions led by some of the nation’s top health care professionals.
Educational sessions include:
- Innovations in Kidney Disease
- The CKD Friendly Diet
- Transplantation 101: How Do I Get a Kidney Transplant?
- How to Have a Good Future with Kidney Disease
- And a special session for health care professionals, Patient/Family Centered Care.

Continuing Education Credits
Continuing Education (CEs) credits are available for social workers and registered nurses pending approval from the accrediting agencies. For additional information please contact AAKP at (800) 749-AAKP.

Hotel Accommodations
Hotel reservations can be made by calling the Hyatt Regency Denver toll free at (800) 233-1234. To receive the preferred rate of $120 per night (single or double occupancy), identify yourself as an American Association of Kidney Patients’ Convention attendee. Please make your reservations as early as possible as the Convention hotel has sold out in past years. The deadline to receive the preferred room rate of $120 per night is Aug. 4, 2009.

Annual Awards
Each year, during the AAKP Annual Convention, the Association presents its prominent Annual Awards to those who have made a significant contribution to the renal community and helped to carry out the mission of AAKP. We invite you to submit a nomination(s) in each of the award categories for someone you feel should be recognized for their efforts and accomplishments. Award recipients are honored during AAKP’s 2009 Annual Convention.

New this year, AAKP presents the Kris Robinson Memorial Award. The award, in honor of AAKP’s former Executive Director, is given to a patient who shares her (Kris’) vision of improving the welfare of patients and their quality of life. To download award descriptions and a nomination form, please visit www.aakp.org/events/convention/2009/awards. Self nominations are accepted and encouraged. Annual Award nominations must be submitted or postmarked by June 30, 2009 to be considered. Nominations can be mailed to the address below or faxed to 813-636-8122.

American Association of Kidney Patients
Attn: Awards Nomination Committee
3505 E. Frontage Rd., Suite 315
Tampa, FL 33607

The official Convention registration 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 send an e-mail to info@aakp.org and include your name and full mailing address in the body of the e-mail.
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Medicines that Help Slow the Progression of CKD

By Stephen Z. Fadem, MD, FACP, FASN

While diet and exercise are very important components to therapy, several clinical trials have demonstrated the value of medications to help patients prevent the progression of kidney disease. The success of these therapies depends upon what stage of kidney disease the patient is in and the underlying cause of the patient’s kidney disease. For instance, diabetics in the earliest stages do much better with treatment aimed at preventing the disease from getting worse. The Diabetes Control and Complications Trial (DCCT trial) showed aggressive management of diabetes was able to stall not only the progression of proteinuria (large amounts of protein in the urine), but also retinopathy (damage to the eye retina) in early stages. (1)

However, the focus should also be on minimizing diseases that sometimes go along with kidney disease. These include cardiovascular disease, blood vessel disease and stroke.

Unfortunately, some of the medications which have shown great promise in the oral treatment of type 2 diabetes may increase cardiovascular risks as suggested in two recent trials known as DREAM (2) and ADOPT studies. (3) Large international trials such as the Study of Heart and Renal Protection (SHARP Study) are designed to look at treatments with a class of drugs that lower cholesterol and protect the heart in patients with kidney disease. People who took part in the study also did not have any heart damage and did not have a large amount of fatty molecules in their blood stream. (4)

Medications are also used to keep the blood pressure within 130/80 mm Hg. For African Americans and people who suffer from proteinuria, targeted blood pressure is lower. (5) (6) Other targets include trying to lower the amount of protein abnormally leaked by the kidney using drugs that work on blood vessel tone through a well-known mechanism known as the renin-angiotensin system. These medications are classed as either the angiotensin receptor blockers or converting enzyme inhibitors (7). Adding an additional medication that works on the body’s blood and fluid system, aliskaren, may further reduce the small amounts of protein in the urine associated with early kidney disease. (8)

The use of angiotensin receptor blockers in type 2 diabetics, along with the management and control of blood pressure, has been proven to delay the progression of CKD. This was seen in three trials - RENAAL (9), IDNT (10) and IRMA trials. (11) The Collaborative Study Group showed an angiotensin converting enzyme (ACE) inhibitor

Physician Article, continued on next page
would delay progression of kidney disease in type 1 diabetes. (12)

A recent study, the ACCOMPLISH Trial(13), has shown combining an ACE inhibitor and a calcium channel blocker helps delay progression to cardiovascular endpoints in high risk cardiovascular patients (60 percent of whom are diabetic), many of whom have abnormal kidney function. The final results of this study have yet to be published.

Of course, with respect to disease progression and the other associated diseases that accompany CKD, medications alone do not substitute for continuing to live a healthy lifestyle. Obesity has been shown to be a predictor of CKD(14), so has smoking (15) – so it is crucial to remain attentive to the lifestyle aspects of therapy. In addition to exercise, watching salt intake, processed foods and keeping your body mass index in control, it might also be advisable to take an aspirin daily, (check with your physician first) and keep your cholesterol in normal range. Taking generic vitamin D in early kidney disease, and switching to a vitamin D analog if the disease progresses might prove to be of therapeutic benefit, but future research is needed to reveal the value of vitamin D therapy in reducing kidney disease endpoints. (16)

References

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

Two vitamin products that are potassium free are Nephro-Vite and Nephrocap. Not only are these vitamins free of potassium, but also contain ideal quantities of other vitamins and minerals for patients with kidney disease, and are prescribed by your doctor. It is best to be cautious in taking over the counter (OTC) vitamins. Although most OTC multivitamins have relatively small amounts of potassium (Centrum has 80 mg and One-A-day has 99 mg of potassium for example), there are other micronutrients present in these products that may be harmful to people with kidney disease.

Food and supplement labels can be confusing. On every vitamin product, the label will list the quantity of each vitamin or mineral and then give the percent daily value. The percent daily value is based on the daily reference intake (DRI) and daily reference values (DRV). The DRI and DRV are the estimated amount of a nutrient per day that is needed to maintain health. However, these guidelines were developed for the general population and are not intended for those with kidney disease. As a kidney patient, you should disregard the percent daily value for most nutrients because you may need more or less of certain nutrients than the average person.

Many fat-soluble vitamins, such as vitamin A, found in common multivitamin preparations can build up in the body of patients with kidney disease and become toxic. In addition, vitamins E and K can increase clotting time and interfere with blood thinning medications. Many multivitamins also contain phosphorus, which needs to be limited in kidney disease. It is best to only take vitamins your doctor has prescribed. The Nephro-Vite and Nephrocap contain vitamins needed by patients with chronic kidney disease (such as the B-complex vitamins) and none of those that may be potentially harmful. Always remember to discuss any nutritional supplement regimen with your doctor.

The Dear Doctor answer is provided by Frederick J. Kaskel, MD, PhD and Lauren Graf, RD, MS. Dr. Kaskel is a pediatric nephrologist, Chief of the Section of Pediatric Nephrology at the Children’s Hospital at Montefiore, Albert Einstein College of Medicine.

Ms. Graf is a registered dietitian, having completed a Bachelors of Science Degree in dietetics from the University of Connecticut in 2003. She then went on to earn a Masters of Science in clinical nutrition from New York University. She works as a dietitian for the Department of Pediatric Nephrology at the Children’s Hospital at Montefiore.

Editor’s note: This article describes just two vitamins that are potassium free and healthy for kidney disease patients. Please talk to your health care team if you have questions about other vitamin products.
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If you would like to learn more about the Liberty cycler or questions to ask your physician about the option to dialyze while you sleep, please contact 1-800-662-1237 x HOME (4663) or visit our website www.dreammachine.com.

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AAKP HealthLine

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- Understanding Diabetes and Hypertension
- Understanding My Stage of Kidney Disease
- Meal Planning 101
- Understanding and Coping with Depression

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Chronic kidney disease patients, those at risk of developing kidney disease and their family members can now become Principal Level - Kidney Beginnings Members for just $15. Principal Level - Kidney Beginnings Members receive *Kidney Beginnings: The Magazine*, access to AAKP educational materials and much more. For those with a more advanced stage of kidney disease, AAKP now offers Principal Level – Renalife Membership. This $15 per year membership comes with a year’s subscription to *aakpRENALIFE*, access to AAKP educational materials and more. For just $25 per year, AAKP offers the Premiere Level membership. Premiere Level members receive *Kidney Beginnings: The Magazine*, *aakpRENALIFE* and *At Home with AAKP*.

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It is estimated over two-thirds of chronic kidney disease (CKD) cases were caused by diabetes or hypertension, two chronic illnesses with strong nutritional aspects to their management. Obesity is a major factor in type 2 diabetes and weight loss can help control blood pressure. Decreasing salt intake also helps control blood pressure and the need for additional or higher doses of medication. Since the kidneys control blood pressure, most patients with CKD develop hypertension, even if they didn’t have it before.

The Centers for Disease Control and Prevention (CDC) consider CKD and diabetes (primary cause of CKD) a public health problem. CKD now costs Medicare $49 billion dollars a year and is increasing, putting a significant financial strain on future generations. Fortunately, there are steps we can take to prevent the onset and progression of CKD. Since each patient responds differently to their health condition and medications can affect nutritional needs/restrictions, a doctor can write an order for a diet and refer you to a qualified dietitian. This article covers the relationship between nutrition and CKD. It is not a substitute for a consultation with a registered dietitian (RD). Medicare and many insurance companies pay for visits with a RD. Besides diet, it is important to see your doctor regularly and take all medications prescribed. Certain blood pressure medications your doctor prescribes can help protect the kidneys. Also, ask your doctor about exercise.

**Protein**

restriction, it has been argued, could slow the progression of CKD and help relieve symptoms of advanced CKD known as uremia. However, protein restriction can also lead to malnutrition. There’s a careful balancing act patients must adhere to. Too much protein can also lead to high levels of phosphorus and potassium, which CKD patients must keep a close eye on. Once on dialysis, protein intake should be increased, but to prevent the progression of CKD, the focus should be on controlling conditions that cause progression: diabetes and hypertension. Weight and carbohydrate control can help manage or prevent the onset of diabetes. For hypertension management and prevention, weight as well as sodium control should be the focus. Fat intake can play a role with many patients because the cardiovascular disease risk is 10-30 times greater in patients with CKD. Some causes of CKD have little relation to diet, but once diagnosed, diet is an important part of therapy.
Sodium increases blood pressure and is a “fluid magnet.” Reducing salt helps reduce diuretic (water pills) use, which can make patients get up at night to urinate and stay home during the day for fear of wetting themselves. It can also reduce the need for other blood pressure medications.

Restaurant food is often high in sodium, and thirst is your body’s way of trying to get rid of it. Even eating many family recipes will cause this thirst. Just because you don’t add salt to your foods doesn’t mean you’re not preparing foods high in sodium. We’re not born with a hunger for salt, it is learned. It is what I call your “family dictionary.” Now is the time to start a legacy of healthy eating that generations can follow. Reducing salt a little at a time will reduce your need to use it. Some spices are a good substitute for salt. Besides, just think, eventually you could enjoy the natural flavor of food, not the taste of salt! What a novel idea!

Phosphorus must be restricted in most advanced CKD patients. High phosphorus can cause heart, lung and bone problems, and lead to amputations. Since many foods have phosphorus, your doctor may prescribe phosphate binders. High phosphorus food lists are readily available. They include:

- Dairy
- Colas
- Nuts
- Beans
- Frozen waffles
- Biscuits
- Chocolate

What I call “grazing,” snacking on a bowl of popcorn while watching television, is an unhealthy habit. If you’re hungry, eat a snack, take your binders and be done with it. Besides, the more times you eat, the greater the chance of forgetting your binders.

Potassium restriction may or may not apply to you. Diuretics and peritoneal dialysis can cause low potassium, making it necessary to take potassium supplements. Some blood pressure medications can raise potassium but protect the kidneys, so they are prescribed. It is important to remember the poison is in the dose. Just because a food is low in potassium doesn’t mean you can eat all you want. The most common foods that have potassium are produce, some salt substitutes, most dairy products and meat. High or low potassium can be life threatening. If your potassium is low, your life could be at risk if you develop nausea, vomiting or diarrhea. Make sure you contact your doctor in this case.

There are other nutritional components to the care of kidney patients that cannot be discussed in the scope of this article. This information is readily available on the Internet. A renal dietitian has the time to discuss issues such as vitamin needs, recommended calcium intakes and how the medications you take affect your nutritional status. There are also CKD courses that are taught by many providers. Ask you doctor about these resources. Knowledge can help you take control of your life!

Reference:

Angelo P. Capozzoli, RD, CSR, LD, is the president of Southeast Clinical Nutrition Centers, Inc., an Atlanta practice of registered dietitians who help people manage their chronic diseases through medical nutrition therapy (MNT) and lifestyle changes. Capozzoli is also president of Renal Reserve, a dialysis staffing agency.
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** Supportive but not conclusive research shows that consumption of EPA and DHA omega-3 fatty acids may reduce the risk of coronary heart disease.

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  • Subscription to aakpRENALIFE and aakpDelicious!

Premiere Level
  • Subscription to aakpRENALIFE and Kidney Beginnings: The Magazine
  • Discounts to AAKP Annual Convention

Plus! All membership levels include:
✓ Subscription to At Home with AAKP
✓ Access to all AAKP educational brochures and publications
✓ And much more!

Health care professionals and physicians, please consider becoming a member as well. AAKP has resources that will help educate your patients. As a professional or physician member your dues also provide vouchers for FREE Premiere level trial memberships to distribute to your patients.

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

Membership Application

Member Information

Name:___________________________________________
Address:_________________________________________
City:_____________________________ State:__________
ZIP: _______________Phone: (       )__________________
Email:___________________________________________

Choose a Membership Category:
Patient/Family Membership Levels:
☐ Patient/Family Principal Level – Kidney Beginning…$15 annually
☐ Patient/Family Principal Level – Renalife……………$15 annually
☐ Patient/Family Premiere Level………………………$25 annually
☐ Life Member………………………………………….$1000*

Health Care Professional Membership Levels:
☐ Professional Member………………………….$45/annually
☐ Physician Member…………………………...$100/annually
☐ Institutional Member………………………….$200/annually
☐ Life Member……………………………………$1,000*

*or four payments of $250 every six months for two years

Payment Method
☐ Check (enclosed and payable to AAKP)
☐ Visa ☐ American Express
☐ MasterCard ☐ Discover
Account number:_______________________________
Name on Card:_________________________________
3 or 4-Digit Security Code:________________________
Expiration Date:________________________________

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

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

www.aakp.org