



Advocate Professional

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Message from the CEO

AKF and You: Partners in Caring for Patients

Thirty-six years ago, a small group of people joined together to form a nonprofit organization so they could raise money to help one of their friends pay for dialysis treatments. They named this organization the American Kidney Fund.



LaVarne A. Burton

This small group of friends may never have dreamed that their tiny nonprofit would eventually provide crucial financial assistance to thousands of dialysis patients nationwide. But over the years, as the dialysis population grew and new patient financial needs emerged, the American Kidney Fund was able to develop new programs in response to those needs. Last year, AKF provided \$81.9 million in grant assistance to more than 63,500 patients nationwide.

In keeping with our mission, we continually work to identify areas in which AKF may help qualified dialysis patients with their financial needs. Soon after last year's launch of Medicare Part D, we began to hear reports from renal social workers that dialysis patients were quickly falling into the coverage gap, or "donut hole." We conducted a national survey of renal social workers which confirmed the anecdotal evidence we'd heard. We formed a plan to launch a Medicare Part D assistance program for dialysis patients, and we obtained from the United States Department of Health and Human Services Office of Inspector General a favorable opinion on this proposal.

On April 1 of this year, we launched our Medicare Part D Assistance Program for Bone Disease Medications. Eligible dialysis patients may receive up to \$2,000 per year in prescription assistance for bone disease medications. Most significantly, the program helps patients with "donut hole" costs—and assistance from the program counts toward patients' true out-of-pocket expenses, helping them to reach the catastrophic coverage level sooner.

We began our Part D assistance with bone disease medications because they are so frequently taken by dialysis patients, and because they are expensive. We hope to introduce additional programs in the future to assist dialysis patients with medications; including those for additional co-morbid conditions.

I invite you to visit www.kidneyfund.org/fpa_Medicare-D.asp or see page 5 of this edition for full details about our Part D assistance program. We are pleased to be able to offer this new assistance program to dialysis patients who are in need of help.

American Kidney Fund Names 2007 Clinical Scientist in Nephrology

The American Kidney Fund is proud to announce Dr. Carmen Peralta as the AKF-Amgen Clinical Science in Nephrology Scholar for the 2007-2008 year.

Dr. Peralta is a Nephrology Fellow at the University of California, San Francisco with a specific research interest in the combination of nephrology, genetics, and epidemiology. As a fellow, her research will examine the roles that individual genetic ancestry and socioeconomic status play in chronic kidney disease, and whether these factors are potential mediators or confounders for progression to end stage renal disease.

Our new fellow joins our current fellows, Drs. Tammy Brady and Orlando Gutierrez. We look forward to hearing more about their research in the coming year.

**2008 CSN applications are available at www.kidneyfund.org/fpr_csn.asp.
Completed applications are due by December 1, 2007.**

Dietitian Dish

CKD and Bone Health

By Christine Salaita

Renal osteodystrophy is one of the leading causes of mortality in patients with chronic kidney disease (CKD). Contributing factors may include abnormal calcium and phosphorous metabolism, calcitriol deficiency, secondary hyperparathyroidism, resistance to PTH and aluminum toxicity. Management of bone health involves issues of education and adherence to medications and diet. This can often be a complex process that involves a multi-disciplinary approach. The renal dietitian plays a significant role as part of the multi-disciplinary team in ensuring patients' overall quality of life.

One primary role for the dietitian is education of the patient and family. An individualized diet must be designed to maintain proper sodium, phosphorous, protein and calcium intake. Beyond education of the patient, communication with the medical team regarding recommendations for phosphorus binders, as well as calcium and calcitriol supplements are important. In addition, a dietitian's interaction with the patient may bring to the surface other medical and social issues such as food insecurities, food intolerances and allergies, food and medication costs and other emotional and environmental obstacles to adherence. Social workers and physicians should be alerted to these issues so that the patient's obstacles may be mitigated.

The second opportunity that is present for the renal dietitian is coordination and implementation of continuous quality improvement and clinical performance measures. This is a leadership role that helps bring together multiple disciplines in CKD patient care. It involves setting up weekly or biweekly meetings with an administrator, a nephrologist, a dietitian, a pharmacist and a social worker to focus on a change or a test aimed at improvement. The Plan-Do-Check-Act (PDCA) Cycle is an easy tool and dynamic model that uses charts and diagrams to guide in the process of targeting a clinical concern and implementing change. It follows in the spirit of continuous quality improvement in which the completion of one turn of the cycle flows into the beginning of the next.

The following is an example of quality improvement. K/DOQI recommends serum phosphorus levels between 3.5-5.5 mg/dL in CKD patients. The goal of the new continuous quality initiative is to increase the percent of patients meeting this level from 60% to 75% within the next 3 months. Once this goal has been established, all team members should participate in a brainstorming session to develop theories as to why only 60% of patients are meeting goal phosphorus values. Once a cause has been identified, such as lack of education on use of phosphate-binders, a solution should be implemented such as having an in-service by the pharmacist or dietitian on their proper use. Results of the efforts should be checked to determine how successful they were and whether they should be acted on and adopted or abandoned.

A renal dietitian's role is of great value when it comes to managing bone health in people with CKD. This is evident not only with renal diet and vitamin supplementation recommendations, but also by serving as a leader in quality improvement initiatives for the health team and the patient that lead to overall improved quality of life.

Christine Salaita is the Clinical Research Dietitian at NIH and collaborates with the Clinical Investigators to design unique nutritional programs for newly transplanted patients. She also has special expertise in the area of diabetes.



CSN Alumnus Receives Torchbearer Award

Glenn Chertow, M.D., of the University of California-San Francisco received the American Kidney Fund's highest honor, the Torchbearer Award, during a reception on February 18, 2007, in conjunction with the Annual Dialysis Conference in Denver. Pictured, from left, are Karl D. Nolph, M.D.; LaVarne A. Burton, CEO of the American Kidney Fund; and Dr. Chertow. The Torchbearer Award recognizes an individual who has made a substantial contribution to enhancing the health and welfare of others in the renal community.

Tech Tips

Water Purification System in the Dialysis Industry

By Dennis Schell CHT, OCDT

How would you like to push a button, leave your dialysis center, and have your water purification system clean itself? No chemicals would be needed. This process would disinfect the reverse osmosis and the distribution line. Then it would turn itself off and wait for the clinical staff to arrive the next day.

New technology has been developed that uses hot water to disinfect the water purification system. Dialysis centers currently disinfect dialysis machines with hot water. Now a similar but expanded technology will allow this same convenience for the entire water system to be disinfecting. The disinfection process is accomplished through an appropriate combination of temperature and time. The optimum temperature is maintained for a specified time period resulting in a sanitized system.

Hemodialysis centers struggle to maintain low levels of bacteria and chemical contaminants in the water. The current use of chemicals can be costly and can pose safety risks to staff and patients. As industry standards impose stricter guidelines for more routine disinfections, this newer technology will be safer for patients and staff and make it easier to meet those demands. Additionally, a hot water system for disinfection of the water loop will reduce staff time and cost for chemicals.

The water purification system is the heart of the dialysis center. Water is used in the dialysate preparation. It mixes with bicarbonate and acid to make dialysate. It bathes the membranes to facilitate fluid and waste product removal, rinses the dialyzer and cleans and disinfects the system. There are regulations, recommendations and standards that are set to insure that the purified water is free of contaminants and bacteria. These standards are set by an organization called The Association for the Advancement of Medical Instrumentation (AAMI). This organization sets standards that are used throughout dialysis facilities to ensure patient safety.

The latest AAMI standards published for the water bacteria:

- The standard for bacteria in purified water is 200CFU/mL with an action level of 50CFU /mL
- LAL testing also known as limulus amoebocyte lysate testing is used to test for endotoxins. The standard is 2EU/mL with an action level of 1EU/mL
- The standard for bacteria in dialysate solution is 200CFU/mL with an action level of 50CFU/mL, and an endotoxin concentration lower than 2EU/mL with an action level of 1EU/mL.

The standards are tough, but that is good because high water quality is paramount to good patient care.

Dennis Schell is a Board Director of the Board of Nephrology Examiners, Inc. Nursing and Technology (BONENT).

Diagnosis for Hope

By M. Ted Ferris

The most affecting moment I ever had as a patient came not when I was a patient, but when I was a study coordinator.

I was seeing a patient for his first visit, and he was shaking. A nervous and unassuming guy by nature – we had talked on the phone prior – made all the more jittery by the prospect of coming to the hospital, getting his labs drawn, seeing the doctor. He reminded me of myself as a kid, coming in to a pediatric clinic.

After visiting with him and filling out some forms, the doctor came in and started going over disease and family history. What started out as a few, short sentences became a very long story about the illnesses in his family. Everyone either had diabetes, kidney disease, or cancer. And here he was, newly diagnosed, a young guy with little to no knowledge of what to expect from his disease and his life. He's optimistic though; because he's here to see the doctor and he's gonna get better.

I almost cried.

He's a really nice guy, my patient. Very polite, and with a kind word for everyone - even the phlebotomist who couldn't find a vein in three sticks. And he's looking at this doctor – one of the best – and he's hoping to be fixed. His eyes look at the white doctor's coat like a modern version of a knight's shining armor.

And I feel for him.

Because his disease doesn't have a cure yet – so the hope he has, so full in his heart that it fills his eyes, won't be met. Sure, we can help him. And he would be happy, so happy. Later, he would smile wide and thank us for tapering down his disease, and he would offer to bring us cake and flowers. But that glint of hope, the one I saw on this first visit, would be gone by then.

As a patient, I know that look. I've lived that look. I'd been there before - we all have. We take our car to the mechanic when it breaks, we take our cat to the vet when it is sick, and we go to the doctor when we're sick. In all those situations, we hope and pray - even expect - things to be all right. They'll get fixed. We went to the pro.

But what happens when the mechanic says your car won't run again? Or the vet says your favorite little friend has to be put down? What happens when the doctor can't, no matter how hard he or she tries, fix the problem?

There's another story, one that nobody knows the ending to yet. It's about a young boy, still in the hospital after three months, struggling to survive. Going back and forth from the children's floor to the Pediatric ICU, his condition gets better and worsens every day. It's one thing after another, and when it starts to look bright again, something else happens. That alone is enough to try the hardest hearts and strongest wills.

But it's something else about this story that hits me right in the gut – the doctors don't know what's wrong with him. They're trying their best, and they've performed every test, but still they are clueless. The reason the family is still holding up though, under an enormous emotional weight, is they have faith in the doctors. They're gonna fix everything, it just takes time, they say. We don't know what's happening but we're going to find out, the doctors say.

As a patient, that story upsets me in words I can't describe. Because to me, doctors have all the answers, they can fix any problem. But the thought hits me hard: doctors aren't miracle workers.

Sure, they can facilitate miraculous recoveries, but they can't wave their hands and make everything better. But patients have to think they can. Otherwise, in the most dire of situations, the hope inside has nothing to hold onto. And it's that hope, that confidence in our doctors that can get us through an unknown disease, an incurable one, or just a little roadblock along the way.

M. Ted Ferris is a kidney patient and former Study Coordinator in the Division of Nephrology and Hypertension at the University of North Carolina, School of Medicine in Chapel Hill.



New Medicare Part D Grant Program Available

The American Kidney Fund (AKF), the nation's #1 provider of financial assistance to kidney patients, is pleased to announce its new Medicare Part D Grant Program.

Qualified dialysis patients may receive up to \$2,000 in grant assistance per year to help with their deductibles, copays and coverage gap (donut hole) costs for prescribed bone disease medications. Products covered through this program include Fosrenol®, Hectorol®, Phoslo®, Renagel®, Sensipar® and Zemplar® Capsules. Grants will count toward TrOOP (True Out of Pocket) costs.

To be considered for assistance, patients may not have an annual household income exceeding 350% of the Federal Poverty Level. ESRD dual eligibles and patients receiving the Limited Income Subsidy (LIS) from Social Security for extra help with Medicare Part D, are eligible for partial grants up to \$500.

For more information, please contact the Patient Services Department by calling (800) 638.8299 or by email to patientservice@kidneyfund.org. Applications and complete program guidelines and eligibility criteria may also be downloaded from AKF's website at www.kidneyfund.org.

Planned Giving

All of the American Kidney Fund's programs and services rely on the generosity of individuals and organizations that provide crucial financial support. Are you interested in helping the American Kidney Fund provide assistance to kidney patients in need and education to professionals like you? As a top charity in the US, 96 cents of every dollar AKF spends goes directly to programs and services. Please consider making a gift online today or planning a future gift of support through your estate or securities. For ideas and options, or to make a gift today, visit www.kidneyfund.org or call Carissa Ciuca, Director of Individual and Planned Giving, at (301) 984.6667. Thank you!

Calendar Kids

After receiving nearly 100 outstanding entries, AKF has selected the thirteen winning artists for its 12th Annual "Kid"ney Kids contest. The contest gives pediatric kidney disease patients the opportunity to submit their artwork to be included in our annual "Kid"ney Kids calendar.

This year's winners are from nine different states and range in age from 7-17. The winners and a parent or guardian will receive an all-expense-paid trip to Washington, D.C., where they tour the monuments and are celebrated in an awards dinner.

The calendars will be ready in mid-July and can be ordered by visiting www.kidneyfund.org or calling (866) 300.2900.

Take Our Online Survey!

The American Kidney Fund wants to know how to better serve the needs of healthcare professionals.

Take a survey to tell us how!

Please visit: www.kidneyfund.org
or email: conferences@kidneyfund.org

Respondents will receive a free gift from AKF.

Attention Social Workers, Nurses, Physician Assistants and Dietitians!

EARN CEs/CMEs!

Attend "Empowering Patients to Overcome Barriers to Adherence"

Please join us in:

Atlanta – August 9, 2007
Baltimore – October 4, 2007

To register for our conferences please visit our website at:

www.kidneyfund.org/fpr_regional_con.asp

or call (800) 638.8299

American Kidney Fund Supports the Kidney Care Quality and Education Act of 2007

By Phylis Ermann, LCSW-C

On February 27, 2007 Senator Kent Conrad (D-ND) and Representatives John Lewis (D-GA) and Dave Camp (R-MI) introduced the Kidney Care Quality and Education Act of 2007 (S. 691, H.R. 1193). The American Kidney Fund (AKF) supports the passage of this legislation because it contains provisions that will:

- raise public awareness about kidney disease and teach self management and prevention skills,
- educate people with chronic kidney disease to slow the progression and make informed treatment choices,
- evaluate the barriers to home dialysis,
- establish uniform training of dialysis technicians, and
- create incentives for continuous quality improvement in dialysis care.

Over 470,000 Americans have end stage renal disease (ESRD), meaning they must have either regular dialysis treatments or a kidney transplant in order to survive. Another 20 million people are estimated to have earlier stages of chronic kidney disease (CKD) and many millions more have risk factors for kidney disease. In 1972, Congress made a commitment to people with ESRD by providing Medicare coverage for dialysis and transplantation. However, the Medicare program has not kept pace with the advancements in renal care or in stemming the tide of CKD.

The Kidney Care Quality and Education Act (KCQEA) addresses issues that are central to AKF's mission to raise awareness and provide prevention strategies to people at risk for kidney disease. It directs the Secretary of the Department of Health and Human Services to create demonstration projects to increase public awareness about the factors that lead to chronic kidney disease, how to prevent it, how to treat it, and how to avoid kidney failure, as well as enhance surveillance systems and expand research to better assess the prevalence and incidence of kidney disease.

KCQEA also provides education sessions for people with Stage IV CKD (the forerunner to ESRD) to help them slow the progression of the disease and learn about treatment modalities, as well as mandating an Institute of Medicine study to evaluate the barriers to increasing the number of individuals with ESRD who elect to receive home dialysis services or other treatment modalities under Medicare.

The American Kidney Fund is committed to enhancing the quality of care provided to kidney patients. Dialysis remains the only Medicare prospective payment system without an annual update mechanism. The KCQEA creates an annual update linked to a three-year Continuous Quality Improvement Initiative that would reward providers for quality improvements based on measures developed in cooperation with the kidney care community. It also establishes standards for the training of dialysis technicians who work most closely with patients.

The American Kidney Fund is urging Congress to pass the Kidney Care Quality and Education Act of 2007 to help the public maintain their kidney health, to support people with CKD in managing their disease, and to provide the highest quality care to people with ESRD.

The KCQEA was developed in cooperation with Kidney Care Partners (KCP), a coalition of patient advocates, dialysis professionals, care providers and suppliers working together to improve quality of care for individuals with Chronic Kidney Disease. To assist policymakers, KCP has also formed the Kidney Care Quality Initiative (KCQI) to develop a well-designed continuous quality improvement program that meets the needs of patients, other members of the kidney care community, and federal policymakers.

Phylis Ermann is Director of Patient Advocacy at the American Kidney Fund.

**For more information or to take
action, please visit
www.kidneycarepartners.org.**

Dialysis patients give ceiling tiles a touch of art and whimsy

By David Templeton, Pittsburgh Post Gazette

Dialysis. Four hours of utter boredom. Reclined in a chair and hooked to a machine with a spaghetti tangle of tubes coming from the chest or arm, one cannot leave or maneuver much. So people nap, watch television, read books, or when really bored, stare at ceiling panels.

And it's those ceiling panels that are the focus of today's tale.

Stacy Morgan, administrator at DaVita Dialysis in Bloomfield, PA, returned months ago from a meeting with an upbeat idea. She asked John Hart and Sandra Frison, both undergoing dialysis due to renal failure, to use their artistic talents to spice up the clinic.

So Mr. Hart, 70, and Mrs. Frison, 58, decided to transform ceiling panels into something the clinic's patients, doctors, and employees could enjoy. The result is a ceiling full of curious, sometimes riveting, and forever fun-loving artwork.

"I congratulated them," said Dr. David Levenson, a nephrologist with patients at DaVita. "I told them it looked like the Sistine Chapel. Most of the time these people are staring at the ceiling, so everyone gets a kick out of it. The idea of brightening up the world is a message they carry to all the patients."

It takes up to an hour to paint one panel and about 50 have been completed. The artwork includes landscapes, portraits of Malcolm X and Muhammad Ali, cartoon characters such as Mickey Mouse, Donald Duck and the Tasmanian Devil, along with lions, pandas and other animals. Blank panels await their attention, but work has been halted until a roof leak is repaired.

Mrs. Frison, on dialysis for six and a half years, said having needles stuck into her arm is an unpleasant proposition three times a week, but painting gives her a worthy goal. She's improving her painting skills, prefers doing biblical topics and landscapes and now desires to take art lessons.

"It's really soothing when I'm into a painting," she said. "People love it – really love it. When I'm working at home, kids stop by the house to see what I'm doing."

Although Mr. Hart and Mrs. Frison are not his patients, Dr. Levenson said their work rallies spirits in a place that can be depressing for those who spend 12 hours there each week.

While most patients fritter away the hours on the machine, Dr. Levenson said, he's impressed that Mr. Hart and Mrs. Frison use the time wisely.

"I was inspired that someone can take an ordinary routine and mundane experience and turn it into something exciting and beneficial to the entire patient population," he said. "It gives everyone something special."

Ms. Morgan agreed: "The artwork has improved patients' moods and reduced stress." Once the leak is repaired, the two said they are determined to continue until every last ceiling panel is painted.

"I'm going to finish it," said a jovial Mr. Hart as he watched his grandchildren at home. "I'm just glad to do something others can enjoy."

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6110 Executive Boulevard
Suite 1010
Rockville, MD 20852

AKF Events

<p>Golf Classic 2nd Annual New York Golf Classic August 6, 2007 Commack, NY Honoring: Frank Pelliccione</p>	<p>Regional Professional Conference August 9, 2007 Loudermilk Conference Center Atlanta, GA</p>	<p>Shop & Share Program Jewel-Osco August 27 – 29, 2007 August 30 – September 2, 2007 Participating Locations Chicagoland Area, IL, IN, IA, WI</p>	<p>Exhibit American Association of Kidney Patients August 30 – September 2, 2007 America's Center St. Louis, MO</p>
<p>"Kid"ney Kids Weekend September 14-16, 2007 Washington, DC</p>	<p>Wine Tasting Fundraiser September 19, 2007 Baltimore, MD</p>	<p>Golf Classic Annual Southeast Golf Classic October 1, 2007 Atlanta, GA</p>	<p>Regional Professional Conference October 4, 2007 Holiday Inn – Laurel West Baltimore/Washington Region (Laurel, MD)</p>
<p>AKF Walk "Steps that Count" Walk Event October 6, 2007 New Jersey</p>	<p>AKF Walk "Steps that Count" Walk Event October 27, 2007 Washington, DC</p>	<p>Exhibit American Society of Nephrology Moscone Center October 31 – November 5, 2007 San Francisco, CA</p>	<p>Wine Tasting Fundraiser 4th Annual National Capital Wine Tasting Dennis & Phillip Ratner Museum November 7, 2007 Rockville, MD</p>

CONTACT US

Toll-Free
800.638.8299
Espanol
866.300.2900

E-Mail
helpline@kidneyfund.org
Website
www.kidneyfund.org

Donate Your Vehicle
888.638.1171

**6110 Executive Blvd.,
Ste. 1010
Rockville, MD 20852**

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