



# Advocate *Professional*

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## One Man's Gift

By Doug Penrod, RN

I have been a registered nurse for 30 years and a transplant nurse for more than 20 years, working first in procurement for The Gift of Hope Organ and Tissue Donor Network (formerly the Regional Organ Bank of Illinois) and later on the recipient side for kidney, pancreas and islet cell transplant at the University of Chicago Hospitals, and for the last 17 years at Northwestern Memorial Hospital (NMH). I have worked with thousands of recipients and hundreds of live kidney donors over the years and have seen the field of transplantation change dramatically. Years ago, when we received calls from total strangers who offered to donate a kidney to anyone we viewed these individuals as having some type of emotional or mental problem and dismissed them. Today, altruistic donation or non-directed donation has become a much more common practice throughout the United States and most transplant centers have Independent Donor Advocate Teams (IDAT) to help individuals through the donation process and ensure that they have someone who is only concerned with their well-being and is not involved with the recipient.

When I decided to donate a kidney to my best friend's father, it was something I had been contemplating for many years. I had always considered myself to be the backup, in the event his first transplant from his daughter failed. Some eight years later his transplanted kidney did fail and I immediately volunteered to be his donor. I went through the entire evaluation without any problems, but was required to be seen and evaluated by a psychologist outside the kidney transplant program at NMH. I also consulted my own primary care physician, who felt that I was a good candidate to donate from a medical perspective.

We set surgery date for mid-September and two weeks before the date of the surgery, my recipient and I came in for a meeting with our transplant surgery staff. My recipient had a new physical finding that left us both reeling. Further testing revealed that my friend could not be transplanted. We were both devastated. Neither of us was prepared for this type of news. I decided in an instant however, that I had taken it this far, so why not donate to someone else in need. I told our donor transplant nephrologist of my decision. He was delighted, but asked me to be patient while the team worked on



(continued on page 2)

# Message from the President and CEO

## Helping Patients with Medicare Part D



LaVarne A. Burton

Dear Renal Professionals,

In the fall of 2008, the American Kidney Fund marked a milestone: we provided financial assistance for prescription bone care medications to the 2,000th patient enrolled in our Medicare Part D assistance program.

We have been able to develop and administer this program successfully because of your help. In 2006, hundreds of renal social workers from around the country responded to a survey we conducted to determine how Medicare Part D was affecting dialysis patients. The responses helped us to determine that the need existed for a Medicare Part D assistance program. Since we've launched the program, renal professionals have been invaluable in getting the word out to patients that help is available from the American Kidney Fund, and you've worked closely with us as we've made improvements in the administration of the program.

Our program helps patients to bridge the "donut hole" and move to catastrophic coverage where Medicare will again assist patients in paying for medications. As you know, the donut hole is a significant financial hurdle for many patients; in 2009, patients will need to expend \$4,350 out of pocket. Our Medicare Part D assistance program provides up to \$2,000 toward out-of-pocket assistance.

Currently, the AKF program covers one class of drugs: bone disease medications. The products covered under this program are: Fosrenol®, Hectorol®, PhosLo®, Renagel®, Renvela®, and Sensipar®. We are in the process of seeking sponsorship for the program so that it may expand to cover additional classes of drugs frequently taken by dialysis patients.

Based on your feedback, we have developed a pharmacy benefit card, which allows patients to access their AKF Part D assistance benefit through most retail pharmacies and mail service pharmacies. And we're pleased to report that awareness of our program is growing; *Renal Business Today* ran a detailed article about the program, and AKF was recently mentioned in *The Wall Street Journal* as a source of financial assistance for pharmaceutical expenses.

If you have questions about the program, please visit [www.kidneyfund.org](http://www.kidneyfund.org) and click on the tab labeled Patient Grants, or give our Patient Services department a call at 800-638-8299. As always, thank you for your dedication to the nation's dialysis patients.

Sincerely,

LaVarne A. Burton  
President and CEO



## One Man's Gift (continued from page 1)

finding the right situation. I was not sure what he meant, but asked if we could get this completed within six months. Six months passed and finally I was told in mid-March that a kidney swap was in the works for the first week of April.

On April 3, 2008, I participated in a four-way domino paired kidney exchange at NMH, the largest done to date in the Midwest. Upon meeting the other donors and recipients a day later for the first time, it finally dawned on me the impact of what just one person's decision to donate to *anyone* can do.

*Doug Penrod, RN, is the Transplant Nurse Coordinator and Outreach Liaison at The Kovler Organ Transplantation Center at Northwestern Memorial Hospital. He has 20 years of experience in all areas of abdominal organ transplantation.*

## Renal Dietitians Face Ethical Issues Everyday

By Judith Beto, PhD, RD, FADA

We need to protect the patient while protecting ourselves. This can be complex and challenging. Registered dietitians are guided by the Code of Ethics (COE) of the American Dietetic Association (ADA). We may also interface with employer guidelines defined within corporate parameters. This brief article will discuss two COE statements that relate to current areas of potential concern to renal dietitians: the electronic medical record and fairness in delivery of services.

*"The dietetics practitioner recognizes and exercises professional judgment within the limits of his/her qualifications and collaborates with others, seeks counsel, or makes referrals as appropriate."* The electronic medical record presents a legal, non-changeable documentation of the delivery of services to dialysis clients. Even when a record is changed or corrected, an electronic trail of evidence is produced showing when entries were changed and by whom. Electronic signatures and passwords control your identity so the security of these sign-on mechanisms is central to the process. What is written is considered to be action. Our language (which is now very readable and legible) explains what our thought process is, how we arrived at our practice decision, and how we implemented our evaluation. We need to assure we are practicing within our scope of practice. If your responsibility includes bone management, for example, the algorithm you use that is approved for your autonomous decision making should be clear and understandable. When you find yourself faced with decisions outside those parameters, you need to document how you consulted with others to obtain medications and laboratory testing that might be considered outside of your defined practice.

*"The dietetics practitioner conducts himself/herself with honesty, integrity, and fairness."* Fairness in delivery of services to your dialysis clients is more challenging. For example, perhaps you are responsible for 150 patients at two dialysis centers. How do you divide your time between those two centers? How do you divide your time between all of the shifts and days of service? How do you put priority on the services you deliver yet still give equal opportunity and time to everyone? This is not easy to do—yet, ethically we have to make decisions. Which patient requires our time before another? Is it morally correct to "give up" on patients who do not respond to our educational efforts? If we receive free or reduced cost nutritional supplements, does this infer we only recommend or distribute these products? Would other products be more beneficial or equally effective in the same patient? How can we deny access due to financial constraints?

Yes, perhaps we have more questions than answers. Professional collaboration, discussion, and awareness of these issues is an essential focus of renal dietitians today.

*Judy Beto, PhD, RD, FADA, is a Professor of Nutrition Sciences as well as the Director of the American Dietetic Association Accredited Didactic Program in Dietetics at Dominican University. She is member of the American Kidney Fund Board of Trustees and chair of the education committee.*

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**Weighing the Outcomes:  
Ethical Issues in Kidney Disease**  
Regional Conference

Houston - March 19, 2009  
Baltimore - October 1, 2009

Register at [www.kidneyfund.org](http://www.kidneyfund.org)

# Patient Perspective

## Perspectives on Caring

### *The Patient Perspective*

By Jeff Lewin

Adult polycystic kidney disease runs throughout my family, and I was diagnosed with the disease in 1984. The course of this disease is truly progressive; I noticed a subtle decline in my health from one year to the next. On February 24, 2008, while umpiring a collegiate baseball game, I became tired in a way I had never experienced before. After the doubleheader, I began experiencing severe cramping and knew that I had reached a crossroads in my life.

I truly thought that I could avoid dialysis until transplant. I absolutely did not want anything to do with dialysis. I had watched my mother experience dialysis some 25 years prior. I knew that technology had changed, but I also knew how much disdain my mother had for her three trips a week.

My nephrologist, Dr. Gertrude Findley-Christian, reviewed my lab values and reminded me that dialysis should begin before I become too sick—too sick is too late. I visited the dialysis unit at Kent General Hospital the following day to begin the acclimation process. Dr. Findley-Christian told me that it would be beneficial for me to meet with the nurse manager of the dialysis unit, Karen Palmer.

I figured that this meeting should take no more than 15 minutes. Karen spent nearly two hours with me. She recognized quickly that I was both uncomfortable talking about dialysis and that I was afraid—afraid of losing my independence.

Karen spent time talking to me about what to expect during the first treatment. She showed me the dialysis unit, introduced me to the staff, and provided me a brief about the machine itself. She showed me the needles which would be used, and explained the procedure for going on and removal from the machine. She advised me to take a day at a time. She said the first priority was to get me started and focused on improving my health. She said that I would steadily improve, but told me that I would experience peaks and valleys—she was right.

The intervening period between my visit to the unit and my start date was fraught with emotion. I was concerned about the needles; I was concerned about the limitation on my liberty; I thought about how this would affect my work, I wondered if I would ever get back to a normal activity level, and I struggled with the notion that I would now be dependent on this machine in order to live.

I will never forget my first treatment. Karen met me at the door and took me to a patient bed. Along the way, no fewer than four staff members greeted me and smiled. My wife joined me and I was as ready as I could be.

Karen explained the procedure in its entirety and then proceeded to explain every detail before she did anything. She sat with us during the entire treatment, asked how I was tolerating the treatment, asked about my responses to medications being administered and assessed my vital signs at every juncture of the treatment. Because of Karen's compassion and attentiveness, I was able to concentrate on getting through the treatment. I was no longer worried about my safety or the procedure...she put that to rest.

It is true that I grieved my loss of freedom and my reliance on this machine, but I turned the corner. I am not celebrating my dialysis treatments, but I have accepted them and I feel fortunate that I have an option. I am not as productive at work as I would like to be, but I am still working and have not missed a day due to dialysis treatments. I want to believe my perspective on life has changed over the past several months. Optimism dominates pessimism; I listen much more attentively to people; altruism trumps selfishness; I have manufactured an internal strength which cannot be rivaled; and I now know how fortunate I was to have been a part of the Bayhealth Dialysis Service.

I umpired my first collegiate baseball game since I began dialysis on September 14, 2008. I have been umpiring baseball games for over 20 years and I never felt so privileged to be on the field of play as I did on this day. It is amazing how a little caring can change an outlook—thanks to Dr. Findley-Christian, Karen, and all the staff of the dialysis unit.



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## Perspectives on Caring

### *The Professional Perspective*

By Karen Palmer, RN

At the Bayhealth Dialysis Unit, we believe that each patient must feel safe, relaxed, and positive about their future in order to get the most out of their treatments. We are deeply concerned for every single person who enters the unit, no matter who they are or what they do. We see every patient as part of our dialysis family. Each is special in his or her own way and deserves special care—the same extends to their family. We recognize that our patients have experienced a loss... a loss of freedom and a loss of control. While the loss may be temporary for some, for others it is a permanent life-altering event. We not only address the medical management of our patients, we address the difficult adjustments each of our patients must make.

We are an acute dialysis unit providing care to patients who are beginning dialysis, patients who are unstable for an outpatient transfer, and patients who return to the hospital due to illness. Our objectives are to facilitate an adjustment, promote healing and progress, and to help our patients develop and regain confidence in themselves.

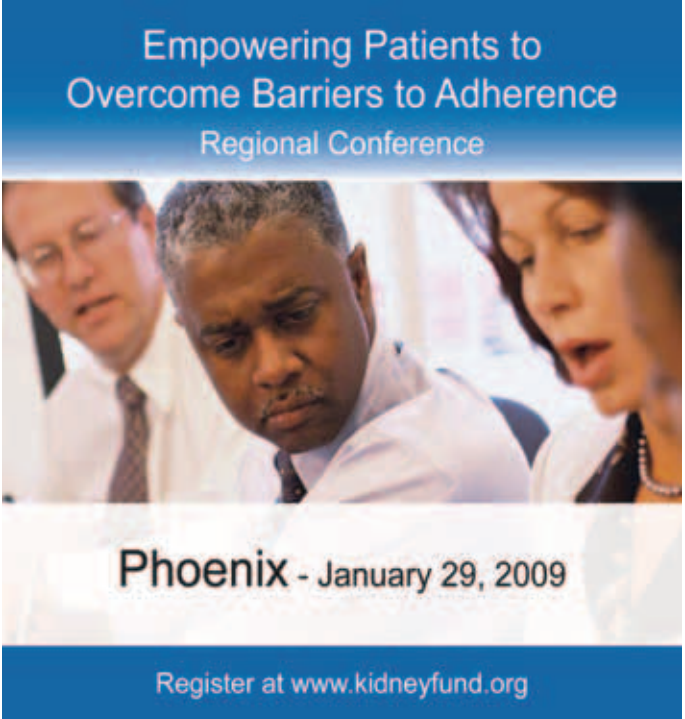
Our staff knows that they make a positive impact every day. Their enthusiasm is contagious and our patients and their families see it. I believe it is this attribute that instills trust and confidence in our patients. We spend a great deal of time with families every step of the way. From preparing our patients for their first treatment to discharging patients to an outpatient facility, we engage multiple resources and most importantly we take the time to explain every step of the way.

The first impression we leave with our patients is that they are the most important part of our day. We spend a lot of time with our patients, listening, teaching, and, yes, injecting humor. Our patients and families love the informal atmosphere—they are truly part of our extended family.

I have never experienced a patient who thinks it is time to start dialysis. We recognize that our patients will experience a roller coaster ride—almost all of our patients experience a flood of emotions at some point during their first few weeks of dialysis. When our patients want to talk, we want to be there to listen...and we are. The most powerful instrument we have is time—time to spend with our patients. It is the time we spend that truly makes the difference. Our staff always has time; our staff never takes time, we give it.

I am not going to try to distinguish our unit from any other. All I know is everyone who works here does not think of this as a job. We are a team in the true sense of the word and we all complement each other well. Everyone makes a contribution, regardless of position, toward the healing of our patients. This is a calling for us; our patients call on us and we respond with care, compassion, and heart. When our patients respond with great courage, strength, and a positive spirit, we have received instant gratification. That's what it's all about—our formula for success. We all love what we do and I believe it shows each and every day!

*Karen Palmer, RN, is the nurse manager at Bayhealth Dialysis units at both Kent General and Milford Memorial Hospitals in Central Delaware. She has been with Bayhealth Medical Center for 20 years and has managed the dialysis units for five years.*



Empowering Patients to  
Overcome Barriers to Adherence  
Regional Conference

Phoenix - January 29, 2009

Register at [www.kidneyfund.org](http://www.kidneyfund.org)

### Building Public Trust Through Outreach and Education (Part II)

By Kenneth A. Getz, MBA

*The American Kidney Fund offers visitors to its website ([www.kidneyfund.org](http://www.kidneyfund.org)) the ability to search for upcoming and ongoing clinical trials on most kidney diseases. Through a partnership with the Center for Information & Study on Clinical Research Participation (CISCRP), patients and their families can search for clinical trials in their area or across the United States and Canada. The article below is part two of a three-part series about clinical trials written by Kenneth A. Getz, the chairman of CISCRP.*

#### Historical Response

Research sponsors and investigative sites have largely responded by spending money on patient recruitment advertising and promotion with marginal – if not diminishing -- results. During the past decade, spending on patient recruitment programs by investigative sites and research sponsors has grown by 12% annually, reaching nearly \$500 million (CenterWatch, 2006). In that same period, volunteer randomization and retention rates have declined steadily (Tufts CSDD 2008). At the present time, investigative sites report that more than 90% of all clinical trials must extend their original study timelines in order to enroll the requisite number of volunteers (CenterWatch, 2007).

Research sponsors have turned their attention to recruiting volunteers from markets abroad – typically from regions including Latin America, Central and Eastern Europe, India and China. These regions offer well-trained professionals, large numbers of treatment-naïve and motivated patients, and lower relative costs. The Tufts Center estimates that nearly half of all FDA-regulated clinical trials are now being conducted by investigators based outside of the United States. But sponsors have done a poor job of explaining these practices to the media and the public. As a result, the media tends to portray the conduct of clinical trials overseas as exploitive and financially motivated.

Regulatory agencies and the clinical research community have responded to public confusion and concern by implementing reforms designed to assure higher levels of compliance and reduce errors that might result in physical and ethical harm to study volunteers. These reforms and measures are an important step, but they are not nearly enough. They satisfy regulatory agency and research sponsor requirements to minimize potential errors, noncompliance and fraud but they fail to acknowledge and address the fundamental need to educate and engage the public and prospective study volunteers. As such, these reforms will only be marginally effective until these communities understand why they are necessary and how they will influence and inform decision-making about the risks and benefits of clinical research participation and new medical therapies.

*Kenneth A. Getz, MBA, is the founder and chairman of CISCRP and a Senior Research Fellow for the Tufts Center for the Study of Drug Development, both in Boston, MA. He is the author of two nationally recognized books, [The Gift of Participation](#) and [Informed Consent: A Guide to the Risks and Benefits of Volunteering for Clinical Trials](#).*

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## Social Worker Scoop

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### AKF's New Online System for Managing Patient Grants Is Coming!

Applying for patient grants from the American Kidney Fund will become a more user-friendly experience for renal professionals, as the American Kidney Fund launches its new online Grants Management System (GMS) in spring 2009.

This comprehensive, Web-based system will make it easier to apply for patient grants—and it will allow the American Kidney Fund to process an ever-growing number of grant applications in a timely and efficient manner.

Many renal professionals are already very familiar with the American Kidney Fund's existing online grant application system. The soon-to-launch GMS will take this online system to a new level of service. Renal professionals will be able to complete online applications for all of AKF's financial assistance programs—HIPP, Safety Net Grants and Part D.

The GMS will expand upon the American Kidney Fund's existing online grant capabilities in other ways, as well.

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## My Life's Work: The Prevention of Chronic Kidney Disease

By Carmen Peralta, MD

"Chronic kidney disease is an epidemic; the medical community just hasn't recognized it yet." As a second year medical student just beginning my clinical rotations, this statement left me with a blank stare. I had loved my nephrology physiology teaching during my first years of medical school, and I considered the nephron as one of the most exciting units of physiology, but "an epidemic"? Little did I know that this statement would launch me into what would become my life's work.

During medical school, I had the wonderful experience of working with the leaders in the field of CKD, and I became aware of the impact of CKD in people's lives, the healthcare system and the medical community. I decided to pursue nephrology training with the idea of prevention always at the forefront of my mind. I began to discuss with my mentors the overwhelming evidence the community was collecting on racial/ethnic disparities in CKD outcomes, increased incidence in ESRD and the burden of these for minority populations. Data was published, and the remaining overwhelming question in my mind was "why?"

Therefore, I decided to focus my research on risk factors for early decline in kidney function, particularly among African Americans and Hispanics. My current research endeavor utilizes a translational approach that uses tools from genetics, epidemiology and social sciences. My aim is to understand the potential influences of genetics, social, environmental factors and their interactions in kidney disease development and early kidney function decline. Thanks to the AKF Clinical Scientist in Nephrology Program, I was able to meet and share ideas with some of the leaders in the field. I hope that my work will result in important prevention strategies. As I grow more experienced, I hope to inspire other nephrologists to focus on prevention of CKD incidence and progression.

*Carmen Peralta, MD, completed her American Kidney Fund-Amgen Clinical Scholar in Nephrology Fellowship at the University of California, San Francisco, in July 2008. Dr. Peralta's research examined the roles that individual genetic ancestry and socioeconomic status play in chronic kidney disease and how these factors impact the progression to end stage renal disease. In July 2008, Dr. Peralta joined the faculty of the University of California, San Francisco School of Medicine.*



## Social Worker Scoop (continued from page 6)

Renal professionals will be able to log in and obtain real-time grant application status updates and patient grant histories, and can use the system to upload required back-up documents. GMS also will generate automated e-mails to registered renal professionals and alert them when a grant application is incomplete.

AKF is empowering patients by allowing them to register as a GMS user so they can track their grant requests online. In keeping with longstanding American Kidney Fund policy, patients will not be able to apply directly for a grant; a renal professional must still apply on their behalf. However, patients will be able to obtain real-time status updates, see if their application is complete and obtain grant history information.

### System Highlights:

- Expected launch date in March 2009
- Features instantaneous pre-approval of grant requests pending receipt of required documents
- Expands the current online grant request submission capability to all of AKF's programs
- Provides registered renal professionals and patients with comprehensive, personalized grant application information
- Offers automatic e-mails/reminders to renal professionals regarding grant status
- Users will be able to register through AKF's website at [www.kidneyfund.org](http://www.kidneyfund.org) to use this service. (Renal professionals will be required to use a corporate e-mail address.)
- Group submissions will be available for the Health Insurance Premium Program
- Incorporates paperless features, making it a "green" initiative

### Training

To ensure a smooth transition and level of comfort, AKF is developing an online training module for renal professionals that will provide detailed training regarding the use of the new GMS system and all of AKF's grant programs.



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## AKF Event Calendar

<p><b>Regional Professional Conference</b> January 29, 2009 "Empowering Patients to Overcome Barriers to Adherence" Phoenix, AZ</p>	<p><b>Regional Professional Conference</b> March 19, 2009 "Weighing the Outcomes: Ethical Issues in Kidney Disease" Houston, TX</p>	<p><b>Third Annual Spring Event</b> March 26, 2009 New York, NY</p>	<p><b>Exhibit</b> American Association of Nurse Practitioners June 17-21, 2009 Nashville, TN</p>
<p><b>Exhibit</b> American Association of Diabetes Educators August 5-8, 2009 Atlanta, GA</p>	<p><b>Regional Professional Conference</b> August 27, 2009 "Strength in Caring: Taking Better Care of Others by Taking Better Care of You" Atlanta, GA</p>	<p><b>Exhibit</b> American Association of Kidney Patients September 3-6, 2009 Denver, CO</p>	<p><b>Regional Professional Conference</b> October 1, 2009 "Weighing the Outcomes: Ethical Issues in Kidney Disease" Baltimore / Washington, D.C.</p>
<p><b>Exhibit</b> American Academy of Family Practitioners October 14-18, 2009 Boston, MA</p>	<p><b>Exhibit</b> American Society of Nephrology Oct. 27- Nov.1, 2009 San Diego, CA</p>	<p><b>Clinical Scientist in Nephrology</b> Application Deadline December 1, 2009</p>	<p>Visit our website to sign up to receive this newsletter electronically</p>

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