National Kidney Foundation®
Making Lives Better

Family Focus

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National Kidney
Foundation

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PATIENT ADVOCACY

PEOPLE LIKE US: The National Kidney Foundation's Patient Empowerment Program

By John Davis, CEO

JOHN DAVIS,
Chief Executive
Officer of the
National Kidney
Foundation

MORE THAN ANY OTHER CONDITION, CHRONIC KIDNEY DISEASE (CKD), its treatment and outcomes are affected by decisions and actions of the federal government. The National Kidney Foundation (NKF) has always kept government relations high on its priority list. And we have had many successes: immunosuppressive drug coverage legislation, a law banning organ sales and hundreds of improvements in the Medicare rules have all been a result of NKF action.

Now more than ever, the NKF has to fight harder more often on behalf of everyone with CKD. It has to be a daily priority and a constant choice for the investment of NKF resources. The changes made by the government in the last year demand that we gear up for an active campaign to have a positive impact every single day on government decision makers. It has always been part of our mission and now it has to become part of our structure, budget and the very definition of what we stand for as an organization.

The NKF Board of Directors recently voted to transform the NKF into the United States' leading patient advocacy organization. We have been the largest; now we will also be the strongest, most active, most responsive and most influential voice for patients in the country. Our Patient and Family Council, along with our National Donor Family Council and transAction Council, have 42,000 members. Each of those individuals and families, along with 40,000 KEEP™ participants, 6,000 professional members and 15,000 doctors will form the core of a new NKF patient empowerment organization called People Like Us (PLU).

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FROM THE EDITOR

Karren King

WHAT DOES ADVOCACY HAVE TO DO WITH YOU? The *Family Focus* Editorial Board thought advocacy was so important for each of you to consider that we decided to devote an entire issue, out of just four annual issues, to the topic.

When you were diagnosed with chronic kidney disease (CKD), first began dialysis or even after being on dialysis for months or years, there may have been times when you felt you were all alone in facing life with CKD. It is important for you to be aware that there are others who support you. You already know many of them, such as your family and friends, but you may be unaware that there are others who are behind you. Organizations such as the National Kidney Foundation (NKF) and the End Stage Renal Disease Networks have always been strong advocates and supporters of all those who live with CKD. NKF was there from the very beginning of the dialysis and kidney transplant program in the United States and was active in getting Medicare to extend coverage to those with CKD who needed dialysis or kidney transplantation. NKF is still there for you now, and you will learn in this issue about some of its current efforts on your behalf.

In addition to others advocating on your behalf, it is equally important that you, just like each and every one of us with or without CKD, learn to be an effective self-advocate. Who knows better than you what issues are of concern to you and what your needs are? Once you identify them, whether they are health, employment, emotional, education or family related, it is important that you learn to speak clearly about these issues to those who can make a difference. There are several articles in this issue of *Family Focus* that can give you direction on how you can begin to advocate for yourself.

I think you will also be very impressed, as I was, with the numerous and varied advocacy activities of those who responded to this issue's *Family Focus* Voices question. Reflecting upon what these selfless individuals have done to advocate for those with CKD and the differences they have made in others' lives is very inspiring.

As I write this editorial, 2005 is just beginning. I challenge each of you to end this year by reflecting on your own advocacy efforts, either for yourself or others with CKD. Working both individually and together, we can all make a difference and improve the lives of those affected by CKD.

Karren King, MSW,
ACSW, LCSW
For the Editorial Board

Family Focus

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Professionals Take ACTION *With Advocacy Training*

Kidney health care professionals will turn their advocacy efforts up a notch with new and exciting advocacy events at the National Kidney Foundation (NKF) 2005 Spring Clinical Meetings, which will be held May 4–8 in Washington, D.C. These professionals will hold a Legislative Workshop on how to influence chronic kidney disease (CKD) care through advocacy in government. Participants will learn from health policy experts, network with other kidney care professionals and visit members of Congress. Through visits to the offices of their Congressional representatives, participants will learn firsthand about the role of advocacy at the state and national levels to promote political action on behalf of the CKD community. For more information on the Legislative Workshop and other sessions for health care professionals at the NKF 2005 Spring Clinical Meetings, visit **www.kidney.org** and click on "CM.05" or contact Kristen at 800-622-9010, ext. 206.

PEOPLE LIKE US...

Continued from page 1

PLU is a comprehensive program to join patients, families and other NKF groups to establish a strong, unified, proactive approach to patient advocacy for the care and treatment of those affected by CKD. Through People Like Us, the NKF will mobilize, educate and encourage individuals from around the country to represent and speak out about the issues that are vital to their lives.

To kick off the People Like Us program, the NKF will hold a series of advocacy and empowerment activities during our Spring Clinical Meetings in Washington, D.C., May 4–8, 2005. One hundred advocates—patients and family members—are being recruited from around the country to participate in this exciting new initiative. They will attend a training session to teach them about the various aspects of advocacy, the need for and importance of their participation in both national and grassroots public policy initiatives and the skills required to become persuasive and confident spokespeople. This session will prepare PLU participants to talk to their elected and government officials, and a subset of this group will immediately put these skills into action as they visit Congressional offices on Capitol Hill. The NKF will announce the establishment of People Like Us and encourage lawmakers to seek our views before acting on legislative initiatives that would affect the care of people with CKD.

To be successful, we know that People Like Us will require the energy and dedication of thousands of people in all stages of CKD and all treatment modalities, as well as their families and those dedicated to their care. At the NKF, we have the means to effectively recruit individuals to accomplish this task. In addition to the thousands of individuals in our patient and professional councils, our 50 affiliates around the country will work hard to help achieve our goals to empower and educate patient advocates.

We will recruit and train participants to join PLU from around the country in every Congressional district to represent the needs of kidney patients. PLU will evaluate, assess and formulate responses to issues presented from patient perspectives.

Issues related to kidney disease are both varied and complicated, and the NKF's PLU will work tirelessly to make sure that together we meet the challenges faced by kidney patients. We will create cohesive strategies to promote public education and awareness about CKD, increase research resources, expand access to proper health care and ensure adequate reimbursement for treatments.

The NKF is aware of the many affiliate groups and individuals who are active in advocacy efforts; we are in frequent contact with people in dialysis centers who are organizing support groups and orienting new patients, speaking with their elected officials and the media about CKD and who continue to forge relationships with health organizations. People Like Us needs people like you to continue to get the messages out about kidney disease! As the most powerful and effective patient-centered consumer movement that truly represents the voice of the patients, People Like Us will strive to make kidney disease a part of every public policy and lawmaker's vocabulary when they talk about chronic illness. The strong voices of People Like Us can have a major impact on the care and treatment of CKD by encouraging and persuading national and local governments to adopt and implement policies to ensure that people with CKD receive the best care and support.

To learn more about or to join People Like Us, call the National Kidney Foundation at 800-622-9010 or send an e-mail to **peoplelikeus@kidney.org**

The NKF gratefully acknowledges the following for their support of People Like Us. Sponsorship information is available by contacting Stephanie Gross at 800-622-9010 or stephanieg@kidney.org

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NOVARTIS

Advocacy Within the School Setting

By Fred Kouri, LMSW

Your child will thrive at school if you learn now how to advocate effectively.

Any caregiver of a child with special needs knows that the need for advocacy extends beyond the medical setting to all facets of the child's life: educational, vocational, social, emotional and spiritual. The first step in being an advocate for your child is being educated about your rights and the enormous responsibility in educating others on the special needs of your child.

This article is not intended to be an all-inclusive overview of the educational rights of your child from birth to age 21. Instead, it is intended to give you a general overview and a number of resources that will guide you though the special education maze. As you begin through this maze, remember that you are not alone. Utilize local and national support organizations for children with special needs. Also, other caregivers of children with chronic kidney disease can be a great resource to you as well. They have walked in your shoes and know firsthand the challenges that may await your son or daughter.

BACKGROUND OF YOUR CHILD'S EDUCATIONAL RIGHTS

Until 1975, children with disabilities faced unequal and often unfair situations when they sought an education. This all changed when P.L. 94-142 (The Education for All Handicapped Children Act) was signed into law by President Gerald Ford. The federal law mandated that children between the ages of six and 18 receive a wide rage of educational and vocational services. The law was revised in 1997 and signed into law by President Bill Clinton to include early education services from birth to age three and educational services for children ages three through 21 years through the Individuals with Disabilities Education Act (IDEA, P.L. 101-476).

BIRTH TO THREE YEARS OLD

Advocacy for your child can begin at birth when evaluating the need for developmental and educational services. In many states, children with chronic kidney disease (CKD) qualify for early intervention services either based on known or possible developmental delays. These delays can be in the areas of

Continued on page 14

The Key to Exercise: Knowing Where To Begin

By Pedro Recalde, MS, ACSM, Adult Fitness/Cardiac Rehabilitation

Learn these building blocks of exercise to improve your exercise regimen.

What is your **CARDIOVASCULAR ENDURANCE?** This is the ability of your heart, lungs and extensive system of blood vessels to supply fuel to your working muscles during exercise. Your cardiovascular endurance refers to how long you can maintain the activity of walking, running, bicycling, skating, dancing, jogging, swimming and even shopping at a particular pace. It also plays a part in how tired you will be after you complete those activities. Improving your cardiovascular fitness means that you can complete an hour's worth of those activities along with your other normal daily activities without being as tired as you used to be.

What is your **ANAEROBIC FITNESS?** The word anaerobic means "not depending on oxygen" and refers to activities that occur on a daily basis that use quick and ready-stored fuel—not oxygen—for energy. You use this anaerobic system to quickly run for a taxi, lift your children, get out of a chair and walk up stairs—in other words, activities that require quick bursts of energy, but usually only last up to two minutes in duration.

COMPONENTS OF ANAEROBIC FITNESS INCLUDE:

>> **STRENGTH** is usually measured by the maximum amount of force that can be generated by your muscles in a single movement. You need strength to open a heavy door, get in and out of the dialysis chair, climb the stairs of a bus and lift a heavy object without struggling or injuring yourself.

>> **POWER** is measured by how fast you can use your strength. You have to use your power to throw a ball, walk quickly across the street at a traffic light or catch a falling package. As you can see, power is not just for athletes.

>> **MUSCULAR ENDURANCE** is the ability of your muscles to perform the same motion time and time again. Examples of muscular endurance include pedaling a bicycle, treading water in a pool, walking up several flights of stairs or doing arm exercises on an upper body cycle. In the case of low muscular endurance, your heart and lungs are just fine, but your muscles are tired and limit your ability to continue the exercise.

>> **FLEXIBILITY** is the ability to move your moving joints (waist, knees, elbows, neck) through their normal range of motion safely and easily. Good flexibility is necessary for all activities, such as placing groceries on the shelf, pulling weeds in the yard, washing dishes and getting in and out of your car.

Good flexibility is necessary for all activities.

Now that you know what you are actually improving with your exercise program, how can you tell if it is really working? Here are some useful tips:

■ Resting heart rate refers to the number of times your heart beats in one minute without exercise, which also represents the efficiency of your heart at rest. A sign that your heart is improving with its ability to pump blood is a lowering of your resting heart rate after several months of exercise.

■ Exercising heart rate refers to the number of times your heart beats in one minute while doing exercise. A lower heart rate while exercising represents the ability of your heart to meet the needs of your working muscles with greater efficiency.

■ Before beginning an exercise program, you should measure your resting heart rate and your heart rate after walking once around a city block, then record those numbers in a training log. After your first three months of exercise, take your resting and exercise heart rates again to see if there are any changes. You might be surprised.

■ Sit to Stand: This test for measuring changes in the muscular endurance of your lower body is simple to perform at home. Count the number of times you can stand up, then sit down, then stand again, etc., in one minute. After three months of exercise, such as walking in the park or stair climbing, count the number of times again that you can sit to stand in one minute. Once again, you may see some changes.

Pedro Recalde, MS, ACSM

■ Therapy bands are great options for working on muscular strength and endurance, even while on dialysis. These bands often are sold with color codes representing different levels of resistance. Start with the lowest resistance and perform the exercise until it becomes easy to complete. Move on to the next color and progress in the same manner, always moving to the next resistance level when the exercise becomes too easy. Different versions of these resistance bands can be found in the sports/exercise sections of major department stores and retail sporting goods stores.

It is important to recognize which area of fitness you want to work on before starting your exercise program. If you find that you become short of breath after only a few minutes of continuous activity, a walking program might be needed to help improve your cardiovascular endurance. If you find that the muscles of your arms and legs are too weak to continue your exercise, creating an exercise program with the elastic bands might suit you better. **As always, it is a good idea to talk with your doctor before beginning any new exercise regimen.**

K/DOQI Guidelines: Empowering You and Your Family

By Karen Glowacki, MA, K/DOQI Information Director

While you may think the National Kidney Foundation's (NKF) Kidney Disease Outcomes Quality Initiative (K/DOQI) clinical practice guidelines are written mainly for doctors, they are really created for you. The goal of K/DOQI is to help make lives better for people with any stage of chronic kidney disease (CKD). To help ensure that you are getting the best care available, we encourage you to get to know the guidelines and to be sure that your doctors and health care team know when new guidelines are published. This article is the first in a series about the K/DOQI guidelines. In future articles, we will give you information about specific guidelines. Following are “Frequently Asked Questions” to help you understand what you need to know about K/DOQI.

WHAT IS K/DOQI?

K/DOQI is the part of the NKF that brings together leading medical experts to review published medical research, pull out the most important findings and put them into guidelines for health care professionals to use to help diagnose and treat CKD and its complications.

HOW LONG DOES IT TAKE TO WRITE K/DOQI GUIDELINES?

It takes about two years to develop a guideline. In that time, a Work Group of approximately 15 medical and health care professionals meets several times in person and also has conference calls to examine and discuss the latest research. After studying this research, they develop the guidelines. Other professionals and organizations review the guidelines before they are finalized and then published in the American Journal of Kidney Diseases, a NKF journal written for kidney professionals.

IS THE NKF WORKING ON NEW K/DOQI GUIDELINES?

The NKF has several guidelines under development. Some of the guidelines are new and others are being updated to include new research that has been published since the guidelines were originally available. Following is a list of K/DOQI guidelines that are underway and when they are expected to be published:

- *Cardiovascular Disease in Dialysis Patients* (April 2005)
- *Hemodialysis Adequacy* (update, Fall 2005)
- *Peritoneal Dialysis Adequacy* (update, Fall 2005)
- *Vascular Access* (update, Fall 2005)
- *Anemia of Chronic Kidney Disease* (late Winter 2005)
- *Diabetes in Chronic Kidney Disease* (early Winter 2006)

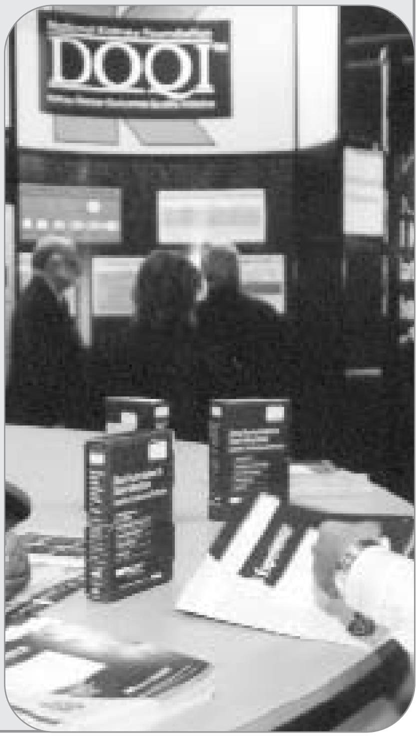
HOW CAN I GET A COPY OF THE GUIDELINES?

All the K/DOQI guidelines are available at no charge on the K/DOQI Web site at **www.kdoqi.org** Make sure your health care team knows they— and you—can get all of the K/DOQI guidelines at any time on the K/DOQI Web site. Also, the NKF's Kidney Learning System (KLS ™, **www.nkfkls.org**) has a variety of educational resources—based on the science of K/DOQI—especially for people with CKD and their families. You can call the NKF Information Center at 800-622-9010 to request a brochure about any one of the K/DOQI guidelines.

HOW MANY K/DOQI GUIDELINES HAVE BEEN PUBLISHED?

The year 2005 marks the 10 year anniversary of K/DOQI. In that time, NKF has published the following guidelines:

- *Hypertension and Antihypertensive Agents in Chronic Kidney Disease* (May 2004)
- *Bone Metabolism and Disease in Chronic Kidney Disease* (October 2003)
- *Managing Dyslipidemias in Chronic Kidney Disease* (April 2003)
- *Evaluation, Classification and Stratification of Chronic Kidney Disease* (February 2002)
- *Nutrition of Chronic Renal Failure* (2000)
- *Hemodialysis Adequacy* (1997, updated 2000)
- *Peritoneal Dialysis Adequacy* (1997, updated 2000)
- *Vascular Access* (1997, updated 2000)
- *Treatment of Anemia of Chronic Renal Failure* (1997, updated 2000)



My Doctor

By Kathleen Collins

My doctor wears a stethoscope,
With my problems he helps me cope.
He always has a nice big smile
And he travels many a mile.
Now dialysis is the place,
Where once a week I see his face.
He wakes me up if I'm asleep
And gives sound advice I can keep.
His chair-side skills are good most days.
He tells us how to mend our ways.
To our town he comes to see us,
Sometimes to praise, sometimes to fuss.
Our monthly lab work he reviews,
Then gives us the bad and good news.
Prescriptions for us he will write.
Most of my pills I take at night.
He listens to hearts and complaints.
And to our “O.K.”s and our “can't”s.
(Example: “Oh, no, Doc, I can't do that.”)
I'm glad my doctor visits me,
Though he charges a great big fee.

Kathleen Collins, RN is a hemodialysis patient in Hampton, SC.

Easter

By Anna

While Easter eggs are
being dyed,
Easter clothes are
being tried.

Little chicks and
baby bunnies
are in the mix.
There's an Easter ham to fix.

Songs of “He Arose”,
are being sung.
Early morning, church
bells are being rung.

Anna is a hemodialysis patient in Portland, OR.

Choosing Your Hemodialysis Vascular Access

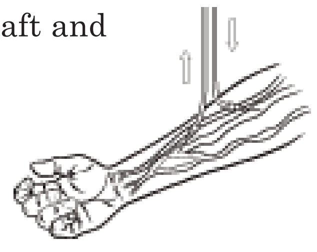
By Bobbie Knotek, RN, BSN, CNN

Get all the facts before making this decision.

You have options when it comes to choosing how you will receive hemodialysis. You can educate yourself about your options and with your physician choose the best one for you. Keep reading to learn all your options.

WHAT IS A VASCULAR ACCESS?

The vascular access, put in during surgery, allows blood to safely leave your body, travel to the artificial kidney (dialyzer) and return to your body during a hemodialysis treatment. A vascular access is usually placed in your arm, leg or neck. There are three kinds of vascular access—fistula, graft and catheter.



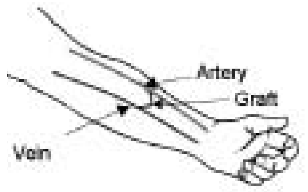
FISTULA

A fistula (also called an arterio-venous fistula, or AVF) is made within the person's own arm or leg during surgery when a vein is connected to a nearby artery. After the vein and the artery are connected, the stronger arterial blood passing through the vein makes the vein larger and stronger. It takes about six weeks for the fistula to get large enough to deliver enough blood flow and be used for hemodialysis. Even though you have to wait longer to use a fistula, a fistula that works well is worth the wait. **A fistula is often the preferred and recommended form of access for hemodialysis patients** because it:

- Lasts longer than other access types.
- Has fewer infections than grafts or catheters.
- Needs fewer follow-up procedures to keep it working, which means fewer hospital visits. A fistula may only need two to three follow-up procedures in 20 years.

A fistula may not work for everyone, but new surgical techniques and vein mapping make it possible for more and more people to have a working fistula. Vein or vessel mapping tells the surgeon where your blood vessels are located, how large and deep they are and if they are healthy enough to be used for a fistula.

GRAFT



A graft (also called arterio-venous graft, or AVG) is a small, soft tube placed under the skin during surgery. One end of the graft is attached to an artery, the other end to a vein. Dialysis AV grafts should be placed at least three weeks before an anticipated need for hemodialysis. Grafts:

- Usually only last three to five years.
- Are more likely to get infected than fistulas.
- Clot more often than fistulas.
- May require two to three or more follow-up procedures in one year for clotting problems.

CATHETER

A catheter is a small, Y-shaped plastic tube that is put into a large vein in the neck. The top part of the catheter is outside the body and the bottom part sits in the heart. Although catheters can be used right away and seem easier and less painful, they can be a serious risk to your health. Only a small number of people on hemodialysis who have run out of other access sites should be using a catheter for their permanent access. If a catheter is needed for immediate dialysis, a fistula (or graft, if a fistula cannot be created) should be placed at the same time the catheter is placed. Once the fistula or graft starts working, the catheter should be removed. Catheters:

- Clot frequently, leading to poor removal of waste products and fluid during dialysis.
- Have the highest risk of infection. Catheter infections can turn into serious infections.

If you are currently using a catheter for dialysis (and do not have a graft or fistula waiting to be used) ask your nephrologist to refer you to a surgeon to be evaluated for a fistula.

WHICH ACCESS IS BEST FOR ME?

You owe it to yourself to make sure you have the best possible vascular access. To find out which access will work best for you, read the access tips below and talk to your doctor and your surgeon.

If you will be starting dialysis within the next year and have not had a vascular access placed, ask your doctor to refer you to a surgeon who has experience placing fistulas. Tell your doctor and surgeon you would like to be evaluated for a fistula first.

- If the surgeon cannot tell if you are a good candidate for a fistula by examining your arms, ask to have vessel mapping done on the arteries and veins in both arms.
- If the surgeon says you are not a candidate for a fistula, get a second opinion. If you need the name of a surgeon in your area with experience placing fistulas, contact your End Stage Renal Disease (ESRD) Network.
- If you are already scheduled for fistula surgery, tell your doctor and surgeon you do not want the surgeon to substitute a graft or catheter for a fistula without your permission.
- If you will be getting a fistula placed, make sure to schedule your fistula surgery at least six months before you expect to start hemodialysis.

Often, people who know they will need hemodialysis will delay getting a vascular access placed. When asked why they delayed, people may say, "I don't want to admit my kidneys are failing," "I'm nervous and scared about starting dialysis" or "If they're telling me to have a vascular access placed now, it must mean that I'll be starting dialysis sooner than they're telling me." Talk with your nephrologist about your concerns or fears about starting hemodialysis. Refer to the *Clinical Practice Guidelines for Chronic Kidney Disease (CKD)* Part 4, Guideline 2 on the National Kidney Foundation Web site **www.kdoqi.org** to get an idea of when you need to have your fistula surgery. New K/DOQI Guidelines on vascular access are under revision and will be available in Fall 2005.

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Choosing Your Hemodialysis Vascular Access

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After your blood vessels have been mapped and you have been evaluated for a fistula by a fistula surgeon, you may learn that your blood vessels will not work for a fistula. If that happens, you should be evaluated for a graft.

> *If you have had multiple catheters and/or grafts and want to have a fistula, you will want to find a surgeon with experience placing fistulas.*

If you are currently using a graft for dialysis, ask your kidney doctor to refer you to a surgeon for a fistula evaluation. Then, when your graft starts to fail, you and your doctor will already know whether you are a fistula candidate. Many people with lower arm grafts have large, unused upper arm blood vessels that can be used for a fistula.

If you have had multiple catheters and/or grafts and want to have a fistula, you will want to find a surgeon with experience placing fistulas. It is also extremely important that you have pre-surgical vessel mapping done to locate the larger, deeper veins that have not yet been used for access. Vessel mapping also looks for narrowing of the veins that can occur after catheter use.

The surgeon should check the fistula four to six weeks after surgery to make sure it is getting bigger and stronger.

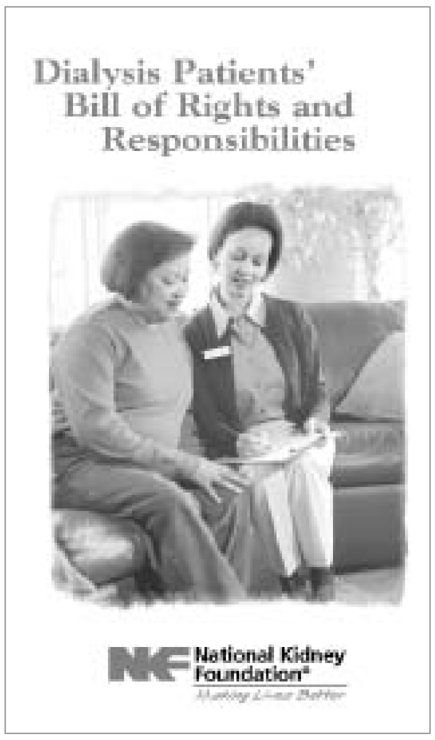
TAKING CARE OF YOUR NEW ACCESS:

- KEEP the area around your fistula or graft clean and dry. Once you start dialysis, you need to wash your fistula or graft thoroughly with soap or special cleaner and water before EACH dialysis treatment.
- CHECK your access first thing in the morning for the “buzz” or pulse over your access scar. If your fistula or graft is working, you should always feel the buzz or pulse.
- GET USED to the feel of your “personal” buzz (called the bruit, brew-ee) or pulse so you will know how it is supposed to feel when it is healthy.
- AFTER YOU CHECK your bruit, check the color, temperature and size or your access arm or leg.
- IF YOU HAVE an arm access, check the hand and fingers of that arm every day. Make sure your fingers (or toes, if you have a leg access) stay pink and warm, that you can move them easily and you do not have pain (or an increase in previous pain).
- IF YOU NOTICE ANY of the signs below, call your doctor or surgeon right away:
  - YOUR BRUIT (buzz or pulse) becomes weaker or a lot stronger.
  - YOUR ACCESS arm or leg changes color or begins to feel hot or cold.
  - YOUR ACCESS arm or leg begins to swell.
  - YOU FEEL PAIN in your access.
- DO NOT WEAR tight clothes or jewelry on your fistula or graft arm or leg.
- DO NOT HANG plastic grocery bag handles or a purse on your access arm.
- IF YOUR FISTULA or graft is in your arm, do not sleep on that arm.
- BE CAREFUL not to bump or cut your fistula or graft. If you work around sharp objects, cover your access with something strong enough to protect it. Ask your surgeon what to do if you get a bruise or cut on your fistula or graft.
- DO NOT LET anyone (including doctors or nurses in the hospital or doctor's office) take your blood pressure, draw blood or put IV's anywhere in the arm or leg that has a working fistula or graft.

It will be challenging to apply these suggestions. But remember: It is YOUR life and YOUR access, and the rewards of choosing the best possible vascular access will be with you for many years to come!

WHEN CHOOSING YOUR FISTULA SURGEON, ***bring this list of questions with you to the appointment and discuss with your surgeon.***

1. How many fistulas did the surgeon place in the last three to six months?
2. How many of the fistulas placed by this surgeon in the last year are working well?
3. How many fistulas did the surgeon place compared to grafts and catheters?
4. What type of pre-surgical assessment does the surgeon do?
5. Does the surgeon do vessel (vein) mapping?
6. Does the surgeon map the arteries and veins in both arms?
7. Does the surgeon do the vessel mapping him or herself or send patients to an ultrasound lab?



Dialysis Patients' Bill of Rights and Responsibilities

National Kidney Foundation®

The Dialysis Patients' Bill of Rights and Responsibilities is available for order by calling 800-622-9010, ext. 175.

Invest In Yourself: Be A Personal Advocate

By David Jones

You are the most important person in your life with CKD.

YOU MIGHT BE WONDERING what being an advocate is all about and why it is so important. An advocate is someone who takes a stand for a cause that is important to him or her. For someone with chronic kidney disease (CKD) there are many ways to translate that definition into action, starting with learning all you can about CKD. By developing a better understanding of CKD and your personal medical condition, you will be better prepared to speak the language of kidney disease and be an advocate for yourself within your health care team.

> *Our families can be our best advocates and morale boosters, especially in tough times, so keep communication open and do not be afraid to ask for help.*

IT IS A RARE MEDICAL PROFESSIONAL who does not respect and respond to people with CKD and families who ask questions in an attempt to understand their disease and take control of their health care. It is helpful when talking with medical staff to keep in mind that a positive approach can make all the difference. One spouse of someone with CKD pointed out that "Nitpicking nonessential details and expecting staff members to solve all of our personal problems is just unrealistic."

DOCTORS ARE OFTEN STRETCHED for time, so you can achieve the best results at your appointments by preparing your medical questions in advance and writing down the explanations and advice. Also, consider having someone else present at your medical appointment who can listen and take notes. Who has not left a doctor's office feeling sure they understood all that was said, only to arrive home with unanswered questions? Also, if you are confused by what your doctor is saying, do not be afraid to speak up.

OUR FAMILIES CAN BE OUR BEST ADVOCATES and morale boosters, especially in tough times, so keep communication open and do not be afraid to ask for help. Many people withdraw from their families when times are the toughest. Dotty Zecca, the wife of a person with CKD, stated that "Families want to help, but often will not say anything unless they are asked." Do not leave your loved ones guessing about what you are feeling.

TRIED AND TRUE TECHNIQUES FOR SELF-ADVOCACY

Here are some practical suggestions that individuals with CKD can use to help them become effective self-advocates:

- PREPARE WRITTEN QUESTIONS before your medical appointments and write down the answers.
- KEEP A LOG OF MONTHLY LAB WORK and medical tests. Date and record doctor's instructions. Over time, these records could be an important source for your history of shots, medications, x-rays, tests and treatment changes.
- CONSIDER LOOKING FOR SECOND OPINIONS when making important decisions if you have doubts about a recommended course of treatment. Remember that it is okay to tell a doctor or other health care professionals that you do not agree with their recommendations while explaining why you disagree. Ask your insurance provider for a list of health care providers who are covered by your policy. Often, Medicare and many insurance plans may provide payment coverage for second opinions.
- EXPECT PRIVACY when discussing personal and sensitive issues. Do not be afraid to ask for a confidential meeting rather than having a discussion in the dialysis center.
- TALK WITH OTHER PEOPLE who have CKD about their experiences, especially the ways they have adapted to the stress of kidney failure. Every person is unique, but we can all learn from each other.
- ENCOURAGE YOUR FAMILY to give active support and to serve as a sounding board. Remember to thank them for being there for you.

David Jones

ACCOUNTABILITY FOR YOUR MEDICAL CARE does not rest solely on the medical staff. Each of us must take an active role in our treatment. Tell your doctor when new symptoms or problems appear. This will help to ensure that problems are "nipped in the bud" rather than waiting until conditions worsen to the point where your doctor recognizes you have a problem. Jim Rogers, who is on peritoneal dialysis and is a longtime diabetic, advises, "Track your lab tests and watch for trends; if something does not feel right, tell the doctor what you are feeling." With pride, Jim adds, "I am in control as a partner with my doctor and my family!"

YOU CAN HELP YOURSELF in spite of the complex nature of medical care today. Recognize that when you have multiple doctors, as most of us do, there can be a lack of coordination or communication among your doctors about your care plans or medications. Take an active role by ensuring that information is shared among your health care providers.

IF YOU HAVE NOT THOUGHT OF YOURSELF as an advocate before, why not start now? By playing an active role in the control of kidney disease you can make it a manageable part of your daily life and get on with the things that really make life worth living.

Taking Control of Your Transplant Process

By Nancy Swick, RN, BSN, CCTC

Ask questions. Learn all you can. Take control!

Nancy Swick, RN, BSN, CCTC

ARE YOU THINKING ABOUT BEING EVALUATED FOR A KIDNEY TRANSPLANT? Are you awaiting a kidney transplant? Maybe you have decided that a kidney transplant is not for you, a decision made, perhaps, by both you and a transplant team which includes a transplant surgeon, a transplant nephrologist, a nurse coordinator and a social worker.

IT IS IMPORTANT TO KNOW that each of you has a right to be offered the option of a kidney transplant. If there is a reason, such as something in your medical history, that makes the option of transplant not an option for you, you also have the right to have that reason explained to you. At whatever point you find yourself, however, you will benefit greatly from active involvement in the process. Being an advocate for yourself during the entire transplant process will assure that you get the answers you need to make good decisions. A decision to pursue transplantation as a treatment for kidney failure should be a fully informed one. Active involvement in this process will also enhance your outcome.

THE JOB OF THE TRANSPLANT TEAM during the transplant evaluation is to help you determine if kidney transplantation is appropriate for you. Is it medically safe for you? Are you at increased risk of medical complications? Do you have resources in place to deal with the costs associated with the transplant process? Will the transplant improve your quality of life? These are questions you should not only ask yourself but ones that the transplant team will also discuss with you and your family if you want family members to be involved.

IN ADDITION, THERE ARE QUESTIONS you should ask the transplant team. Who will be taking care of me while I am in the hospital? What about my care after being discharged? Will I be followed by the transplant team or my primary physician? What kind of support do I need in place after the transplant? Will there be a social worker or someone to help with concerns if needed? How many kidney transplants has the center performed and for how many years has the center done kidney transplants? How do the center's transplant results compare with recognized national standards? Check online at **www.ustransplant.org**, which is the Scientific Registry of Transplant Recipients (click on "Transplant Statistics"), or on **www.OPTN.org**, The Organ Procurement and Transplantation Network; click on "Data." You may go to the NKF transplant recipient Web site **www.transplantrecipient.org** to post a message or read others' messages. Also, it is important to ask hard financial questions. Are there hidden financial expenses? Does my insurance company have a preferred transplant center that they want me to work with? Gather as much information as you need to make the right decision for you.

ONCE YOU ARE PLACED ON A WAITING LIST, your involvement needs to continue. The wait for a suitably matched organ can be very long—for some, the wait and uncertainty are the most difficult parts of the transplant process. A question that everyone on the kidney transplant waiting list wonders about at some time is "Why am I waiting so long?" There are many factors that affect your waiting time. These factors include the availability of donor organs, your blood type and your Panel Reactive Antibody, commonly called PRA. The more antibodies you have in your blood, the higher your PRA will be and the more difficult it can be to match you to a donor organ. Therefore, your waiting time can be longer than someone with a low PRA.

You have the right to call your transplant center to check your status on the waiting list.

YOU HAVE THE RIGHT TO CALL YOUR TRANSPLANT CENTER to check your status on the waiting list. Although no one will be able to tell you an exact date for a transplant (unless you have a living donor), you can be supplied with information on your PRA, your status on the list (active or inactive) and the amount of time you have accrued on the waiting list. You can be made temporarily "inactive" on the national waiting list if something would prevent you from being safely transplanted. This could be an infection or a temporary change in your current health status. You will continue to accrue time on the waiting list when inactive and should be informed by your transplant center before any change is made. It is your right and responsibility to get as much information as possible about the transplant process. Ask questions, keep asking questions and take responsibility for getting the answers you need.

One of the questions that can arise is how to get information on living donation, as well as the best way to ask someone about being a donor for you. Ask your transplant center for information on living donation, look at the National Kidney Foundation Web site on living donation (**www.livingdonors.org**) and chat with living donors, potential donors, professionals, family and friends of donors or join the e-mail discussion group.

One way to approach family or friends about the possibility of being a living donor is to make sure they know your options. Let them know what you know about transplantation and living donation. Let them also know that you met with a transplant team and one of your options would be to go on a national waiting list and another option could be living donation. They may also want to meet with the transplant team to have their questions answered. Once others understand your situation, the door is often open to more discussion about donation.

The more informed and involved you are, the better prepared you will be to make the decision of whether a transplant is right for you—and, if so, to deal with problems that might arise before, during and after the transplant. You are the most important part of the transplant team! Be an advocate for you!

Speaking Up for Your Good Health

By Mary Beth Callahan, ACSW, LCSW

Communicating with your health care team will boost your self-advocacy.

As I sat down to write this article, I began by developing a list of the people or organizations that you, as someone on dialysis, might talk with on a regular basis about your disease and its effects on your life. There are the "usual suspects" in a dialysis clinic: doctors, nurses, social workers, dietitians, technicians and secretaries. I came up with an additional list of 15 more contacts you might need. This list includes representatives from Medicare, Social Security, the local Department of Health and Human Services, your insurance carrier, transportation providers and your employer, to name a few.

The point of this exercise is to show that when you live with a chronic illness such as chronic kidney disease (CKD), you are often faced with the task of speaking with many people about personal matters, such as your health and financial situation, that you might not typically choose to discuss. In addition to the private nature of some of these conversations, you might be asked to have these discussions when you are not feeling well, are unprepared for the subject matter or when there is a lack of privacy.

> *Remember, the clinic staff is there to care for you and give you the education you need to understand your disease.*

YOUR HEALTH CARE TEAM

Aside from your loved ones, perhaps the most important people for you to be in constant and productive communication with are those who provide care for you on a regular basis. This includes your doctors, nurses, dialysis technicians, social workers and dietitians.

Talking with these individuals, however, can be trying at times and next to impossible at other times. Medical settings—and dialysis clinics in particular—are often noisy, chaotic and not conducive to privacy. Despite these circumstances, two constants remain in place: One, you have a right to be fully informed about your care and treatment options, and two, you should always be given the chance to fully participate in your treatment planning. You also have the right to meet with staff privately.

Communicating with your health care team within this difficult setting depends on your willingness to express your needs. Remember, the clinic staff is there to care for you and give you the education you need to understand your disease. Interrupting those who care for us can be intimidating and difficult. An effective way to start a conversation about your care can be with a simple statement such as "I know you are busy, but I have some questions about my treatment. Before I leave today I would appreciate it if you would sit down with me and go through my questions." This makes it clear to the health care professionals that you have questions, and it allows them the opportunity to plan their day to allow for the time needed to answer your questions.

Communicating with your health care team… depends on your willingness to express your needs.

Asking for a "care conference" is another good way to talk with your health care team. Care conferences are designed for you and your family members to sit down privately with the doctor, nurse, technician, social worker and/or other health care team members for an in-depth discussion about your current health needs. Prepare for the conference by writing down your questions in advance. In addition, request copies of certain lab reports or other parts of your medical record that might be helpful to you before the meeting. If you identify with one staff member, invite that person to the conference. Also, be sure to bring someone, such as a family member or friend, who can take notes for you and ask clarifying questions of the medical team. And, most importantly, do not hesitate to ask for explanations of things you do not necessarily agree with or do not understand.

A final and very effective way to talk with your health care team is to appoint an individual(s) who can help you raise questions or concerns in the clinic. You can do this by signing a release of medical information form, which allows the clinic to share information with the person or persons you choose. By doing this you will be selecting an individual who can ask questions for you that might be difficult, who can receive information on your behalf on those days you are not feeling well and who can relay your goals and desires for treatment to the health care team if you cannot express them yourself. Of course, you must be open and honest with the person you choose to help with these issues. By being open and honest, you might find that you relieve some pressure from feeling responsible for all aspects of your care.

Communication can be a tricky process. Remember that the professionals who care for you every day are there to offer education, resources and support, but they can only do these things if you communicate your needs to them.

Thoughts About Advocacy

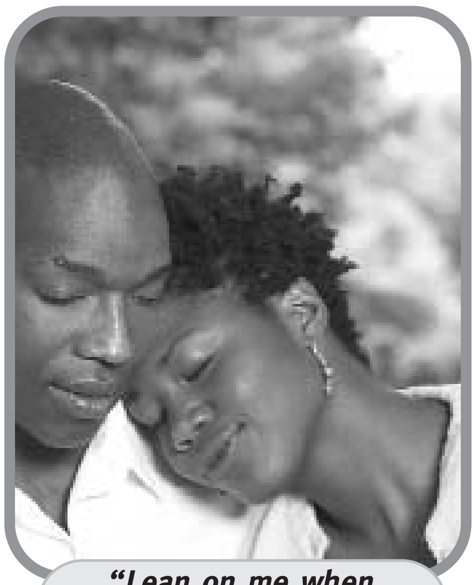
By Roberta Bachelder, MA

Support is all around you. You just have to know where to look.

"Lean on me
when you're not strong,
I'll be your strength,
I'll help you carry on."

The lyrics of the well-known song "Lean on Me" by Bill Withers express a reassuring, universal truth: We all need help at some time in our lives. People on dialysis and transplant recipients, loved ones of those with chronic kidney disease (CKD) and those who may be at increased risk for CKD can be sure that help that is custom-made for people with CKD is available to them.

Advocacy is a word for help—it simply means "to support." Where can we look for the advocacy we need?



"Lean on me when you're not strong."

Looking for advocacy usually begins with a source close to home. If you have CKD, you may be surprised to learn that your spouse, loved one or a special friend may be the strongest advocate you will ever need. Or you could discover that you have all the strength you need to advocate for yourself. Facing a life challenge like CKD could bring out a self-help skill that you did not even know you had. If a person is on dialysis or is either beginning the evaluation process for or has already had a kidney transplant, there is an automatic advocate right in the dialysis or transplant center: the social worker. Under Medicare regulations, each dialysis clinic and transplant program must have a master's level, licensed social worker available to you. The dialysis or transplant social worker can assist you with issues that are psychological, social or financial in nature.

People on dialysis and transplant recipients should be aware of another source of advocacy when a question or problem presents itself.

This includes a wide range of supportive and advocacy services, including referral to resources within your community. Do not hesitate to ask to talk with the social worker.

People on dialysis and transplant recipients should be aware of another source of advocacy when a question or problem presents itself. That source is the End Stage Renal Disease (ESRD) Network system, which was started by Medicare. ESRD Networks are available when you have a problem that cannot be resolved in the center where you receive your treatment. The ESRD Networks have people who are trained to resolve problems and to advocate for people who are on dialysis or have a kidney transplant. You can contact the ESRD Network serving your area by visiting the Web site or by calling the Forum of ESRD Networks office.

There are a number of advocacy agencies and organizations specifically committed to various aspects of CKD. The National Kidney Foundation (NKF) is a well-respected national non-profit agency devoted to advocacy and education for individuals and families affected by all stages of CKD. The organization also offers a wide range of services and educational materials and programs about CKD, in addition to providing a multitude of other activities and services.

Other agencies, organizations and services to help those with CKD and their families include the American Association of Kidney Patients (AAKP), The American Kidney Fund (AKF) and The Life Options Rehabilitation Program. All of these organizations are dedicated to helping people on dialysis live long, healthy lives.

There are literally hundreds of other sources of CKD-specific education and support in the form of Web sites. If you just need to talk, there are also a number of Internet chat rooms and message boards full of other people affected by CKD who benefit from "cyber sharing" their ideas and experiences. Beyond the supportive element, however, one should be cautious about information posted on Internet message boards and chat rooms. Verify advice or recommendations with your nurse, doctor, dietitian or social worker.

This issue is filled with ways to advocate for yourself. You can also contact your local NKF affiliate by visiting our Web site (see the contact information listed on this page) and clicking on "Affiliate Addresses and Web sites."

Find an advocate—someone to support you when needed—or be your own self-advocate. You can do it.

QUICK FIND *Resource List*

www.kidney.org • National Kidney Foundation • 800-622-9010

www.esrdnetworks.org • ESRD Network • 804-794-2586.

www.aakp.org • American Association of Kidney Patients (AAKP) • 800-749-2257

www.lifeoptions.org • Life Options Rehabilitation Program • 800-468-7777

www.akfinc.org • The American Kidney Fund • 800-638-8299

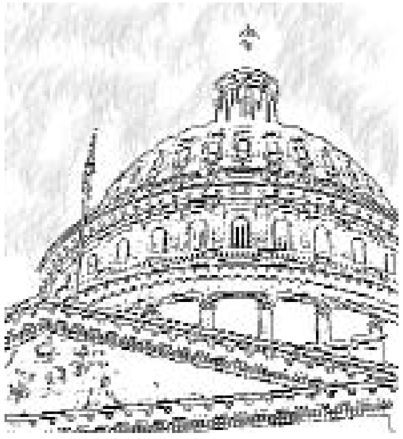
Calling for Patient Advocacy on Capitol Hill

By Dolph Chianchiano, JD, MPH

The NKF is already working with the federal government to support those with chronic kidney disease.

Advocacy has many faces. The term is often used to describe attempts to influence governmental policy. An example is the National Kidney Foundation's (NKF) advocacy regarding the Medicare prescription drug legislation that President George Bush signed into law at the end of 2003. NKF wants people with chronic kidney disease (CKD) who have Medicare to benefit to the fullest extent possible when Medicare begins to pay for oral medications on January 1, 2006. Therefore, whenever an opportunity arises, NKF becomes involved in public advocacy and speaks out about how Medicare's plans could be improved. People with CKD can also play an important role in this kind of advocacy by expressing how the design of a government program could affect their health and health care.

In regard to the new Medicare coverage for oral medications, known as "Medicare Part D," it is important to understand that the program will be run by private insurance companies. These companies will publish lists of the drugs that they will cover financially. (Note: There is no universal list of brands of medicine that Medicare plans must cover. Each insurer can decide what specific drugs it will pay for.) These drug lists are called "formularies." The Medicare Part D program will have different levels of co-payment for different medications. This is meant to steer patients toward the drugs that the insurance company has bought in large quantities. However, Medicare can pay as much as 95 percent of the cost of drug purchases in excess of $5,100 during a calendar year.



All of the drugs that a doctor prescribes for CKD may not be listed in the formulary, which means that they would not be covered by Medicare. Also, if a drug is not listed in a formulary and you buy that drug at your own expense, the cost of that medicine will not count towards the $5,100 threshold that triggers Medicare payment at the 95 percent level.

> *"NKF brought this potential gap in coverage to the attention of Medicare staff, citing the clinical practice guidelines that NKF has developed through the Kidney Disease Outcomes Quality Initiative (K/DOQI), which refer to the need for these medications."*

One of the concerns that the kidney community raised with the Medicare Part D plan is that most people with CKD need special categories and classes of drugs that are not included in typical formularies. In particular, there could be limited choices for anti-rejection medications needed by transplant recipients and for oral bone and mineral metabolism regulators (such as vitamin D, phosphate binders and calcimimetics).

Dolph Chianchiano, JD, MPH

NKF brought this potential gap in coverage to the attention of Medicare staff, citing the clinical practice guidelines that NKF has developed through the Kidney Disease Outcomes Quality Initiative (K/DOQI), which refer to the need for these medications. NKF also encouraged the Medicare program to develop an exceptions process to review requests for drugs that were not listed in a formulary. The exceptions process that Medicare had proposed in its initial draft regulation would only apply if a drug was removed from coverage after it was listed in the formulary when the patient enrolled in a plan. Updates on the Medicare Part D plan, published in December, seem to follow NKF's suggestion.

In addition to the kind of public advocacy described above, there is also individual advocacy—by a specific patient, a family member or health care professional on behalf of that patient—to convince specific Medicare drug plans to provide needed drugs. Only the Medicare beneficiary, his or her authorized representative and/or the doctor who prescribed the medication can ask for an exception to decide if a specific drug should be covered in a particular formulary. The patient and his or her doctor will have to prove that the similar drug or drugs listed in the formulary would cause negative effects or would not be effective for the person or both. The insurance company must review the exception request immediately if the doctor who prescribes the medication says that the usual time frame for making this type of decision could place the person's health or life at risk.

For a detailed description of the Medicare Prescription Drug Act, and the potential impact of this legislation for people with CKD, click on "Government Relations" on the NKF Web site's home page: **www.kidney.org** Samples of public advocacy tools that you can use for your public advocacy efforts are also posted on the Web site.

A Successful Journey

By Leslie Spry, MD and Lori Fedje, RD, LD

Take that first step: Learn about your CKD.

A Chinese proverb tells us that the most important step in any journey is the first. Treatment of chronic kidney disease (CKD) is a journey through many medical treatments that results in unique care for each person. The journey through CKD is best started with knowing the facts about CKD and self-advocacy (for example, asking questions, telling your health care provider what works and does not work for you, being firm about your needs). This means that to successfully complete the journey, you need to know what to expect: what are the risks of treatment, the chances for success and failure and the basic goals of treatment. Those who successfully make the journey through CKD generally have three things in common: (1) motivation—they want to be involved with their health care treatment; (2) comprehension—they know the facts about themselves and kidney disease; and (3) resources—people, such as friends, family and caregivers on whom they can rely. Look at your own medical care with each of these things in mind and join with your health care provider in creating your special plan for kidney replacement therapy.

Before getting to chronic kidney failure (CKD Stage 5), you need to plan for your treatment. Good questions at this point are: Have you found a nephrologist (kidney doctor) to help you along the road? Do you know your stage of CKD? Are you doing everything you can to slow the decrease in kidney function? Is anemia (low blood count) a problem, and if so, has it been treated? Do you have a dialysis access, and know that the AV fistula is often a preferred access? Do you have information about the different types of dialysis treatments, transplantation and conservative treatment (the option not to begin dialysis or have a transplant)? Are you informed about paying for treatment? Do you have family or friends to support you? Getting the answers to these questions and others will help you feel more prepared for your treatment.

Once you reach CKD Stage 4 or 5, you and your health care provider need to decide what type of kidney replacement therapy you want. Have hemodialysis, peritoneal dialysis and transplant options been explained to you? Do you know the risks for each treatment that may be unique to you? Are all types of treatment available where you live, including treatment at a dialysis center or treatment in your home? Can you move from one type of treatment to another as changes occur in your particular circumstances? These are some of the questions you will want to learn the answers to before you make a treatment decision.

Once on dialysis, and/or in preparation for a transplant, you will need the help of many health care providers. You will need to talk with your kidney doctor, nurse, social worker, patient care technician and dietitian on a regular basis. You need to understand what is expected to help you achieve the best possible results from your treatment. For example, you should "know your numbers." Just as you should "know your cholesterol" and "know your blood pressure," you need to know the guideposts along the journey of dialysis and transplant. Knowing your urea reduction rate (URR) or adequacy (KT/V) (which tell how well your blood has been cleaned)—both for what the numbers are and how they fit into your total treatment—is important for successful kidney replacement therapy. You need to see your numbers for cholesterol and lipid (fat or cholesterol) measurements, anemia management, blood pressure and bone chemistries such as calcium, phosphorus and PTH. Talk with your doctor about how to understand their causes, know how different prescriptions for treatment affect each of these measurements and how to be aware of what symptoms you may expect.

The table on page 16 shows some of the important numbers that are an important part of your dialysis treatment. The targets are arrived at by the agreement of many kidney experts from the NKF and are published as the K/DOQI (Kidney Disease Outcomes Quality Initiative) Guidelines. These targets are best thought of as goals to help you understand and obtain good management of your kidney disease.

For transplant candidates, an entirely new list of questions must be considered. Is your overall health good enough for a transplant? How do the risks of transplantation stack up against the risks of dialysis? Do you have kidney donors available to you? Do you know your transplant coordinator and transplant surgeon? What is your responsibility for seeing the process of transplantation through to a successful conclusion? What medical responsibilities would you have after receiving a transplant?

Regardless of your form of CKD treatment, you also need to know and understand those things the health care providers can treat and those things that are the result of your own lifestyle choices, such as taking your medicine as prescribed, following the recommended diet and going to all your treatments.

Visits to your primary care physician (family doctor) or your primary care nephrologist (kidney doctor) should include your general health and not just dialysis health. You should get all vaccinations up to date, including flu shots, pneumonia, tetanus and hepatitis vaccinations, and have a TB skin test. You should have checkups to detect colon, prostate, breast, uterine and cervical cancer. Lifestyle choice issues such as physical exercise, cigarette smoking and drinking alcohol should be discussed with the health care team. Your emotional health is also very important. This is an area where your social worker can help.

Dialysis units hold multidisciplinary conferences on a regular basis to discuss and plan patients' treatments. Doctors, nurses, patient care technicians, dietitians and social workers all have a role in these conferences. The goal is to make sure a plan is in place to help you make the journey through the complicated maze of kidney disease treatment. You, too, have a right to be involved in these meetings, understand the treatments that are being recommended and voice questions or concerns about your needs. You are the most important member of the health care team!

If you are a self-advocate, you have the best chance of a successful journey. How many of these first steps on the journey have you undertaken?

Advocacy Within the School Setting

Continued from page 3

speech and language, gross motor skills such as walking and fine motor skills such as using a crayon. In other words, babies and children whose speech and language development, fine and gross motor skills and oral motor skills are not at the appropriate stage for the child's age should be evaluated for early childhood services with speech and language, occupational and physical therapy. If this is not happening for your child, you need to advocate for a referral by your kidney team to your state early intervention program. You can locate the providers of early childhood education in your state at the National Early Childhood Technical Assistance Center (**www.nectas.unc.edu**) or the U.S. Department of Education (**www.ed.gov**).

Advocacy begins with a firm understanding of all your child's special needs.

SPECIAL EDUCATION SERVICES FOR SCHOOL AGE CHILDREN

As students progress to school based services at age three, there are two documents that parents should be aware of and advocate for their use if needed by their child: an IEP Plan and 504 Plan.

INDIVIDUALIZED EDUCATION PLAN (IEP PLAN)

IEP stands for Individualized Education Plan and is a written document that describes the educational plan for a student with a disability. The IEP document explains the child's disability, what skills the student needs to learn and the classroom adaptations needed to accommodate the student's learning needs.

The purpose of the IEP is to make sure that everyone—you, your family and school staff —knows what your educational program will be for this coming year. This plan is developed in a formal meeting with school, student, family and medical personnel, all working together on the best plan to achieve success. This formal plan must be reviewed annually or sooner if there are significant changes in the student's life. In summary, the IEP plan addresses the learning needs of the student through special education services.

504 PLAN

The Rehabilitation Act of 1973, including Section 504, applies to people with disabilities. Section 504 requires school districts to make their programs and activities accessible and usable for all people with disabilities. To be eligible for Section 504 services, the student must be evaluated by a school team to see if the special need requires accommodation in order for the student to participate in school related activities. Examples of 504 accommodations needed by students with kidney disease can include:

- Special "kidney-friendly" meals and snacks
- Adjustments with physical education (PE) requirements
- Bus transportation as opposed to walking to school due to anemia or fatigue
- Checking blood pressure or giving medications at school
- A private room with sink for peritoneal dialysis exchanges
- Being able to freely use the restroom or carry water
- Being able to type assignments or do oral testing if shakiness from medications is an issue
- More time to finish in-class assignments or homework if there are problems with concentration
- Modified homebound instruction for students on hemodialysis or following a kidney transplant
- Being notified if there is an outbreak of chicken pox or other contagious illnesses
- Assigning a book buddy (someone to carry books from room to room) for children with arm fistulas or grafts.

If you believe that your son or daughter needs special accommodations at school because of his or her medical or other needs, talk with your medical social worker or the school principal about your desire to write a 504 Plan to address these needs.

IMPORTANT LESSONS

Raising a daughter with special needs and working in pediatric dialysis and renal transplantation has taught me some important lessons about advocacy with schools:

1. Advocacy begins with a firm understanding of all your child's special needs: medical, developmental, educational, social, vocational, nutritional.
2. Ask your dialysis or transplant team to document the special needs of your child and communicate these needs to his or her teachers, counselor, nurse and resource specialist at school.
3. Come to school meetings with notes on what you want to see accomplished and do not be afraid to voice your concerns and goals for your child.
4. Request open communication between your health care team and the school through school visits, letters, e-mails and frequent phone calls.
5. Finally, talk with other parents about their experiences. Life is sometimes the best teacher.

SUMMARY

The goal of raising a child with special needs is to insure that children with special needs are given all that they are entitled through Early Childhood Education Services, Individualized Education Plans (IEPs) or the Individual with Disabilities Act Section 504 Plans (504 Plan). As your child's advocate, use the support and resources around you to make sure the schools appropriately address all the special needs of your child. Advocating for your child is a life-long process that begins at birth and extends throughout the college years.

About the author

Fred Kouri has been a renal social worker at the Children's Mercy Hospital and Clinics for 14 years. He lives in Lenexa, KS.

Resources

- The National Information Center for Children and Youth with Disabilities 800.695.0285; **www.nichcy.org**
- Starbright Video Series: School Re-entry 800.315.2580, ext. 3; **www.starbright.org**

Advocating for People with Chronic Kidney Disease

By Karren King, MSW, ACSW, LCSW

The *Family Focus* Voices question for this issue was, "*What have you done to advocate for people with chronic kidney disease in your community, state or on a national level?*" The responses to this question have come from those who have chronic kidney disease (CKD) and are on dialysis as well as those who have family members with CKD. Their advocacy efforts have ranged from being involved in the dialysis facility to activities on an international level, demonstrating that there are many ways to assist those with CKD.

Serving as an advocate for others in the dialysis facility by doing such things as writing educational materials was how one person chose to be involved locally. Another person works with the dialysis facility to help educate those who have been recently informed they have CKD. Speaking to someone who has actually "been there," in addition to staff education and support, can help emotionally if a person is facing dialysis for the first time. One could also serve as an advocate in the local community. One individual, who is both on dialysis and is also a registered nurse, educates the public about preventing kidney disease through the National Kidney Foundation's (NKF) Kidney Early Evaluation Program (KEEP) at the NKF affiliate level. She also coordinates a monthly education class for those with CKD and their families. Another person is working to start a support group for the caregivers of those with CKD, an important group that is sometimes neglected.

Transportation to and from dialysis facilities is often a problem, and one CKD family member decided to take on this challenge. She teamed up with the state's Disability Law Center and dialysis social workers in her metropolitan area to convince the state Department of Transportation to create a transportation system to meet their needs. She also aided those individuals who needed assistance in paying for medications prior to being accepted to their state kidney disease program by working with a local pharmacy to assure medication availability during this waiting period.

> *Getting involved in advocacy can actually energize you.*

Another example of a family member tackling a problem that affects an entire region is the daughter of someone who is on dialysis and lives in remote Hana, Hawaii. Those who are on center hemodialysis there travel more than 100 miles over a treacherous highway for their dialysis treatments. This advocate has been working with the community and its nephrologist to bring a dialysis facility to their area. She is urging *Family Focus* readers who live in Hawaii to join her advocacy efforts by contacting the media and governor of Hawaii to encourage the establishment of dialysis facilities in remote, underserved areas.

Statewide advocacy was undertaken by yet another family member, a mother of several children with CKD. The state where she lives had a state funded kidney program that assisted those on dialysis and with kidney transplants. When they were alerted that the program was being eliminated, their NKF affiliate organized a meeting at which she spoke, thus beginning her lifelong journey as a CKD advocate. Additional efforts by her and others in the kidney community to protest the program's planned discontinuation consisted of organizing a letter writing campaign, meeting with and testifying before state officials and a media blitz. Their efforts were successful; 14 years later the program is still going strong!

One person who contacted *Family Focus* Voices served as a Volunteer Health Advocate in her state Attorney General's Office and found herself dealing with those with a variety of health needs. One of her tasks was to help callers find resources to meet their special needs. This prompted her to create resource materials for people of all ages with special health needs.

Public speaking before local, regional and statewide groups, such as the Visiting Nurses Association and the state's Legislative Black Caucus, is a way one family member gets the word out about CKD and the needs of those who have it. She points out that hearing from family members who are living daily with CKD can have a major impact on others.

Other examples of advocacy that were shared with *Family Focus* included involvement with various regional and national kidney organizations, such as serving as the patient representative to an End Stage Renal Disease Network committee and on the NKF's national Patient Empowerment Program, Kidney Learning System's (KLS™) task force and Patient and Family Council Executive Committee.

There were also examples of federal government advocacy. One advocate was a member of various panels and committees for the Centers for Medicare and Medicaid Services such as Fistula First and Dialysis Facility Compare. Another individual has worked with others in an attempt to expand Medicare coverage regarding transplantation and has written a draft of a Medicare booklet about children with CKD.

Lastly, one energetic person has even served as an international advocate. She has written a book chapter for a German nephrologist on the role of a patient advocacy group and has created a Web site to educate patients and families worldwide about CKD.

The various advocacy roles undertaken by these individuals are inspiring and admirable, and *Family Focus* applauds each of them. Some of you may think that there simply is no time or energy for such activities. I challenge you to rethink that. Getting involved in advocacy can actually energize you. It can be personally rewarding and helps others at the same time. Think about what issues affect you, and possibly others with CKD, and what you, either individually or jointly with others, can do about them. Allow yourself to take action rather than feel helpless or victimized. BE PERSONALLY EMPOWERED.

Family Focus VOICES

WE LOVE TO HEAR FROM OUR READERS, so every issue of *Family Focus* includes a special question.

Read the question below, also posted online at **www.familyfocusvoices.org**, and let us know what you think.

Please share why you did or did not select a form of home hemodialysis? Also, was home hemodialysis ever offered to you as a treatment option?

You may visit the Web site above to share your thoughts, or send your response in writing to:

Family Focus Voices
30 East 33rd Street, New York, NY 10016

KNOW YOUR NUMBERS *(Cont'd from page 13)*

LAB VALUE	RECOMMENDED NUMBER/REFERENCE	WHAT IT MEANS	WHAT YOU CAN DO ABOUT IT
Creatinine	Depends on muscle mass (1)	It is a waste product of muscle breakdown.	Stay as healthy as you can and exercise as your doctor directs.
BUN	60-100 mg/dl for HD (1) 60-80 mg/dl for PD (1)	BUN level gives us an idea if you are eating enough protein in your diet. Many conditions can also affect this value.	Eat the right amount of protein that is prescribed for you by your doctor and dietitian.
Albumin	> 4.0 g/l (1)	Major marker that tells how well nourished you are.	Eat the right amount of protein that is prescribed for you by your doctor and dietitians.
Potassium	3.5-5.5 mEq/l (1)	Low or high potassium can be dangerous as it affects your heart muscle.	It is important to follow the level of potassium that has been planned in your diet. Fresh fruits and leafy green vegetables are generally high in potassium. Check with your dietitian for a list of high potassium foods.
Phosphorus	3.0-5.5 mg/dl (2)	High phosphorus can affect your bones. High levels can cause you to itch, have joint pain, weaken bones and lead to calcium deposits in your soft tissues and organs.	Follow a low phosphorus diet and take phosphate binders as prescribed by your doctor.
Calcium	Normal range but preferred at lower end (8.4-9.5 mg/dl) (2)	Calcium levels affect your bones-having a normal calcium level helps build strong bones.	If your level is low, you may be asked to take an oral supplement (pill). If your level is high and you are on calcium-containing phosphate binders, they may have to be changed.
Bio Intact-PTH (BiPTH)	75-150 pg/ml (2)	A hormone that controls calcium and phosphorus in your blood and helps to prevent bone disease. High phosphorus levels can lead to high BiPTH.	Follow your phosphorus controlled diet and take phosphate binders as prescribed to keep your phosphorus levels normal. If your BiPTH is high, vitamin D may be prescribed for treatment by your doctor.
Ca X P product	< 55 mg/dl (2)	Measures risk of bone disease and calcium and phosphorus buildup in your blood vessels and other tissues	Follow your phosphorus controlled diet and take phosphate binders as prescribed.
% Saturation	>20 %, < 50 % (3)	This measures the amount of iron that is readily available to make red blood cells.	Do not miss any dialysis treatments so you do not miss your dose of IV iron. Take oral iron as prescribed by your doctor.
Serum Ferritin	100 -800 ng/ml (3)	Ferritin is the amount of stored iron that is available. It is essential for the formation of red blood cells.	Do not miss any dialysis treatments so you do not miss your dose of IV iron. Take oral iron as prescribed by your doctor.
HCT	33-36 % (3)	Measures if you have enough red blood cells to carry oxygen to your tissues.	Show up for every treatment so you can get your dose of EPO (erythropoietin) to help make healthy red blood cells.
Cholesterol	100-150 mg/dl (4)	Normal cholesterol helps to prevent heart disease.	Follow a low fat diet. Eat less fatty meats and dairy products made with whole milk. Use mono- or polyunsaturated fats. Exercise regularly. Talk to your dietitian and discuss any medications needed with your doctor.
HgA1C	< 7.0 % (5)	Means that your average blood sugars have been in good control (average less than 150) for the last three months.	Check your blood sugars as often as your doctor has requested and bring your daily record when you come to dialysis. Follow your diet plan for diabetes. Get regular exercise.
URR Hemodialysis	> 65% (6)	Measures the adequacy of your hemodialysis treatments (how well they are cleaning your blood) or your dose of dialysis.	Come to your treatment every time. Stay for your full treatment. Ask your doctor if a fistula for a dialysis access is right for you. Know your dialysis prescriptions.
Kt/V Hemodialysis	> 1.2 (6)	Another measure of the adequacy of your hemodialysis treatments.	Come to your treatment every time. Stay for your full treatment. Ask your doctor if a fistula for a dialysis access is right for you. Know your dialysis prescriptions.
Kt/V CAPD	≥ 2.0 (7)	Measures the adequacy of your peritoneal dialysis treatments or your dose of dialysis.	Do your treatments as prescribed by your doctor. Know your dialysis prescriptions.
Kt/V CCPD	≥ 2.1 (7)	Measures the adequacy of your peritoneal dialysis treatments or your dose of dialysis.	Do your treatments as prescribed by your doctor. Know your dialysis prescriptions.