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# Family FOCUS

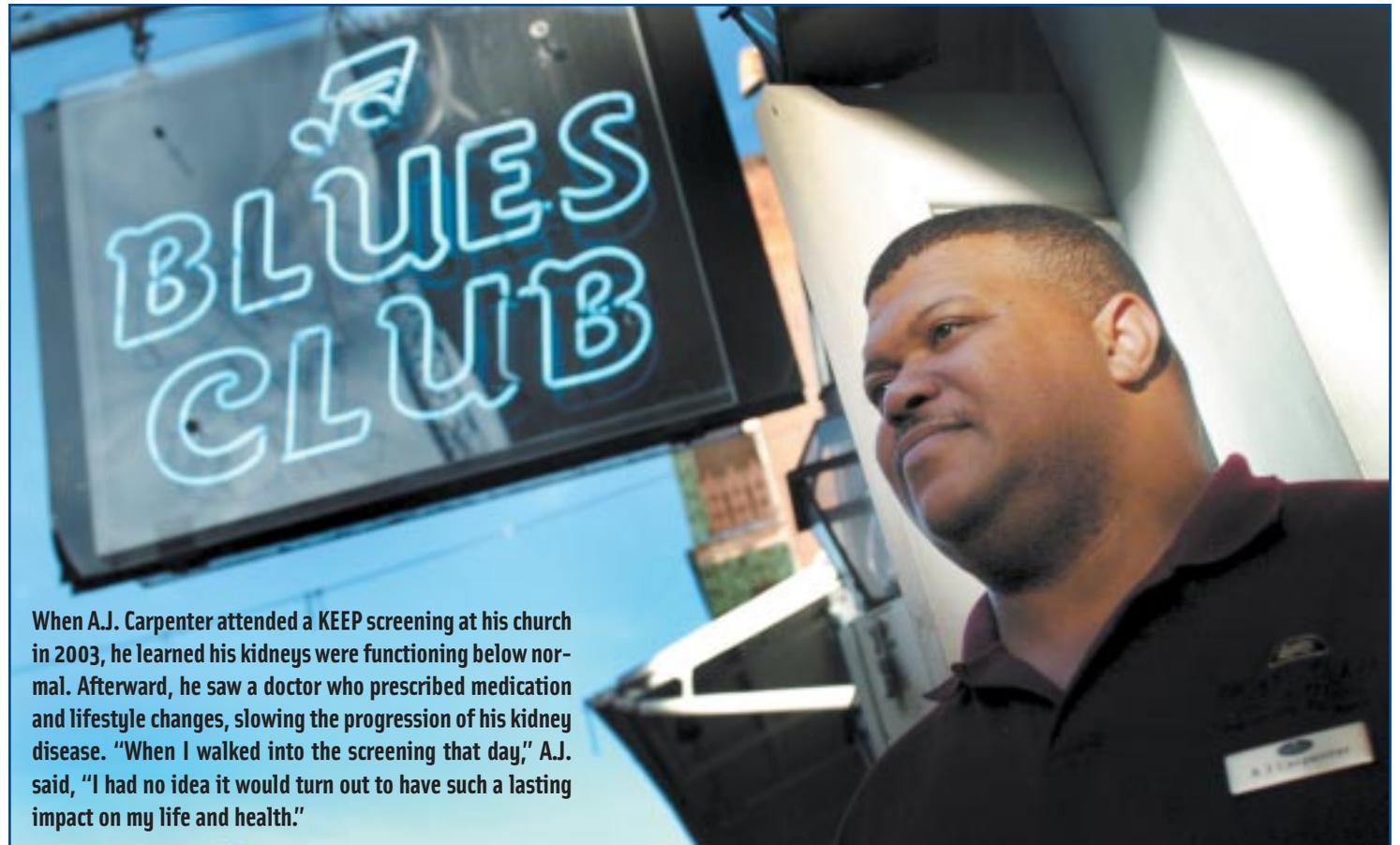
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**KIDNEY DISEASE: DOES IT RUN IN THE FAMILY?**

## Finding Kidney Disease Early

By Allan Collins, MD



When A.J. Carpenter attended a KEEP screening at his church in 2003, he learned his kidneys were functioning below normal. Afterward, he saw a doctor who prescribed medication and lifestyle changes, slowing the progression of his kidney disease. "When I walked into the screening that day," A.J. said, "I had no idea it would turn out to have such a lasting impact on my life and health."

**T**RADITIONALLY, KIDNEY DISEASE HAS BEEN MOST OFTEN recognized in those individuals who reach dialysis or receive a kidney transplant.

At the present time, there are about 430,000 people with kidney failure treated with either dialysis or a functioning kidney transplant. One hundred thousand individuals start treatment for kidney failure each year. In addition, about 20 million individuals have mild to advanced chronic kidney disease (CKD) and 8 million of those have less than 60 percent of kidney function remaining. Seventy-one percent of those people who start dialysis have either diabetes or hypertension (high blood pressure). These numbers may be startling, but

we need to be aware that CKD has reached epidemic proportions, and those individuals who have hypertension and diabetes or a family member with hypertension, diabetes or kidney disease, are at increased risk for developing CKD. Kidney disease can and should be identified and treated as early as possible.

The National Kidney Foundation (NKF) has developed CKD education programs to encourage those at high risk for kidney disease to seek medical attention. Targeting individuals known to have diabetes,

high blood pressure or a family history of diabetes, high blood pressure and/or kidney disease, the NKF's Kidney Early Evaluation Program (KEEP) is the most widely known of these efforts to identify and treat CKD in its early stages. The KEEP program is a community-based program delivered by local NKF affiliates. KEEP provides free blood pressure and weight measurements, and blood and urine tests for signs of diabetes and kidney disease. The program has now reached more than 35,000 people. The first KEEP Annual Data Report, published in the *American Journal of Kidney*

*Continued on page 2*

*This publication is a part of the National Kidney Foundation's Kidney Learning System (KLS)™ and is made possible through an educational grant from AMGEN.*

At first glance you may see this issue of *Family Focus* and think it has absolutely nothing to do with you. When most of us first think of inherited chronic kidney diseases (CKD), we may think of diseases like polycystic kidney disease (PKD). While it is true that PKD is one form of CKD that can be passed to family members, many other causes of CKD also have family ties. According to the United States Renal Data System's 2003 Annual Report, 45 percent of people who began dialysis in 2001 had diabetes mellitus and 26 percent had hypertension (high blood pressure) as their primary causes of CKD. As you will read in Dr. John Sedor's article on page 11, both diabetes and hypertension tend to run in families. The fitness and nutrition articles both provide very beneficial information about things you can do to be proactive in your care if either you or someone in your family has diabetes or high blood pressure.

I hope that you always share *Family Focus* with the members of your family. The information can help them understand your illness and its treatment, as



Karren King

well as some of the things you might experience. If something affects you, it will also affect those who care about you, and just as it is important for you to be educated, it is also important for them. However, it is especially important for you to share this particular issue. Your family needs to know if they may be at risk for either the diseases that can lead to CKD, or for CKD itself, and what they can do about it.

I also want to thank our readers who voiced their opinions on *Family Focus* Voices and the Patient and Family Council listserv about whether to have genetic testing. I hope you find the article that

shares what they had to say as interesting as I did. I also want to remind you that there will be a question that relates to the theme of each *Family Focus* issue posted on the National Kidney Foundation's Web site. Since our next issue is on transplantation, we want you to share with us either what made you decide to go on the transplant list or receive a kidney transplant or why you elected not to pursue a transplant. Please go to [www.familyfocusvoices.org](http://www.familyfocusvoices.org) to add your thoughts to our message board. While you are there, you might also want to browse the responses to previous questions, or back issues of *Family Focus*, which are available online.

Once again, it is nearing the time for our Editorial Board to plan *Family Focus* for 2005. Help us keep the newspaper relevant for you by sharing ideas you may have for future themes for a *Family Focus* issue or ways we may be able to improve the publication.



Karren King  
For the Editorial Board

## Finding Kidney Disease Early

Continued from page 1

*Diseases* in October 2003, summarized the findings of this effort to reach and improve the health of people at risk for CKD. These findings are important in helping health care providers learn more about individuals who are at greater risk of developing CKD.

The majority of KEEP enrollees were minorities, and women were twice as likely to participate. Enrollees were more likely to be overweight or obese than people in the general population. More than half of the participants had a history of hypertension, with a comparable amount still having blood pressures greater than 140/90 mm Hg. Almost a quarter reported having diabetes, and 68 percent reported a family history of the disease. Although only two to three percent reported having CKD, 50 percent had signs of the disease through evidence of a reduced kidney filtering capacity or by abnormal amounts of protein in the urine (microalbuminuria). Women and minorities were more

likely than men and whites to have evidence of kidney damage.

KEEP enrollees were more likely to have anemia than people in the general population. Diabetic participants with Stage 3 CKD (moderate decline in kidney function) were three times more likely to be anemic.

The KEEP program is now performed in almost all of the 50 NKF affiliates nationwide with 1,500 to 2,000 people a month participating in screenings for CKD and receiving education about its diagnosis, treatment and long-term care. Participants are encouraged to share the information with their doctor to ensure good follow-up medical care.

To find out about KEEP screenings in your area, contact the NKF at 1-800-622-9010 or visit [www.KEEPonline.org](http://www.KEEPonline.org). If you have kidney disease, either encourage your family members to attend or bring them to one of these free kidney health screenings.



## About the Author

Allan Collins, MD, is a professor of medicine at the University of Minnesota, and Director of the National Kidney Foundation's Kidney Early Evaluation Program.

# Family Focus

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**M**y name is Cate Lewis and I would like to share my story of a hereditary genetic disorder called polycystic kidney disease (PKD). I have been a volunteer for the National Kidney Foundation (NKF) since 1999 and proudly serve as the immediate past chair of the Patient and Family Council (PFC) Executive Committee.

My story began in 1972 when I was in my last year of nursing school. My dad had just been diagnosed with PKD by his family physician, when probing the cause of his uncontrolled high blood pressure. An ultrasound of his kidneys revealed many large fluid-filled cysts in both kidneys. I vividly remember that not only did his doctor have little knowledge of this disease, but my medical textbook had a one paragraph description ending with the words “prognosis is poor.”

As good fortune would have it, in 1974 there was an RN position available in a newly opened dialysis unit at the local hospital. It made sense to me to learn as much as possible about caring for people with chronic kidney disease (CKD) in order to prepare for what was potentially in store for my dad.

Later that same year I was also diagnosed with PKD. My situation followed the same scenario; dangerously elevated blood pressure readings triggered the need for an ultrasound to examine my kidneys. Another test called an intravenous pyelogram (IVP) confirmed that the diagnosis was PKD.

My biggest concern at that time, being 23 years old and engaged to be married the following May, was making the decision about having children. I have a clear picture of my kidney doctor sitting in my hospital room after receiving the final test results and discussing PKD with my fiancé and me. His advice, in response to our concerns about this disease being hereditary, was that advances would continue in not only the research of PKD but in dialysis and transplant technology. He also advised that the key elements in controlling kidney function were to keep my blood pressure and salt intake under control.



Cate Lewis, RN

## Kidney Disease Across Generations

By Cate Lewis, RN

*A registered nurse tells the story of kidney disease in her family—her father, her son and herself*

We were married in May 1975 and our only child, Jay, was born in March of 1978. We were blessed with a beautiful healthy baby, but would not know until he was 18 that he had acquired PKD. Jay had a hard fall during a snowboarding jump and developed bloody urine. My hope was that this bleeding was from a bruised kidney, but my heart told me that he needed to have PKD ruled out. Ultrasound results showed that his kidneys were filled with numerous fluid filled cysts. These cysts can become extremely large and cause various degrees of pain. They can rupture and cause hematuria (bloody urine) and have the potential to become infected. The cysts

*My biggest concern at that time, being 23 years old and engaged to be married the following May, was making the decision about having children.*

tend to grow slowly and are generally not visible by ultrasound until late teen years.

My dad’s kidneys failed in 1979, and he and my mom successfully performed home hemodialysis for the next four years until his death in 1983.

I continued to work in the dialysis unit and my kidney function remained normal until November 1998. At that time my crea-

tinine (a waste product in the blood that is normally removed by the kidneys and should be less than 1.0) reached a level of 4.0, which meant I had stage 4 CKD. It was time to have an initial transplant evaluation and a vascular access created, called a fistula, for hemodialysis. It is essential to have the fistula created early, as the blood vessels need to enlarge or mature prior to use.

Having the transplant referral and workup completed before dialysis begins can sometimes eliminate the need for even starting dialysis. This may occur when a transplant candidate has a living donor or when a perfect antigen match from a non-living donor becomes available.

Throughout the years I was troubled with severe pain in both cystic kidneys, episodes of cysts rupturing and bleeding and one severe kidney infection requiring hospitalization.

My kidneys failed in May 1999. Although my first choice for therapy was continuous ambulatory peritoneal dialysis (CAPD), I had the fistula created “as a back-up” because I knew that CAPD sometimes is not effective when people with PKD have huge kidneys due to the cysts. Too much of the abdominal space is taken up by the massive kidneys and this may interfere with the filtration of waste products through the CAPD process. I also knew that having several abdominal surgeries might eliminate CAPD from my

dialysis choices because scar tissue can prevent good removal of waste products. As it turned out, I was unable to do CAPD and I began hemodialysis while waiting for a kidney transplant.

Hemodialysis worked well from May 1999

until I was blessed with a successful transplant from a non-living donor on November 18, 2001. There was, however, one major surgery that took place six months before the transplant. Although it is not a common practice to have native kidneys removed before a transplant, it is sometimes recommended. My transplant surgeon felt strongly about the need to remove both kidneys before receiving a transplant, because the risk of infection of

*Continued on page 6*

# Family Planning With a Genetic Condition

By Stephanie Herbert

*A genetic counselor explains her work.*

In the last few decades, genetics has brought about a completely different element to health care that once did not exist. Previously, a diagnosis was made and very little thought was given to how it might affect a family's future generations. Today, the medical community is buzzing with the word "genetic," and health care professionals are spending their lives finding cures for the diseases that are all too familiar to many families.

In my role as a genetic counselor, I talk with families who are enrolled in our studies on inherited forms of **Focal Segmental Glomerulosclerosis (FSGS)**. The two most common questions that people ask are: "How did I get this disease?" and "Will I pass it on

to my children?" Both questions demand thoughtful and sensitive answers.

**Genetic conditions** are by definition "inherited conditions." However, conditions can be inherited in different ways. In some cases both parents, who are healthy, need to be "carriers" to pass on the condition to their child. Examples of this type of disease are **cystic fibrosis** and **Sickle Cell Anemia**. In other cases, such as

with the most common form of polycystic kidney disease and **Huntington's disease**, one parent who has the condition can pass it on to his or her child. And finally, in other cases, a mother may be a "carrier" of a condition that she can pass on to her sons. This is what happens with **hemophilia**. Sometimes one genetic condition, such as **FSGS**, may have many genetic causes and may be inherited in more than one

way. Therefore, having a correct diagnosis and knowing exactly how the disease was inherited are important for understanding the risk of inheriting it or passing it on.

Parents cannot choose which of their **genes** they pass on, so it is often hard to know for certain if a child will inherit the genes that cause a disease. Some parents may choose to adopt a child, or not to have a child. Sometimes social, religious or family pressures and personal beliefs may make the choice of not having children difficult for many families, especially for those who are facing a risk of passing on a genetic condition.

Genetic counselors help families who are worried about genetic risks. They offer a

*Continued on page 5*

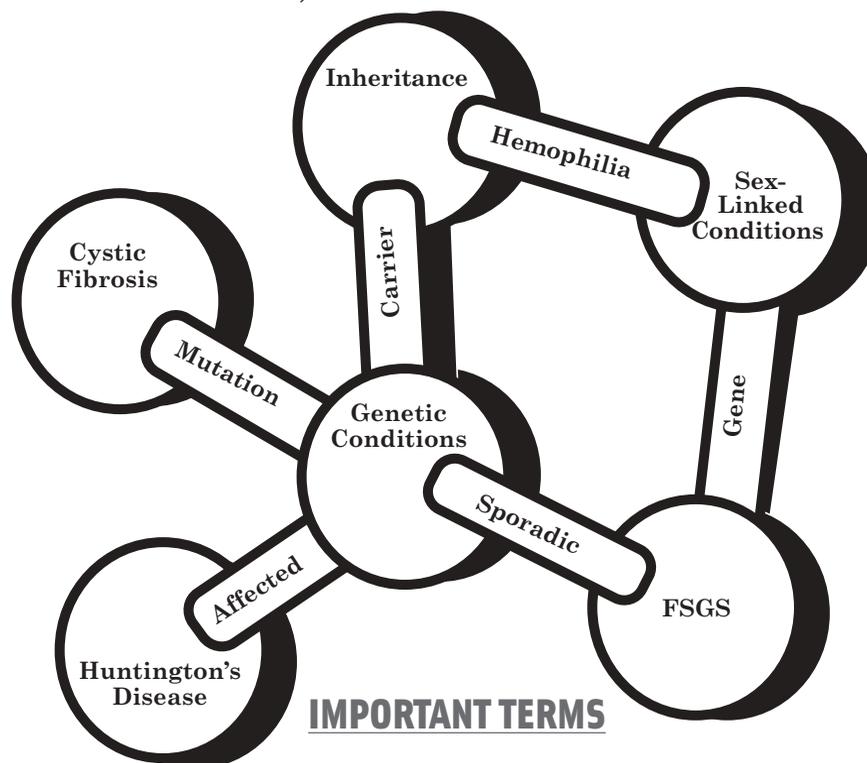
## Glossary of highlighted terms from the article

**AFFECTED:** a genetic term used to describe a person who has a genetic disease and is showing physical symptoms of the disease.

**CARRIER:** a term used to describe a person who "carries" the genes that cause a genetic disease, but may or may not be showing physical symptoms of the disease.

**CYSTIC FIBROSIS (CF):** a common, recessively inherited genetic disease that can cause an overproduction of mucus in the lungs. This can lead to severe breathing difficulties and possible respiratory or heart failure.

**FOCAL SEGMENTAL GLOMERULOSCLEROSIS (FSGS):** an inherited disease that destroys the normal function of the kidney and can lead to kidney failure.



**GENE:** the chemicals in living creatures with the instructions for how to build and run the organism.

**GENETIC CONDITIONS (GENETIC DISEASES):** diseases that can be passed on from one generation to the next.

**GENETIC RISK ASSESSMENT:** an examination of a person's medical history to determine if there are chances of developing a genetic condition, or passing on a genetic condition to the next generation.

**HEMOPHILIA:** a sex-linked, genetic condition that causes a person's blood to lose its ability to clot. Therefore, increased bleeding, bruising, and painful swelling can often result from cuts, abrasions and injury.

**HUNTINGTON'S DISEASE:** a genetic disease that leads to severe degeneration of the brain.

**INHERITANCE:** To receive a gene and the properties of that gene from an older generation.

**RECESSIVE INHERITANCE:** both mother and father have to donate a copy of the gene for their child to have inherited the trait, characteristic or disease.

**DOMINANT INHERITANCE:** only one copy of the gene needs to be inherited from either parent for the child to inherit the trait, characteristic or disease.

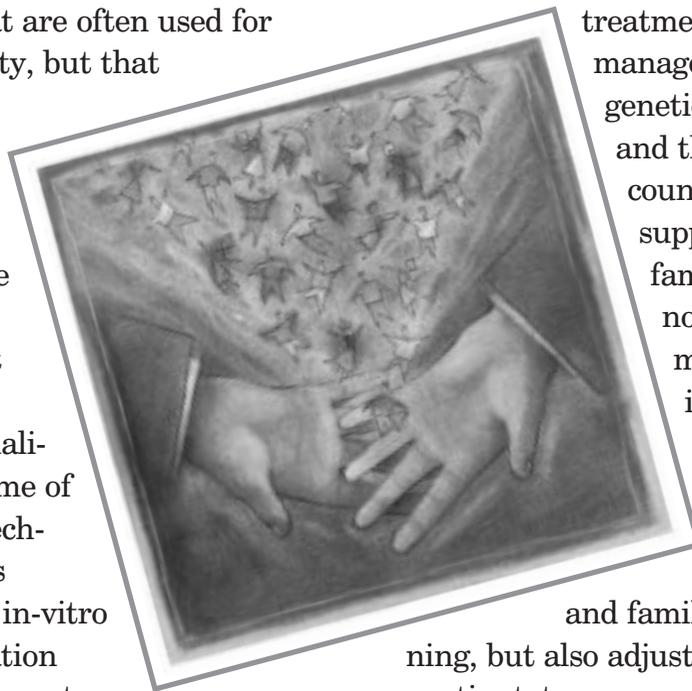
**MUTATION:** a "change" in a person's genetic make-up; often responsible for causing genetic diseases/conditions.

**SEX-LINKED CONDITION:** a genetic condition that is often passed from mother to son.

**SPORADIC:** a term used to describe something that has happened randomly.

genetic risk assessment and information about the genetic concern(s) and testing options (prenatal, carrier and confirmational). Prenatal testing is done during pregnancy, when blood drawn from the fetus is tested to detect possible genetic or chromosomal abnormalities. Carrier testing is usually performed to determine if a person “carries” the gene for a certain genetic condition, even if the person does not show any other signs of the condition. This information can help a person determine what chance he or she may have of passing the condition on to his or her children. “Confirmational testing” is done to confirm, or rule out, a genetic diagnosis in someone who is showing signs of the condition.

Counselors can also talk with families about assisted reproductive options. These are technologies that are often used for infertility, but that can be used to help parents conceive a child without genetic abnormalities. Some of these technologies include in-vitro fertilization (IVT), gamete intra-fallopian transfer (GIFT), pre-implantation genetic diagnosis (PGD) and intraplasmic sperm injection (ICSI).



Finally, genetic counselors also help families with information about the treatment and management of genetic disorders, and they provide counseling and support so families can not only make well-informed decisions about their health and family planning, but also adjust to their genetic status.

As our understanding of genetics improves and genetic testing options increase, par-

ents and families will be faced with increasingly complex reproductive options and choices, making genetic counseling services more valuable than ever. To learn more about genetic counseling or to find a genetic counselor in your area, visit the National Society of Genetic Counselors Web site at [www.nsgc.org](http://www.nsgc.org) 

**About the Author**

*Stephanie Herbert is a Genetic Counselor in the lab of Dr. Martin Pollak at Brigham and Women's Hospital/Harvard Institutes of Medicine in Boston, Massachusetts.*

If you began to experience burning or tingling in your hands and feet and a decreased ability to sweat when overly hot, would you think of the rare genetic illness known as Fabry disease? Would your doctor?

Unfortunately, because Fabry disease is so rare, it is easily missed. Patients are often initially misdiagnosed because their symptoms are confused with other illnesses.

Fabry disease is a genetic disorder in which the body becomes unable to break down a fatty substance called globotriaosylceramide, causing it to build up in the body. Over time, the fat buildup damages cells in blood vessels and tissues of the kidneys, heart, skin and brain. This can eventually lead to life-threatening problems, including heart attacks, strokes and kidney failure.

*The following symptoms are often the first warning signs of Fabry disease:*

- Burning or tingling in hands and feet;
- Decreased ability to sweat, causing overheating, frequent fever and sensitivity to hot weather; and
- Reddish-purplish skin rash.

Over time, the damage to blood vessels can lead to problems in the stomach, heart, kidney and nervous system. Doctors who suspect that a

## Fabry Disease: Diagnosing a Rare Genetic Disorder

*Scientists have finally developed a treatment for the condition known as Fabry disease.*



**Doug Morgan was misdiagnosed several times before doctors learned he had Fabry disease. Since beginning his new treatment, his kidney function has stabilized and he continues to work as a research assistant at the University of Alabama.**

person has Fabry disease may order certain tests needed to diagnose the condition, which look at the individual’s genetic makeup and measure the activity of an enzyme missing in people with the disease.

The disease is more common in men and is caused by a defective gene located on the X chromosome,

meaning that it runs in families. And many families suf-

fer alone—recent estimates suggest the disease affects only one in 40,000 males.



Because the disease is so rare, few treatments exist. In April, the U.S. Food and Drug Administration approved the first treatment targeted for Fabry disease, made of a version of an enzyme people with the disease either lack or carry in very low amounts. The treatment, given by injection into a vein, reduces fat deposits in many types of cells. It is hoped that this treatment will help prevent life-threatening damage to important organs and enable those with Fabry disease to live healthier lives.

For a free brochure on Fabry disease, contact the National Kidney Foundation at 1-800-622-9010 or online at [www.kidney.org](http://www.kidney.org) 

High blood pressure is a leading cause of chronic kidney disease (CKD) in the U.S. African Americans are affected by high blood pressure and CKD at a very high rate. Holly Kramer, MD, an NKF Young Investigator Grant recipient at Loyola University Medical Center in Maywood, Illinois, is conducting studies of the roles played by genetic and environmental factors in the increased risk of high blood pressure and CKD among African Americans.

African Americans experience kidney damage because of high blood pressure more often than other groups. However, it is not clear whether this increased risk of kidney disease among African Americans is due to genetic factors, environmental factors or both. Environmental factors include such things as socioeconomic status and access to health care, both of which could play a role in developing high blood pressure or kidney disease. It is impossible to know if African Americans have a greater genetic susceptibility to high blood pressure and CKD simply

## National Kidney Foundation Young Investigator Studies High Blood Pressure and Kidney Disease in African Americans

by comparing black and white Americans, since this would assume that the two groups have been exposed to the same environmental factors. A different test for racial tendency to a disease is to compare genetically related populations living in different social environments. Currently, data on the prevalence of CKD among blacks living in other parts of the world, such as Africa or the Caribbean, remains extremely limited.

### THE PURPOSE OF DR. KRAMER'S STUDY IS TO:

**1** Perform a cross-cultural study of the prevalence of CKD in several different black populations and see whether the prevalence differs by environment

**2** Determine the association between high blood pressure and CKD in several different black populations and determine whether this association differs by environment

**3** Examine the prevalence of certain genetic mutations (changes in genes) that are associated with high blood pressure and CKD in several different black populations

Dr. Kramer's findings may be used to better understand why high blood pressure and CKD are more common among African Americans. Her ultimate goal is to provide information that will help lower the risk of kidney disease and kidney failure in the African American population.

### About the Author:



Holly Kramer, MD

Holly Kramer, MD, is an assistant professor in the Department of Preventive Medicine and Epidemiology and the Department of Medicine at Loyola University Medical Center in Maywood, Illinois. She received her medical degree from Indiana University School of Medicine in 1994. She also earned a Master of Public Health in 2001 from the Harvard School of Public Health. Dr. Kramer has been involved in research for several years and has published in many prominent medical journals. She began her study as an NKF Young Investigator in 2003.

### Kidney Disease Across Generations

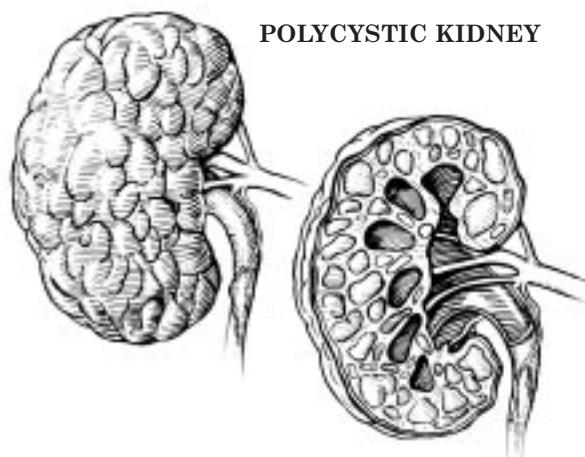
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the enlarged kidneys after a transplant would be dangerous when the immune system would be suppressed, or basically "sleeping," because of the anti-rejection drugs. Coincidentally in 2002, I was among three people with CKD from our facility, all on waiting lists at different transplant centers, requiring kidney removal (nephrectomy).

Thirty-two years have passed since a name and face were connected to PKD for our family. I continue as a nephrology nurse at the same facility and treasure every moment of life with the gift of a kidney. My son continues to do well and

has also chosen to care for people with kidney disease as a dialysis Patient Care Technician.

Technological advances continue to improve the quality of life for people facing kidney disease. Research efforts to find a cure for PKD are ongoing. An excellent way to learn about this disease



POLYCYSTIC KIDNEY

as well as follow medical advances is to contact the PKD Foundation by calling 1-800-753-2873 or by visiting their Web site at [www.pkdcure.org](http://www.pkdcure.org)

The National Kidney Foundation also offers a brochure, *Polycystic Kidney Disease*, that can help you make healthy decisions for yourself. Call 800-622-9010 for more information.

Meanwhile, my best wishes to you all. Stay as healthy as possible, learn as much as you can about kidney disease and enjoy life to the fullest. 

### About the Author

Cate Lewis is the Immediate Past Chair of the National Kidney Foundation's Patient and Family Council.

When we talk about traits that “run in the family,” we often think about things that are “in the genes,” but we sometimes forget that everything we do can possibly be passed on to the next generation. The habits you form are often passed on and repeated by those around you. The types of things that can be passed on include eating habits, such as the types of food we eat and how much we eat at each meal. Also, exercise habits and interest in your own personal health can be learned traits that are passed on to those around you.

For some Americans, exercise has been associated with unpleasant feelings and experiences. Many people have started an exercise program, but quit early because they could not exercise for more than a few minutes at a time or because they begin to cramp. They may then decide that exercise is not for them. Far too often, unpleasant experi-

*One of the most important gifts that you can pass on to your children, nieces, nephews or grandchildren is the love for exercise.*

ences happen because we try to do too much exercise on our first try. Only a very small percentage of Americans can compete in marathons or try to make a living by winning fitness competitions. However, if you want to exercise to improve your health, increase your energy or lose some body fat, then the best thing to do is join the rest of America and exercise one step at a time.

One of the most important gifts that you can pass on to your children, nieces, nephews or grandchildren is the love for exercise. Fitness experts recommend that you reach the goals of walking for 45 minutes to one hour, most days of the

## Getting Into the Swing of Exercise

By Pedro Recalde, MS, ACSM

*Sometimes we learn exercise habits from our family—but it's never too late to start!*

week. The benefits of getting your family involved are important for you and for them. By getting your friends and family involved, you are creating an environment that makes your exercise routine enjoyable, plus you are having a positive effect on the lives of those you care for. So go ahead and take the next step of sharing your new interest in your own health and the health of the ones you love.

I recently had the privilege of talking with Gary Klaz, who lives in Los Angeles, California, and he wanted to share his exercise success story. Gary has been receiving hemodialysis treatments three days a week for nearly two and a half years,

but began exercising six years ago. He confesses that it has been difficult to stay with an exercise routine, but for the last eight months Gary has been going to an outpatient cardiac rehabilitation program on a regular basis.

### HERE IS WHAT GARY HAS TO SAY.

“I have been exercising due to my doctor’s recommendations, but I do it so that I can lose weight and because it is good for my heart. I enjoy cardiac rehab because the people are so nice to me. I love coming here twice a week for one hour, 7 a.m. to 8 a.m. I do not eat breakfast until after I exercise and I feel good doing that. I



**Gary Klaz walks 50 minutes twice a week between 7 am and 8 am before breakfast.**

usually walk 50

minutes on the treadmill. I do feel tired for several hours after each exercise session, but then it goes away and I am okay. Before starting here, I did nothing for my health. All I did was eat and gain weight, but exercise helps me manage my weight.”

### HOW IS YOUR ENERGY LEVEL?

“I feel good. I have an increase in my energy level. When I go to exercise, I am happy. I used to be extremely overweight, weighing 600 pounds, and I almost died. I was very sad and decided to have my stomach stapled. That helped me lose weight, but now I exercise with cardiac rehab and I am happy because the staff looks out for me.”

### WERE YOU ENCOURAGED TO EXERCISE AS A CHILD?

“Well, my sister passed away in the early ‘90s with an illness associated with being overweight. She gave up on life. My father had one of his kidneys removed during the ‘60s

and he did not exercise because he was always tired. My parents did not encourage me to exercise at home. I would definitely encourage all kids today to exercise and take care of themselves. Stop eating junk food, as well!”

### DO YOU HAVE ANY ADVICE FOR OTHERS ON DIALYSIS?

“Yes. Just do it! Exercise! For your health! There are nice people here to help and we should take advantage of that.”

*Thank you for your words of encouragement, Gary!* 

# JUMP START

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Cars That Save Lives.**



**NKF National Kidney Foundation®**  
*Making Lives Better*

\*Consult your tax advisor for details.

**D**id you know that if you have kidney failure, the members of your family have a greater chance of getting chronic kidney disease (CKD)?

This is because health problems that cause kidney failure “run in the family.” Experts say that if one member of a family has kidney failure, all blood relatives over the age of

## Does Someone You Love Have Chronic Kidney Disease?

By Bobbie Knotek, RN, BSN, CNN

*Have your family members read this letter about chronic kidney disease.*

18 should be tested for CKD. Blood relatives include your

parents, grandparents, brothers, sisters, sons and daughters.

I encourage you to talk to your family members about getting tested for CKD! It may be hard to talk to them, but you could be saving their lives. Copy “A Message to My Family” written below, give it to all of your family members, ask them to read it and then talk to them about it.

### A message to my family:

**YOU NEED TO GET TESTED** to see if you have chronic kidney disease (CKD). Finding and treating chronic kidney disease early may slow it down and keep you from needing dialysis or a kidney transplant. You may think you do not need to be tested for chronic kidney disease because you are feeling “fine.” **What you may not know is – you can feel fine and still have CKD.** So, even if you are feeling “fine,” you should get tested.

You can get tested at a clinic, a doctor’s office or a National Kidney Foundation (NKF) KEEP screening. To find out where the KEEP screenings are being held, go to the KEEP Web site at [www.KEEPonline.org](http://www.KEEPonline.org) or call the NKF at **800-622-9010** and ask about KEEP screenings.

**WATCH FOR THESE WARNING SIGNS OF CKD.** Call to make a clinic or doctor appointment right away if you get one or more of these warning signs!

- Swelling in parts of the body, especially around the eyes or ankles.
- Pain in the lower back.
- Burning or an unusual “feeling” while passing urine.
- Bloody, foamy or coffee-colored urine.
- Passing urine more often, especially during the night.

#### WHEN YOU GO TO THE DOCTOR TO GET TESTED FOR CKD:

- Bring someone with you to help you understand and remember what the doctor says
- Buy a notebook and bring it to the appointment. In the notebook, write:
  - ◆ Questions for the doctor.
  - ◆ Information and instructions from the doctor.

■ Tell the doctor your health history. It is especially important for the doctor to know:

- ◆ You have a blood relative who has kidney failure (and the cause of the kidney failure, if you know it).
- ◆ About health problems that put you at risk for kidney failure (including diabetes, high blood pressure, kidney infections, kidney stones, prostate problems,).
- ◆ How you are treating these health problems. If you have diabetes or high blood pressure, the doctor needs to make sure you are doing everything you can to protect your kidneys.
- ◆ All of the medications that you are taking including prescription drugs and non-prescription supplements.

#### ASK THE DOCTOR TO PERFORM THESE THREE SIMPLE TESTS TO SCREEN FOR CKD:

##### 1. Urine Microalbumin

This test gives better information than urine protein and urine albumin tests are usually done in the doctor’s office. It is one of the most important tests used to screen for CKD. Even though it is a simple test, not every doctor’s office has the supplies to do the test. If your doctor does not have the right supplies in the office, ask to have a urine sample sent to a lab that can do the test.



## 2. Blood Pressure Reading

Talk about your blood pressure with the doctor—ask these questions:

- What is my blood pressure? (Write your blood pressure results in your notebook during every visit).
- Is my blood pressure in the normal range (using the most recent blood pressure recommendations)?
- Would lowering my blood pressure cut down my risk of getting kidney disease?
- If my blood pressure is higher than it should be, what can I do to make it better?

If you are already being treated for high blood pressure, tell the doctor:

- Whether or not you are taking your blood pressure medicine the way you are supposed to.
- If you are having side effects, especially those that keep you from taking the blood pressure medicines as ordered.



## 3. Serum Creatinine

This is a simple test to see how much creatinine is in your blood. Creatinine is a chemical made by the muscles in your body. When the muscles “dump” creatinine into the blood, the kidneys get rid of the creatinine and keep it from building up. When the kidneys are damaged (as in CKD), they cannot get rid of creatinine and it builds up in the body. Ask your doctor to:

- Check your serum creatinine level.
- Use your creatinine level to figure out your Glomerular Filtration Rate (GFR). GFR is used to help estimate kidney function. There is a math formula (called MDRD) that “translates” the creatinine level into GFR. Your doctor can find the MDRD math formula by going to the National Kidney Foundation’s Web site and clicking on the “K/DOQI Clinical Practice Guidelines” tab.

**EVEN IF THESE THREE TESTS ARE NORMAL**, you could still be at risk of getting CKD (because of medical and family history). Ask how often you should come back to see the doctor and repeat the above tests. 



## What you should know About CKD

**IF A MEMBER OF YOUR FAMILY** has kidney failure, you have a greater chance of getting CKD. This is because health problems that cause kidney failure “run in the family.” Experts say that if anyone in your family has kidney failure, you should be tested for CKD.

**IT IS EVEN MORE LIKELY YOU COULD GET CKD** if one or both of these statements are true:

- Diabetes, hypertension or an inherited disease (like polycystic kidney disease) caused your family member’s kidney failure.
- You belong to one of these racial groups: African American, Hispanic, Pacific Islander, Native American or Native Alaskan.

**EACH YEAR 25,000 PEOPLE WITH DIABETES** get kidney failure and need dialysis or a kidney transplant.

**AFRICAN AMERICANS ARE MORE LIKELY TO HAVE** severely high blood pressure at a younger age and are also more likely to get diabetes. (1 out of 3 people with kidney failure is African American).

**IF YOU ALREADY HAVE CKD AND ARE BEING TREATED** for high blood pressure, ask your doctor if you could switch to one of the special blood pressure medicines that helps to protect your kidneys. These blood pressure medicines are called ACE inhibitors and ARBs.

There is a question posted on the National Kidney Foundation (NKF) Web site that relates to each issue of *Family Focus*. The question that 17 of our readers responded to for this issue was, "DO YOU THINK IT IS HELPFUL OR HARMFUL TO HAVE GENETIC TESTING TO FIND OUT IF YOU HAVE AN INHERITED DISEASE?"

Most of those who responded believed that those who may have a potentially inherited illness should have testing, while only one of the respondents believed that a person should not have genetic testing. Of course, others did not see this as an "either or" situation—several respondents believed that there were possible positive and negative outcomes of genetic testing. The largest percentage of those who responded, 41 percent, did not identify how the decision impacted them, while 35 percent were individuals who have chronic kidney disease (CKD), 12 percent were mothers of children

## To Have Genetic Testing...Or Not?

By Karren King, MSW, ACSW, LCSW

*Family Focus readers give their opinions on genetic testing.*

tested, but the other two were uncertain.

The feelings of those who recommended testing could be



summed up with this comment: "Knowledge is power; the more you know, the less you fear." There were three main reasons that people favored having genetic testing. The first is that knowing you have the gene for an inherited disease allows you to do all you can to "delay or

This individual wrote that those at risk for PKD, even if they do not know whether they have the gene, should be aware of their diet and blood pressure. Another concern was the possible negative impact that testing could have on one's ability to get insurance. If a test showed the presence of a gene that causes an inherited dis-



ease, readers worried that this information could affect the cost or availability of insurance.

Those who were mixed in their feelings about genetic testing also expressed concern about getting health

insurance, at least at an affordable rate, and possible job discrimination if it was known that a person had an inherited disease. Others expressed concern that knowing that a disease was inherited could cause negative feelings among family members who might place blame or feel guilt. The emotional stress that people might feel knowing they have a disease for which there is no cure was also a concern. One respondent pointed out that a person may have a genetic link that is an indicator of potentially developing a disease but may never develop the disease. This could place someone under tremendous, needless stress.

As you can see from reading the thoughtful responses of our readers, there is no right or easy answer for everyone when faced with the question of whether to have genetic testing. This is a question that can only be answered by each person for himself or herself after carefully considering all the issues raised by genetic testing.



*"Knowledge is power; the more you know, the less you fear."*

with CKD and a spouse and a staff person each represented 6 percent of the sample. Three of those with CKD have polycystic kidney disease (PKD). Two of them thought people at potential risk of developing a disease should be tested, but the other person did not agree. The other individuals with CKD, one with systemic lupus erythematosus (SLE) and the other with IGA nephropathy, both believed that genetic testing should be done. Family members of those with CKD were mixed in their responses. One, a mother of two children with inherited CKD, definitely thought that individuals at risk should be

minimize the potential side effects of the disease." In the case of CKD, this may include such things as early referral to a nephrologist, physical exercise and dietary changes. Others pointed out that knowing about potentially inherited diseases could aid people in their decisions about whether to have children. Lastly, some stressed the importance of helping scientists further understand the disease and develop a cure.

The opposite viewpoint, not to be tested, stemmed from the belief that in the case of PKD, there is little that can be done to stop the disease process.

### Family Focus VOICES

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

Read the question below, also posted online at [www.familyfocusvoices.org](http://www.familyfocusvoices.org), and let us know what you think.

*How did you make the treatment decision about whether or not to pursue a kidney transplant?*

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

Family Focus Voices  
30 East 33<sup>rd</sup> Street  
New York, NY 10016



Chronic kidney disease (CKD) is common in the United States. During the 1990s, the U.S. government found out how many people had kidney disease by measuring markers of kidney function (such as waste products in the blood and protein in the urine) in a group of volunteers who were representative of the U.S. population. The results showed that about 6 to 8 million people had moderately severe kidney disease, a number that increased to 10 to 20 million if people with abnormal amounts of protein in their urine were included. Nearly 100,000 people start dialysis or receive a kidney transplant each year. That number is greater than the number of people who learn that they have breast or colon cancer annually. The cost to medically treat all transplant and dialysis patients is more than the entire National Institutes of Health (NIH) yearly budget—greater than \$1.3 billion. Those with CKD and their families risk becoming poor because of health care costs that are not covered by insurance. CKD is a common, but unrecognized, epidemic.

The good news is that there are some treatments to slow the progression of kidney disease. Because diabetes and high blood pressure are the two main causes of CKD, it is important to see a doctor for examinations, especially if you have a family member with

*Starting treatment early, when damage to your kidneys is limited, increases the chance that kidney disease can be controlled.*

high blood pressure, diabetes or CKD. However, not all people with diabetes or high blood pressure will develop kidney disease. If you have diabetes, keep your blood sugar con-

trolled. If you have high blood pressure, take your medicines and keep your blood pressure normal. All treatments need to start early to be most helpful. Unfortunately, no treatment is a cure. Even with the best therapy, those with CKD often continue to lose kidney function.

How do you know if you or a loved one should be tested for CKD? Research has found another important risk factor for kidney disease, one that many people do not know. Doctors have known for a long time that some types of relatively uncommon kidney diseases, like polycystic kidney disease, run in families. Now we have learned that more common causes of kidney disease, such as kidney disease from diabetes and high blood pressure, also run in families. If you have diabetes and have a brother, sister or parent with diabetic kidney disease, the chance that you will have kidney disease during your lifetime is almost 75 percent. If you have diabetes but do not have a relative with diabetic kidney disease, you only have a 25 percent chance of having diabetic kidney disease over the course of your lifetime.

Throughout the U.S., 20 to 30 percent of people on dialysis have close family members on dialysis or with decreased kidney function. Family members of those with CKD need to be screened for kidney disease,

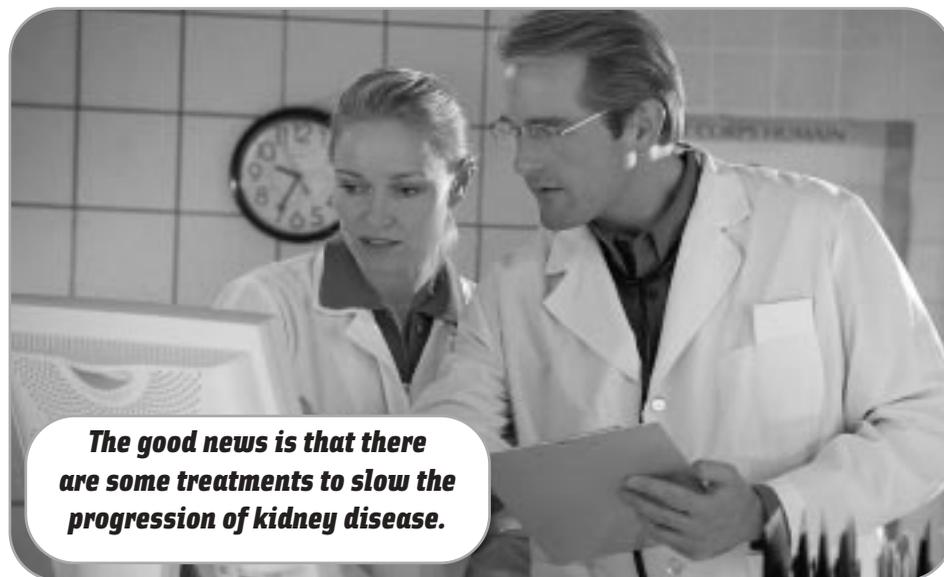
## Chronic Kidney Disease: It's All in the Family

By John R. Sedor, MD

### *What have genes taught us about CKD?*

even if they do not have diabetes or high blood pressure.

Why does kidney disease run in families? Genes contain the plans for each of us: our eye color, hair color, blood cholest-



**The good news is that there are some treatments to slow the progression of kidney disease.**

terol. Each gene has a code to produce a building block called a protein. Many diseases are, in part, caused by faulty genes. Problems in the plans contained in our genes mean protein building blocks are not made properly or not made at all. If made with faulty proteins, our organs either do not function normally or may not heal completely when injured. Since kidney disease runs in families, scientists think CKD is caused, in part, by faulty (incorrect) genes. Faulty genes can be identified by collecting blood samples from people with CKD and their families or by comparing the genes in those with CKD to a group of individuals who do not have CKD. The NIH and the Juvenile Diabetes Research Foundation have each organized teams of scientists to identify the faulty genes that cause CKD. Understanding the causes of CKD will help scientists identify new ways to treat these medical problems. In

addition, knowing which people carry CKD genes will allow doctors to know who is at risk for developing CKD and who may benefit most from early treatment and more frequent doctor visits.

What can you do now? If you have diabetes or high blood pressure, you are at risk for having CKD. Work hard to control your blood pressure and blood sugar. Your risk is even greater if you are African American, Mexican American,

Pacific Islander, American Indian or Alaska Native. If you have a sister, brother or parent with CKD, you are at risk for having CKD. Ask your doctor to check you for CKD. Simple tests of your blood and urine can determine if you have it. Starting treatment early, when damage to your kidneys is limited, increases the chance that kidney disease can be controlled. You can help prevent kidney disease in yourself and in your family members. 

#### About the Author

*John Sedor, MD, is a member of the Departments of Medicine and Physiology and Biophysics, School of Medicine, Case Western Reserve University and the Rammelkamp Center for Research and Education, MetroHealth System, in Cleveland, Ohio.*

People with chronic kidney disease and their family members should know that recent decisions by the United States Supreme Court have expanded the legal protections for individuals with chronic disease and the members of their families made possible by the Americans with Disabilities Act (ADA) and the Family and Medical Leave Act (FMLA). In addition, the U.S. Senate (although not the U.S. House of Representatives) has passed legislation that would prohibit insurance companies and employers from discrimination on the basis of genetic information.

The Senate bill, S. 1053, the "Genetic Information Nondiscrimination Act of 2003," was designed to ease the public's fears about the potential for genetic discrimination. This bill would allow people to take advantage of genetic testing and research projects and new treatments developed through genetic research without the fear of losing access to health insurance or hurting career opportunities. If this bill becomes law, health insurers, including those providing either group or individual coverage, could not request or require an individual (or a family member who would be covered by the insurance) to have a genetic test. Similarly, once S. 1053 is enacted, health insurance premiums or contributions could not be adjusted on the basis of genetic information. The bill would also make it illegal for an employer not to hire, to terminate or to discriminate in hiring (discrimination in hiring includes hiring people for less than appropriate pay) because of genetic information. It would also outlaw any attempt by an employer to classify employees based on genetic information if that practice might deprive any employee of opportunities available to other workers. A similar bill in the U. S. House of Representatives, H.R. 1910, has

## Congress and the Supreme Court Concerned with Chronic Disease Protection

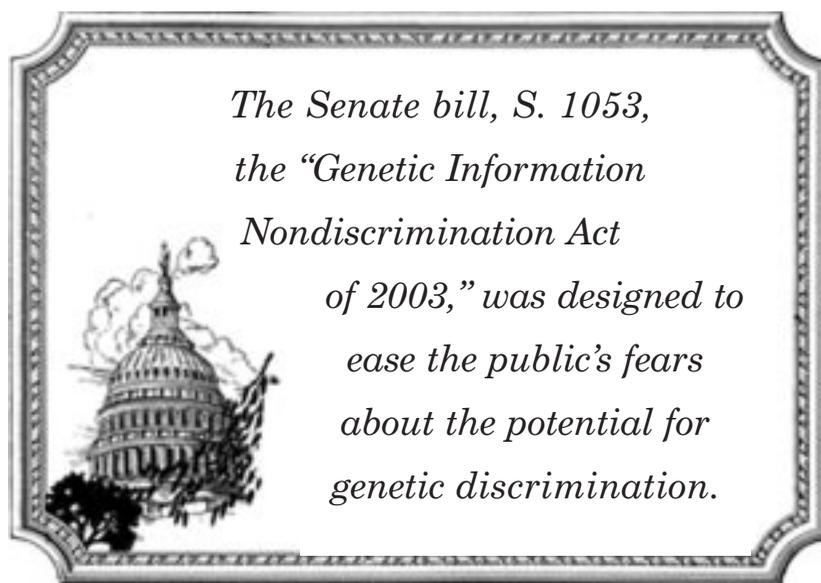
By Dolph Chianchiano, JD, MPH

*What is the government doing about genetic advances?*

been co-sponsored by 240 members of that chamber. However, it has not been placed on the calendar for a vote.

The Family and Medical Leave Act (FMLA) entitles employees who have been on the payroll for at least 12 months to take up to 12 weeks of unpaid

that the protections provided by FMLA, including the right to sue for damages for violation of the statute, are also available to employees of state governments. In this case, Mr. Hibbs was discharged from employment by the Nevada Department of Human Resources after the agency



leave annually, when needed, to care for their own health or to provide care for a child, spouse or parent who has a serious medical condition. The employer must also keep the same group health plan coverage during the entire leave. However, an employer can require that the employee use any accrued paid vacation time, personal leave or family leave before granting FMLA leave. When the need for the leave is foreseeable, the employee must provide 30 days advance notice. When the need is not foreseeable, the employee must provide notice as soon as practical.

IN THE CASE OF NEVADA DEPARTMENT OF HUMAN RESOURCES V. HIBBS, decided May 27, 2003, the U.S. Supreme Court made it clear

informed him that he had used all of his FMLA leave to care for his ailing wife and that no further leave would be granted. He went to court to get reinstated in his job and to sue for monetary damages. The state of Nevada challenged his right to sue, but the Supreme Court decided that the case should go to trial.

Since 1990, the ADA has prohibited discrimination against disabled individuals in the areas of employment, public services, public accommodations, transportation and communication (especially for those with hearing or visual impairments). Removal of architectural barriers (e.g., by building ramps and elevators) is, perhaps, the most visible impact of this legislation in the last 14 years.

THE CASE OF PGA TOUR, INC., V. MARTIN, decided on May 29, 2001 by the U.S. Supreme Court, concerned the part of the ADA statute governing public accommodations. Title III of ADA requires an organization operating a "public" accommodation to make reasonable modifications when necessary to accommodate individuals with disabilities. Mr. Martin, a professional golfer with a degenerative circulatory disorder, requested permission to use a golf cart, rather than walk from hole to hole, during the third stage of a qualifying Professional Golf Association (PGA) tournament. The PGA argued that the play areas of its tour competitions are not places of public accommodation with the scope of Title III. The Supreme Court, however, found that the PGA golf tours and their qualifying rounds fit within Title III's coverage of public accommodations, even though the PGA required a \$3,000 entry fee to play in these events.

It is not necessary to go to court to claim your rights under FMLA or ADA. ADA complaints can be made to the Equal Employment Opportunity Commission. Employees who believe their FMLA rights have been violated may file a complaint with the Department of Labor.

Similarly, *Family Focus* readers can play an active role in fostering genetic nondiscrimination by encouraging members of the U.S. House of Representatives to support passage of H.R. 1910. To identify your representative, check the Government Relations page at the NKF Web site, [www.kidney.org](http://www.kidney.org) 

*Dolph Chianchiano, JD, MPH, is the National Kidney Foundation's Vice President of Health Policy and Research.*

Growing up I always carried the fear in the back of my mind that my kidneys might one day fail. My mother would do urine tests on us following any infection, cold or sore throat to make sure we were not “losing protein.” Why? My father’s kidneys had failed. He had a kidney transplant in 1967, which lasted seven years before he passed away. My father’s brother died, at the age of 21, of congestive heart failure—a cause of death for many in the final stages of kidney failure—due to too much fluid on his heart. The doctors called my uncle’s kidney problems different things—post streptococcal glomerulonephritis or pyelonephritis. However, it was not until my brother and I were diagnosed with kidney failure in the 1990s that a hereditary form of focal segmental glomerulosclerosis (FSGS) was diagnosed in my family.

Finding out I “officially” had chronic kidney disease was a blow. Knowing that it is inherited and that I could pass it on to my children—children I wanted but did not yet have—was heartbreaking. Our family was referred for genetic counseling where specialists conducted multiple tests and

## Looking To the Future Without Fear

By Norma Knowles, MSW, LCSW

### *Making decisions in families with kidney failure.*

studies to try to verify the disease process and the hereditary pattern (how it is passed on). Blood tests were obtained and physical examinations were done on those family members who did not show signs of the disease, as well as those of us who did. Grandparents, aunts, uncles, cousins—everyone who was willing gave blood samples. Part of me thought, “Why bother? These counselors will not cure me, so what difference will it make? It is not going to change anything. I will still have this disease regardless of whether or not we know how I inherited it.”

I had resigned myself to the fact that I “could not” have children, since I was not sure if I would pass this disease on to them. However, in 1992 we were blessed with a miracle when our son was born. What would the future hold for him? I wanted to know more. Was my son going to get sick? Will

my nieces get FSGS, even though my sister has not shown symptoms?

Now, remember those genetic counselors? Those specialists whom I had grown tired of and had become so frustrated with because they could not “fix” me? They were working hard all along, researching FSGS and my family, while I had been living my life. And although some of the original family members who participated have passed away, the samples they provided years ago have continued to help the study of my family’s progress. And their effort was not in vain. It turns out that researchers have targeted the genes in some cases of familial FSGS. Of course there is still a lot yet to learn, but there is also a lot they know. They believe it is an autosomal dominant gene. What does that mean for our family’s children? They have a 50 percent chance

of having this disease—or *not* having it! If they do not have the gene, they likely will not get FSGS and cannot pass it on. Thanks to genetic counseling, we can choose to have our son tested and know a little bit more about his future.

Is this *good* or *bad*? That depends on your perspective. If tests show he does not have the gene, it could get rid of the stress that lingers around every aspect of our lives. If tests show he has the gene, the doubt is gone, and he can live a full and wonderful life prepared for whatever may come. Knowledge can be very powerful if you do not let fear consume you.

I had not planned on biologically having children. I planned on adoption. Would I have done things differently knowing what I know now? Absolutely not. But having more answers earlier on may have made the road a bit easier. I am thankful that my mother had the foresight to look into the future and know that although we are on a long road, through persistence and cooperation with genetic counselors, eventually all the pieces of the puzzle will fit together. 

## Anemia, Blood pressure, Chronic kidney disease...

### Everything You Need to Know from A to Z

[www.kidney.org/atoz](http://www.kidney.org/atoz)



Find quick answers to your health-related questions. All information is approved by the NKF Scientific Advisory Board.

Search for topics alphabetically.

Search for information by browsing through categories, such as “Nutrition,” “Dialysis,” “Transplantation.”

Adjust the size of the text to a comfortable size for reading.

E-mail information to a friend or family member.

Download NKF brochures for more detailed information.

**NKF** National Kidney Foundation®  
Making Lives Better

Dear Editor,

Dear Editor,

I love the paper *Family Focus*. It comes to our dialysis center, and I love all of the information provided.

I am writing because I am still alive, thanks to a great group of people who really care for their patients! I have been on dialysis for over five years. The nurses and staff where I go are the best in the world. They are very friendly, helpful and well trained. I love going for my sessions three times a week. At first, I was very depressed, but they changed my life.

I have made a lot of new friends at my center who will love and respect all my life. They are the best people and "family" I know.

Eddie Williamson  
*Eddie Williamson dialyzes in Marietta, Georgia.*

**Editor's Note:** Do not forget that you can receive *Family Focus* directly at your home by contacting the National Kidney Foundation at 1-800-622-9010.

When I went on dialysis I wanted something to occupy my time when on the machine. I also wanted to know something about all of the medicine I was taking. As a result, in May of 2002 I enrolled in a pharmacy technician course. I received my diploma in February 2003 and finished with a "96" average.

After finishing the pharmacy course, I decided to try to complete my engineering degree. I had started years ago before I developed TB in 1980 and had to give up my studies. I finally completed all of the requirements for the Bachelor of Electronics Engineering in 2004.

My future plans are to continue on for a Master of Science in electronics engineering and a Master of Sciences in computer science.

Sincerely,

James M. Gibbons, Jr.  
*James Gibbons has been on dialysis since January 2002 at Hudson Valley Dialysis in Tarrytown, New York.*

### Haiku

By Trey Sager

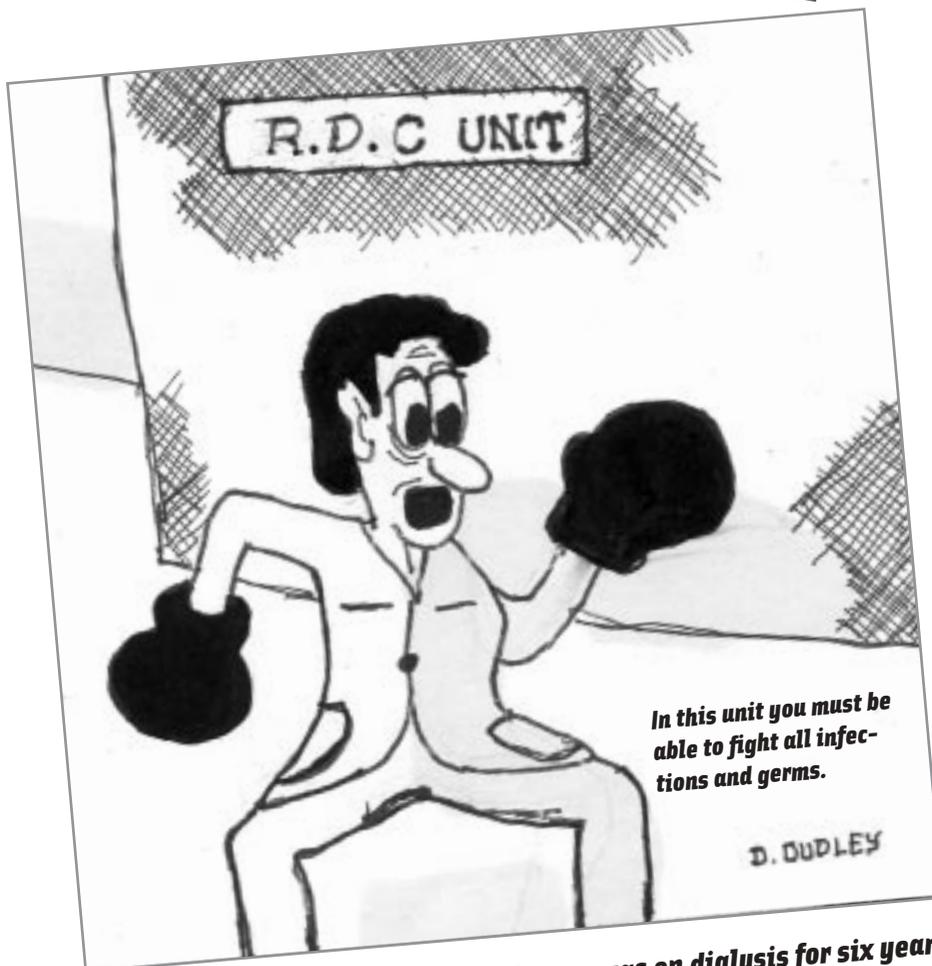
O dialysis  
 1, 2, 3, 4, 5, 6 - I  
 will do it again.

### Mrs. Annie and Mrs. Yuka

By Brian K. Davis

As they beautifully smile with ease  
 At the numerous faces that pass them by  
 They are as comfortable as they can be  
 With pillows, blankets, and chair reclined  
 Day after day their smiles are unchanged  
 Even when they're not feeling so well  
 Their lovely attitudes remain the same  
 These wonderful women are a Godsend  
 They enhance the daily lives around them  
 It is a comfort to see their lovely smiles  
 And to know that God is favoring them  
 Even in some of their most fearful moments  
 They manage to ease our minds with a grin  
 We are greatly privileged to know them  
 And to have them both as friends.

*Brian K. Davis is a dialysis technician in Neptune, New Jersey. He dedicates this to Ann Ross and Grace Yuka.*



**Drency Edward Dudley of Flint, Michigan, was on dialysis for six years. He received a kidney transplant in 2002.**

Has someone in your family been told their kidneys do not work well? Perhaps they need dialysis several times a week to replace the job their kidneys did or have had a kidney transplant. About one in nine Americans have kidneys that do not work well. Over 350,000 Americans receive dialysis for kidney failure. If someone in your family has been told their kidneys do not work well, that they may need kidney replacement treatment in the future or is already receiving dialysis, you too may be at risk. How would you know?

Begin by finding out more about your family's medical history. If one or more family members has needed dialysis you should find out what caused their kidneys to stop working. Diabetes and high blood pressure are the two diseases that most often cause the kidneys to stop doing their job over time. Both diabetes and high blood pressure run in families or can be passed from one generation to the next. If your family members have been told that they have one or both of these diseases you may be at risk of developing diabetes or high blood pressure which, if not taken care of, could lead to chronic kidney disease.

You should tell your family doctor if you have a family history of diabetes, high blood pressure or kidney disease. Regular blood sugar checks once or twice a year can moni-

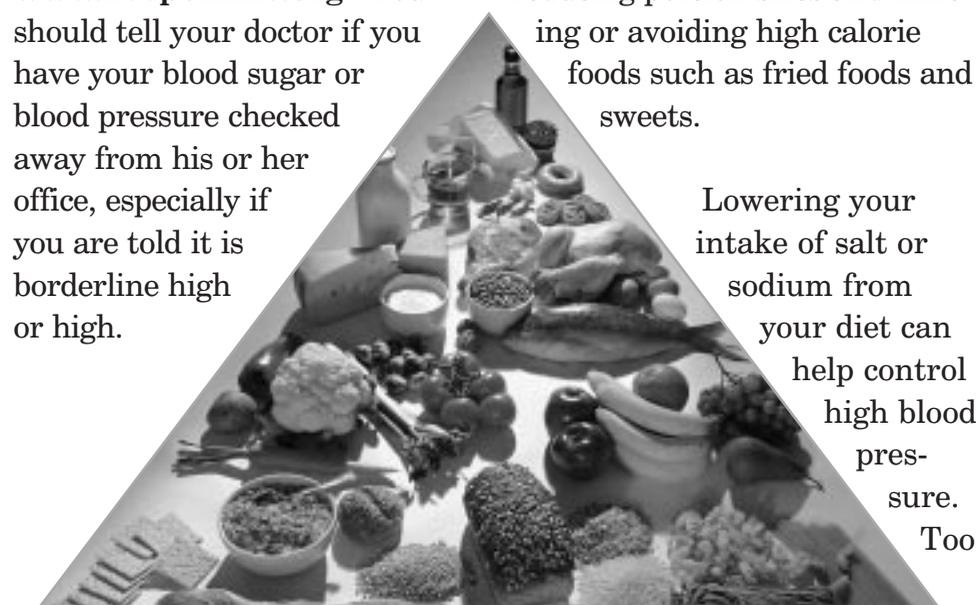
## Eating Right for At-Risk Families

By Ann Beemer Cotton, MS, RD

*Your dietary choices can make a big difference*

tor for diabetes. Blood sugar and blood pressure can be checked during a doctor's office visit or at other community health screening programs such as the National Kidney Foundation (NKF) Kidney Early Evaluation Program (KEEP). You can find out more about KEEP programs in your community by calling the National NKF office at 1-800-622-9010 or by visiting the NKF's KEEP Web site

[www.keeponline.org/](http://www.keeponline.org/) You should tell your doctor if you have your blood sugar or blood pressure checked away from his or her office, especially if you are told it is borderline high or high.



**Talk to your dietitian to review the best food choices for your condition. For example, people with diabetes need to limit sugars and starches, so they should avoid bread, fruits and some other foods.**

Medicine, diet and exercise are important to help control diabetes and protect your kidneys. Working with a dietitian, you can find an eating plan to help manage your blood sugar. You can ask your doctor to recommend a dietitian. Carbo-

hydrates, or the sugars and starches you eat, will need to be limited and spread out in meals and snacks over the day. Breads, fruits, milk, some vegetables, desserts and other sweets have most sources of carbohydrates in the diet. Losing weight can also aid blood sugar control. Slow, steady weight loss of one to two pounds per week to a weight goal set by you and your dietitian is best. Changing your eating habits might include reducing portion sizes and limiting or avoiding high calorie foods such as fried foods and sweets.

Lowering your intake of salt or sodium from your diet can help control high blood pressure. Too

much sodium causes more fluid to be held in the body and can cause a rise in blood pressure. Processed foods and those with a lot of sodium such as sausages, many deli meats, canned or dehydrated foods, and those frozen foods with breading or sauces are just some of the foods that should be avoided. Most fast foods are also poor choices because they are often high in fat and sodium. A review of your usual

food choices with a dietitian will point out high sodium foods to limit or avoid, as well as identify better, lower sodium food choices to help control high blood pressure.

If kidney disease runs in the family, learn about your family medical history. If diabetes or high blood pressure is the cause of the kidney disease, make sure you and your family members get checked regularly for these diseases as early as possible. Finding out if you have diabetes or high blood pressure and protecting your kidneys from the damage that diabetes or high blood pressure can cause demands your effort. Follow the treatment plan prescribed by your doctor, including any changes in eating habits to control diabetes or high blood pressure. **Family Focus**

### About the Author

Ann Beemer Cotton, MS, RD, lives in Appleton, WI. She has over 20 years of experience and research with people who have chronic kidney disease. Ann has written prolifically about kidney failure and was recently elected as the Region 3 Representative for the National Kidney Foundation Council on Renal Nutrition.

*Medicine, diet and exercise are important to help control diabetes and protect your kidneys.*

## Medicare Web Site for Kidney Patients

IN JUNE 2004, THE CENTERS FOR MEDICARE & MEDICAID SERVICES (CMS) INTRODUCED A REVISED VERSION OF THEIR DIALYSIS FACILITY COMPARE (DFC) WEB SITE ON [www.medicare.gov](http://www.medicare.gov)

CMS is committed to providing patients with information to assist them in making choices about their health care.

Patients with chronic kidney disease (CKD) can find information to compare dialysis facilities on the Dialysis Facility Compare Web site at [www.medicare.gov/dialysis/home.asp](http://www.medicare.gov/dialysis/home.asp)

Patients and family members can compare dialysis facilities by the services they offer, as well as by three measures of quality care: hemodialysis adequacy, anemia and survival. The Web site also offers additional

resources for hemodialysis and peritoneal dialysis patients, pre-dialysis patients, pediatric patients and those who are transplanted. CMS is continually testing and improving the Dialysis Facility Compare Web site to better assist CKD patients in managing their care.



## The Drug Discount Card

IN 2003, A NEW LAW WAS PASSED TO CHANGE PARTS OF MEDICARE. One of the changes is the new Medicare Drug Discount Card, which became available in May 2004. Some people can save up to 15 percent on prescription drugs with the Drug Discount Card. The card is free to some individuals with low incomes, and can cost up to \$30 for others. You can also get a \$600 credit on your card in 2004, but you need to apply before January 2005 or you will not get the credit.

There are many discount cards available. You may need help finding out if you are eligible for a card, choosing a discount card and filling out the enrollment forms. Here is a list of programs and services for help and information on the Drug Discount Card:

**Medicare** 800-MEDICARE or 1-800-633-4227 (TTY/TDD 1-877-486-2408) Web Site [www.medicare.gov](http://www.medicare.gov)

**SHIP** (State Health Insurance Assistance Program) Call Medicare or visit [www.medicare.gov](http://www.medicare.gov) for your state's SHIP

**AARP** 888-687-2277 (TTY/TDD 1-877-434-7598) Web Site [www.aarp.org](http://www.aarp.org)

Visit NKF's Patient and Family Council Web page at [www.nkfkidneypatients.org](http://www.nkfkidneypatients.org) and click on The Drug Discount Card for more details on the discount cards.

THERE'S ONLY ONE WAY TO FACE DIALYSIS. TOGETHER.

No one should have to face dialysis alone, and thanks to Amgen, no one has to. Because Amgen—the world's largest biotech company—is dedicated to helping you deal with the many issues that can go along with kidney failure and dialysis. For example, many people with chronic kidney disease on dialysis develop **anemia**, a shortage of red blood cells. Anemia can make you very tired and unable to complete routine daily tasks. Anemia may also lead to more serious problems like heart disease.

An important gland called the **parathyroid** can also be affected by kidney disease, leading to a condition called **secondary hyperparathyroidism (secondary HPT, for short)**—which can cause serious problems in your bones and blood vessels. Amgen offers an entire family of products and services to help support people on dialysis and the people who love them. Because we're not just dedicated to improving the lives of people with kidney failure, we're dedicated to protecting them.

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