

# National Kidney Disease Education Program

Reducing Disparities. Improving Care.



A Summary Report



## Letter from the NIDDK Director

Dear Reader,

Since it began eight years ago, the National Kidney Disease Education Program (NKDEP) has led the way in reducing disparities related to chronic kidney disease (CKD) by reaching out to people at risk for kidney disease as well as the professionals and systems that serve them. NKDEP aims to raise awareness among the public and health care providers that testing and treatment for CKD exist and can make a real difference in slowing the progression of the disease. As more and more Americans are affected by CKD—due in part to rising rates of diabetes and high blood pressure—NKDEP’s charge becomes even more important.

NKDEP works with a range of government, nonprofit, and health care organizations to promote testing among people at risk, provide resources and tools for health care providers, and support changes in the laboratory community to improve accuracy and reliability of test results.

NKDEP continues to strive to improve care for CKD, working with partners to educate health care providers and those at risk, and to promote systems change. As CKD awareness rises and the numbers of those affected grow, NKDEP will continue to provide the necessary leadership, guidance, and support to tackle the challenges ahead.

Sincerely,

A handwritten signature in black ink that reads "Griffin Rodgers". The signature is written in a cursive, flowing style.

Griffin P. Rodgers, M.D., M.A.C.P.

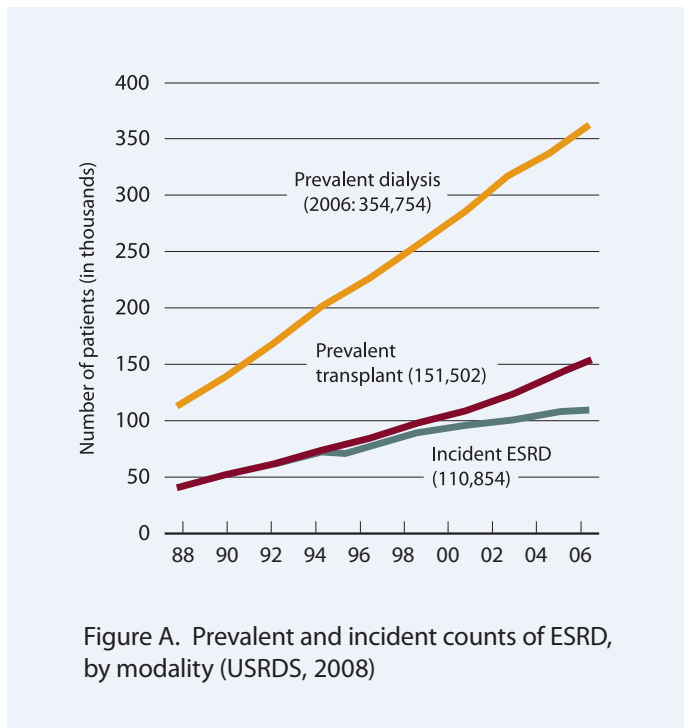
Director

National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK)  
National Institutes of Health

# Why a National Kidney Disease Education Program?

## Chronic Kidney Disease: A Serious Public Health Problem

Chronic kidney disease (CKD) is a serious and growing public health problem in the United States. CKD is a condition in which the kidneys become damaged, decreasing their ability to filter the blood and remove water and waste products. Wastes then build up in the blood, harming the body. When kidney function decreases to less than 15 percent, a patient has kidney failure. Kidney failure that requires dialysis or kidney transplant is often referred to as end-stage renal disease (ESRD).



More than 20 million Americans aged 20 and older may have CKD, based on a decreased glomerular filtration rate (GFR), a measure of kidney function (Levey, et al., 2009). Although CKD is common, many Americans with the key risk factors—diabetes and high blood pressure—do not know they are at risk. In addition, the rising rates of diabetes and obesity will continue to fuel its growth, as both conditions increase the risk of developing CKD and speed its progression.

Therapies exist that can significantly slow the progression of CKD to kidney failure; particularly blood pressure control and use of medications that protect kidney function—called angiotensin-converting enzyme (ACE) inhibitors or angiotensin receptor blockers (ARBs). However, many people who would benefit from treatment are not receiving it.

The number of Americans being treated for kidney failure continues to grow. Recent data show that 506,256 Americans are on dialysis or living with a kidney transplant (USRDS, 2008). The incidence (new cases) of people with ESRD, however, has started to level off in recent years. (See Figure A.)

In addition to kidney failure, other serious complications—particularly cardiovascular disease (CVD)—are associated with CKD. Other complications include anemia, malnutrition, bone disease, and depression.

## Public Health Burden

CKD and ESRD impose a tremendous public health burden, costing the U.S. health care system billions of dollars. In 2006, costs for Medicare patients with CKD exceeded \$49 billion, accounting for nearly one-quarter of general Medicare costs (USRDS, 2008). Medicare spending for ESRD reached \$22.7 billion during the same year (USRDS, 2008). By 2020, Medicare ESRD costs are expected to reach \$55.6 billion (USRDS, 2007).

## Disparities

ESRD disproportionately impacts racial and ethnic minorities, particularly African Americans, Hispanics, and Native Americans. (See Figure B.)

- Non-Hispanic African Americans experience early CKD at rates similar to non-Hispanic whites, but African Americans are 3.6 times more likely than whites to develop kidney failure.
- Since 1996, the number of Hispanics with kidney failure has more than doubled.
- Native Americans are 1.8 times more likely than whites to develop kidney failure.

A focus on enhancing detection and treatment of CKD in these populations is critical.

## NKDEP: A National Response

The National Kidney Disease Education Program (NKDEP) works to reduce the burden of CKD, especially among communities most impacted by the disease. Established in 2000 by the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), the program's chief objective is to reduce the morbidity and mortality caused by CKD and its complications. NKDEP aims to improve early detection of CKD, facilitate identification of patients at greatest risk for progression to kidney failure, promote evidence-based interventions to slow progression of CKD, and support the coordination of Federal responses to CKD.

To achieve its goals, NKDEP works in collaboration with a range of government, nonprofit, and health care organizations to raise awareness among people at risk for CKD about the need for testing; provide information, training, and tools to help health care providers better detect and treat CKD; and support changes in the laboratory community that yield more accurate, reliable, and accessible test results.

Central to NKDEP's approach is the concept that CKD should be identified and addressed in the primary care setting, and that managing CKD prior to referral can improve patient outcomes. CKD has long been perceived as a "specialist disease," and primary care providers have tended to defer treatment prior to subspecialty referral, missing opportunities for early treatment. Yet many of the therapeutic interventions for CKD are similar to those required for optimal diabetes care (e.g., control of glucose, blood pressure, and lipids), and

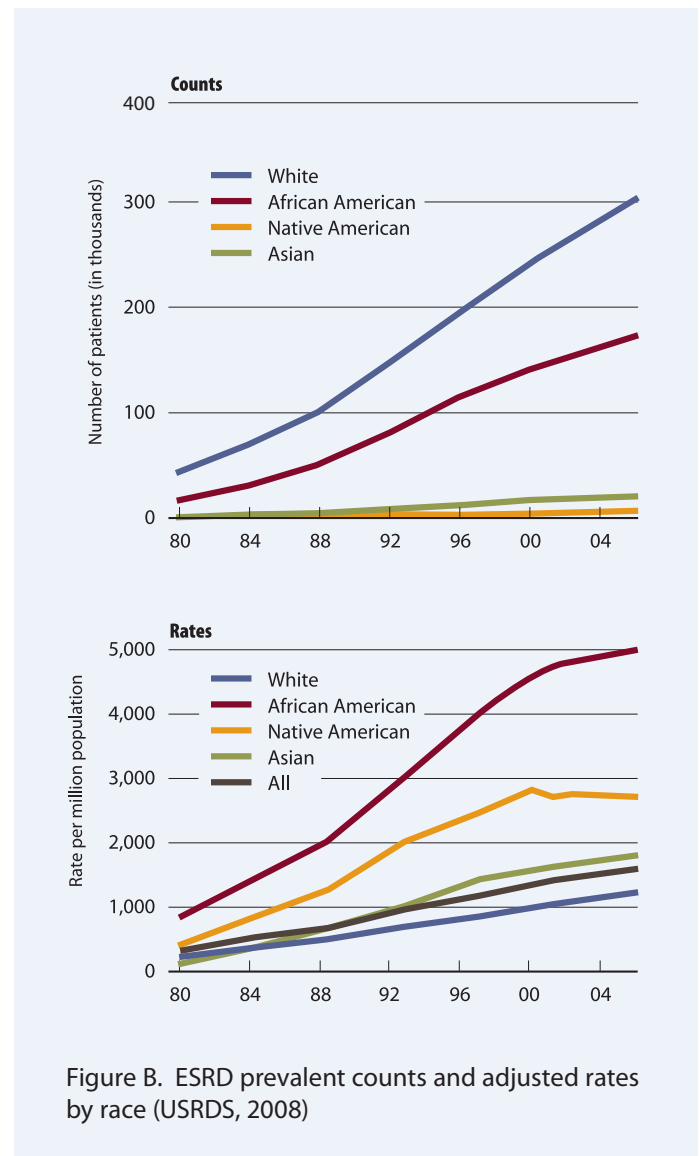


Figure B. ESRD prevalent counts and adjusted rates by race (USRDS, 2008)

other key interventions can be integrated into primary care (e.g., screening for co-morbidities, dietary counseling).

The Chronic Care Model (CCM) points the way to reducing disparities by achieving better care for chronic illnesses in the primary care setting. NKDEP works to help providers include CKD as part of primary care, using the CCM as an organizing principle for its efforts. The CCM summarizes the basic elements for improving care in health systems, including community, organization, practice, and patient levels, and offers a systematic way to identify needs and set priorities within these elements. The ultimate goal of the model is to have informed patients who are active in their care, and providers who have resources and expertise. NKDEP is working to foster systems-level change by supporting improvements in each element of the CCM to advance CKD detection and care nationwide.

# Program Highlights

This section provides brief overviews of NKDEP's accomplishments and current activities as they relate to various components of the Chronic Care Model (see pages 4 and 5).

## Community/Resources and Policies

### Encouraging testing among at-risk populations

African Americans are at highest risk for kidney failure and, as such, NKDEP places a special emphasis on reaching out to this community. The centerpiece of NKDEP's outreach efforts is the **African American Family Reunion Initiative**, which encourages families to talk about CKD risk factors at their annual reunions and other gatherings. The cornerstone of the Initiative is the *Family Reunion Health Guide*, a free, do-it-yourself kit that includes key information about CKD and options for sharing information with family members.

NKDEP promotes the Initiative via partnerships with more than 45 national organizations, including the National Medical Association and the American Diabetes Association; community events; and African American and other media outlets. An evaluation of the Guide is currently taking place.

**Kidney Sundays** is another initiative intended to increase awareness about CKD among this population. This initiative provides the African American faith-based community with tools and materials, such as talking points that help health champions talk about CKD with the congregation. The Kidney Sundays website was launched in July 2008, and the program is being expanded in 2009.

NKDEP has developed a series of **publications** for the at-risk public and distributes them through various partners to encourage people at risk for CKD to get tested.

Materials include:

- *Make the Kidney Connection*—for the general public
- *Kidney Disease: What African Americans Need to Know*—for African Americans
- *Aprenda a Proteger sus Riñones (Learn How to Protect Your Kidneys)*—for Hispanics

### Supporting community level change

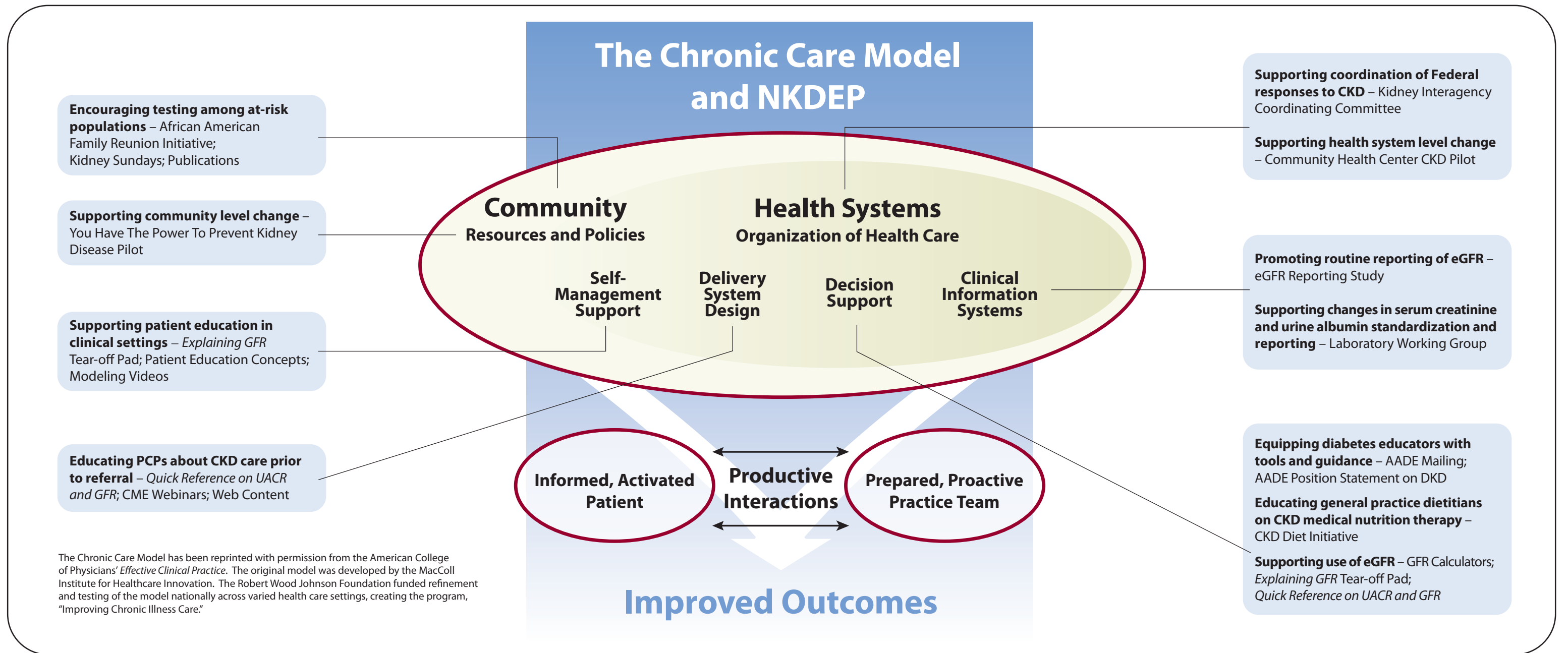
In 2003, NKDEP piloted its first awareness campaign, **You Have The Power To Prevent Kidney Disease**, in four cities: Atlanta, Baltimore, Cleveland, and Jackson, MS. In each city, interested volunteers formed coalitions to plan and implement kidney disease awareness activities utilizing NKDEP materials and resources. The coalitions built community partnerships, worked with mass media, conducted programs with the African American community and primary care providers, and reached out to local dialysis clinics and laboratories.

## Health Systems/Organization of Health Care

### Supporting coordination of Federal responses to CKD

NKDEP is working to improve the coordination of the Federal response to CKD. Through NIDDK's **Kidney Interagency Coordinating Committee (KICC)**, NKDEP developed a government-wide initiative in which Federal agencies share information about their CKD activities and look for opportunities to collaborate. NKDEP supports communication among KICC members through *KICC News*, a quarterly e-newsletter that highlights CKD-related activities across the Federal government, and hosts information-sharing meetings.

NKDEP has developed an online resource that summarizes—and organizes by type—the numerous CKD-related activities taking place across Federal agencies. The Federal CKD Matrix includes contact information for agency representatives to encourage communication and partnerships.



## Supporting health system level change

NKDEP initiated the Community Health Center (CHC)-CKD Pilot in 2008 to identify effective strategies for improving CKD detection and treatment in community health centers—critical primary care settings for many people at increased risk for CKD. The pilot involves a small group of centers in the Northeast that work together to design, implement, and monitor performance improvements related to CKD.

NKDEP provides technical assistance and modest financial support to the centers, while working with them to improve clinical information systems for CKD-related data collection and analysis,

### CHC-CKD Pilot Participants

Pilot participants, chosen from participants in the Health Resources and Services Administration's Diabetes Health Disparities Collaborative, include:

- Eric B. Chandler Health Center (NJ)
- Fair Haven Community Health Center (CT)
- Hudson River HealthCare (NY)
- Manet Community Health Center (MA)
- Neponset Health Center (MA)

provide decision support and patient education tools, and conduct continuing medical education (CME) trainings for clinical staff. NKDEP aims to expand the project to health centers nationwide.

### Self-Management Support: Supporting patient education in clinical settings

Patient education is a key intervention in CKD care. Educators play an important role in educating their patients about the risk for CKD, the importance of testing, and risk reduction steps they can take. Through education, they can also begin to prepare their patients for the possibility of kidney failure and treatment.

To support patient education, NKDEP has developed the following resources for providers:

- *Explaining GFR: A Tear-off Pad for Clinical Use* that helps providers explain GFR test results and CKD basics to patients. The pad has been adapted into Spanish, Chinese, and Vietnamese. (A companion pad is being developed to help explain urine albumin results.)
- Patient education concepts and suggested talking points on four key topics: CKD and risk, testing, treatment, and kidney failure.
- Short web videos that model provider-patient discussions around common CKD questions.

## Delivery System Design: Educating PCPs about CKD care prior to referral

Many of the therapeutic interventions for CKD are similar to those required for optimal diabetes care, such as control of blood pressure, lipids, and glucose. To support the delivery of CKD care prior to referral—thereby helping to improve patient outcomes—NKDEP provides a variety of information, tools, and resources that educate primary care providers (PCPs) and other health professionals. These include the *Quick Reference on UACR and GFR*, a clinical reference sheet that explains the two key tests (urine albumin-to-creatinine ratio, or UACR, and GFR) used to diagnose and monitor CKD, and two free CME webinars—“Improving Outcomes in Chronic Kidney Disease” and “Nutritional Management of Chronic Kidney Disease”—accredited by the American Academy of Family Physicians. Available for a limited time, both webinars can be accessed at [www.nkdep.nih.gov](http://www.nkdep.nih.gov). NKDEP plans to facilitate more webinars on various topics, including nephrology referral.

NKDEP is redesigning its website with help from its Coordinating Panel and the American Society of Nephrology’s CKD Advisory Group. The site will feature expanded content about CKD care and new interactive elements for health professionals.

## Decision Support: Equipping diabetes educators with tools and guidance

Diabetes is the leading cause of CKD; therefore, diabetes educators—who help people with diabetes better manage the condition and its complications—are a key audience. NKDEP worked with the American Association of Diabetes Educators (AADE) to inform their members through a mailing about tests to monitor kidney health and key kidney disease patient education concepts. NKDEP routinely exhibits and presents at AADE’s Annual Meeting, and has helped shape the Association’s Position Statement on Diabetic Kidney Disease (DKD).

## Decision Support: Educating general practice dietitians on CKD medical nutrition therapy

Diet plays a critical role in CKD management, yet many general practice dietitians may not be familiar with the specific challenges of CKD and diet. To launch

its CKD Diet Initiative, NKDEP held exploratory discussions with renal dietitians—published in *Renal Nutrition Forum*—that confirmed the need for simple patient and dietitian educational materials. In 2008, NKDEP worked with the American Dietetic Association to conduct primary research with a diverse group of registered dietitians on current practices and research in education on CKD and diet, and to pretest provider and patient education materials on diet intervention for CKD. NKDEP is finalizing these materials and planning to develop a CKD training program for general practice dietitians.

## Decision Support: Supporting use of eGFR

One of the two tests that are critical to early detection of CKD is a blood test that measures kidney function by estimating GFR. NKDEP provides clinical information and tools to providers to facilitate use of estimated GFR (eGFR). NKDEP’s website features online and downloadable GFR calculators, as well as information

### NKDEP Partners

The following agencies and organizations are just some of the groups with which NKDEP has worked over the years. Many of them have been represented on NKDEP’s Coordinating Panel.

Agency for Healthcare Research and Quality  
Alpha Phi Alpha, Inc.  
American Academy of Nurse Practitioners  
American Association of Diabetes Educators  
American College of Physicians  
American Diabetes Association  
American Dietetic Association  
American Public Health Association  
American Society of Nephrology  
Association of Clinicians for the Underserved  
Centers for Disease Control and Prevention  
Centers for Medicare & Medicaid Services  
Chi Eta Phi Sorority, Inc.  
Federal Drug Administration  
Forum of ESRD Networks  
Health Resources and Services Administration  
Indian Health Service  
National Heart, Lung, and Blood Institute  
National Kidney Foundation, Inc.  
Renal Physicians Association  
Veterans Health Administration

about benefits of—and limitations to—using eGFR. Other tools include the *Explaining GFR* tear-off pad (see Self-Management Support) and the *Quick Reference on UACR and GFR* (see Delivery System Design).

NKDEP also works to increase use of eGFR by encouraging clinical laboratories to automatically report eGFR (see below) and the at-risk public to know their eGFR.

## Clinical Information Systems: Promoting routine reporting of eGFR

In 2006 and 2007, NKDEP conducted a study on eGFR reporting by clinical laboratories in the U.S. The study found that 38.4 percent of serum creatinine reporting labs were reporting eGFR (Accetta, et al., 2008). It also found that routine (automatic) reporting of eGFR was relatively low among independent labs—the lab type that tends to run high volumes of serum creatinine tests—compared to other lab types. While eGFR reporting is on the rise, the study showed that it is not yet universal and that room for improvement exists among labs already reporting it.

### National Institutes of Health Plain Language Awards

#### 2005

- Family Reunion Initiative Website
- *You Have The Power To Prevent Kidney Disease* Brochure
- *Help Your Family Prevent Kidney Failure* Brochure

#### 2006

- *Apreda a Proteger sus Riñones (Learn How to Protect Your Kidneys)* Brochure
- *Family Reunion Health Guide* Booklet

#### 2007

- *Kidney Disease: What African Americans Need to Know* Brochure

#### 2008

- *Explaining GFR* Tear-off Pad (Spanish)
- *Explaining GFR* Tear-off Pad (English)
- *Quick Reference on UACR and GFR* Fact Sheet

## Clinical Information Systems: Supporting changes in serum creatinine and urine albumin standardization and reporting

NKDEP works with laboratory professionals worldwide to improve key diagnostic tests for CKD. NKDEP's **Laboratory Working Group (LWG)** brings together the world's top clinical chemists, laboratory services providers, equipment manufacturers, and CKD experts to improve the accuracy of the blood test used to measure kidney function and the urine albumin test that reflects kidney damage, and to ensure that test results are reported properly and consistently.

The LWG is widely recognized for its work on serum creatinine, which is critical to the diagnosis of CKD. Historically, creatinine measurements were not standardized—the same blood sample sent to five different labs could have returned five different results. The LWG's Creatinine Standardization Program worked to eliminate this inter-laboratory variability by recalibrating measurement methods.

The LWG also developed protocols for whole blood measurement of creatinine, revised an equation for estimating GFR in children, and held symposia at annual meetings of the American Association for Clinical Chemistry. It currently is working on new tools to help prescribers safely and effectively dose certain medications in patients with decreased kidney function.

Most recently, the LWG began a major collaboration with the International Federation of Clinical Chemistry and Laboratory Medicine to standardize the measurement and reporting of urine albumin—a measure of kidney damage. An international group of experts met in March 2007 to discuss priority issues and actions (Miller, et al., 2009). A number of related research projects have begun.

### Materials Dissemination Highlights

- 350,000 educational brochures disseminated for at-risk populations since 2004
- 32,000 *Quick Reference on UACR and GFR* fact sheets disseminated since 2008



# The Road Ahead

In the years ahead, NKDEP will continue to look to the CCM to identify priority activities—identifying areas of need where the program can make the greatest difference. NKDEP will work to reduce health disparities through a focus on populations at highest risk for CKD and the providers who serve them. And it will continue to invest in partnerships and tools that amplify the program's reach and impact.

First, NKDEP hopes to expand its work with CHCs, among whose 18 million patients are many of the people at high risk for CKD. Building on the materials, training programs, and other resources developed as part of the CHC-CKD Pilot, NKDEP plans to adapt the program for use by CHCs nationwide.

Second, NKDEP will continue its commitment to patient education, creating materials that help time-starved health care providers quickly communicate essential information. In addition to materials for at-risk groups, and African Americans in particular, NKDEP is developing materials for recently diagnosed CKD patients. A key goal: supporting self-management—helping patients play an active and informed role in their care.

Third, NKDEP will continue to create materials and programs to meet the needs of the broader health care team. NKDEP is currently helping general practice dietitians and other health care professionals assess CKD patients and educate about diet. It is also exploring new programs for diabetes educators, clinical pharmacists, nurse practitioners, and others who play a role in identifying and managing CKD.

## 2008 Website Data Highlights

- NKDEP Website: Average of 21,300 unique visitors per month
- *Family Reunion Health Guide*: 38,000 downloads, including individual discussion approaches
- Adult GFR Calculator Page: Average of 14,300 visits per month

In addition, NKDEP's LWG will continue to work with its international colleagues to standardize the measurement and reporting of urine albumin. Once completed, NKDEP will communicate the resulting recommendations to laboratory and health professional communities through partners and other communication channels.

Improving CKD detection and management requires changing clinical practice, and NKDEP hopes to be instrumental in translating clinical evidence into improved clinical outcomes. It is a complex challenge, but working in close collaboration with current and future partners, NKDEP can help reduce disparities and improve care.

## References

1. Accetta NA, Gladstone EH, DiSogra C, Wright EC, Briggs M, Narva AS. Prevalence of estimated GFR reporting among US clinical laboratories. *American Journal of Kidney Diseases*. 2008; 52(4): 778-787.
2. Levey AS, Stevens LA, Schmid CH, Zhang YL, Castro AF 3rd, Feldman HI, Kusek JW, Eggers P, Van Lente F, Greene T, Coresh J; CKD-EPI (Chronic Kidney Disease Epidemiology Collaboration). A new equation to estimate glomerular filtration rate. *Annals of Internal Medicine*. 2009; 150(9):604-612.
3. Miller G, Bruns D, Hortin G, Sandberg S, Aakre K, McQueen M, Itoh Y, Lieske J, Seccombe D, Jones G, Bunk D, Curhan G, Narva A. National Kidney Disease Education Program-IFCC Working Group on Standardization of Albumin in Urine. Current Issues in Measurement and Reporting of Urinary Albumin Excretion. *Clinical Chemistry*. 2009; 55:1.
4. U.S. Renal Data System, USRDS 2007 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2007.
5. U.S. Renal Data System, USRDS 2008 Annual Data Report: Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases, Bethesda, MD, 2008.

**Andrew S. Narva, M.D., F.A.C.P.**

Director  
National Kidney Disease Education Program  
National Institute of Diabetes and Digestive and Kidney Diseases  
National Institutes of Health  
Two Democracy Plaza  
6707 Democracy Boulevard, MSC 5458  
Bethesda, MD 20892-5458  
301-594-8864  
narvaa@niddk.nih.gov

**Eileen P. Newman, M.S., R.D.**

Associate Director  
National Kidney Disease Education Program  
National Institute of Diabetes and Digestive and Kidney Diseases  
National Institutes of Health  
Building 31, Room 9A06  
31 Center Drive, MSC 2560  
Bethesda, MD 20892-2560  
301-435-8116  
eileen.newman@nih.gov


For more information about the National Kidney Disease Education Program (NKDEP), call 1-866-4 KIDNEY (1-866-454-3639) or visit the NKDEP website at [www.nkdep.nih.gov](http://www.nkdep.nih.gov). For a complete list of NKDEP resources, visit [www.nkdep.nih.gov/resources](http://www.nkdep.nih.gov/resources).

For more information about National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) programs, call 301-496-3583 or visit [www.niddk.nih.gov](http://www.niddk.nih.gov). For a complete list of NIDDK resources, visit NIDDK's Clearinghouses Publications Catalog at [www.catalog.niddk.nih.gov](http://www.catalog.niddk.nih.gov).



U.S. Department of Health  
and Human Services  
National Institutes of Health

**NIDDK** | NATIONAL INSTITUTE OF  
DIABETES AND DIGESTIVE  
AND KIDNEY DISEASES

 **NKDEP**  
National Kidney Disease  
Education Program