



people
with
kidney
disease
PRIMARY
CARE
PROVIDER
NURSE
FAMILY

nurse
practitioner
nephrologist
community
health worker
promoters
physician's
assistant
communities
pharmacist
LAB
TECHNICIAN
dietitian
physician
nursing assistant

A SUMMARY REPORT

National Kidney Disease Education Program

REDUCING DISPARITIES. IMPROVING CARE.



A program of the National Institutes of Health

About the National Institute of Diabetes and Digestive and Kidney Diseases

The mission of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) is to conduct and support medical research and research training and to disseminate science-based information on diabetes and other endocrine and metabolic diseases; digestive diseases, nutritional disorders, and obesity; and kidney, urologic, and hematologic diseases, to improve people's health and quality of life. NIDDK is part of the National Institutes of Health.

Letter from the NIDDK Director

Translating clinical science into better patient outcomes is an integral part of the mission of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK). The National Kidney Disease Education Program (NKDEP), based in NIDDK, works to improve the identification of people with chronic kidney disease (CKD) and promotes the implementation of evidence-based interventions, with the goal of reducing disparities and improving care. NKDEP focuses on populations at highest risk for CKD, the providers who serve them, and the health care systems that enable quality care.



NKDEP collaborates with government, nonprofit, and health care organizations to raise awareness among people at risk for CKD about the need for testing and to educate people with CKD about disease management. NKDEP also works to provide information, training, and tools to help health care professionals better identify and manage CKD patients prior to referral, and support health system changes that facilitate effective CKD detection and management.

As rising rates of obesity and diabetes drive an increase in the burden of CKD, NKDEP's role in raising awareness and spurring systems change becomes even more critical. The Program is moving into new areas such as health information technology to improve identification of people with CKD and ensure that new clinical evidence is integrated into routine care.

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
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 (U.S.). 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—or increased albuminuria, a sign of kidney damage.¹ Although CKD is common, many Americans with the two leading risk factors, diabetes and high blood pressure, do not know they are at risk. The rising prevalence of obesity and diabetes is driving an increase in the burden of CKD, as well as cardiovascular disease (CVD), which is associated with CKD.

Existing therapies can significantly slow CKD, particularly blood pressure control and use of medications that protect kidney function, called angiotensin-converting enzyme (ACE) inhibitors and angiotensin receptor blockers (ARBs). However, many people who would benefit from treatment are not receiving it. As a result, a growing number of Americans with CKD are progressing to kidney failure. Recent data show that close to 600,000 Americans are on dialysis or living with a kidney transplant.² In 2010, about 86,000 adults were waiting for a kidney transplant—compared to 23,000 in 1995.² In addition to kidney failure, other serious complications are associated with CKD, including CVD, anemia, malnutrition, bone disease, and depression. Fortunately, the incidence of people with end-stage renal disease (ESRD) has begun to stabilize in recent years. (See Figure A.)

Public Health Burden

CKD and ESRD impose a tremendous public health burden. In 2010, costs for Medicare patients with CKD exceeded \$40 billion, accounting for 17 percent of general Medicare costs—up from six percent in 2000.² Medicare spending for ESRD reached \$33 billion during the same year, with total ESRD spending in the U.S. reaching almost \$48 billion.² Within Medicare, combined CKD and ESRD costs accounted for almost a quarter of the budget—a share slightly higher than congestive heart failure.²

Disparities

ESRD disproportionately affects 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 3.4 times more likely than whites to develop kidney failure.
- Incidence rates of kidney failure among African Americans and Native Americans are declining, yet prevalence rates of kidney failure remain highest in these populations.
- Hispanics are 1.5 times more likely than non-Hispanic 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, or the Program) works to reduce the burden of CKD, especially among communities most affected by the disease. Established in 2000 by the [National Institute of Diabetes and Digestive and Kidney Diseases](#) (NIDDK), the Program aims to reduce the morbidity and mortality associated with kidney disease by promoting evidence-based interventions to improve understanding, detection, and management of kidney disease.³

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; to educate people with CKD about

how to manage their disease; to provide information, training, and tools to help health care providers better identify and manage CKD patients; and to support health system changes that facilitate effective CKD detection and management.

Central to NKDEP’s approach are the concepts that CKD should be identified and addressed in the primary care setting, and that managing CKD prior to referral can improve patient outcomes.³ CKD has long been perceived as a “specialist’s disease,” and primary care providers (PCPs) have tended to defer treatment prior to specialty referral, missing opportunities for early treatment. Yet many of the therapeutic interventions for CKD are similar to those required for optimal diabetes care, including control of glucose, blood pressure, and lipids. Other key interventions can be integrated into primary care, including screening for comorbidities and dietary counseling. Because patients are more likely to visit a PCP

than a nephrologist after a CKD diagnosis,² NKDEP encourages physician and non-physician health professionals to take an active role in CKD screening, education, and management prior to referral. The Program also encourages patients to better understand and more actively manage their CKD and related conditions.

The Chronic Care Model (CCM), an approach that has been shown to improve care for chronic disease and reduce disparities, provides a framework for NKDEP activities.⁴ 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. By supporting improvements within each element, NKDEP strives toward the CCM goal of informed and engaged patients and communities, prepared and proactive health care providers, and efficient and effective health care systems.

FIGURE A: Incident and prevalent patient counts, by modality (USRDS, 2012)

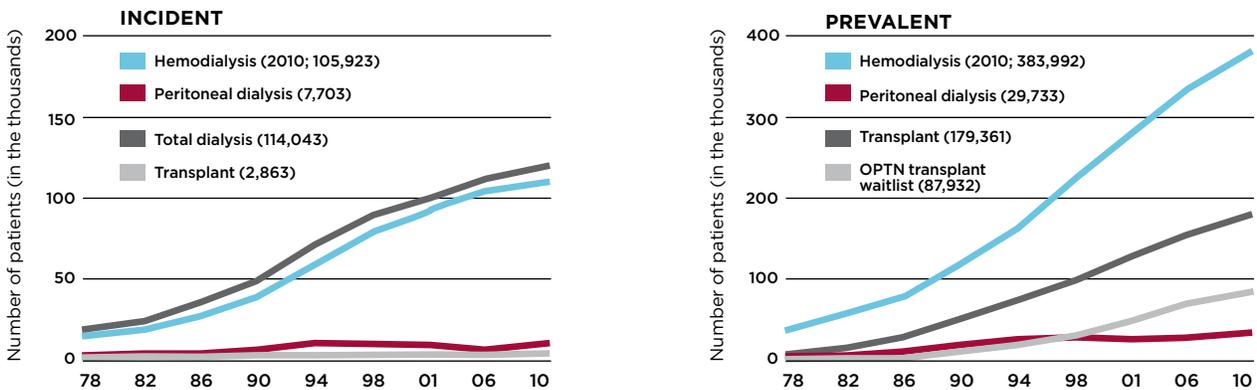
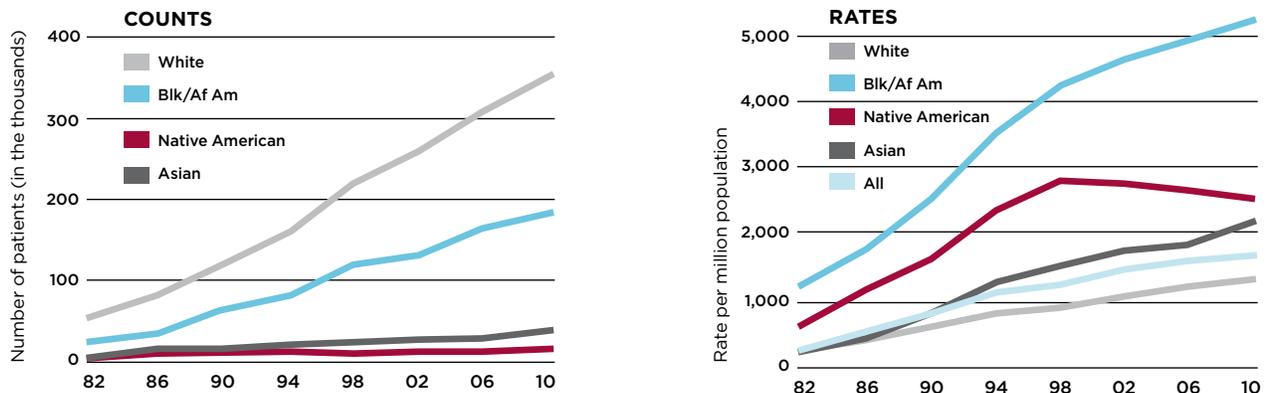


FIGURE B: Prevalent counts and adjusted rates of ESRD, by race (USRDS, 2012)



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.

Community/Resources and Policies *Encouraging testing among at-risk populations*

NKDEP focuses on raising awareness among people at risk for CKD about the importance of testing. Over the past few years, NKDEP has broadened its community outreach initiatives, particularly for African Americans and Hispanics, who are at highest risk for developing kidney failure. Each initiative, and the materials that support it, are the result of audience-specific research to create a culturally relevant and appropriate educational experience for these key audiences.

African American Outreach

NKDEP encourages the African American community to “Make the Kidney Connection” between diabetes, high blood pressure, and kidney disease. NKDEP’s main outreach programs, the Family Reunion Initiative and Kidney Sundays, leverage the influence of African American women, who are community gatekeepers and whose opinions and circle of influence center around loved ones. The Family Reunion Health Guide and Kidney Sundays: A Toolkit equip these women and others to share kidney health information with their families, friends, and faith community.

Efforts in recent years have focused on refining and expanding the Kidney Sundays initiative, which was created to reach African Americans through their faith communities.

Formative research confirmed that African American faith organizations welcome health information, yet prefer a customized approach with free or low cost materials. Additionally, research identified the need for accessible, easy-to-understand information about kidney disease, its risk factors, and treatment. As a result, NKDEP developed *Kidney Sundays: A Toolkit* to include factsheets, brochures, and event planning materials.

NKDEP promotes Kidney Sundays and the Family Reunion Initiative through community events, media efforts, and partnerships to inform others about the importance of testing and encourage loved ones to make the kidney connection.

SPOTLIGHT ON SUCCESS: Engaging Kidney Health Champions

Dr. Bennie Marshall is a NKDEP kidney health champion. Through various leadership roles, including chair of the Nursing & Allied Health Department at Norfolk State University, health minister at Mt. Gilead Missionary Baptist Church in Norfolk, Virginia, and member and past president of Chi Eta Phi Nursing Sorority’s Eta chapter, Dr. Marshall has made it her mission to educate others about their risk for kidney disease. A nurse with 40 years of experience, Dr. Marshall has been using NKDEP materials at faith-based and community events throughout Virginia’s Tidewater region since 2009 to help people make the connection among diabetes, high blood pressure, and kidney disease.

“I use the Kidney Sundays toolkit as the centerpiece of [my] educational processes. I use it for a Sunday announcement or to distribute materials at community health fairs, church Family and Friends Day activities, and monthly blood pressure screenings.”

—Dr. Bennie Marshall

SPOTLIGHT ON SUCCESS: Reaching African Americans through Traditional and Social Media

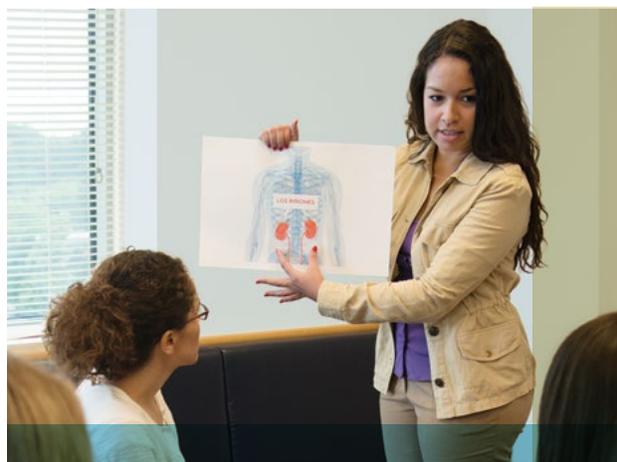
NKDEP engages traditional and social media outlets to raise awareness among African Americans about their risk for kidney disease. As part of outreach efforts for National Kidney Month in March, NIDDK director Dr. Griffin P. Rodgers has participated in Facebook chats with *Blackdoctor.org* to answer fan-submitted questions about kidney health. Each year fans submitted an increasing number of questions, showing a growing appetite for information about kidney health. Dr. Rodgers has also appeared on the Tom Joyner Morning Show, a nationally broadcast radio program that averages nearly 670,000 listeners. During and after Dr. Rodgers' segments, listeners texted in questions about kidney health, which the show posted with Dr. Rodgers' answers on *BlackAmericaWeb.com*. In addition, *Blackdoctor.org* shared the link to the Tom Joyner Q&A on its Facebook page to reach an even wider number of fans.

Since 2012, NKDEP has coordinated a nationwide Kidney Sundays event each March in partnership with the [American Diabetes Association's Live Empowered Initiative](#), the [Chi Eta Phi nursing sorority](#), and the National Coalition of Pastors' Spouses (2012 only). Through grassroots activation via these partners, the Kidney Sundays events in 2012 and 2013 engaged more than 420 African American faith communities across the country, reaching more than 335,000 congregants, to dedicate a day to talking about kidney health. Chi Eta Phi nurses conducted more than 6,420 blood pressure screenings at the congregations and referred more than 200 people to local area PCPs for further evaluation. The Kidney Sundays events have supported the distribution of 130,000 kidney health-related materials from NKDEP and other NIDDK programs.

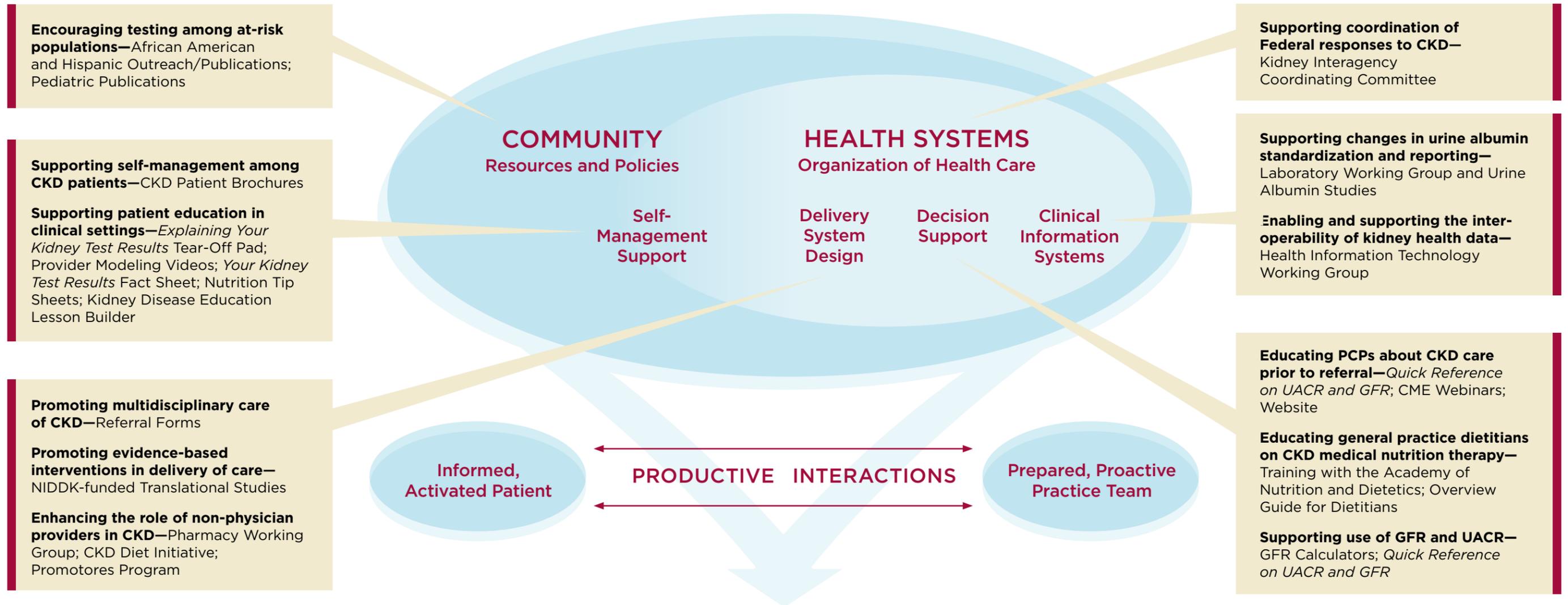
Hispanic Outreach

In 2011, NKDEP conducted formative research that showed a significant gap in Spanish-language programming and materials for Hispanic/Latino audiences. Working since then to close this gap, NKDEP has culturally adapted its print and digital materials for the Hispanic audience, garnering positive attention and feedback. The brochure outlining the basics of kidney disease, [La Enfermedad de los Riñones: ¿Qué Significa para mí?](#), received a National Health Information Award for its cultural relevance. Additionally, in 2012 NKDEP launched a [Spanish-language website](#), adapted from its English site by Spanish speakers and tested with at-risk Hispanics. The site was designed to be mobile-friendly in response to research indicating that Hispanics are more likely to use smart phones to access the Internet than non-Hispanics. Media outreach to promote the website resulted in more than 35 million exposures and a significant increase in the number of visitors to the website.

NKDEP is developing a new educational initiative, [“Riñones, Tesoros. Cúdalos”](#), or “Kidneys, Treasures. Take Care of Them,” a program for promotores (lay health educators) to educate Hispanics about the link between diabetes and kidney disease. Every aspect of the initiative, including its name, is being developed in Spanish by Spanish speakers and tested with kidney patients, health professionals, and promotores to ensure that all content is culturally relevant and easy to understand.



The Chronic Care Model is the organizing principle of NKDEP



The Chronic Care Model has been reprinted with permission from the American College of Physicians' Effective Clinical Practice. The original model was developed by the MacColl Center for Health Care Innovation. The Robert Wood Johnson Foundation funded refinement and testing of the model nationally across varied health care settings, creating the program, "Improving Chronic Illness Care." Copyright 1996-2013 The MacColl Center.

Health Systems/ Organization of Health Care

Self-Management Support: *Supporting self-management among CKD patients*

NKDEP offers resources to support self-management among CKD patients to help them understand their disease and the treatment and actions required to slow disease from progression. All materials are based on published evidence; have been reviewed by practitioners and experts; and aim to convey accurate, yet easy-to-understand, information about CKD. Materials include:

- ***Chronic Kidney Disease: What Does It Mean for Me? (Brochure)***—Explains the basics of CKD for recently diagnosed patients.
- ***Chronic Kidney Disease and Medicines: What You Need to Know (Brochure)***—Explains the safe use of medications to people with CKD and encourages them to turn to pharmacists for information and support.
- ***Is Your Child At Risk for Kidney Disease? (Poster)***—Lists risk factors for kidney disease and explains the importance of urine testing for children at risk. The poster is intended to be used in clinician waiting rooms to spark discussion between parents of children at risk and the health care provider, and is complemented by the *Is My Child At Risk for Kidney Disease?* brochure.
- ***High Blood Pressure and Children: What Parents Need to Know (Brochure)***—Helps parents understand high blood pressure in children and provides steps to keep children healthy. This brochure was developed with the [National Heart, Lung, and Blood Institute](#) and the [American Society of Pediatric Nephrology](#).

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

Health behavior change can be achieved most effectively when health care providers have a patient-centered approach, cultivate a collaborative relationship, communicate clearly, and provide education when patients are ready to hear and learn.^{5,6} Recognizing that the productive interactions between a CKD patient and a provider most often take place within the primary care clinical setting, NKDEP has developed a variety of materials and tools to help providers educate patients about CKD and promote self-management. Materials include:

- ***Explaining Your Kidney Test Results: A Tear-off Pad for Clinical Use***—Helps providers explain the two most common tests to identify and monitor kidney disease (urine albumin and GFR) as well as basic information about CKD. The pad has been adapted into [Spanish](#), [Chinese](#), and [Vietnamese](#).

SPOTLIGHT ON SUCCESS: ***Explaining Your Kidney Test Results:*** ***A Tear-off Pad for Clinical Use***

NKDEP originally developed this clinical tool to give providers a simple, visual way to explain estimated GFR (eGFR) test results and basic kidney information to low literacy patients. Providers appreciated the information and pad format—a patient tear-off sheet and provider talking points—and subsequently urine albumin and blood pressure test results were added. The revised, expanded tear pad continues to be a popular NKDEP resource in print and online versions, garnering more than 3,000 orders and 25,000 web views across languages annually. Providers have praised the “GFR dial” as a useful resource in facilitating education about kidney disease and engaging patients in self-management. A formal evaluation of the dial found that it increased patient understanding of kidney disease;⁷ other evaluation is currently under way.

- **Short web videos**—Brief provider-patient discussions around common CKD questions. NKDEP expanded the library to include videos in Spanish and videos about transition to renal replacement therapy (RRT).
- ***Your Kidney Test Results* (Fact sheet)**—Helps providers assess and discuss test results with CKD patients. The fact sheet has been adapted into Spanish.
- **Nutrition Tip Sheets**—Present key information about CKD and diet. Individual tip sheets focus on sodium, protein, phosphorus, potassium, and food label reading and are intended to help general practice registered dietitians (RDs) provide effective medical nutrition therapy (MNT) to CKD patients who are not on dialysis. All tip sheets have been adapted into Spanish.
- ***Kidney Disease Education Lesson Builder* (Online tool)**—Helps educators create and implement lesson plans for counseling CKD patients about managing their disease and preparing for RRT (dialysis or transplant). This resource is divided into six unique, content-based lesson plans, including learning objectives, sample session starters, recommended session content, patient materials, clinical information for educators, sample outcome assessment questions, and visual teaching aids.



SPOTLIGHT ON SUCCESS:

Kidney Disease Education Lesson Builder

NKDEP created the Kidney Disease Education Lesson Builder to assist in the comprehensive education of people with progressive CKD. The Lesson Builder is designed to fulfill the requirements of the Kidney Disease Education Services benefit, as defined by the Centers for Medicare & Medicaid (CMS). This modular, adaptable tool helps providers craft lesson plans on a range of topics covered by the CMS benefit and points them to free educational resources. Each lesson can be tailored for audience considerations such as literacy levels or cultural preferences, allowing for optimal understanding among each set of learners. The Lesson Builder received more than 15,000 web visits in the year after its launch—with more than 5,000 to the first lesson on the basics of kidney disease.

Delivery System Design:

Promoting multidisciplinary care of CKD

NKDEP recognizes that appropriate care for patients diagnosed with CKD requires collaborative, interdisciplinary care. To assist PCPs and consultants, including nephrologists and RDs, with maintaining continuity of care and improving outcomes, NKDEP created two interactive clinical tools, including:

- ***The Nephrology Referral Form***—Helps referring PCPs share important patient data with the consulting nephrologist.
- ***The CKD Diet Counseling Referral Form***—Helps referring providers share important patient data with the consulting RD. While all providers can use this form, Medicare requires a physician order for dietitian reimbursement for MNT.

Delivery System Design: Promoting evidence-based interventions in delivery of care

NKDEP's programmatic elements are informed by research conducted by the growing number of investigators working on the translation of clinical evidence to improved care in the community. Current Type 2 Translational Research funded by NIDDK and linked to NKDEP includes:

- Medication Intervention in Transitional Care to Optimize CKD Outcomes and Costs, University of Washington
- Decision Support Interventions to Improve Renal Replacement Therapy, Johns Hopkins Bloomberg School of Public Health
- Health Information Technology Enhanced for CKD in Safety-net Primary Care, University of California, San Francisco
- Navigating the Challenges of Chronic Kidney Disease, Cleveland Clinic
- Improving CKD Detection and Care in a High Risk Underserved Population, University of Texas Southwestern Medical Center at Dallas
- Improving Evidence-based Primary Care for Chronic Kidney Disease, State University of New York at Buffalo
- Multi-factorial Intervention to Slow Progression of Diabetic Kidney Disease, Duke University

Delivery System Design: Enhancing the role of non-physician providers in CKD

NKDEP recognizes that improvements in care for CKD patients often result from changes implemented by non-physician health professionals, such as registered nurses, nurse practitioners, and physician assistants (PAs). Because of the critical role that they play in delivering primary care, NKDEP aims to engage the non-physician professionals who regularly interact with CKD patients. NKDEP has focused the



past few years on meeting the needs of general practice RDs (see Decision Support section on page 11), and more recently has begun supporting CKD management and education by pharmacists.

In 2012, NKDEP convened a Pharmacy Working Group (PhWG) comprising government, academic, and community pharmacists to explore ways to increase pharmacists' knowledge in order to more effectively participate in the management of CKD patients. In addition to developing educational resources for pharmacists, the group will also provide tools to promote medication therapy management (MTM) in CKD patients.

Other potential allies in reaching high-risk populations are community health workers. NKDEP is developing resources to help community health workers such as promotores integrate CKD into their educational efforts (see page 5).

Decision Support: Educating PCPs about CKD care prior to referral

Early identification and management of CKD has been associated with improved outcomes and NKDEP encourages PCPs to take an active role in CKD screening, education, and management prior to referral to a nephrologist.

To support PCPs in this endeavor, NKDEP accepts invitations to present on CKD care at relevant professional conferences for primary care professionals and educators, and shares its materials at conference exhibit booths. NKDEP also creates educational resources that help “demystify” CKD and convey key scientific information. Resources include:

- **Quick Reference on UACR and GFR (Clinical reference sheet)**—Explains the two key tests, urine-albumin-to-creatinine ratio (UACR) and eGFR, used to diagnose and monitor CKD.
- **Nutritional Management of Chronic Kidney Disease (Webinar)**—A free continuing medical education webinar accredited by the American Academy of Family Physicians. Explains the importance of diet in the management of CKD, how to counsel patients with CKD, and the referral process and Medicare coverage of MNT. The webinar can be accessed at www.nkdep.nih.gov/nutrition.
- **Identify and Manage Patients (Web section)**—NKDEP redesigned its website to offer expanded, comprehensive content for health care providers on identifying, managing, and educating CKD patients.

Decision Support: Educating general practice RDs on nutrition for CKD

Dietary counseling is important to slowing the progression of CKD and treating complications. To equip general practice RDs to counsel patients with progressive CKD, NKDEP developed the [CKD Diet Initiative](#) (see box on page 12), which includes the following resources and tools:

- **Chronic Kidney Disease and Diet: Assessment, Management, and Treatment**—Guide includes background on CKD, as well as information on assessing kidney function and damage; slowing CKD progression; and preventing, monitoring, and treating complications. The guide is accompanied by a suite of English- and Spanish-language patient education materials on food label reading; kidney test results; and sodium, protein, phosphorous, and potassium intake.

- **Chronic Kidney Disease Nutrition Management**—Certificate training program designed with the Academy of Nutrition and Dietetics (the Academy) to prepare RDs for providing MNT to CKD patients who are not on dialysis. The program consists of a series of five modules that use engaging activities and case studies to provide in-depth information around a specific area of nutrition management for kidney disease patients, including a review of kidney anatomy, function, and disease; slowing the progression of CKD; CKD complications; the CKD “diet;” and the transition from CKD to kidney failure. The module content is free through the NKDEP website and is also available for continuing education credit through the Academy at www.eatright.org/cpd/online.

The Academy is currently surveying members who completed the training to evaluate the program, and sharing the data with NKDEP. The survey aims to assess the quality of the modules, measure their impact on reported dietitian behavior, and identify barriers to implementation of MNT.

NKDEP has developed [case studies and classroom materials](#) to support improvements in CKD training of dietetic students and interns. Presentations and webinars will be provided to dietetic educators and preceptors to enhance their use of these resources in their curricula.

Decision Support: Supporting use of UACR and eGFR

NKDEP provides clinical information and tools to providers to facilitate use of UACR and eGFR, including the Quick Reference on UACR and GFR. Additionally, its website features online and downloadable [GFR calculators](#), as well as information about benefits and limitations of eGFR. In 2011, NKDEP updated its calculators for use with creatinine methods calibrated to be isotope dilution mass spectrometry traceable. The calculators continue to be NKDEP’s most popular online tool.

***Clinical Information Systems:
Supporting changes in urine albumin
standardization and reporting with the
Laboratory Working Group (LWG)***

NKDEP collaborates with the clinical chemistry community to improve the laboratory assessment of CKD. NKDEP's LWG brings together clinical chemists, laboratory services providers, equipment manufacturers, and CKD experts to improve the accuracy of these tests and to ensure that test results are reported appropriately and consistently. The LWG coordinated the effort to standardize creatinine measurement and implement routine reporting of eGFR.

**SPOTLIGHT ON SUCCESS:
Supporting MNT for CKD**

Recognizing the critical role RDs play in enhancing CKD patient self-management, NKDEP conducted a series of roundtables with general practice RDs to better understand the needs and barriers for working with patients with progressive CKD. Through this research, NKDEP identified several opportunities to support RDs in caring for CKD patients and developed resources and tools to help RDs practice effective MNT, including a comprehensive [online training program](#), [clinical guide](#), and [patient factsheets](#). NKDEP collaborates closely with the Academy for dissemination and evaluation of the training program. The Academy promotes the training to its members and includes the materials in its *Nutrition Care Manual*. The training has received positive feedback in initial evaluation findings, and the materials have become NKDEP's most popular—with thousands of the diet factsheets downloaded and ordered each month. A RD who completed the training said,

“The training has been undoubtedly the best educational resource I have ever taken through the Academy of Nutrition and Dietetics. I have been a renal RD for over 25 years and really appreciate the information in these modules!”

Building on the success of the LWG's [Creatinine Standardization Program](#), NKDEP and the [International Federation of Clinical Chemistry and Laboratory Medicine](#) (IFCC) are collaborating to address urine albumin measurement and reporting issues. Lack of standardization in urine albumin measurement makes it difficult for providers to effectively use test results to inform treatment decisions and monitor patients' kidney health.⁸ NIDDK has funded several studies organized by the LWG to improve harmonization and standardization of the test, which will inform urine albumin standardization recommendations. These include:

- Serum Creatinine Method Specificity, IFCC Working Groups for Glomerular Filtration Rate Assessment
- Urine Albumin Method Harmonization Assessment, Virginia Commonwealth University
- Urine Albumin Reference Measurement Procedure, National Institute of Standards and Technology and Mayo Clinic
- Urine Albumin Reference Material, National Institute of Standards and Technology

***Clinical Information Systems:
Enabling and supporting the interoperability of
kidney health data with the Health Information
Technology Working Group (HITWG)***

In 2012, NKDEP created a HITWG to help enable and support the widespread interoperability of data related to kidney health among health care software applications to optimize CKD detection and management. This important effort aims to provide easy and uniform access to information that will enable researchers to better understand the burden of CKD, health care professionals to better care for CKD patients, and people with CKD to better manage their health. The initial focus will be on incorporating CKD measures into electronic health records (EHRs) in a consistent and searchable manner.



Supporting a Coordinated Federal Response to CKD

The Federal government commits significant resources to addressing the burden of kidney disease in the American population. A range of agencies play distinct and complementary roles, e.g., NIH supports basic and clinical research, Centers for Disease Control and Prevention maintains a [surveillance program](#), and CMS funds and oversees care provided to dialysis patients and other Medicare beneficiaries. Congress has mandated a [Kidney Interagency Coordinating Committee \(KICC\)](#) to encourage cooperation, communication, and collaboration among all Federal agencies involved in kidney research and other activities. NIDDK convenes KICC. Through KICC, NKDEP partners with its Federal counterparts to improve the programs, services, and information delivered to the public and the health care community.

NKDEP's Digital Ecosystem

A redesigned website (www.nkdep.nih.gov) launched in 2012 provides improved navigation, expanded web content for professionals, and plain language content for patients. NKDEP's social media platforms complement the web presence, informed by research that revealed that health professionals, patients, and the public actively discuss kidney disease via social media channels.⁹ NKDEP created a [Facebook page](#) to leverage use of Facebook by patients and the public to demonstrate knowledge about CKD and share personal stories. The page was

created for people affected by kidney disease and health champions to facilitate meaningful conversation and information exchange. Based on research showing that health professionals use Twitter to discuss kidney disease, NKDEP also created a Twitter handle ([@NarvaNKDEP](#)), managed by NKDEP Director Dr. Andrew Narva, which aims to generate conversation among PCPs about CKD.

Multifaceted Approach to Evaluation

NKDEP monitors use of its programs and activities and, when possible, examines increased knowledge and behavior change among its target audiences. NKDEP regularly analyzes print materials orders, website metrics, satisfaction surveys, and social media analytics to help determine if the Program is meeting the needs of its audiences and its activities are successful. NKDEP also works with partners to collect feedback on its initiatives and materials. In addition, partners share data collected on collaborative projects for program evaluation. For example, to measure the usefulness and impact of the [CKD Nutrition Management Certificate Training Program](#), the Academy is conducting a two-phase survey project with RDs who complete the certificate program. NKDEP analyzes the survey data to help inform development of additional resources for RDs and other health professionals.

NKDEP also builds impact evaluation into program development, implements pilot projects, fields surveys, and conducts large-scale evaluation for select projects. Currently, NKDEP is developing a pilot study of its new promotores training program with Hispanic audiences. The study will assess the effectiveness of the materials, training, and delivery of the program. It will also inform the development of evaluation methodology and instruments for national dissemination of the promotores program.

RECOGNIZING NKDEP PARTNERS

The following agencies and organizations are some of the groups with which NKDEP has worked over the past 10 years. These partners provide strategic input and assist NKDEP with materials testing and program implementation, substantially contributing to NKDEP's efforts. In addition, many of these organizations serve on [NKDEP's Coordinating Panel](#).

- Academy of Nutrition and Dietetics
 - Agency for Healthcare Research and Quality
 - American Academy of Family Physicians
 - American Academy of Nurse Practitioners
 - American Academy of Physician Assistants
 - American Association for Clinical Chemistry
 - American Association of Diabetes Educators
 - American Association of Kidney Patients
 - American College of Physicians
 - American Society of Nephrology
 - Association of Clinicians for the Underserved
 - Centers for Disease Control and Prevention
 - Centers for Medicare & Medicaid Services
 - Department of Defense/Veterans Affairs
 - Eunice Kennedy Shriver National Institute of Child Health and Human Development
 - Food and Drug Administration
 - Forum of ESRD Networks
 - Health Resources and Services Administration
 - HHS Office of the Assistant Secretary for Planning and Evaluation
 - Indian Health Service
 - Medical Education Institute, Inc.
 - National Diabetes Education Program
 - National Heart, Lung, and Blood Institute
 - National Kidney Foundation
 - National Kidney and Urologic Diseases Information Clearinghouse
 - National Medical Association
 - National Quality Forum
 - NephCure Foundation
 - Renal Physicians Association
 - Weight-control Information Network
- ### African American Outreach Partners
- American Kidney Fund
 - American Diabetes Association
 - Blackdoctor.org
 - Chi Eta Phi Nursing Sorority
 - Dallas Convention and Visitors Bureau
 - Detroit Metro Convention and Visitors Bureau
 - Hampton University
 - National Coalition of Pastors' Spouses
 - Norfolk State University
 - Urban Housecall Magazine
 - Visit Fairfax Convention and Visitors Bureau
- ### Hispanic Outreach Partners
- AARP
 - American Diabetes Association
 - CDC en Español
 - La Clínica del Pueblo
 - League of United Latin American Citizens
 - National Eye Institute
 - HHS Office of Minority Health
 - Visión y Compromiso
 - New York Presbyterian Hospital, WIN for Health

AWARDS

The following is a sample of recent NKDEP awards.

- National Health Information Award
 - *La Enfermedad de los Riñones: ¿Qué significa para mí?* (Chronic Kidney Disease: What Does It Mean for Me?), Silver Award (2012)
 - *High Blood Pressure and Children: What Parents Need to Know*, Bronze Award (2012)
 - *Make the Kidney Connection Outreach Video*, Merit Award (2012)
 - *NKDEP Website*, Web Health Merit Award (2012)
- NIH Plain Language Award
 - *Quick Reference on UACR and GFR*, Bronze Award (2009)
 - *For People with Diabetes and High Blood Pressure: Get Checked for Kidney Disease*, Silver Award (2010)
 - *Kidney Sundays: A Toolkit*, Silver Award (2010)
 - *Provider modeling web video series*, Bronze Award (2011)
 - *Chronic Kidney Disease: What Does It Mean For Me?*, Gold Award (2011)
- PRSA-NCC Thoth Awards — Kidney Sundays: Best in Show, Integrated Communications–Government, Multicultural Public Relations (2012)
- Health Improvement Institute’s Aesculapius Award of Excellence for health-related websites (2012)

References

1. Levey AS, Stevens LA, Schmid CH, et al. CKD-EPI (Chronic Kidney Disease Epidemiology Collaboration). A new equation to estimate glomerular filtration rate. *Annals of Internal Medicine.* 2009; 150(9): 604–612.
2. U.S. Renal Data System, National Institutes of Health, National Institute of Diabetes and Digestive and Kidney Diseases. USRDS 2012 Annual Data Report. Atlas of Chronic Kidney Disease and End-Stage Renal Disease in the United States, Bethesda, MD, 2012.
3. Narva A, Briggs M. The National Kidney Disease Education Program: improving understanding, detection, and management of CKD. *American Journal of Kidney Diseases.* 2009; 53(3) Supplement 3: S115–S120.
4. Wagner EH. Chronic disease management: what will it take to improve care for chronic illness? *Effective Clinical Practice.* 1998; 1(1): 2–4.
5. Funnell MM, Anderson R.M. Empowerment and self-management of diabetes. *Clinical Diabetes.* 2004; 22 (3): 123–127.
6. Rollnick S, Mason P, Butler C. *Health Behavior Change: A Guide for Practitioners.* Edinburgh, UK: Churchill Livingstone; 1999.
7. Wright Nunes J. Pilot study of a physician-delivered education tool to increase patient knowledge about CKD. *Advances in Chronic Kidney Disease.* 2013; 20(4): 370–378.
8. Miller G, Bruns D, Hortin G, et al. 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): 24–38.
9. Goldstein K, Briggs M, Oleynik V, et al. Using digital media to promote kidney disease education. *Advances in Chronic Kidney Disease.* 2013; 20(4): 364–369.

Future Directions

NKDEP will continue to use the CCM as a strategic model for organizing its efforts to translate new knowledge into improved outcomes. The Program will work to reduce health disparities through a focus on populations at highest risk for CKD, the providers who serve them, and the health care systems that enable quality care.

While sustaining the comprehensive outreach efforts and momentum it has built within the African American community, NKDEP will build a foundation with the Hispanic/Latino community, forging meaningful partnerships with organizations that can expand NKDEP efforts and reach within this important audience.

NKDEP will continue to develop and update materials and programs that foster prepared, proactive health care professionals and multidisciplinary teams. While sustaining efforts to grow and promote the CKD Diet Initiative, the Program will also build new training tools and materials for other health practitioners, including primary care providers, pharmacists, nurses, and diabetes educators.

Using lessons learned from the successful approach of the LWG, NKDEP is expanding its systems change initiatives to improve detection and management of CKD. Through the HITWG, NKDEP will promote use of health information technology to provide easy and uniform access to kidney health data to both patients and health care professionals.

NKDEP works to facilitate and encourage the adoption of evidence-based interventions among the public, health care professionals, and their health care systems. NIDDK is funding two important longitudinal cohort studies of CKD, Chronic Kidney Disease in Children Prospective Cohort Study (CKiD) and Chronic Renal Insufficiency Cohort (CRIC), as well as an expanding portfolio of type 2 translational research in CKD. NKDEP will work to disseminate and promote implementation of the findings from this research. As the research community develops new understanding about the delivery of care to CKD patients, NKDEP will refine its strategies, ensuring that its initiatives continue to reflect the NIH mission to turn discovery into health.

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For a complete list of NKDEP resources, visit
www.nkdep.nih.gov/resources.

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of Diabetes and Digestive and Kidney Diseases
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