



NKDEP

National Kidney Disease Education Program

Strategic Development & Planning Meeting

BASELINE REPORT

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Contents

1	Introduction
2	Kidney Disease and Its Consequences
4	Who Is at Risk?
5	The Human Burden
5	The Fiscal Burden
6	Evidence-Based Studies
8	Available Science-Based Guidelines
11	Public and Private Sector Support and Recommendations
12	Current Educational Programs as Models
16	Conclusion

The National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), National Institutes of Health (NIH), has initiated a National Kidney Disease Education Program (NKDEP). The program's goals are to slow the progression of kidney disease and its complications in people with early kidney impairment and prevent or slow the development of the disease in those at risk. Issues that drive the need for this education program include:

- Recognition of kidney disease as a major national health problem by Healthy People 2010.
- Striking racial disparities in the prevalence, morbidity, and mortality of kidney disease and the provision of optimal care.
- A steady, alarming growth in incidence of kidney disease, especially kidney failure, which has been doubling every 10 years.
- Rapidly growing numbers of people at risk.
- Cost to the Nation of these diseases.
- Consensus that some early stage indicators are available.
- Existence of science-based guidelines to slow progression of kidney disease.
- Pragmatic evidence that the best available practices for managing the disease are not being used uniformly.
- Support from both the public and private sectors for NKDEP.
- Success of other national education programs in preventing or managing diseases.

A major goal of Healthy People 2010 is to reduce new cases of chronic kidney disease and its complications, disability, death, and economic costs. According to the authors of the Healthy People 2010 kidney disease objectives, “[I]deally, programs should be directed at preventing the development of chronic renal insufficiency and its subsequent progression to ESRD.”

NIDDK responded to this call for a national education program on kidney disease by initiating NKDEP in the summer of 2000. NIDDK held a series of meetings to review the current state of kidney disease in the United States, optimal clinical practices, known risk factors and the populations at risk, evidence-based studies and available guidelines, and current national education program models.

Kidney Disease and Its Consequences

The kidneys serve many functions in the body. In addition to filtering waste from the blood, the kidneys regulate the body's level of chemicals such as sodium, phosphorus and potassium. The kidneys also release three hormones: erythropoietin, which stimulates the production of red blood cells; renin, which regulates blood pressure, and the active form of vitamin D, which helps maintain calcium for bones and for normal chemical balance in the body.

Kidney damage can happen quickly, but most often develops slowly and silently, often taking years or decades for the injury to become apparent. Gradual loss of kidney function is called chronic kidney disease. The major causes of kidney disease in adults are diabetes (both type 1 and type 2), hypertension, glomerulonephritis, and cystic diseases. In children, the major causes of kidney disease are congenital abnormalities of the kidneys, glomerulonephritis, and some hereditary diseases.

Kidney failure (also called end-stage renal disease or ESRD) occurs when kidney function drops below 10 to 15 percent and the patient requires dialysis or a transplant to survive. Diabetes and hypertension account for about 70 percent of kidney failure in adults. Some kidney ailments such as simple bladder and kidney infections seem to rarely, if ever, cause kidney failure by themselves. Furthermore, not all people with conditions such as diabetes will develop kidney failure. Thus, there are additional factors such as ethnic background and family history that influence risk. There are surely also other risk factors that are presently unknown.

Kidney disease can be detected through blood and urine tests that measure substances such as creatinine, urea nitrogen, and protein.

- **Serum Creatinine:** A measure of creatinine (waste product) in the blood that indicates the kidney's functioning ability. Creatinine levels in the blood can vary somewhat in people without CKD. In most labs, the normal serum creatinine range is 0.6 to 1.2 mg/dl.
- **Creatinine clearance:** A test to measure the rate at which the kidneys filter the blood, termed the glomerular filtration rate (GFR). It is determined by comparing creatinine in the blood to creatinine in the urine. For men, a normal creatinine clearance rate is 100 to 140 ml/min. For women, the normal rate is 90 to 130 ml/min. The kidneys are not filtering at full capacity if the number falls below this normal range.
- **Blood urea nitrogen (BUN):** A measure of the amount of urea (waste product) in the blood. Normal blood contains 7 to 20 mg of urea nitrogen per deciliter of blood. If the BUN is more than 20 mg/dl, the kidneys may not be working at full strength. Generally, creatinine and BUN change in parallel.
- **Proteinuria:** A measure of the amount of protein that is evident in the urine and is often a sign of CKD. Normally, healthy kidneys filter the blood but without appreciable protein leakage. Impaired kidneys often develop leaks in their filtering capillaries, allowing pro-

tein to appear in the urine. Small amounts of the protein albumin in the urine have been termed microalbuminuria and can be an early sign of CKD.

- Additional tests: Kidney imaging methods such as ultrasound, computed tomography (CAT scan) and magnetic resonance imaging (MRI), and kidney biopsy are often used to define certain kidney diseases.

Treatments to prevent kidney failure or slow the progression have improved over the last 10 years. There are several important examples of these advances in our treatments. First, we now know that blood sugar control can prevent diabetic kidney injury. Also, blood pressure control to levels somewhat lower than needed for ordinary hypertension can reduce further kidney damage in people with kidney injury and high blood pressure. The angiotensin-converting enzyme (ACE) inhibitor class of blood pressure drugs is especially beneficial in diminishing kidney deterioration. As a final example, dietary protein reduction seems to attenuate the decline in kidney function for people with kidney disease.

For people whose kidneys have completely failed, dialysis, either peritoneal dialysis or the more common hemodialysis, are effective in sustaining life. Peritoneal dialysis uses the lining of the abdomen to filter blood whereas hemodialysis uses a machine to filter the blood.

Some patients do well on these treatments and lead fulfilling lives. Many, however, remain limited in their daily functioning and some are quite debilitated even with adequate dialysis. Patients are often plagued by fatigue, anemia, bone disease, dietary restrictions, and infections of the blood and access areas. The annual mortality rate is about 20 percent for people on dialysis. Furthermore, the treatment is costly, about \$60,000 per year in total costs, and even though this cost is born largely by Medicare, the costs in time and disability are still large for essentially every patient.

Transplantation offers better quality of life for many but the number of transplants available is very low compared to the number of patients entering ESRD. In 2000, about 100,000 people developed ESRD but only about 14,000 transplants were done. Transplantation also is expensive and entails risks and morbidities for many, even with satisfactory replacement of kidney function.

Despite these advances in treatment and prevention, the evidence suggests that only a small fraction of people at serious risk or with established but early kidney disease are receiving proper screening or treatment. For example, only about one-third of patients who were discharged from a hospital with hypertension or diabetes and kidney injury were on the correct medication to treat their kidney disease.

Who Is at Risk?

NKDEP will address two major groups of people—those at risk for kidney disease and those with chronic kidney disease whose kidneys are still partially functioning.

Persons at risk include those who have:

- Type 1 and type 2 diabetes.
- High blood pressure.
- Proteinuria.
- Increased serum creatinine.
- Family members with chronic kidney disease (CKD).

A major concern of NKDEP is the growing incidence of kidney disease among some racial and ethnic groups. This is due in large part to an increase in the number of new cases of diabetes, particularly type 2 diabetes, in these populations.

- African Americans have a disproportionately high risk of chronic kidney disease.
- African Americans, American Indians, and Alaska Natives are four times more likely to develop kidney failure than are whites.
- Native Hawaiians and other Pacific Islanders are 1.5 times more likely to develop chronic kidney disease than are whites.
- Hispanics are two times as likely to develop kidney failure, largely due to diabetes.

The Human Burden

The United States Renal Data System (USRDS) 2000 *Annual Data Report* and the Third National Health and Nutrition Survey (NHANES III) report that:

- More than 8 million Americans have major reductions in kidney function.
- Nearly 400,000 Americans require dialysis or a kidney transplant to stay alive.
- New cases of kidney failure are increasing by 7 percent per year for African Americans, 10 percent per year for American Indians and Alaska Natives, and 11 percent per year for Native Hawaiians and other Pacific Islanders, compared to 6 percent per year for whites.
- Total number of patients with kidney failure is projected to rise to more than 660,000 patients by 2010.
- Less than 50 percent of patients with kidney failure receive pre-dialysis counseling and preparation.

The Fiscal Burden

In the 1972 Social Security Amendment (P.L. 92-603), the Federal Government assumed financial responsibility for the health care costs of dialysis and transplantation for patients with kidney failure through the Medicare/Medicaid program. The following expenditures are according to USRDS:

- Nearly \$18 billion was spent to treat patients with kidney failure in 1999.
- Medicare spending for kidney failure has been increasing at 5-10 percent per year, based primarily on growing numbers of patients.
- Total Medicare kidney failure program costs are projected to more than double in the next 10 years to more than \$28 billion by 2010.
- Kidney failure patients are less than 1 percent (0.6%) of the Medicare population but require approximately 6 percent of the expenditures.

Evidence-Based Studies

The body of evidence supporting the intervention and treatment strategies being considered by NKDEP comes from a variety of studies rather than from a single clinical trial. Numerous individual studies recommend blood sugar control, blood pressure control to lower levels than in primary hypertension without CKD, the use of an ACE inhibitor, early referral to a renal team and preparation for dialysis, and dietary protein restriction as effective strategies to treat people with CKD. Furthermore, several meta-analyses that aggregate many of these studies give further weight to the use of ACE inhibitors as well as dietary protein restriction. The formal review of these studies and their meta-analyses is beyond the scope of this report. Several pertinent NIH trials, both ongoing and finished are summarized briefly.

The NIDDK 1993 **Diabetes Control and Complications Trial** and the 1998 **United Kingdom Prospective Diabetes Study** reported that intensive glycemic control delays or prevents the development and progression of nephropathy in people with diabetes.

NIDDK's **African American Study of Kidney Disease and Hypertension** trial demonstrated that an ACE inhibitor or a beta blocker—rather than a calcium channel blocker (CCB)—is more likely to postpone kidney failure in people with kidney disease who have protein in their urine. CCBs tend to increase protein in urine. This trial supported the evidence of a 1993 **Collaborative Study Group**, conducted by E.J. Lewis et al. that showed that ACE inhibitors reduced the risk of

death, dialysis initiation, and transplant by one-half among diabetics with kidney disease who have protein in their urine compared to placebo.

The **Modification of Diet in Renal Disease (MDRD)** multi-center study tested whether protein restriction or lower-than-usual blood pressure goals would prevent progression of kidney disease in patients with moderate or severe kidney disease. The study found that only the lower blood pressure goal of 125/75 mm Hg protected the kidneys, and only in patients who had at least 1 gram of protein in a 24-hour urine sample. Protein restriction was not shown to be beneficial, but this concept is still under discussion with meta-analyses of several trials supporting a discernible but relatively modest benefit.

Other studies have shown that lowering blood pressure in people with diabetes also lowers proteinuria.

The **Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure (JNC 6)** recommends 130/85 mm Hg for people with diabetes and 125/75 mm Hg for patients with chronic kidney disease and greater than 1 gram/day of proteinuria.

In 1993, an NIH study on early intervention strategies with predialysis patients recommended that patients in predialysis should be referred to a renal team, risk factors for cardiovascular disease should be treated early, and vascular access should be placed at least 6 months before dialysis. The study showed that delayed referral and

treatment of risk factors and co-morbid conditions results in emergency dialysis, poor preparation for dialysis, and excessive hospitalization as well as poorer quality of life and outcome.

Ongoing studies funded by NIDDK include the Family Investigation of Nephropathy and Diabetes (FIND) study to identify genetic loci and ultimately genes that influence susceptibility to and severity of diabetic nephropathy in Caucasian, African American, Hispanic and Native American populations in the United States. An ACE inhibitor intervention is being conducted with Pima Indians in Arizona to study its effectiveness in slowing progression of advanced diabetic kidney disease. Another Pima Indian randomized, double-blind, control trial is investigating whether blockade of renin-angiotensin

system can prevent or attenuate development and progression of early diabetic kidney disease.

The Prospective Cohort Study of Chronic Renal Insufficiency is an NIDDK 2001 initiative intended to provide new information on the risk factors for progression to kidney failure and the incidence and risk factors for cardiovascular disease in persons with chronic kidney disease and mild to moderately reduced kidney function. The study will examine patient, genetic, environmental, and health care utilization factors that indicate risk for rapid loss of kidney function in CKD patients. It will seek to include appropriate representation of women and minority groups. Approximately 50 percent of the study group will be people with diabetes, but patients with other causes of kidney disease will also be specifically recruited.

Available Science-Based Guidelines

NKDEP is fortunate to have science-based guidelines available and under development on which to base its messages to physicians and patients. Current prominent guidelines for optimal kidney disease health care practices are briefly described in this section.

Guidelines based on evidence and current professional knowledge assist practitioners and patients to make decisions about appropriate health care. They help improve medical practices and produce better health outcomes. They also help patients participate constructively in the management of their illness.

Unfortunately, compliance with guidelines for most diseases or disorders tends to be poor. This may be due to a lack of belief in and/or understanding of the guidelines, having too many guidelines, or limited doctor-patient time and encounters. Many times patients do not comply with physician referrals or recommendations. One of NKDEP's goals will be to provide physicians and patients with tools and strategies to reduce barriers to using science-based guidelines.

K/DOQI (Kidney Disease Outcome Quality Initiative) is sponsored by the National Kidney Foundation (NKF). NKF initially sponsored DOQI (Dialysis Outcome Quality Initiative) to develop guidelines for optimal dialysis practices. The evidence-based DOQI guidelines on hemodialysis, anemia management, vascular access, peritoneal dialysis, and nutrition are being incorporated into K/DOQI. K/DOQI is intended to cover treatment,

monitoring, and management of all stages of kidney disease and dysfunction. The goals of the first Work Group charged with developing guidelines were to:

- Standardize terminology of kidney disease.
- Classify stages of chronic kidney disease.
- Evaluate lab measurements.
- Associate level of kidney function with complications.
- Stratify risk for kidney failure and cardiovascular disease.

K/DOQI classifies five stages of kidney function using the glomerular filtration rate (GFR), indicating the ability of kidneys to filter, as a measure of kidney function. The guidelines will stress that patients and physicians “know their number” to understand their level of risk. A work group commencing in July 2001 will develop guidelines on optimal GFR and blood pressure for patients with chronic kidney disease and those at risk. Other work groups are reviewing clinical evidence and identifying evidence-based practices in bone metabolism and disease in chronic kidney disease and dyslipidemia in atherosclerotic cardiovascular disease among patients with kidney disease. Empirical evidence indicates that physician and patient compliance with the NKF guidelines is steadily improving. Further education should help to increase this trend.

NKF provides health care professionals with handbooks and quick reference tools to integrate the guidelines into the patient care process. For patients, NKF developed treatment and diet publications, translated the guidelines into easy-to-understand language, and created a log for the patients to track their important lab results. The www.kdoqi.org web site offers up-to-date patient and professional information.

The goal of the **RPA /ASN** (Renal Physicians Association/ American Society of Nephrology) clinical practice guidelines is to optimally prepare CKD patients—medically and psychosocially—for successful renal replacement. The project was initiated to respond to the alarmingly high morbidity and mortality associated with renal replacement therapy. The guidelines, called “Appropriate Preparation for Renal Replacement Therapy,” focus on potential interventions, including (1) management of anemia, (2) prevention and management of metabolic bone disease, (3) appropriate choice and timing of access for dialysis, (4) blood pressure control, (5) nutrition management, (6) management of lipid disorders, (7) appropriate timing for initiation of dialysis, and (8) patient preparation for dialysis from psychosocial, economic, and rehabilitation perspectives. In addition to the guidelines, the RPA plans to develop clinical performance measurements and implementation tools. While the RPA /ASN guidelines are focused on a narrower spectrum than the NKF’s K/DOQI guidelines, there are overlaps. The two groups are, therefore, coordinating their efforts to ensure consistent language in the guidelines.

JNC VI (Joint National Committee on Prevention, Detection, Evaluation, and Treatment of High Blood Pressure, 1997) guidelines, sponsored by the National Heart, Lung and Blood Institute, recommend:

- 130/85 mm Hg for diabetics and non-diabetics with chronic kidney disease and proteinuria <1 gram/day.
- 125/75 mm Hg for patients with chronic kidney disease and >1 gram/day of proteinuria.
- ACE inhibitors as best choice of antihypertensive drugs for people with diabetes and proteinuria and high blood pressure.

The **Veterans Health Administration/Department of Defense Clinical Practice Guideline for the Management of Chronic Kidney Disease and Pre-ESRD in the Primary Care Setting** was developed by the Veterans Health Administration of the U.S. Department of Veterans Affairs. Final approval is expected in 2001. These guidelines will provide a tool for primary care physicians to manage patients with chronic kidney disease. The goals of the guidelines are to:

- Identify patients at risk for progression of kidney disease or patients with reversible conditions.
- Promote the recognition of abnormal kidney function.
- Slow the progression of kidney disease.

- Prevent or treat metabolic, hematologic, and cardiovascular abnormalities.
- Describe the referral points to specialty care.
- Encourage the preparation of the patient for end-stage kidney disease (access) at an appropriate time.

For patients, the guidelines stress the importance of blood pressure control and other management techniques to slow the progression of their illness. In making patients aware at diagnosis of the possibility for dialysis in their future, the guidelines will help them better prepare for this event by understanding the means for and importance of early readiness for vascular access. The guideline stresses that primary care physicians inform chronic kidney disease patients at diagnosis of the need for regular forearm exercises to build up muscles and vein size in the non-dominant arm that will be used for arteriovenous (AV) fistula access, the preferred method, and the need to preserve the integrity of the veins in that arm by not having any needle punctures. Standards for AV-fistula access for hemodialysis were provided in a February 2001 letter from the Undersecretary. Information on the approved VHA guidelines will soon be on the Web. At the latest, patients should be referred for AV fistula surgery when the estimated eGFR is <20mL/min by Cockcroft formula in diabetics, and when eGFR is <15mL/min in nondiabetics. The guideline also recommends that on diagnosis of reduced kidney function, a patient should be referred to a nephrologist for an initial evaluation and recommendations.

The **Health Care Financing Administration's** ESRD Clinical Performance Measures (CPM) Project, which began in 1998, is based on NKF's DOQI and K/DOQI Clinical Practice Guidelines. HCFA was charged with developing and implementing a method to measure and report on the quality of kidney failure services under the Medicare program.

The **American Diabetes Association's** standards of care guidelines include screening for microalbumin, glycemic control, blood pressure goals, use of ACE inhibitors, and dietary protein restrictions under specific circumstances. ADA recommends:

- Annual test for the presence of microalbumin.
- For people with type 1 and type 2 diabetes, preprandial blood glucose (BG) of 80–120 mg/dL, bedtime BG of 100–140 mg/dL, and HbA1c <7%.
- Blood pressure < 130/80 for people with diabetes.
- ACE inhibitors for people with type 1 diabetes with microalbuminuria, even if they have normal blood pressure.
- ACE inhibitors for blood pressure control for people with type 2 diabetes if high blood pressure or microalbuminuria develops.

Public and Private Sector Support and Recommendations

Over the past 3 years, support and recommendations for a national kidney education program have come from several reports and meetings sponsored by public agencies and private organizations.

The NIDDK-sponsored **Kidney Disease Education Task Force** held a meeting on July 18, 2000, in Bethesda, Maryland, and made the following recommendations:

- Develop patient-centered messages that integrate strategies for reducing risk of chronic illness.
- Develop outreach programs for high-risk minority populations.
- Develop new guidelines as appropriate.
- Develop performance measures to track implementation of guidelines and methods to assess the effectiveness of outreach activities.
- Develop science-based criteria to assess NKDEP.

An Expanded Public-Private Partnership To Improve Management of Renal Disease: A Feasibility Study Prepared for the National Kidney Foundation (March 5, 1999) was prepared by Van Scoyoc Associates of Washington, D.C., for the National Kidney Foundation and other Council of American Kidney Societies (CAKS)

members. The study was initiated because members believed kidney disease patients, including those who are asymptomatic, were not benefiting from the available, high-quality science in the kidney disease field. CAKS believes there is strong science-based evidence that specific medical interventions such as measurement of proteinuria, microalbuminuria, and serum creatinine can lessen the human and fiscal cost for patients and the Federal Government. They recommended that a program be designed to translate findings to physicians, patients, and the general public.

The **Renal Disease Research Plan, Progress and Priorities**, is a report from two Strategic Planning Conferences, December 5–6, 1998 and February 4–5, 1999, sponsored by NIDDK and CAKS. The consensus of more than 100 researchers at this meeting was that a kidney disease education program was needed. They stated, “Despite the complexity of renal disease and the many remaining research and treatment challenges, there is evidence that the public and many medical professionals are unaware of important management tools now available that may prevent the progression of kidney disease.” Meeting participants agreed that patient and physician education is vital to bridge the gap between what is known and what is practiced.

Current Educational Programs as Models

NKDEP will have the advantage of lessons learned by current successful national education programs. Following on the heels of these programs, it will create its own niche with evidence-based messages designed to reach its target audiences. Like its models, NKDEP will effectively:

- Raise awareness of kidney disease and its risk factors.
- Create changes in behavior of both professionals and the lay public.
- Prevent or slow the progression of kidney disease and its complications.
- Improve treatment practices and patients' self-management of kidney diseases and its comorbidities.
- Improve quality and years of life.
- Foster evidence-based research studies, laboratory standardization, and use of consensus guidelines.

Like NKDEP, the following factors were the impetus for the **National High Blood Pressure Education Program (NHBPEP)**, the **National Cholesterol Education Program (NCEP)**, and the **National Diabetes Education Program (NDEP)**:

- Evidence of a public health problem with high human and fiscal burden.
- Proof that an effective intervention exists.
- Recognition of a lack of compliance with effective interventions.

Major factors in the success of these programs have been the strong commitment of public and private partners to the goals of the program, partner input in the planning of program messages and activities, and their dedication of resources to the program.

National High Blood Pressure Education Program (NHBPEP), sponsored by the National Heart, Lung, and Blood Institute (NHLBI), was established in 1972 to reduce death and disability related to high blood pressure and to assist in achieving heart disease and stroke objectives of Healthy People initiatives. Through its media campaigns, publications, Web site and technical assistance to health professionals, NHBPEP has successfully improved public awareness and knowledge of this

“silent” illness. In 1972, less than 25% of the population was aware of the relationship between high blood pressure and stroke and heart disease; today more than 75% do. More Americans regularly have their blood pressure checked and more persons who have high blood pressure are on medication to treat it. As a result, national blood pressure measurements decreased by 10 mm Hg systolic pressure and 5 mm Hg diastolic pressure from 1960 to 1991. The program has successfully helped to lower the death rate from cardiovascular disease and stroke by nearly 53% and 60%, respectively. This decline is evident in men, women, whites, and African Americans.

National Cholesterol Education Program (NCEP)

was initiated by NHLBI in November 1985 to reduce illness and death from coronary heart disease in the United States by reducing the percentage of Americans with high blood cholesterol. NCEP has helped the public reduce their intake of saturated and total fat and reduce their blood cholesterol levels. NCEP guidelines for blood detection and treatment have become established practice. More physicians have initiated diet and drug treatment with their patients at much lower cholesterol levels. The percentage of the population who has had their blood cholesterol checked rose from 35% to 75% from 1983 to 1985. Death from coronary heart disease has also declined.

National Diabetes Education Program (NDEP),

sponsored by NIDDK and the Centers for Disease Control and Prevention, was established in 1997 as a result of findings from the 1993 Diabetes Control and Complications Trial that definitively showed that lowering blood glucose levels can delay or prevent the complications of diabetes. The program’s purpose is to improve the treatment and outcomes for people with diabetes, to promote early diagnosis, and, ultimately, to prevent the onset of diabetes. The program uses a multi-component approach that includes public awareness and education campaigns, special population approaches, community based interventions, and health systems changes. NDEP has developed a series of diabetes awareness campaigns targeting general audiences and the racial and ethnic populations disproportionately affected by the disease. It also develops patient and professional education materials, tools and resources for community organizations to conduct diabetes activities, and materials for payers and purchasers of health care. Much of its success with grassroots activities is based on its strong network of over 200 public-private partnerships, which are actively involved in all levels of program development, including planning, implementation, and evaluation.

Related Kidney Education Programs

NKDEP intends to complement and supplement, not duplicate, existing educational efforts. The new program will collaborate with existing kidney education programs and related educational programs to ensure that consistent messages are presented.

NIDDK's **National Kidney and Urologic Diseases Information Clearinghouse** (NKUDIC) has been answering inquiries and providing free print and on-line educational materials to patients, their families, health care professionals, and the general public since receiving Congressional authorization in 1987. The NKUDIC toll-free phone line is 1-800-891-5390 and the e-mail address is ndic@info.niddk.nih.gov. NKUDIC works with a coordinating panel of representatives from Federal agencies; voluntary organizations on the national, regional, and local levels; professional groups; and State health departments to identify and respond to informational needs about kidney and urologic diseases. NKUDIC also exhibits at national meetings of kidney and urologic organizations and maintains the kidney and urologic diseases subfile of the **Combined Health Information Database** (CHID), a bibliographic database of health education materials produced by health-related agencies of the Federal Government. CHID includes fact sheets, brochures, and audiovisual materials for patients and health care professionals.

The **National Kidney Foundation** (NKF) sponsors a number of educational efforts. These include books, brochures, quarterly newsletters, slides, audiocassettes and videos for patients and professionals; national programs including live and video-based courses for people with chronic kidney disease and their families who may soon need treatment for kidney failure; rehabilitation programs; school-based programs; grassroots activities through their local affiliates; and extensive information on the Internet. All patients are offered free membership in the Patient and Family Council, which provides access to information and a voice in program development. Information and programs have been specifically developed for and by high-risk populations and include several brochures for Hispanics, African Americans and American Indians. Local outreach programs have taken place in schools, churches, hair dressing salons, community centers, and at regional conferences. NKF publishes *Minority Outreach Update*, a newsletter of success stories from local groups.

The National Kidney Foundation's **Kidney Early Evaluation Program** (KEEP) is a health screening program designed to identify populations at higher risk of developing kidney disease due primarily to hypertension and diabetes. Blood and urine testing, consultation by a physician, referrals, and additional followup are provided to screening participants. Participants are also given information to share with their physicians. Currently, approximately 60 percent have followed up with a physician. Screenings are conducted in a variety of settings. A KEEP survey of physicians' knowledge regarding creatinine levels and GFRs indicated a wide variation in their

perception of patients at risk. Plans are underway for another version of KEEP that will be conducted as a 3- to 5-year cohort study. Individuals will receive long-term followup (annual screenings provided at no cost and additional followup as recommended) to monitor their condition and treatment over time. Additionally, a database of physicians who are treating these participants will be developed and recommendations from the K/DOQI (Kidney Disease Outcomes Quality Initiatives) Clinical Practice Guidelines for Chronic Kidney Disease will be provided to assist physicians in the management of these patients. NKF strongly supports further education among health care professionals, patients, and those at risk.

The **MOTTEP**, Minority Organ and Tissue Transplant Educational Program, was established in 1995 and is sponsored by NIDDK and the National Center on Minority Health Disparities (NCMHD) (formerly the Office of Minority Health). Its goals are to encourage healthier lifestyles to prevent kidney diseases and kidney failure, and to increase organ and tissue donation among racial and ethnic minorities. Since its inception, MOTTEP has contributed to the observed national trends of increased minority organ and tissue donation, an important advancement since African Americans, who make up 12.6 percent of the general population but 29.8 percent of patients with ESRD, are less likely to receive needed transplants.

The **Medicare Disease Surveillance System** was developed by the Health Care Financing Administration (HCFA) to use existing resources to improve pre-kidney failure care. Currently five hospitals voluntarily participate. Peer Review Organization (PRO) staff abstract and analyze hospital charts of randomly selected patients with

either diabetes or high blood pressure on use of ACE inhibitors and other recommended interventions and provide feedback and educational materials to the doctors and hospitals for their continuing quality initiative (CQI) programs. The system has enabled HCFA to improve quality of care in some areas where it was needed in both inpatient and outpatient settings. Personal contact with the physicians to provide feedback and informative materials helped increase performance and compliance with recommended interventions.

In March 2001, Baxter Healthcare Corporation, in partnership with the American Association of Kidney Patients, initiated the **Stay in Touch™** education initiative for persons at risk for or diagnosed with kidney disease. The goal of Baxter's programs is to help people make informed decisions about their care by better understanding their disease and treatment options. The multi-faceted program offers assistance from nurse educators, an Internet-based tool, a toll-free hotline, and customized patient education mailings timed to a patient's progressive needs. The company also offers on-line information and links to other resources through its kidney.directions.com web site. Baxter is gathering data to demonstrate the fiscal benefits of early treatment of kidney disease. Its early intervention program for patients with kidney failure has resulted in a decrease in number of emergency room visits and hospital days. Baxter is currently working on a similar program for patients with chronic kidney disease.

AMGEN's on-line **Patient Center** (www.amgen.com) provides information on AMGEN-sponsored clinical trials, financial assistance programs, relevant medications, and links to other resources. Its renal advances Web site

(www.renaladvances.com/resources), designed to meet the growing informational needs of anemia managers and other nephrology professionals, offers a K/DOQI Guidelines library, patient materials, and links to professional resources such as publications, bulletin boards, continuing education, national and international associations, a calendar of nephrology events, and disease-specific resources.

Ortho-Biotech, Inc., a Johnson and Johnson company, has two Web sites that provide patients and health care professionals with information on anemia and kidney disease. The www.4anemia.com site includes a fact sheet on kidney disease basics and treating anemia with recombinant human erythropoietin therapy. The www.procrit.com site discusses kidney disease, especially related to diabetes and high blood pressure, and provides patients with a printable anemia self-assessment questionnaire and a monthly energy calendar to complete and take to the patient's doctor. There is also a list of questions to ask the doctor. The professionals-only portion of the PROCIT® site provides physicians with medication information, reimbursement information and assistance, a list of upcoming events, and answers to patients' most frequently asked questions. Patient educational materials will soon be available to professionals for downloading. Both sites give addresses and links to other resources.

Conclusion

The NKDEP was developed in response to compelling evidence that kidney disease will continue to increase in prevalence and incidence, that effective interventions exist but are not being readily utilized, and that education programs can make a difference in improving morbidity and mortality. The program should become a major step in closing the gap between current and desired kidney disease care and practices. With the support of both public and private sectors, NKDEP is ready to meet the challenge of implementing a program so that it truly makes a difference for people with kidney disease.

