

National Kidney Disease Education Program

Steering Committee Meeting

Summary of Meeting – April 26, 2002

Appendix A Attendees

Appendix B Acronyms

I. Welcome, Introductions, and Purpose of the Meeting/Dr. Hostetter

After all participants introduced themselves, Dr. Hostetter reviewed the objectives of the National Kidney Disease Education Program (NKDEP), a project of the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK), which are to increase awareness and treatment of people at risk and with chronic kidney disease (CKD) and to decrease the incidence of end-stage renal disease (ESRD). The long-term objective of decreasing the incidence of ESRD is a national health goal, as defined in *Healthy People 2010*. The purposes of this meeting included reviewing NKDEP goals, decisions, and activities; discussing research regarding and planning for the use of media; receiving updates from Steering Committee members; receiving and discussing three workgroup reports; and obtaining advice from the Steering Committee.

Target audiences for the first NKDEP initiative are African Americans, who are disproportionately affected by kidney disease, especially those with CKD, diabetes, hypertension, or a relative with ESRD. Most findings of the NKDEP will be applicable to other racial/ethnic groups. NKDEP hopes to reach primary care providers to assist in developing messages about how to approach individuals at risk, in part because there are not enough nephrologists to care for this at-risk group.

The four pilot sites, Jackson, Mississippi, Atlanta, Georgia, Baltimore, Maryland, and Cleveland, Ohio, have been chosen to ascertain whether the NKDEP approach is effective. After evaluating results from the pilot sites and modifying the NKDEP approach as necessary, the program will be used more widely. The sites were chosen because they have large African-American populations; a high incidence of hypertension, diabetes, and ESRD; and an infrastructure to help NKDEP implement plans. For example, the Jackson Heart Study sponsored by the National Heart, Lung, and Blood Institute (NHLBI), an active chapter of the National Kidney Foundation (NKF), and existing research programs such as the African American Study of Kidney Disease and Hypertension (AASK) and the Chronic Renal Insufficiency Cohort (CRIC).

At all four pilot sites, NKDEP staff hopes to develop coalitions of partners.

Pilot site objectives are to form coalitions in each city (which has already begun), to disseminate messages, and to test materials and intervention strategies in order to ascertain the most effective education methods that will strengthen the program as it becomes a national endeavor.

The partnership network will be composed of representatives from non-profit voluntary and professional associations with an interest in the relevant patient population; common interests of network members will facilitate carrying the message to the target audiences.

Three workgroups are currently active. The Patient/At-risk Workgroup met in January to discuss specific messages and how to deliver them. The Evaluation Workgroup developed objectives for the NKDEP Program and the pilot sites and is discussing how to evaluate the program, first creating a baseline for individuals and providers. The Professional Workgroup will be meeting in July 2002 and has already held several conference calls; they will develop simple messages for primary care providers (PCPs), drawing from evidence-based literature.

II. Overview of NKDEP: Progress/Ms. Lising

Ms. Lising reviewed NKDEP activities for the past 6 months and discussed future plans .

In Fall 2001, the NKDEP staff collected data about the incidence and prevalence of kidney disease in the United States and about existing CKD programs and educational materials and began considering target populations. NKF briefed NKDEP staff about the Kidney Disease Outcomes Quality Initiative (K/DOQI) education campaign. Pilot sites were selected as described above.

Progress during the winter of 2002 has included conducting a focus group with Indian Health Service PCPs. Long-term and pilot site objectives have been developed based on a comprehensive behavioral change model, which identifies various factors to consider as NKDEP evolves. Staff reviewed the recent medical and social sciences literature on African Americans and kidney disease to help us understand the knowledge, attitudes, and practices of this population.

Wave I focus groups were conducted with at-risk African Americans in Baltimore. Phone focus groups with ESRD patients and family members from the pilot sites helped determine that whether ESRD patients might be an appropriate channel for would be interested in delivering information to families and to others who are at risk for kidney disease. Outreach efforts include a new exhibit and web site for NKDEP; Ms. Lising presented the 2002 exhibit schedule. An announcement will be made to the Steering Committee when the website goes live, and the website promotion plan will be implemented. A literature review has been conducted to help us understand the knowledge, attitudes, and practices of PCPs.

Plans for Spring 2002 include 20 in-depth interviews with PCPs.

Summer 2002 plans include (1) a meeting with national and local plans/payers to share progress and plans, to garner support, and to enlist partners; (2) wave II focus groups in Cleveland,

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Atlanta, and Jackson to test messages; (3) strengthening partnerships; (4) developing materials; and (5) conducting a national baseline survey of about 2,000 people, weighted heavily with minorities.

During the Fall of 2002, we plan to pretest materials at the American Association of Kidney Patients (AAKP), meet with pilot site coalition members, and launch the NKDEP media campaign in Washington, D.C., with data from the national baseline survey. We are scheduled to launch campaigns in pilot sites and various media activities during the Winter of 2003. The national campaign will be launched in March 2004.

III. Overview of NKDEP: Compendium/Ms. Payne

Ms. Payne explained that the CKD Compendium identifies print and online resources for patients and professionals, including education programs, guidelines, and a directory of organizations. Ms. Payne thanked the Steering Committee for their assistance and useful feedback and encouraged continuing comments about this evolving document.

IV. Formative Research/Dr. Melcher

Dr. Melcher discussed the formative research being conducted to develop messages and media campaigns that will be tested at the four pilot sites. The initial target audience is African Americans who have hypertension, diabetes, or a family member with ESRD.

The formative research has included an extensive review of studies published in the social sciences and medical literature about the knowledge, attitudes, and behaviors of African Americans related to kidney disease, and the general cultural beliefs and practices of African Americans. Scant information was available about African Americans and kidney disease. Key findings of the literature review were not surprising:

- Dietary practices contribute to illness incidence — fried, high-fat, and salty foods and generally poor diet lead to hypertension and contribute to diabetes and difficulty in managing those illnesses. This finding was confirmed with the healthcare provider interviews, in which it was found that hypertension was managed better because it merely involved taking a pill rather than significantly altering one's diet.
- Obesity tends to be more tolerated among African Americans.
- Socioeconomic and environmental factors are barriers to health care. Socioeconomic status (rather than race) may be the main cause of progression to kidney disease, accounting for such factors as lack of health insurance, food preferences, paucity of grocery stores nearby, and lack of transportation to health care.
- Disease understanding may impact preventive behaviors. Focus groups showed that there is no real disease model; individuals do not know much about kidney disease.
- Lack of symptoms encourages inaction, and African Americans tend to be more focused on their present situation rather than the future.
- Spirituality and religion play a central role in the lives of African Americans. Some churches attempt to provide health care through church nurses and outreach; however, such services were not discussed in the focus groups.

Six focus groups comprised the first wave of this portion of the formative research. The goal of these focus groups was to obtain a better understanding of what people know about kidney disease; the second wave of focus groups will test for understanding and response to proposed message concepts. Wave I focus groups included African Americans in Baltimore who have had hypertension and diabetes for at least two years and who are managing their disease. In addition, focus groups were conducted with two groups each of patients with ESRD (via phone from all four pilot sites) and with family members of ESRD patients.

Key findings of the focus group research with people at risk for kidney disease were that:

- Knowledge about kidney disease, symptoms, causes, seriousness, and who should be tested is low.
- Doctors are regarded as important sources of health information, although an individual's relationship with a doctor is not always positive. Individuals generally took information from doctors and then decided what to do with that information.

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- Fear appeals were regarded as effective. Preliminary messages were tested to identify which were most compelling, and the preferred message was based on fear. Although lacking a self-efficacy component, the preferred message read: Kidney disease is a serious illness. Left undiagnosed and untreated, it can lead to kidney failure. When your kidneys fail, you cannot live without dialysis or a kidney transplant. Kidney failure can seriously hurt your ability to work and lead a productive life.
- Different messengers can provide different messages.
- The major task will be to raise people's knowledge and awareness, keeping in mind that African Americans may be sensitive about being targeted.

Key findings of the focus group research with family members of ESRD patients were that:

- There is little understanding of what causes kidney disease and that fact that there are no symptoms.
- Kidney disease was perceived as being as serious as AIDS.
- Most family members had not been tested for kidney disease.
- Doctors are considered an important source of health information.

Key findings of the focus group research with ESRD patients were that:

- Few knew they had CKD before going on dialysis.
- There was no awareness of the seriousness of CKD and the symptoms were not understood.
- Most wished someone had told them ahead of time about how serious ESRD would be.
- Some individuals had a sense of fatalism about their future.
- Most seemed willing to provide information about kidney disease to family members and others.

Focus groups were limited The focus group was limited to people who made no more than \$75,000. Participant ages ranged from 20 to 60 in the at-risk group and, in the patient groups, the youngest focus group participants were in their mid-20s. Overall findings from the focus groups indicated that African Americans may be becoming weary of being told something was wrong with them. The lesson to be learned here is that individuals and groups should be addressed as being at risk because of hypertension or diabetes, not because they are African American. Cultural appropriateness should be achieved in other ways that are not so blatant.

Dr. Melcher offered to provide the complete focus group report to participants. Key findings from the focus groups were distributed at the meeting.

Formative research for health care providers, the other primary target audience, included both a literature review and 23 20-minute in-depth telephone interviews. Key findings were that:

- Screening and treatment could be improved for CKD. Patients may not know for what they are being tested.
- Guidelines are understood but not always followed.

- Race is not regarded as a primary risk factor; PCPs may know that race is a risk factor but may not be saying so.
- PCPs would like more materials. Examples of materials desired included posters, videos, and/or brochures to give to patients to take home; few or none are currently available. Break-apart models might help to show patients exactly what they are facing. Flowcharts are well used by at least some physicians.
- Buy-in from physicians is critical. PCPs are weary of feeling like they have to do everything, and being told so by a national education program feels like a threat to their credibility. It will be critical to include PCPs as partners to ensure the success of the NKDEP.

V. Discussion

The following issues, concerns, and questions were raised during the discussion that followed the above presentations:

- It may be important to segment/stratify focus groups even more, because subgroups issues may be totally different. However, additional stratification may not be necessary because everyone's knowledge level is so low.
- The lower end of the SES spectrum should be targeted, for instance people who do not have telephones or doctors. Federal dollars should be used where industry or nonprofit organizations are least likely to reach.
- The fear message is irrelevant for young black males because threats from their environment are much greater than the threat of kidney disease. Some young black men do not think they will live past 25 years of age.
- Even in higher income groups, there is little knowledge about kidney disease; it is important to remember those audiences as well.
- Do not discount directly dealing with African Americans. For example, a breast cancer workbook for African-American women published in Philadelphia was quite successful. Some focus group participants did say they paid more attention when they saw a reference to African American.
- It is often the woman who is the nurturer and the disseminator of information.
- If the goal is to discover whether education will change outcome, NKDEP should target populations where available means of communication can potentially succeed. Some groups may be important to reach but may not be reachable by the methods at hand, which might force a (specious) conclusion that education does not work.
- Researchers were surprised by the importance of the role of physicians providing information because other surveys have indicated a mistrust of the medical community within lower SES groups.
- If scare tactics are used in educating people, physicians will face an increasing resistance from their patients to go on dialysis. Many patients equate dialysis with slow death.
- A sense of fatalism may keep people from being tested for kidney disease. There exists a strong sense that kidney disease runs in the family and that, therefore, there is nothing the individual can do to prevent its occurrence or progression.

- Concern about loss of employment or promotion or being dropped from one's health insurance because of a kidney disease diagnosis did not emerge as a reason for not being tested for kidney disease, although the focus group researchers did not probe specifically for that reason.

VI. Roundtable Reports From Steering Committee Members and Discussion

A. Indian Health Service/Dr. Narva

Dr. Narva explained that the prevalence of diabetes mellitus in Indian populations is 2.8 times the rate of Caucasians. The ESRD incidence rate for Indians in general is 3.1 times the Caucasian rate; however, Southwest American Indians ESRD incidence rate is 6.2 times the Caucasian rate. Dr. Narva summarized the public health model of the Indian Health Service (IHS), which is an integrated healthcare system in which the community is the patient; clinics are multidisciplinary; community outreach includes direct care, screening, and patient education; and health educators, nutritionists, and social workers are part of the usual care. The mission of the IHS is to improve the health status of American Indians.

A focus group was held with 10 IHS physicians and 1 facilitator; the physicians were medical directors and all were PCPs as family practitioners, internists, pediatricians, and psychiatrists. The purpose of this focus group was to determine IHS physicians' interest in kidney disease. The following results were reached from this focus group.

- *General issues.* Kidney disease was the preferred term; renal insufficiency was deemed not descriptive enough. Twenty percent of the American Indian population had kidney disease and 50 percent are at risk.
- *Kidney disease screening.* General (broad) screening was questioned due to lack of resources. Aggressive surveillance of high-risk subpopulations is preferred — individuals with diabetes, hypertension, and relevant family history. Screening is conducted using urinalysis, creatinine, blood urea nitrogen (BUN) level, and urine albumin.
- *Treatment.* Angiotensin-converting enzyme (ACE) inhibitors are utilized as initial treatment for kidney disease. Lowering blood pressure is the first line of treatment, and treating above-normal lipid levels is also important. The PCPs in this group appeared to possess inadequate knowledge about nutrition interventions. Clinical clues for PCPs to intervene or refer are the patient's inability to control blood pressure and a rising creatinine level. Kidney disease is asymptomatic until the level of injury is high, a condition that is problematic to communicate to patients who say they do not feel sick.
- *Referral.* Availability and relationship with a nephrologist is key, including 24-hour telephone access. Nephrologists and PCPs should work cooperatively and should respect each other's expertise.
- *Patient knowledge.* The patients of IHS physicians know little about kidney disease and need to understand that the disease and its outcome are modifiable. The focus group PCPs did not support the fear approach to patient education and noted that multiple professionals are needed to educate their patients, using small chunks of information and a varied approach to the same message. The fear and loathing of kidney disease is evident not only in patients; physicians also need to deal with these feelings.

- *Information and education resources needed.* PCPs in this focus group stated that, for patients, resources should be culturally appropriate materials that can be taken home and discussed with family members; the use of video was endorsed strongly, especially for patients who do not read well. For physicians, resources desired are a computer disk with updated handouts that could be produced as needed, simple guidelines, and information about effective ways to motivate patients.

B. American Society of Pediatric Nephrology/Dr. Kaskel

Dr. Kaskel, president of the American Society of Pediatric Nephrology (ASPN), noted that the ASPN concentrates on kidney disease in children. Many diseases have their antecedents in childhood and there is an epidemic of hypertension, diabetes mellitus, and obesity in adolescent and preadolescent populations.

A longitudinal cohort study is currently being conducted of at-risk pregnant women to search out neonates at risk to develop diseases at various points in the first 20 years of life. A study group of this National Children's Study met in Washington, D.C., recently regarding early markers for adult disease. Approximately 100,000 participants will enter this study; participants will be followed for 20 years.

The Task Force on CKD in Children met last week to talk about CKD in children. Currently, no longitudinal studies exist for children at risk for CKD, but such children should be entered into a registry and followed. Cardiovascular disease (CVD) in children with CKD is a major comorbid event; early evidence suggests early vessel abnormalities, well before the need for dialysis or transplant. This Task Force comprised of many of the same groups that are represented on the NKDEP Steering Committee is developing a screening program that will assist in obtaining information about kidney disease in children; partnerships will be developed with the American Academy of Pediatrics and with pediatric urology colleagues.

C. American Association of Kidney Patients/Ms. Robinson

Ms. Robinson began her involvement with kidney disease education as a pediatric patient. The AAKP has been developing and implementing CKD programs in the renal field for the past 5 years, including an electronic newsletter on hypertension, diabetes, and kidney disease that contains information for physicians and advancements and studies in the medical community. A CKD section has been added to the AAKP web site, including a Dear Doctor section, a glossary of terms, downloadable tools to keep track of medications and blood values, and programs occurring within the renal community.

A program traveling around the country is *Kidney Care: Finding Your Strength*, in which a nephrologist talks about kidney disease in general, the function of the kidneys, and how to slow progression of kidney disease; dieticians and nurses are also featured. So far, five of these programs have been conducted in partnership with Ortho Biotech Products, L.P.

Other education events include a CKD track at the AAKP's annual conference for patients who are already diagnosed with CKD and, coming out in the fall of 2002, a book and newsletter for

individuals with CKD who are 1.5 to 2 years from starting dialysis. Included will be information about slowing progression of the disease, targeted to people outside the renal community.

The AAKP Patient Plan is designed to address questions and concerns at various phases of the disease process, with educational materials that address 1) diagnosis to treatment choice, 2) access and initiation, 3) stabilization, and 4) ongoing treatment. The AAKP Patient Plan has three major components: Patient/Caregiver Check Lists, Phase Books, and Phase Newsletters. Each phase includes a book of educational materials and checklists as well as a phase newsletter containing information related to the specific kidney disease stage. By partnering with various programs, AAKP has distributed 10,000 of these Plans to date.

Ms. Robinson noted that the AAKP has discovered that one of the most effective ways to reach out to individuals with kidney disease is to utilize family members.

D. National Kidney Foundation/Ms. Politoski

Ms. Politoski stated that the NKF is preparing for the national launch of new CKD guidelines and is identifying core implementation programs. The NKF is also about to launch a K/DOQI Learning System that will chart the stages of kidney disease, supported by different publications.

February 5, 2002, was the launch date of the CKD guidelines; full attendance at the press briefing resulted in 33 million media impressions. Since then, another 2.5 million media impressions have occurred. The *American Journal of Kidney Disease* version of the CKD guidelines will include packaged core implementation programs. Corporate partners have helped support a specially designed caddy that includes the executive summary of the CKD guidelines, the full text of the CKD guidelines, the Quick Reference Clinical Handbook for the Evaluation, Classification and Stratification of CKD, a patient education booklet, a full-size flowchart poster, and a pocket chart on CKD. Currently, a PDA application of all these resources is being pilot-tested.

Many clinical action plans have resulted from the Kidney Early Evaluation Program (KEEP), of which 28 have been pilot-tested. These are being adjusted and eventually will be sent to doctors who have KEEP patients. Approximately 160 KEEP programs have been conducted and about 8,000 people have gone through the program, almost 80 percent of whom have at least one kidney-related value outside normal. From the 8,000 KEEP participants, approximately 6,000 physicians have been identified. These physicians could eventually become teachers. KEEP is providing an extremely rich data set.

Public education campaigns include the following activities:

- Shawn Elliott and Alonzo Mourning have become involved in developing messages. Major activities will be launched the end of the summer or beginning of the fall (2002). Posters, ad slicks, and audio conferencing will focus on people who have been touched by kidney disease. Mr. Mourning is interested in working with school-age children, who can then discuss with family members the risks for kidney disease.

- NKF met with *Woman s Day* magazine to pitch a story for the July issue, with a side bar promoting KEEP screening. In March 2003, the magazine will publish an article on the impact of the July 2002 article on their readers.
- The NKF is about to announce the 16 pilot sites for the KEEP 3.0 longitudinal cohort study.

Ms. Politoski showed a television spot advertisement about kidney disease and distributed brochures.

E. Discussion

The following issues, concerns, and questions were raised during the discussion that followed the above presentations.

General Comments

The proliferation of guidelines has put the PCP in a difficult position; physicians are inundated with pocket cards and it is not clear that guidelines already in place are translating into physician behavior change, although they may translate into referrals. Guidelines are useful, but they are only a first step. Strategies are needed to implement the guidelines and to cultivate physician support, such as a PDA-based or electronic-records system.

Adequate preparation for ESRD in the CKD period is critical. Individual facilities are beginning to look at that void in terms of educating patients.

Patients with polycystic kidney disease (PKD) are keen on obtaining information but fear discrimination for being identified as having PKD. If genetic discrimination were eliminated, more individuals would come forward to receive treatment at an earlier stage.

Other Groups Activities

Dr. Eugene Freund from the Centers for Medicare and Medicaid Services (CMS) mentioned that from his perspective as a family practitioner, the Guidelines will make a big difference will provide clarity for primary care doctors. He noted that CMS has Quality Improvement Organizations (QIOs) in some of the pilot cities. These QIOs are working with the ESRD Networks to improve the quality of dialysis care and would be natural coalition partners. In addition, CMS will cover dietary counseling for people with diabetes and CKD; this coverage is close to being finalized and implemented nationally. For CMS to cover the cost of screening tests, the tests must be mentioned in a statute must be part of a law.

The Society of General Internal Medicine (SGIM) represents researchers, educators, and practitioners. SGIM can help get kidney disease material into the hands of those who are educating students and residents around the country.

The Forum of ESRD Networks offered to carry information to the families and reiterated that adequate preparation of the CKD population is key to quality care for ESRD patients.

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The Renal Physicians Association's major initiative is development of guidelines for renal replacement therapy. This initiative is supported through the Duke Evidence-Based Medicine Center.

The Association of American Indian Physicians (AAIP) noted that public awareness about kidney disease is low among American Indian populations. To address that problem, AAIP developed awareness campaign materials and a network of more than 500 individuals and organizations. AAIP also recently launched a new youth campaign entitled Move It and has conducted several focus groups with youth, with a central message of promoting physical activity.

Chi Eta Phi is devoted to hypertension awareness and offered to serve as messengers for NKDEP.

The National High Blood Pressure Education Program (NHBPEP) reported that May is hypertension awareness month, with the theme of Is your number up? Prevent it/treat it before your number's up. Detroit Boy Scouts will give a merit badge for CVD awareness and, in another novel approach, a Freedom Walk in Baltimore will trace the underground railroad path in an effort to get people walking and moving to deal with high blood pressure. The first Sunday in May is Church Awareness of Blood Pressure Day. A primary prevention working group report will be coming out in the summer of 2002. CMS has authorized support for ambulatory blood pressure monitoring.

NIDDK's Office of Communications and Public Liaison provided an overview of other ongoing programs at the NIDDK. The National Kidney and Urologic Diseases Information Clearinghouse supports NKDEP by disseminating publications and providing a toll-free number for people looking for additional information. The National Diabetes Education Program (NDEP) is promoting the Diabetes Prevention Program Clinical Trial results, which will provide additional data on prevention of diabetes. Minority populations were over-recruited for participation in this trial and messages will be crafted around the resulting prevention issues.

Pre-diabetes is a new term coined by Department of Health and Human Services Secretary Thompson; messages will also be crafted around this concept. The LOOK-AHEAD study is for people who already have diabetes. A workgroup that focuses on children involves school communities, the Department of Education, and multiple school boards, all of whom are attempting to deal with the issue of what to do about increasing development of Type 2 diabetes in children.

Members of the American Academy of Physician Assistants (AAPA) have expressed their weariness at being bombarded with new guidelines; they want strategies and tools instead. AAPA's first initiative is based on this finding; its second initiative ties together obesity, hypertension, diabetes, and hyperlipidemia.

The American Heart Association (Council on the Kidney) is comprised of nephrologists and physiologists. Their newsletter has a limited audience but includes most of the academic community; articles are sponsored. One forthcoming article on kidney disease as a risk factor for

CVD will be coming out in *Circulation*; a press release will accompany the publication of this article. Dr. Eric Simon suggested that this organization could partner with NKDEP on press releases to accompany such articles.

The American Nephrology Nurses Association (ANNA) is concentrating primarily on ESRD; an article on CKD will appear shortly in *Nephrology Nurses Journal*. Two CKD programs were presented at ANNA national meetings, both of which focused on multidisciplinary approach to care. Talks about CKD have been well attended and there appears to be significant interest in CKD within the nurse practitioner community. Ms. Compton mentioned that there is an opportunity to expand the role of the dialysis nurse.

The American Society of Transplantation (AST) offered four comments:

- Kidney transplant patients are at highest risk for hypertension and diabetes. This group of patients ought to be looked at and considered, as many are cared for by PCPs.
- AST is making a deliberate effort to communicate with PCPs because patient care will be much improved if communication is enhanced.
- To maximally impact the way in which PCPs practice, the NKDEP must teach and otherwise reach medical students.
- Patients at high risk of renal failure should consider organ donation.

The Juvenile Diabetes Foundation expressed concern about the fact that only 12 of 68 openings for pediatric nephrologists were filled. There exists a growing lack of appropriate specialists in the pediatric nephrology field, and therefore children are being grossly underserved and are not receiving appropriate testing. PCPs need a refresher course on what they learned in medical school about diabetes.

The American Academy of Nurse Practitioners (AANP) reported that next month the K/DOQI guidelines will be highlighted in its regular column. AANP is a good conduit for disseminating information as it comes out of the NKDEP Steering Committee. Several members have developed a practice-based research network, which may prove to be an effective method of testing implementation of some of the K/DOQI guidelines.

VII. Report on the African American Study of Kidney Disease and Hypertension/Dr. Agodoa

Dr. Agodoa reported that the African-American Study of Kidney Disease and Hypertension (AASK) has been completed and some of its findings have been published in the past year, with additional findings to be published in 2002. He provided a summary of the data from the AASK trial: ESRD incidence and prevalence rates continue to increase, racial and ethnic minorities are disproportionately afflicted with kidney disease, diabetes has become the leading cause of kidney disease in the United States, prior to 1995 hypertension was the leading cause of ESRD in African Americans, and human and economic costs of ESRD are high.

Incidence, prevalence, and death due to ESRD continued to increase during the past decade. Estimated total ESRD costs in the United States in 1997 totaled \$15.64 billion, \$11.78 billion of which was paid by Medicare. The death rate was high but, since 1986, there has been a progressive decline in the death rate; the death rate for Caucasians has been consistently higher than that for African Americans. Diabetes is the most frequent reported cause of ESRD; 44 percent of all incident patients report diabetes as a cause of ESRD and 26 percent of incident patients have hypertension as the primary cause.

Since the time such information has been tracked, African Americans have shown a higher rate of ESRD than all other races. American Indians have come close to the African-American rate, the rate for Asians is close to that of Caucasians, and the rate for Pacific Islanders is closer to the rate of ESRD for American Indians. Hispanics have always been undercounted, representing only 13 percent of diabetes cases but about 20 percent of the U.S. population. For each racial group, diabetes is the most frequently reported cause of ESRD; hypertension is predominantly an African-American problem with regard to ESRD. The 20-44 year age group shows the greatest disparity between African Americans and Caucasians — nearly 20 to 1; this data and other similar data compelled the initiation of the AASK study.

AASK was a multicenter trial to determine whether choice of anti-hypertensive regimen or the level of blood pressure control alters the rate of progression of hypertensive end-stage kidney failure. It was a prospective, double-blind, 21-center clinical trial involving 1,094 African Americans with hypertensive renal disease. Patients were randomly assigned to either usual blood pressure goals or to a low goal and were then randomly assigned to one of three anti-hypertensive drug regimens. The pilot clinical trial was conducted in 1992-1994, the full-scale trial was conducted between 1994 and 2002, and data analysis began in 2001 and is close to completion.

The pilot study randomized 93 patients, followed these patients for 6-10 months, and attempted to verify that the clinical diagnosis of hypertensive kidney disease was correct. Approximately 50 percent of participants agreed to a kidney biopsy; biopsy results confirmed the diagnosis that the clinical criteria were accurate. Through the pilot study, it was discovered that the intervention was feasible and safe; stroke was not seen in the low blood pressure group.

Baseline demographics of AASK randomized participants showed a relatively poorly educated group, with 40 percent of study participants not having finished high school. The study population was also relatively poor economically, with 47 percent having household income less than \$15,000 and another 26 percent with household income between \$15,000 and \$40,000. The median age was 54.5. Only 39 percent of the 1,094 participants were women.

In September 2000, the amlodipine (a calcium channel blocker) arm of the study was terminated early, based on interim analysis that showed that patients who had proteinuria greater than 1 gram were experiencing adverse effects — their kidney function was declining faster and the clinical endpoints were greater in that group. The other two arms of the study used metoprolol (a beta blocker) and ramipril (an ACE inhibitor). It took approximately 1 year for significant differences in mean blood pressures to appear. Overall, it appeared that ramipril was the most effect drug in this study.

AASK demonstrated the ability to control blood pressure in a high-risk African-American population with impaired kidney function. Even small amounts of urinary protein are associated with more rapid kidney disease progression. There was no significant difference in progression of kidney disease between the low and usual MAP goals. This study provides strong evidence in support of the beneficial effect of an ACE inhibitor in patients with hypertensive kidney disease and proteinuria greater than 1 gram, in agreement with other studies. The final AASK findings demonstrate the beneficial effects of ramipril over amlodipine at lower levels of proteinuria than previously observed, but there is no clear evidence of a beneficial effect of ramipril compared to amlodipine for patients with little proteinuria. In contrast to ramipril and metoprolol, amlodipine is associated with significant increment in urinary protein excretion, irrespective of baseline proteinuria level. Ramipril appears to slow kidney disease progression as compared to metoprolol, independent of the level of proteinuria, and ramipril and metoprolol slow progression as compared to amlodipine in patients with baseline proteinuria greater than 300 mg. Overall, beta blocker and ACE inhibitor are superior to dihydropyridine calcium channel blocker.

Dr. Agodoa concluded by stating that the AASK study is the first outcome study to document a beneficial effect of an ACE inhibitor in African Americans as compared to any other class of anti-hypertensive agent. The common practice of not using ACE inhibitors with African Americans, because it was considered not effective, should be abandoned, especially when protein in the urine is present. Blood pressure can be lowered in these high-risk patients and ACE inhibitors do help, a finding that is directly contrary to popular beliefs.

VIII. Report on the Chronic Renal Insufficiency Cohort Study/Dr. Kusek

Dr. Kusek explained that the CRIC Study is just getting underway. He described the rationale for the initiative, specific aims and hypotheses, characteristics of study participants, design and conduct challenges, issues related to measurement of chronic renal insufficiency (CRI) and CVD, and the organization of the study.

CVD is a major cause of death among ESRD patients, with mortality rates substantially higher than in the general population. The relationship between CVD and CKD are not known, nor is much known about the risk factors for the progression of renal disease. To this point, there were no large-scale epidemiological studies of patients with CKD or chronic renal insufficiency. CRIC is a collaborative research group, including clinical centers, principal investigators, and a Scientific and Data Coordinating Center.

Specific aims have not yet been fully developed, but aims of the CRIC are to:

- Recruit and retain a cohort of patients with a spectrum of CRI, 50 percent of whom have diabetes.
- Determine risk factors associated with rates of CRI progression.
- Determine the incidence and risk factors for CVD.
- Study quality of life and health resource utilization patterns.

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- Conduct subgroup analyses among the racial and ethnic groups and between genders.
- Track individuals once they develop ESRD (beyond the CRI phase), whether the patients are transplanted or are in dialysis.

Risk factors associated with CRI progression and CVD will be examined. CRIC will be a national resource for renal studies, in that a data and specimen repository is anticipated that can be utilized by investigators outside the CRIC study group. The initial plan is to collect a great deal of data, looking at traditional as well as novel risk factors. The CRIC study will attempt to elucidate the interrelationship and interplay between these two diseases as the cohort is followed prospectively.

Dr. Kusek enumerated the proposed inclusion and exclusion criteria and noted the list of criteria has not been finalized. The goal is to recruit 3,000 participants into the observational study during a period of 2 years; projected attrition is about 8 percent per year. On average, each center is expected to recruit 400-450 participants, which is 6-7 times the number of participants ever recruited at a single site for any renal trial. Efficient designs for determining risk factors for CVD are under intense discussion.

One major issue is how to measure renal function in this cohort. The AASK study has provided a great deal of information about measurement of renal function in relation to simplified prediction equations, most notably the Levy Equation. In order to measure differences in risk in this population, these equations may not provide adequate precision because they were developed in African Americans with hypertensive renal disease rather than in patients with diabetes. No decision has been made yet on the use of traditional equations, but a subgroup (up to 1,000 participants) may help in developing CRIC's own equations to further validate existing equations.

Another issue is overcoming the limitations of low CVD event rates when using proxy measures of CVD. This issue is one of resources, as well as what will be measured in this cohort and how frequently it will be measured.

The AASK clinical trial cohort will be followed prospectively as well, so 700-800 African Americans with hypertensive renal disease will be studied in parallel with the CRIC study. Efforts are being made to standardize data collection for pooling information from the two studies.

The scientific advisory committee will meet at the end of June 2002 and will examine the observational study's protocol in detail. Early recruitment pilot studies are anticipated to occur in Summer 2002. A recruitment period of 2 years is expected in order to recruit 3,000 participants, and then at least 5 years of followup will occur on the cohort. Data analysis will begin after that time.

Major challenges in the CRIC study include:

- *Recruitment.* The proposed numbers are ambitious.
- *Retention.* Participant retention and burden is not known. Participants will be lost if some of the testing takes a long time; the protocol is constantly being balanced with the concern about participant burden.
- *Selection of subgroups for study.* Questions being considered are what other diseases besides diabetes should be studied and will the subgroups be large enough to allow subgroup analyses.
- *Equation-based vs. direct measurement of GFR.*
- *Selection/frequency/number of measures for CVD.*
- *Fostering other support for this program.* Enough resources exist to establish the cohort and begin some of the measures, but this will be a rich cohort and will need to append ancillary studies, training opportunities, and career awards. Challenges include getting the investigators to agree that all this work can be done in a timely fashion and interesting study sections in long-term epidemiological studies.

Dr. Hostetter noted that the CRIC study will be the most important renal trial during the next decade. Results from this study will help guide medical professionals in advising patients of their risks and the possibilities of progression.

IX. Work Group Progress and Plans

A. Patient/At-Risk Workgroup Report/Ms. Compton

Ms. Compton discussed the progress of the Patient/At-Risk Work Group, including target audience selection, pilot site selection (Atlanta, Baltimore, Cleveland, and Jackson), preliminary messages, and pilot-site intervention.

Three audience segments are targeted: African Americans at risk for CKD, African Americans who already have CKD (K/DOQI stages 3 and 4) to improve adherence and slow progression, and health care providers to encourage them to be more aggressive in treating and helping to slow CKD. Health care provider groups include PCPs as well as specialists such as nephrologists, nurse practitioners, physician assistants, OB/GYNs, and emergency room staff.

For the at-risk audience, preliminary messages that have been discussed by this workgroup include:

- If you are African American and have diabetes, hypertension, or a close relative with kidney failure, you are at high risk for kidney disease.
- Early detection is important. Talk to your doctor today. Ask if you should have your kidneys checked.
- Effective treatment can prevent and slow kidney damage.
- You won't know you have early kidney disease unless you get tested.

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- Left undiagnosed and untreated, kidney disease can lead to kidney failure. When your kidneys fail, you cannot live without dialysis or a kidney transplant.

For patients, preliminary messages that have been discussed by this workgroup include:

- Effective treatment can prevent and slow kidney damage. (This is the primary message.)
- You can keep your kidneys working.
- Talk with your doctor about treatment options.
- You can live well and long with kidney disease.

For healthcare providers, the preliminary messages that have been discussed by this workgroup include:

- Certain patients are at greatest risk for kidney damage: diabetes, high blood pressure, glomerulonephritis, family history of kidney failure (the KEEP study shows this), and African Americans with one of these other risk factors.
- Test high-risk patients for kidney damage. Early diagnosis and treatment can delay or prevent kidney failure: a) Do a urinalysis (dip for protein); b) Estimate GFR from the serum creatinine measurement by using a prediction equation; and c) Conduct a spot check of urine to determine the protein:creatinine ratio; 24-hour urine collection is not needed.
- You can help your patients maintain their kidney function by prescribing ACE inhibitors or ARBs, monitoring tight blood pressure control, monitoring tight glycemic control, referring patients to a multidisciplinary group including a dietician and recommending a low-protein diet, and advising patients to quit smoking.

This workgroup offered the following general recommendations for the NKDEP:

- Focus on people of lower socioeconomic status and education levels, who tend not to seek care.
- Educate providers.
- Ask African Americans to participate in planning.
- Find African-American messengers to carry the messages.
- Use a community-based approach.
- Concentrate on face-to-face interactions.
- Do not rely solely on print media.

Recommended channels for dissemination of NKDEP messages include churches, dialysis and transplant units, a speakers bureau (of lay and professional speakers), diabetes and high blood pressure organizations, professional medical associations, health insurance companies, and barbershops and beauty salons. Partners should include industry; activities and products should produce culturally sensitive materials. Barriers to health behavior change will be more challenging to overcome, but this workgroup recommended helping individuals deal with denial and then assisting them in obtaining needed health care.

The next steps for the Patient/At-Risk Workgroup are to review the Wave II focus group results and to comment on the messages and concepts being developed as a result of those focus groups.

B. Report on the Plan for the Pilot Site Intervention/Ms. Payne

Ms. Payne reviewed the seven-part plan for the pilot-site intervention:

1. *Complete the formative research.* Concept and message testing in the pilot sites has begun. A literature review and in-depth interviews with PCPs have been completed and are under analysis. Once message testing is completed, the concepts and messages will be reviewed with the Patient/At-Risk Workgroup and the Professional Workgroup.
2. *Contact pilot-site participants (health education coalition partners).* A pilot-site coordinator will be identified to be the primary contact at each location. As many partners as possible will be identified to form a community-based coalition that includes members of the African-American community.
3. *Develop materials.* A community action toolkit will be developed by the end of Summer 2002 and materials will be tested at the AAKP meeting. (Ms. Payne distributed sample toolkits.) The toolkit will likely include facts about African Americans and kidney disease; intervention ideas from other successful education programs, such as the NDEP, the NHBPEP, and the Compendium; how to instructions for building a coalition, working with the media, and finding funding and material resources; and samples.
4. *Select channels to reach at-risk African Americans.*
5. *Support pilot site activities.* A kickoff meeting is planned in Washington, D.C. for representatives from the partner coalitions of each pilot site, and a press conference to coincide with the kickoff meeting will report baseline survey results. Biweekly or monthly technical assistance conference calls will be held.
6. *Evaluate pilot site activities and materials prior to national launch.* Interviews with partners will be conducted regularly and a survey questionnaire will be developed for the web site and the toolkit.
7. *Launch the campaign at the national level.*

Ms. Payne stated that the NKDEP hopes to develop pilot-site partnerships with local chapters of kidney voluntary organizations (e.g., AAKP, NKF, and AKF chapters and affiliates), research and care centers (e.g., the Jackson Heart Study), local chapters of interested voluntary organizations (e.g., the American Heart Association), and chapters of professional associations (e.g., the International Society of Renal Nutrition and Metabolism). In addition, State and local health departments, managed care organizations, churches, and African-American community-based organizations could serve as pilot-site partners.

Questions still remaining for discussion include what could be offered to pilot sites for their participation, how much pilot sites can be asked to do, how to encourage participation at the pilot sites, and how to recognize and reward the people and organizations that assist the NKDEP. Ms. Payne requested that participants contact her with names of additional potential partners or contacts at the pilot sites.

C. Evaluation Workgroup Report/Dr. Hostetter (for Dr. McClellan)

Dr. Hostetter reported that the goal for this workgroup is to provide evaluation of the efficacy of the NKDEP program. He noted that the NKDEP can be more widely innovative, thereby taking more substantial risks in its program development than, industry and nonprofits.

The general plan for the Evaluation Workgroup is to obtain baseline awareness data and follow-up on the general population, African Americans at risk for CKD, and PCPs. Two options are being discussed currently by this workgroup:

- *Option 1: Detailed surveys.* The first option is to conduct detailed surveys of 400 African Americans at each pilot site (1,600 individuals total), 100 PCPs at each site, and a national survey of approximately 2,000 individuals. Level of knowledge and actual practices would be the focus of the survey, and the baseline would be accomplished in the summer or early fall of 2002.
- *Option 2: National survey.* The second option is to conduct a national telephone survey of approximately 2,000 randomly selected individuals. In addition, a qualitative feedback study from pilot site partners would ascertain the extent to which NKDEP messages are effecting behavior change.

Plans for the immediate future include assessing the financial feasibility of the two options. Option 1 is more expensive, but the NKDEP will apply for funds from the National Institutes of Health's (NIH) 1 percent set-aside for such NIH-wide projects. A decision as to which option to pursue will be made shortly. The Evaluation Workgroup is proceeding with the Office of Management and Budget clearance process, established by Congress to protect the public from endless surveys.

It was noted that the KEEP program sends approximately 1,000 followup letters to patients monthly and could include additional questions in order to gather survey results for either of the two NKDEP options.

D. Media Outreach Report/Mr. Miller

Mr. Miller reported that NKDEP staff are planning a national press conference, a satellite media tour, and radio and print interviews to maximize the reach of the program. Prior to these three media approaches, spokespersons will be identified and a media kit will be developed.

To release baseline data, the NKDEP will host a national press conference at the National Press Club in Washington, D.C. Experts, dignitaries, and pilot site representatives will present the data, all of whom will be available for interviews after the press conference. The national media and the trade press will be invited and results will be monitored.

In concert with the press conference, a satellite media tour will be conducted in high concentration African-American markets. Using this method of communicating with the public, a spokesperson for the NKDEP will set up at a television studio and arrange a group of consecutive interviews with visual audio media representatives from around the country.

Satellite media tours have proven to be an effective method of reaching a wide target audience by offering interviews with multiple television and radio stations in a short period of time. Background (B-roll) footage will be developed that might show someone in a healthcare setting receiving information or a laboratory person working. African Americans live primarily in 10 states, so the television interviews will target 10-15 geographic areas. To evaluate effectiveness of the satellite media tour, coverage will be monitored.

Radio and print interviews will also coincide with the national press conference. Radio network interviews will be scheduled for the morning of the press conference and print press and radio interviews will be scheduled following it. Relevant information will be placed on African-American health web sites. Results will be monitored and analyzed.

Mr. Miller requested that ideas for increasing the robustness and effectiveness of this media campaign be addressed to him.

E. Questions and Discussion

The following issues, concerns, and questions were raised during the discussion that followed the above presentations:

Partners and Target Audiences

- HMOs should be targeted, since they are more likely to encounter patients with fewer additional and complicating conditions.
- If the NKDEP targets people who provide patient education within health plans, it will only reach insured individuals.
- Historically black colleges would make excellent partners. Morehouse in Atlanta is one example.
- David Satcher might be an effective spokesperson.
- Urban League affiliates might be helpful.

Pilot Site Issues

- Recognizing and rewarding people who participate at the pilot sites is a challenge. Small stipends or seed money is possible, but money is not the only or main answer. Partners at the pilot sites are voluntary groups; what could the NKDEP do to get people to use this material and take an interest in the NKDEP s programs? Suggestions included a visit to the NIH or to Washington, recognition within the community (e.g., posting their name in a positive light or in information sent to the group s membership), and/or providing positive press within their own communities. If the NKDEP provides significant recognition to the one or two initial communities with which it works, positive word will spread.

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- Engaging people to volunteer at the pilot sites is a challenge. Using lay health advisors and workers could be effective. Training provided to the lay health workers would make them more marketable for future work (e.g., training on how to run a focus group). This approach has been successful in the American Indian community.
- Demonstration grants might be a suitable reward for participation at the pilot sites.

Media Issues

- NKDEP should be built slowly and of the highest possible quality, so individuals, healthcare providers, and media representatives want to come to the program for information.
- A press conference needs a news hook to get people to show up. Two possible newsworthy items are the second phase of the AASK trial and a paper in the *American Journal of Kidney Disease* that shows the cost-effectiveness of treating early CKD to slow progression. As relevant articles are published, the NKDEP can issue appropriate press releases.
- The baseline information collected at the pilot sites will be very interesting. Rich data may warrant some press attention.
- People who make a difference in kidney disease education are people in the community or professionals; their stories may be somewhat newsworthy. However, kidney disease will not lead to the kind of media event that occurs with an acute infectious outbreak.
- A national program needs to do something different in order to stand out. The NKDEP needs a unique approach, for example, walking the Freedom Trail. The NKDEP should be thinking about newer activities with as-yet-unknown partners. Examples of innovative approaches include children in New York State writing an opera on blood pressure and B.B. King's advertisement for the new glucose meter. These innovative approaches are the programs people remember.

General Ideas

- The NKDEP should develop a series of certifications for health professionals, for example, Certified Kidney Disease Educator. Having the imprimatur of the NIH means a great deal.
- Other groups that may not have an interest in health can be convinced to participate. One successful example was a student poster contest on hypertension in which city dignitaries were volunteer judges. The posters of contestants and winners were displayed in city hall, which raised public awareness and involved people who usually have nothing to do with hypertension.

- The Centers for Disease Control and Prevention (CDC) has sponsored a special award for screenwriters who adopt health messages into their storylines. In addition, the CDC writes tipsheets for scriptwriters. Providing tipsheets may be an opportunity for the NKDEP, because the NIDDK has the expertise to provide ideas to storywriters who are always looking for material. This kind of education reveals relevant issues through a story, getting around the fear messages exclusively, and tells how people deal with the disease in terms of how it affects families, what resources might be available, and how to cope. It offers a chance for people to model behaviors. It was suggested that the NKDEP develop a tipsheet about the potential complication of kidney disease as a result of diabetes.
- One group's certified diabetes teacher is their single most effective vehicle for teaching managing diabetes and awareness about the disease. The NKDEP could arrange a similar recognition or certification and encourage it to be reimbursable.
- Communities should be involved early, often, and substantively. Early buy-in is crucial; People from the community value being at the same table and that their advice is sought and incorporated into key decisions. Community involvement enhances the relevance of the research and its applicability.
- The NKDEP could give an award to faculty members (younger faculty or those in nephrology, for example) who choose to talk to community groups. Such an award may serve as incentive since physicians like to satisfy the community service portion on their curriculum vitae.
- Speakers' bureaus have been developed by companies or industries that have significant financial resources. In lieu of a full-fledged speakers' bureau, the NKDEP could provide some sort of certified merit badge.

X. Adjournment/Dr. Hostetter

Dr. Hostetter requested that participants inform him about how to partner with their organization to reach shared objectives, which is one of the purposes of this Steering Committee. He also requested that participants let him know of other groups that should be involved in the NKDEP.

The date for the next Steering Committee meeting has not yet been set, but meeting frequency will change from twice a year to once a year. Dr. Hostetter thanked all participants.

This NKDEP Steering Committee meeting was adjourned at 3:00 pm.

Appendix A

List of Attendees

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Appendix B

List of Acronyms

AAKP	American Association of Kidney Patients
AANP	American Academy of Nurse Practitioners
AAPA	American Academy of Physician Assistants
AASK	African-American Study of Kidney Disease and Hypertension
ACE	angiotensin-converting enzyme
AAIP	Association of American Indian Physicians
ANNA	American Nephrology Nurses Association
ASPN	American Society of Pediatric Nephrology
AST	American Society of Transplantation
BUN	blood urea nitrogen
CDC	Centers for Disease Control and Prevention
CKD	chronic kidney disease
CMS	Centers for Medicare and Medicaid Services
CRI	chronic renal insufficiency
CRIC	Chronic Renal Insufficiency Cohort
CVD	cardiovascular disease
ESRD	end-stage renal disease
IHS	Indian Health Service
K/DOQI	Kidney Disease Outcomes Quality Initiative
KEEP	Kidney Early Evaluation Program
NDEP	National Diabetes Education Program
NHBPEP	National High Blood Pressure Education Program
NHLBI	National Heart, Lung, and Blood Institute
NIDDK	National Institute of Diabetes and Digestive and Kidney Diseases
NIH	National Institutes of Health
NKDEP	National Kidney Disease Education Program
NKF	National Kidney Foundation
PCP	primary care provider
PKD	polycystic kidney disease
SGIM	Society of General Internal Medicine