NKDEP

National Kidney Disease
Education Program

NKDEP Steering Committee Meeting
Friday, September 7, 2001

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WELCOME AND INTRODUCTIONS

Dr. Thomas Hostetter, Director of the National Kidney Disease Education Program (NKDEP), National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) opened the meeting and welcomed participants to introduce themselves. He introduced Dr. Allen Spiegel, Director, NIDDK.

Dr. Spiegel described NKDEP as an exciting opportunity to translate the latest scientific research into practice. He explained that NIDDK would not dictate messages for the NKDEP, but rather work with partners to develop consensus with regard to messages for all NKDEP audiences. NIDDK will help catalyze consensus, so partners can subsume their individual identities and work together toward the common goal of decreasing the incidence and prevalence of kidney disease in the United States.

Dr. Hostetter noted that the organizations represented by many of the meeting participants already have been working to educate patients and the public about kidney disease, including NIDDK through its clearinghouse, the National Kidney and Urologic Diseases Information Clearinghouse (NKUDIC). He explained that today's meeting would help determine how the groups could join forces through NKDEP to work toward common goals.

Dr. Hostetter outlined the three main factors that contribute to the need for NKDEP.

1. Kidney disease and kidney failure are major public health issues in this country.
   - More than 90,000 people developed kidney failure last year, adding to a total population of 300,000 patients who are on dialysis and 80,000 who are living with organ transplants.
   - The cost of kidney disease is approximately $18 billion per year.
   - Centers for Medicare & Medicaid Services (CMS) spends 6 percent of its budget caring for people with End Stage Renal Disease (ESRD).
   - The incidence and prevalence numbers have doubled during each decade for the last two decades.

- The U.S. Renal Data System reported that 175,000 people would come to ESRD during the year 2010 if present trends persist.
- The number of 90,000 people coming to ESRD last year is greater than the total deaths from any single malignancy other than lung cancer. In fact, it is greater than the sum of deaths attributed to prostate and colon cancers.
- The number of people who died from kidney disease despite treatment is also greater than the number of deaths from a single malignancy other than lung cancer.
- Kidney disease is not getting the attention it deserves. One factor contributing to this may be that kidney disease affects older people, minorities, and the poor.

2. Recent research has provided adequate successful primary preventions and good therapies to slow progression of kidney disease.
   - People with diabetes (Type 1 and Type 2) can prevent ESRD through proper glucose control;
   - People with hypertension can prevent ESRD through early and appropriate antihypertensive therapy; and,
   - Therapies are improving every day.

3. The above-mentioned methods are not being used. Drs. Bill McClellan and Wendy Brown have reported data that only one-third of patients who should be receiving medications—antihypertensives and ACE-inhibitors to slow progression—actually do receive appropriate therapy. Two-thirds do not. We need to find out why and address this issue.

Dr. Hostetter concluded by saying that NKDEP can catalyze efforts to address these three problems and contribute a unified Federal voice in addressing them. Previous NIH education programs have had proven success and will be used as models for NKDEP.

- The National High Blood Pressure Education Program, directed by Dr. Ed Roccella, who is a member of the Steering Committee, has contributed to the decline in cardiovascular deaths in this country.
- The National Diabetes Education Program (NDEP) at NIDDK, directed by Dr. Charles Clark, who also is a member of the Steering Committee, has been partly responsible for changing the management of diabetes in this country.

STEERING COMMITTEE ROLES AND RESPONSIBLITIES

Dr. Hostetter explained that NKDEP has assigned terms of service for individuals from each organization represented on the Steering Committee and expressed the hope that the organizations would continue their interest and participation in NKDEP. Please refer to the attached "*Steering Committee Members*". Dr. Hostetter charged members of the committee to communicate the results of the meeting and the plans of the NKDEP with their respective organizations. He stated that in the future it may be important to eventually refresh the committee, but encouraged interested individuals to serve a second term.

Mimi Lising, Associate Director, NKDEP, explained the organizational structure of NKDEP and the roles and responsibilities of members of the Steering Committee. Please refer to "*NKDEP Organizational Structure and Roles and Responsibilities*."

She stressed that members of the Steering Committee are to serve as liaisons to each of their organizations. Ms. Lising listed several specific responsibilities, including:

- Serve as a media spokesperson at key intervals of the campaign, such as its launch.
- Work with your organization to promote campaign products through existing communication channels, such as listservs, etc.
- Place NKDEP on the agenda of your annual conference.
- Attend two Steering Committee meetings a year.

Ms. Lising also highlighted the composition of the Steering Committee and mentioned the need to add representatives from minority organizations, including a health professional and consumer organization from each of the minority groups—the Hispanic/Latino, American Indian, African American communities. She welcomed suggestions of individuals who might be willing to serve as representatives.

Ms. Lising described the role of Work Groups in developing the NKDEP. The Work Groups will consist of Steering Committee members and individuals with expertise or resources to fulfill the group's tasks. The Work Groups will assist in developing, implementing, promoting, and/or evaluating specific program components and will meet once a month (via

conference call) and perhaps once per year to conduct business that can't be done via the telephone.

Ms. Lising made clear that this structure is flexible and will change according to the needs of the NKDEP and the direction of the Steering Committee.

Dr. Hostetter explained that some organizations have named representatives to the Steering Committee who were unable to attend today's meeting, but who will review the minutes of the meeting and contribute to the planning process. Please see the attached "*Steering Committee Members*." He welcomed suggestions of additional organizations that might serve on the Steering Committee.

STRATEGIC PLAN

Dr. Hostetter introduced the "Draft Strategic Plan" and explained that it is a composite formed on the basis of information gathered at prior planning meetings and ideas from the other education programs and projects, particularly the NDEP. He described the current plan as a large "laundry list" of ideas and charged the group to select priorities for NKDEP.

He explained that during the next segment of the meeting the whole Steering Committee would discuss and try to reach consensus on the

- Goals and objectives,
- Target audiences, and
- Messages.

Dr. Hostetter asked Dr. Clark to describe the first steering committee meeting of the NDEP. Dr. Clark explained that the first step for NDEP was to decide what the initial messages should be. The NDEP Steering Committee concluded that most people did not consider diabetes to be a serious disease. The NDEP group also considered how their message would fit in with messages of other groups. The NDEP decided to target people with diabetes and focus on diabetes control.

Dr. Clark advised the group to

- Decide what audience is primary

- Don't ignore other audiences, but choose one for primary message during the first year or two
- Choose one primary message that will make the most difference
- Evolve as evaluation indicates

Dr. Roccella suggested that the group
- Determine the overarching goal
- Conduct an environmental scan to determine what other groups are already doing to address the problem of kidney disease in the United States
- Choose program components

Dr. Hostetter asked participants to begin by developing some consensus on the goals and objectives for the NKDEP that are listed in the draft plan by target audience. He called on Dr. Alan Kliger, representing the Forum of ESRD Networks, to lead the discussion and asked everyone to participate.

Dr. Kliger stated that the current plans looks fabulous because it "includes the universe." He asked participants to select priorities and consider the following:
- The boundary between the general public and kidney patients is blurred because many people who have kidney disease don't know that they are affected.
- The message for health care providers would have to be refined to meet the needs of the many primary care providers and the differing needs of the specialists – kidney disease is not in the minds of those treating diabetes mellitus and hypertension.
- Existing work by other organizations.
- The two areas that we know have the greatest impact on progression of disease and eventual ESRD are diabetes and hypertension—areas attended to by existing, successful education programs
- How should NKDEP relate to the other education programs and add value to them?
- Much effort has focused on ESRD and pre-ESRD, and little effort placed on identifying people at risk and use of prevention and early intervention strategies.

Dr. Clark reiterated the need to choose one primary message and to get partners to help deliver that message. He suggested that the Steering Committee choose the most important audience.

AUDIENCE

Participants expressed varying opinions about which audience would be the most important target for NKDEP. Many participants stressed the importance of reaching people who are at risk for kidney disease because they have diabetes, high blood pressure, or a family member who has kidney disease. Others mentioned that families of patients are critical to increased patient survival. Some participants suggested that the nephrology community should be encouraged to work in partnership with primary care physicians to deliver proper care to kidney patients. Other participants said it would be important to target clinical pathologists to encourage them to estimate glomerular filtration rate (GFR) in laboratory reports. One participant suggested that the group consider Congress as an audience to lobby for legislation against genetic or health status discrimination. Most participants seemed to agree that it would be important to target primary care providers as well as people at risk for CKD in a two-pronged approach.

Participants suggested that NKDEP pay special attention to certain segments of the target audience, including Hispanic diabetics, black hypertensives, and family members of dialysis patients.

GOALS

Dr. Hostetter asked participants to consider NKDEP goals for patients, families, and/or providers. The participants agreed that education is not enough. NKDEP should strive for behavior changes and should use a message of hope to decrease patient and provider fear of kidney disease. PCP's need to know who to screen, how to screen, and when to refer. NKDEP needs to prompt physicians to action and encourage early intervention, not just increase patient monitoring.

MESSAGES

Dr. Hostetter also asked participants to discuss potential messages to patients and providers. Participants agreed that any message for clinicians should increase provider confidence—"You can make a difference!" Messages should contain action steps—"There are simple things to do—you don't need to do a 24-hour urine test." NKDEP should provide tools to patients,

so they know how to take care of themselves—"Ask for a simple dipstick urine test." "It is treatable." In addition, some participants would like to include a message about the use of vascular access.

Participants urged NKDEP to establish consensus on the epidemiology of kidney disease and common approaches to its diagnosis and management, so all partners will be able to deliver consistent messages. Also, NKDEP should work with existing programs, but emphasize the kidney-related messages.

Participants also agreed that the messages should be consistent across all audiences—working together to reach specialists, primary care providers (PCPs), payers, and patient audiences. Also, participants noted that it would be important to provide guidelines to PCPs before conducting a direct-to-consumer marketing effort. It would help to alert PCPs to public awareness activities that might affect their practice.

EVALUATION

Dr. Hostetter asked participants to consider whether it would be worthwhile to conduct pilot studies within certain geographic regions. Some participants suggested that it would be appropriate to establish early success in a pilot area. Others participants made the following suggestions:

- It would be efficient to use existing systems of care, such as Community Health Centers, to test messages and evaluate provider behavior change.
- CMS could participate.
- Developers of the Health Plan Employer Data and Information Set (HEDIS) should participate in Steering Committee meetings.
- Use data from the KEEP Program.
- Change the Diabetes Quality Improvement Project (DQIP) policy to include kidney disease indicators.

PROGRAM STRATEGIES

The participants divided into four small groups to discuss potential program strategies and later returned to provide the following summaries of their group discussions.

Group 4

Group 4 agreed that the first goal for NKDEP would be to develop consensus on the epidemiology, cost, impact (including cardiovascular disease, ESRD, quality of life), and mortality of kidney disease. NKDEP should use consistent messages that work toward the same goal across all audiences. Next, NKDEP should increase awareness of the role of kidneys in healthy lives and encourage clinical pathologists to report GFR. NKDEP should encourage new health systems that would require managed care organizations to report patient GFR or proteinuria in order to receive reimbursement. And later, NKDEP should try to increase the screening for undetected chronic kidney disease (CKD) while at the same time encourage PCPs to manage early kidney disease to prevent negative consequences.

Audiences for the campaign would include:

- People at risk
- General population
- Family
- PCPs
- Clinical pathologists
- Policy makers

Strategies would vary depending on the audience.

To reach the general public, patients, and policy makers, use:
- Mass media
- Partner distribution of the messages

To reach health care providers, use:
- Regional symposia
- Direct mail
- CMS – to assist in integrating kidney activities with existing hypertension and diabetes programs.

Evaluation methods would also vary according to the audience and could include:

For the general public:

- NHANES (National Health And Nutrition Examination Survey)
- BRFSS (Behavioral Risk Factor Surveillance System)
- Other surveys
- KEEP (Kidney Early Evaluation Program) surveys of family members

For PCPs:
- HCQIP (Health Care Quality Improvement Program) or
- Within closed systems that link information to patients, such as Medicaid, HMO's, DMO's, or the Veterans' Administration (VA):
  - Pharmacy data
  - 2728 forms

Surveys could be done to find out how policy makers, systems, and researchers were influenced by the campaign.

Group 3

Group 3 suggested that the first step would be to develop consensus in the renal community with regard to the guidelines for care of kidney patients. After reaching consensus, Group 3 suggested that NKDEP work on these specific projects for each audience:

Primary Care Providers who might ask, "What should I do with patients who come to see me about their kidneys?" "What should I do to screen patients for hypertension, diabetes, and kidney disease?"
NKDEP should develop and disseminate a toolbox with specific steps to take—a list of the most important guidelines:
- Urine analysis
- Estimate GFR
- Spot check of protein:creatinine
- Blood pressure check
- Guideline recommendations—list of most important ones

The kit should encourage doctors to conduct kidney screening (at minimum a urine analysis) when they see patients with diabetes or high blood pressure. NKDEP needs to bridge the gaps with other education programs and learn from them.

High-risk groups
- Expand KEEP Program—provide screening and referral within minority communities to reach African Americans, Latino Americans, and

American Indians, including high-risk adolescents. Send information to primary care providers.
- Screen families of transplant and dialysis patients.
- Screen hospital discharge patients and their families when hospitalized for congestive heart failure, myocardial infarction, stroke, diabetes, or hypertension.
- Message to people at risk is to know the risk factors and "know your number and see a doctor."

Laboratories
- Report uniform modified MDRD measurement of estimated GFR.

Group 2

Group 2 recommended specific messages for each audience and stated that the first two groups should be priorities for NKDEP:

People at risk and people with undiagnosed kidney disease
- Kidney disease is silent, detectable, and preventable.
- You are at risk for kidney disease and you can do something about it.
- Know your risk factors.

PCPs (The tone of messages should instill confidence and comfort.)
- There are treatments available.
- Know the risk factors for kidney disease.
- Know what to do—Know your ABC's:
  Albumin
  Blood Pressure
  Creatinine

People with diagnosed kidney disease and family members (The tone of messages should be hopeful.)
- Know your numbers.
- You can prevent the progression and complications of kidney disease.
- Be in control—know what to do and do it.

Payers and Policy Makers
- It is in your interest to be aware of and foster implementation of guidelines.

Group 2 then answered a set of questions provided by the NKDEP staff.

1. What existing materials/activities/programs are partners already doing that might dovetail with NKDEP, and where are the gaps?

Answers:
- Patient education materials exist (National Kidney Foundation, American Association of Kidney Patients, NDEP, NHBPEP, and NKUDIC).
- Patients need materials regarding prevention and early disease management.
- PCPs need guidelines and information on prevention of development and progression of kidney disease.
- Patients and providers need materials that have a renal focus—NKDEP should work with existing programs to incorporate kidney message.

2. What kind of products/activities could NKDEP do to bridge the gaps?

Answers:
NKDEP should develop:
- Consensus on message using evidence-based science
- NKDEP message
- Agreed upon performance measures for program implementation
- White papers on scientific evidence

All partners should deliver consistent messages through their own dissemination channels.

3. What organizations/agencies should be involved? Should we add new partners?

Answers:
- Representatives of targeted populations, such as:
  - National Council of La Raza
  - National Coalition of Hispanic Health and Human Services Organizations (COSSMHO)
  - Black Women's Organizations
  - National Council of Negro Women
  - National Hispanic Medical Association
  - National Association for the Advancement of Colored People

  - Asian American Pacific Community Health Organizations
- Representatives from private payers
  - HRSA
  - Association of Managed Care companies
- Need to develop a Partnership Network (that includes industry, similar to NDEP)

4. How could NKDEP develop and promote the activity?

Answers:
- Agree on action steps
- Work with contractors on communication activities

5. What should NKDEP do?

Answers:
- Develop materials/messages for people at risk and those caring for them.

<u>Group 1</u>

Group 1 stated that they agreed with other groups in a number of areas:

1. NKDEP needs to develop standards that are reproducible across all groups and set realistic and uniform targets.
2. Acquire, collect, and share information about existing educational materials and programs in order to identify gaps and existing educational pathways. Create a composite of what's being done.
3. Disseminate forthcoming information.
   - Develop a publication plan.
   - Profile appropriate meetings to attend and send acknowledged leaders to repeat the same message to different audiences of health providers from nurse practitioners to physicians.
   - Include students and residents in the NKDEP target audience. This group can act as an advocacy group—the next generation of PCPs. The American Student Medical Association may consider kidney education as a project for its members.
4. Target an enriched population—the dialysis population can pass information on to relatives and other community members.

Group 1 did not determine how to assess the program, but suggested that the geographic uniqueness of kidney disease must be considered when planning the program and its evaluation. They also mentioned that it might be possible to assess effectiveness of some components of a program by using selected performance indicators within a closed system, such as HMOs.

CONSENSUS

Dr. Hostetter asked participants to

- Look for areas of consensus among the groups
- Identify priorities for NKDEP
- List projects that would be appropriate for NKDEP
- Define areas of focus for working groups

He noted the need for reproducible standards and agreement on a uniform message. He mentioned that the NKUDIC could collect existing educational materials and create a composite of what is being done and identify gaps.

Participants developed a list of common themes:

1. Work with CMS and key intermediary organizations to distill guidelines.
   - Achieve evidence-based consensus with regard to the epidemiology of kidney disease.
   - Select an appropriate estimate of GFR—Use a formula or modified MDRD.
   - Select key guidelines with regard to diagnosis and management.

2. Conduct formative research.
   - The target audiences should be PCPs and identified at-risk groups.
   - Review existing kidney education programs and materials for these audiences.
   - Conduct needs assessment of PCPs to determine current level of knowledge with respect to kidney disease.
   - Determine what materials induce PCP behavior change.
   - Use available marketing research to learn about at-risk minority populations.

- Identify partners, including major kidney organizations (patient and provider), CMS, primary care organizations (such as American Academy of Family Physicians and American College of Physicians), and representatives of minority risk groups (patient and providers).

3. Develop messages.
   - Develop a kidney fact sheet to highlight selected guidelines and describe the incidence, prevalence, and cost of disease.
   - Create "tag" line—single statement to all audiences and partners.
   - Train a team of media representatives and approach health reporters with NKDEP message.
   - Develop message about what to do at the doctor's office.

4. Evaluate NKDEP projects.
   - Review and use existing resources to conduct and assess NKDEP interventions, such as CMS, Peer Review Organizations (PROs), and ESRD Networks.
   - Add kidney disease to CMS quality improvement activities.
   - Work with CDC to gather baseline data by adding relevant kidney questions to existing surveys, such as the BRFSS and NHANES.

Participants listed projects and defined areas of focus for work groups:

1. ***Message Development Work Group*** would
   - Develop common messages for the following target groups:
   – PCPs
   – Identified at-risk groups
   – Beyond the scope of what NKDEP could do

2. ***Formative Research Work Group*** would
   - Analyze existing materials/programs and identify gaps
   - Study existing marketing research (from private industry)
   - Work with partners to conduct formative research (such as focus group discussions or surveys) of key audiences
   - Determine baseline(s) to be used in future NKDEP campaign evaluation—NHANES, BRFSS, CMS
   - Determine current level of knowledge among PCPs

- Determine how to get PCPs to change their diagnosis and treatment behaviors
- Ask dialysis patients:
  a. What did you know?
  b. When did you know it?
  c. How can we reach your family members with important information?

3. ***Consensus Development Work Group*** would
   - Achieve consensus with regard to the incidence and prevalence of kidney disease
   - Determine an appropriate estimate of GFR (Use a formula or modified MDRD?)
   - Achieve consensus with regard to guidelines for PCPs regarding the diagnosis and management of CKD
   - Develop a kidney fact sheet for use in media kits and distribution to partners, so that everyone is using the same numbers and discussion points

4. ***Demonstration Project Work Group*** would
   - Plan a demonstration in a setting limited by geography or setting
   - Look at current pilot projects, such as the ongoing effort to reach family members of ESRD and transplant patients
   - Use various components – media, PCP education, patient education, etc. and then evaluate

5. ***Speakers' Bureau Work Group*** would
   - Develop and train a network of speakers from NKDEP and partner organizations
   - Develop and accredit a CME course

NAME CHANGES/NEXT STEPS

Dr. Hostetter asked participants to consider an appropriate name for the program. He explained that since this is the formal inception of the kidney education program, it would be appropriate to discuss its name. One disadvantage of maintaining the NKDEP name is that the acronym is very similar to the NDEP and people might find it confusing. Some participants made the following suggestions:

- National Kidney Health Education Program
- National Kidney Health Care Program
- National Kidney Care Program
- National Kidney Care Project

One participant mentioned that other national health "Education Programs" have been successful and so grouping those two words together maintains a certain level of authority.

Dr. Hostetter thanked participants for their thoughtful consideration of the NKDEP and stated that the next meeting would be in approximately six months. He asked participants to forward names of organizations that might be interested in becoming an NKDEP partner.

Dr. Hostetter adjourned the meeting.