



National Kidney Disease Education Program  
National Institute of Diabetes and Digestive and Kidney Diseases  
National Institutes of Health

Steering Committee Meeting  
Doubletree Hotel at Crystal City  
Arlington, Virginia

**Minutes of the June 24, 2005, Meeting**

**Participants**

**Thomas Hostetter, MD**  
Director, National Kidney Disease  
Education Program

**Elisa Gladstone, MPH**  
Associate Director, National Kidney Disease  
Education Program

**Karen Basinger, MS, LN**  
American Dietetic Association

**DeAnna Cheek, MD**  
Division of Nephrology, Medical University  
of South Carolina

**Dolph Chianchiano, JD, MPA**  
National Kidney Foundation, Inc.

**Gina Clemons**  
Centers for Medicare and Medicaid  
Services

**Ann Compton, MSN, FNP-C**  
American Nephrology Nurses Association

**Forrest Daniels, FACHE**  
Minority Intervention and Kidney  
Education Program, American Kidney  
Fund

**Kris Ernst, RN, CDE, BSN**  
Centers for Disease Control and Prevention

**Barbara Fivush, MD**  
American Society of Pediatric Nephrology

**Eugene Freund, MD, MSPH**  
Centers for Medicare and Medicaid  
Services

**Joanne Gallivan, MS, RD**  
National Diabetes Education Program

**Richard S Goldman, MD,**  
Forum of ESRD Networks

**Mary Jo Goolsby, EdD, MSN, NP-C**  
American Academy of Nurse Practitioners

**Millicent Gorham**  
National Black Nurses Association, Inc

**Mary Harris**  
National Institute of Diabetes and Digestive  
and Kidney Diseases

**Cynda Johnson, MD, MBA**  
American Academy of Family Physicians

**Frederick Kaskel, MD, PhD**  
American Society of Pediatric Nephrology

**Alan Kliger, MD**  
Forum of ESRD Networks

**Beth Kosiak, PhD**

Agency for Healthcare Research and Quality

**Joseph Kuhn, MD, FACP**

American College of Physicians

**Stephanie Mahooty, RN**

Indian Health Service

**Roslyn B. Mannon, MD**

Transplantation Branch, National Institute of Diabetes and Digestive and Kidney Diseases

**Melissa McGowan, MHA**

National Institute of Diabetes and Digestive and Kidney Diseases

**Bob McNellis, MPH, PA-C**

American Academy of Physicians Assistants

**Edgar R. (Pete) Miller, III, PhD, M.D.**

Welch Center for Prevention Epidemiology and Clinical Research  
Johns Hopkins Medical University

**Carolyn W. Mosley, PhD, RN, CNS**

Chi Eta Phi Sorority, Inc.

**Thakor G. Patel, MD**

Veterans Health Administration

**Griffin Rodgers, MD**

National Institute of Diabetes and Digestive and Kidney Diseases

**Laura M. Saint Martin, MD, MPH**

Health Resources and Services Administration

**Eric Simon, MD**

American Heart Association, Council on Kidney

**Elizabeth H. Singer, MS**

Office of Communications and Public Liaison, National Institute of Diabetes and Digestive and Kidney Diseases

**Dale Singer, MHA**

Renal Physicians Association

**Paul C. Smedberg**

American Society of Nephrology

**Staff**

**Nancy Accetta**

NKDEP Contractor

**Michael Briggs**

NKDEP Contractor

**Christen Horn**

NKDEP Contractor

**Victoria McGhee**

NKDEP Contractor

**Lamont Rooker**

NKDEP Contractor

**Karen Toll**

NKDEP Contractor

**I. Welcome, Introductions, Agenda Overview**

Thomas Hostetter, MD, director of the National Kidney Disease Education Program (NKDEP), opened the meeting, and asked participants to introduce themselves. Dr. Hostetter concluded his opening remarks by announcing that he has accepted the Chief of Nephrology position at Albert Einstein. He will continue his role as director of NKDEP until a successor is hired.

## II. CKD Update

Dr. Hostetter provided a brief CKD update, primarily discussing findings from the 2004 United States Renal Data System Annual Data Report, strides in GFR reporting, and the increasingly recognized relationship between chronic kidney disease (CKD) and cardiovascular disease (CVD). He highlighted the fact that there appears to be some attenuation in the rate of the rise of end stage renal disease (ESRD) yet cautioned that, although the rate has been small over the past year (2% to 3% compared to a steady rise of about 10% during the 1990s), it is still an increase in a large number. Thus the number of people affected and the impact remain significant. He also reminded participants that while the link between CKD and CVD is receiving increased attention in the medical community, prevention of ESRD should remain a primary goal of NKDEP's efforts. Lastly, Dr. Hostetter emphasized that routine reporting of GFR is critical to reducing rates of ESRD, and encouraged participants contact their laboratories and encourage them to report it.

## III. Campaign Update

Elisa Gladstone, MPH, associate director of NKDEP, provided an update on program activities during the past year. The activities included: National Kidney Month, African-American outreach, expansion of outreach to new audiences, including Hispanics and American Indians, an audit of the use of NKDEP's dialysis materials, development of new materials, presentations and exhibits, and the work of the NKDEP's Laboratory Working Group. Descriptions of these activities are included in the appendix.

## IV. Update from Steering Committee Organizations

Several Steering Committee members presented updates on their organizations' activities related to kidney disease. Before their presentations, Dr. Hostetter recognized TG Patel and Andy Narva for getting the Veterans Administration and Indian Health Service, respectively, to report estimated GFR.

Cynda Johnson from the **American Academy of Family Physicians** shared her work with East Carolina University, including a CKD mentoring program for primary care clinics, reporting of GFR in their labs, and focused outreach to CKD clinics in rural North Carolina. She also expressed interest in targeting leaders of academic health centers to reach medical residents.

Joseph (Skip) Kuhn from the **American College of Physicians** (ACP) reported that CKD is on the upcoming Board of Regents' meeting agenda to be recognized as a health issue for the organization. ACP offered four CKD modalities for use online last year and is trying to add more. It also is working with RPA and NKF to develop guidelines for Stages 2 and 3 to help internists manage CKD patients.

**American Kidney Fund** representative Forrest Daniels gave an update on the MIKE program, which is focusing on screening African Americans in Atlanta, Washington, DC, and Chicago. AKF is also working with local labs to encourage GFR reporting and with the National Association of Community Health Centers.

Barbara Fivush and Rick Kaskel from the **American Society of Pediatric Nephrology** gave an overview of recent activities, including the Prospective Study of Chronic Kidney Disease in Children, development of a GFR calculator for children, and a template letter for practitioners. It is also doing work with obesity prevention programs in New York.

Eugene Freund and Gina Clemmons from the **Centers for Medicare and Medicaid Services** spoke about the national-level Fistula First Initiative and the desire to get NKDEP involved. They also commented that while the ESRD networks are legislatively mandated to work on ESRD, there may be ways to work through the Quality Improvement Organizations to address CKD.

**National Kidney Foundation** (NKF) representative Dolph Chianchiano played two new television public service announcements in English and Spanish that encourage people to get tested for kidney disease. NKF is continuing the KEEP program and developing guidelines for CKD and diabetes (to be published in early 2006).

Dale Singer of the **Renal Physicians Association** (RPA) displayed its advanced CKD management toolkit. The toolkit is currently being pilot tested with nephrology and internal medicine practices. In addition, RPA worked with NKF and CDC to revise the ICD-9 codes and is trying to educate its members and the PCP community about them.

## **V. Program Direction**

Ms. Gladstone walked participants through NKDEP's strategic plan, capturing current activities and future plans targeting three primary audiences (PCPs, patients at risk, and opinion leaders).

There was discussion about whether the program should maintain its focus on secondary and tertiary prevention or expand into primary prevention. Betsy Singer from NIDDK reassured participants that NIH is working on primary prevention through other programs, such as the National Diabetes Education Program, and can share information about these activities with the group.

Participants discussed some other ideas for NKDEP activities. Some participants suggested NKDEP work more with community health centers, and others suggested working with policymakers, although it was noted that the NKDEP can not lobby legislators. Participants also discussed specific ways NKDEP could work with their organizations in the future.

Ms. Gladstone then reviewed NKDEP's priority activities. These included identifying a new director, keeping current activities moving, integrating the "kidney connection" theme in NKDEP messages and materials, implementing dialysis audit recommendations, expanding provider outreach, and continuing the Laboratory Working Group activities. Other priorities that were not discussed at length included Hispanic outreach, proactive media, and collaboration with federal agencies.

## **VI. NKDEP Accomplishments**

Griffin Rodgers, MD, Deputy Director of the National Institute of Diabetes and Digestive and Kidney Diseases, thanked the Steering Committee for their hard work, and spoke about NKDEP's important and ambitious agenda. He thanked Dr. Hostetter for his work with the program, and reaffirmed NIDDK's support for and commitment to the NKDEP.

## **VII. Steering Committee – A Closer Look, Part I**

Nancy Accetta, an NKDEP contractor, presented findings from the 2005 survey of Steering Committee members. The Steering Committee currently consists of 38 member organizations. Almost half are health professional associations, with the balance including Federal health agencies/programs and non-profit, voluntary health, and service organizations. Consistent with health professional association membership, almost half of primary Steering Committee members are medical doctors, although several other health professionals are also represented on the Committee. Steering Committee organizations have engaged in a variety of NKDEP activities over the last year, including ordering and promoting materials during the NKDEP launch and observing National Kidney Month (March 2005). The majority of survey respondents felt the Steering Committee was operating effectively or very effectively, although they offered several suggestions for how the Committee can function better. Respondents also demonstrated varied perceptions regarding the roles and responsibilities of Steering Committee members.

## **VIII. Steering Committee – A Closer Look, Part II**

Michael Briggs, an NKDEP contractor, moderated a discussion about the current functioning of the Steering Committee. Three organizational models were presented as possible models for Steering Committee involvement in the planning and implementation of NKDEP activities.

Based on the survey findings, members perceive that the Steering Committee currently serves two functions: to set priorities/assist with strategic planning and to implement activities. A participant expressed concern about the group's ability to operate effectively as both a strategic and an operational body—that the group was not equipped to do operational work. This participant said he wanted more refinement on what NKDEP wants the group to be or to consider whether we should be structured differently. Throughout the afternoon much discussion centered on this and related issues—the function/role of the current group, the possibilities for other operational groups, e.g., work groups, and the implications for creating new groups.

There was agreement among Steering Committee members that the current group is more a stakeholders group than a steering committee. Steering Committee members agreed that this yearly Steering Committee meeting is useful to participants and they would like the opportunity to meet in the future to share what their respective organizations are doing and what is happening in the kidney community. They want information to take back to their communities and to hear more about what they can do to support NKDEP. Steering Committee members agreed that the current Steering Committee should take on a new name but that it should continue to exist for sharing and learning purposes.

### ***Steering Committee Composition***

Early in the discussion, Mr. Briggs pointed out that although the Steering Committee currently has 38 member groups, several key groups are not represented, including organizations representing diabetes educators, cardiologists and endocrinologists. Although no one disagreed, a participant later pointed out that there has been no outcry from groups that currently are not on the committee.

### ***Alternative Approaches to the Steering Committee Concept and Function***

Mr. Briggs indicated that the goal of the afternoon session was to outline and discuss alternative approaches to the Steering Committee's role, composition, and function that might better serve the NKDEP, not to remove organizations or necessarily to come to a consensus during the discussion. The models discussed are outlined below.

- Model 1: Ad-hoc working group (WG). Groups would provide guidance on specific tasks. This group would possibly be supplemented with a coordinating committee comprised of the chairs of each working group, among others.
- Model 2: Informal advisory board. Appropriate members would convene as the program requires to provide input on program direction.
- Model 3: Smaller planning committee. Smaller than the informal advisory board, this group of 10 to 12 would meet regularly.

### ***NDEP as a Model***

Joanne Gallivan, director of the National Diabetes Education Program (NDEP), shared with the group NDEP's Steering Committee and (operational) work group structure. NDEP, which is administered jointly by NIDDK and CDC, has a Steering Committee and an Executive Committee, which has the ultimate decision-making power.

### ***Discussion Summary***

Many Steering Committee members indicated that the model NKDEP chooses should be based on the program's needs. If, for example, the NKDEP has strategic planning skills in-house, then NKDEP may just need smaller working groups. Steering Committee members repeatedly stated that the NKDEP should determine what it needs and then implement the best organizational structure to achieve it.

Mr. Briggs confirmed with SC members that it sounds as if a combination of models may best suit the needs of the NKDEP.

## **IX. Next Steps and Closing**

Dr. Hostetter said that the NKDEP would continue to evolve a potential Steering Committee structure, and plans to update the group later this summer. He then thanked Steering Committee members for their participation and closed the meeting.

## Appendix

### Review of NKDEP Activities

**National Kidney Month** – Ms. Gladstone showed participants the website developed by NKDEP to promote kidney disease prevention during March—National Kidney Month. She provided results for the effort, which showed high traffic to the Kidney Month website as well as a significant increase in the numbers of visitors, page views, and downloads on the main NKDEP site. She also recognized and thanked Steering Committee members who helped promote the Kidney Month website.

**African-American Outreach** – Ms. Gladstone introduced the new Family Reunion Initiative for African Americans, and gave an overview of the Kidney Connection Toolkit, the Family Reunion website, and partner resources available on the website. Steering Committee members were encouraged to promote the initiative among their constituents.

**Expansion of outreach to new audiences** – Ms. Gladstone reviewed recent efforts to develop an NKDEP brochure for Hispanics, which included focus groups with those at risk and caregivers, and meetings with Hispanic organizations. The brochure will be tested with community-based organizations in Los Angeles and D.C. before being finalized.

NKDEP is also considering developing culturally appropriate materials for American Indians. Ms. Gladstone gave a presentation at a CKD workshop in Albuquerque and solicited the support of attendees in developing outreach to American Indians. Ms. Gladstone also has conducted numerous interviews with health care providers who work with American Indians to inform the NKDEP's outreach to American Indians.

**Dialysis Audit** – Ms. Gladstone reviewed the process used to evaluate the NKDEP dialysis program materials. The materials were found to be filling an educational gap. NKDEP is currently looking at how to implement the suggestions gained from the audit, and is thinking about repackaging the materials for centers to use with family-oriented events.

**New Materials** – The newest materials developed by the NKDEP are the updated CKD PowerPoint presentation, an NKDEP Resources Sheet, the desktop version of the Nephrology Consult Letter Template (developed with RPA), and a wallet card for providers about diabetes and kidney disease.

**Presentations and Exhibits** – Ms. Gladstone provided an overview of presentations and exhibits given or attended by NKDEP in the past year as well as upcoming presentations and exhibits.

**Laboratory Working Group** – Ms. Gladstone gave an update on the recent activities of the Laboratory Working Group, including its manuscript submission to *Clinical Chemistry*, developing the Understanding GFR educational tool for patients, its work on routine reporting of GFR, and a meeting in July to discuss the timeline for the standardization of the creatinine assay and the rollout of the revised GFR equation. Communications plans will be developed for

audiences affected by these changes. NKDEP has also submitted a proposal to secure NIH evaluation funds to identify how many labs across the US are reporting estimated GFR.