

**NATIONAL INSTITUTES OF HEALTH
NATIONAL INSTITUTE OF DIABETES & DIGESTIVE & KIDNEY DISEASES
NATIONAL KIDNEY DISEASE EDUCATION PROGRAM**

STEERING COMMITTEE MEETING

**Natcher Conference Center
Building 45
National Institutes of Health
Bethesda, Maryland
June 20, 2003**

SUMMARY OF MEETING

I. WELCOME

Josephine Briggs, MD, Director, Division of Kidney, Urologic and Hematologic Diseases at the National Institute of Diabetes and Digestive and Kidney Diseases (NIDDK) at the National Institutes of Health (NIH) welcomed participants to the launch of the National Kidney Disease Education Program (NKDEP). An enormous amount of work has gone into preparing for this launch led ably by Thomas Hostetter, MD, Director of NKDEP at NIDDK. Dr. Briggs also welcomed attendees from the 4 Coalition sites where the program will be tested in the U.S. this year and asked leaders of the Coalition sites to stand to be recognized. The four sites are Atlanta, Baltimore, Cleveland, and Jackson, Mississippi. The effort relies heavily on the work of these Coalition members and their partner organizations.

Participants today will review the plans from the 4 sites and collectively brainstorm ways in which the national effort can be enhanced through the efforts of these Coalitions and others to be formed in their manner in the future. The Coalition partner organizations present at this meeting are leading in their respective areas with programs whose goals overlap those of NKDEP. There is strength in redundancy. The difficult process of social change relies on redundancies in the message. Dr. Briggs reminded attendees of the long process to change smoking habits in this country. She was reminded of the complex array of partnerships of organizations such as the American Cancer Society and other non-profit organizations and the leadership of the National Cancer Institute in the educational campaign to eradicate smoking in the U.S. upon a recent visit to Europe where smoking is still very common. This National Kidney Disease Education Program campaign is similar to that effort in that it is necessary to have partnerships in order to increase awareness of kidney disease. If the effort is successful no one group will take full credit because the messages will overlap and amplify each other. The federal government has a unique role in this partnership.

The Federal involvement in this program brings some special advantages. First, the NIH drives the research agenda. There is a national epidemic of kidney disease. Renal failure

costs the country close to 20 billion dollars per year. The NKDEP effort will help NIH quantify the extent of chronic kidney disease (CKD) and define the research to ascertain which preventive methods are effective and which are not. The volunteer organizations have been very helpful in this area and will continue to help refine the research areas. Second, the Federal interest brings with it the ability to partner with other parts of the government to propel the effort forward. Partnering, for example, with the Centers for Medicare and Medicaid Services (CMS) and the National High Blood Pressure Program allows greater clout and has implications for lobbying to improve payment for prevention techniques. A Federal program for kidney education is very valuable. Third, the Federal government is able to bring together diverse groups to work in the effort under the Federal umbrella. Dr. Briggs closed expressing again her appreciation of the work of the four Coalition groups and introduced Griffin P. Rodgers, MD, Deputy Director, NIDDK.

African American Initiative

Dr. Rodgers welcomed Steering Committee members and guests on behalf of the Director of NIDDK. He briefly reviewed the history of NKDEP. In March 2001 a high-risk performance meeting was held on the spectrum of risk for CKD. In June 2001 many of the participants in the March meeting advised NIDDK to target African Americans with CKD. The need is great. In 2000 there were 400,000 Americans with kidney failure who needed dialysis or transplants. That figure will double by 2010. The annual cost of treating patients with kidney failure in the U.S. is almost 20 billion dollars. African Americans have a four fold increased risk of getting kidney failure. They comprise 13% of the population but they form 1/3 of the dialysis or transplant populations. Diabetes and hypertension are the main causes of kidney disease. This disease disproportionately affects African Americans. There are over 40 different organizations present at this meeting today in support of this NKDEP effort. They are helping NIH bring the message to a larger audience. In order for the message to be heard, understood and retained it must be repeated at least 6 times and have a "stickiness" factor. It is a challenge to make the message contagious and to make it stick in people's minds. The message must be connected to the audience. "Stickiness" is needed for the message to have an impact and change behavior. "You Have the Power to Prevent Kidney Disease" is the message. You are a person at risk if you have diabetes, high blood pressure or a family history of kidney disease. Good methods of diagnosis and treatment for kidney disease exist. That is the message. It is important to keep the message simple. Dr. Rodgers closed with his thanks to attendees for being here and his hopes for working with all in the future.

II. BACKGROUND AND OVERVIEW

Dr. Thomas Hostetter then addressed participants. He thanked the Steering Committee members and the representatives from the coalition sites for coming to the meeting. He thanked coalition members for helping to get the message out in local media, in the physicians' offices, the dialysis clinics, etc. Today's meeting is the first step in rolling out the message nationally. Dr. Hostetter also thanked NIDDK for its support. He then asked attendees to introduce themselves before presenting an overview of the past year for NKDEP. Much has been done but much is yet to be done. Among the main reasons for a National Kidney Education Program are the following:

- Kidney failure is a public health problem
- Economical, effective testing and therapy exist
- Testing and therapy are inadequately applied

In the last ten years testing and therapy have evolved. It is not well understood that effective testing and treatment exist. There is evidence that means exist to find and treat patients. The goals of NKDEP are the following:

- Increase awareness of the risk for CKD
- Increase testing for CKD
- Increase treatment of CKD
- Prevent/slow down progression to ESRD

The main target audiences for this message are:

- African Americans with
 - *Hypertension*
 - *Diabetes*
 - *Family History of Kidney Disease*
- Primary Care Providers

The NKDEP organizational structure is guided by NIDDK at the head of the organizational chart with work groups that feed into the Steering Committee beneath NIDDK and the partnership network. The work groups include the following:

- Patient/At Risk Work Group
- Evaluation Work Group
- Professional Work Group
- Laboratory Work Group

Many industries are interested in this program, which is good. This effort is one of several NIDDK education programs such as diabetes. In this past year NKDEP has developed materials and methods and has worked to aid the pilot sites in doing the same. NKDEP has also worked in improving lab measurements and reporting of kidney function. The program is working with non-profit groups, industry and government. Redundancy is the way to ensure that the message is effectively communicated.

Dr. Hostetter then described some personnel changes at NKDEP in the past year.

- Mimi Lising, MPH, left NKDEP for private business
- Phyllis Payne, MPH, had served as the Interim Associate Director and is now a consultant
- Elisa Gladstone, MPH, is the new Associate Director
- Laura Dillman is the Project Director in the contractor's office
- Ada Goldovsky, MPH is a staff member in the contractor's office.

NKDEP's work on CKD was geared to the primary care physicians (PCPs) in the past year. The process of spreading the message is an evolving one. They also spent much

time working with the Coalitions. NKDEP applied for and was awarded a NIH 1% side aside grant of \$500,000.00. This is for baseline and follow-up study of the knowledge of Primary Care Physicians (PCPs) and African Americans. NKDEP has also participated in many meetings and has exhibited at many meetings in the past year. Meetings included the American Association of Kidney Patients (AAKP), the National Kidney Foundation (NKF) in Virginia and in Houston, Texas; the 24th Dialysis Meeting; the American Heart Association (AHA); Renal Physicians Association (RPA); Prevention Meeting in Toronto and in Singapore; the American Nephrology Nurses Association (ANNA). Pending meetings include the American Association for Clinical Chemistry (AACC), American Kidney Fund (AKF) and the American Society of Nephrology (ASN). NKDEP also held a news conference with the ASN and the NKF. Work groups such as the Professional Work Group and the Laboratory Work Group also held meetings in July 2002 and July 2003.

The Laboratory Work Group has focused on laboratory reporting and harmonization of reported information and standardization of measurement units. The Work Group advocates estimating glomerular filtration rate (GFR) using the 4-variable MDRD equation immediately. The recommendation is to report a GFR greater than 60 ml/min/1.73m² or to report the exact GFR for any below 60 ml/min/1.73m². NKDEP plans to work with professional societies to send letters to nephrologists to ask their labs to report GFR. The letters will include supplementary materials from NKDEP to aid in the implementation of this recommendation. A position paper was written on this issue and it may be published in a national journal. NKF has supported reporting of the estimated GFR for some time. The group is also pursuing the development of a gold standard creatinine assay working with clinical chemistry organizations and is working on further improving the estimating equations. It is not yet known how accurate the equations are for those who were not in MDRD, i.e. diabetics and those minorities who were not in the trial. A joint NKF-NKDEP meeting was held on "Proteinuria and Other Markers of Kidney Disease." The summary is in press in the American Journal of Kidney Disease and contains some good guidelines. The American College of Physicians (ACP) and others have put NKDEP information in their newsletters.

A longer-term goal is to improve the creatinine assay. Gary Myers, PhD of the Centers for Disease Control (CDC) worked on the national cholesterol reporting and standardization effort and is helping NKDEP with this issue. The NKDEP website has a MDRD calculator to estimate GFR. The next step is to make this downloadable for hand held devices. The Joint National Committee on Prevention, Detection, Evaluation and Treatment of High Blood Pressure (JNC), advocates making this available for hand held devices. Other system level aids in which NKDEP has been involved include the following:

- RPA/ASN Guidelines for Pre-ESRD
- JNC VII
- K/DOQI

The JNC talks about kidney disease as a risk factor for cardiovascular disease (CVD). There is harmony among NKDEP, JNC, ADA, NDEP, and NKF in guidelines. The

message is built upon science, as it needs to be. Some current clinical trials of NIDDK include: CRIC, AASK CoHort, Halt PKD, Diabetic Nephropathy Pilot Studies and Focal Sclerosis. A Pediatric CRIC trial is pending.

Dr. Hostetter emphasized that the work of the Coalitions is crucial to the NKDEP awareness campaign. The Coalitions are testing the materials and messages prior to the national campaign and also helping to develop effective methods for dissemination of the information.

Dr. Hostetter asked the group to think about the following:

- What products do we need to develop over the next year?
- What should our next target(s) be?
- Should the scope of this campaign be widened?

Campaign Materials and Efforts

Dr. Hostetter then introduced Betsy Singer, MS, Director, NIDDK Office of Communications and Public Liaison. She began with some references to other resources available to NKDEP in this effort. NIDDK has a National Kidney and Urologic Diseases Information Clearinghouse that was established in 1987. It exists to increase the knowledge of patients, public and professionals. Dr. Briggs also publishes a newsletter for health care professionals. Education will hopefully lead to changes in behavior. The Clearinghouse, however, simply serves as an information source. Ms. Singer also named 3 key staff women who work in the Office of Communications. They specialize in obesity, diabetes and kidney diseases. Some of the information from other areas impacts kidney disease but the NKDEP program is unique in taking a grassroots approach in the four pilot cities.

Formative Research and Materials Development

Ms. Singer then delineated some of the formative research methods used as a foundation for the development of the NKDEP materials. These include the following:

- Compendium
- Literature Reviews
- In-depth interviews with PCPs
- Focus Groups

These materials are available to Steering Committee members upon request.

Ms. Singer then briefly reviewed the process to date by which NKDEP has assessed baseline knowledge among patients, primary care physicians and patients' families. In February 2002 Wave 1 of the effort consisted of focus groups done in Baltimore. Two were in-person while 4 were done over the telephone. The in-person groups were composed of African Americans with hypertension and/or diabetes. The telephone groups were composed of African Americans with kidney failure and family members of kidney failure patients. The purpose was to study CKD knowledge, attitudes and behavior. The findings were: knowledge of kidney disease is low; doctors are important

sources of health information, mild fear appeals are effective and family members and dialysis patients are willing to serve as conduits of NKDEP messages.

Wave II was conducted in June 2002 in Atlanta, Cleveland and Jackson among lower income, at-risk African Americans and middle income African Americans. The purpose was to see how participants reacted to NKDEP advertising concepts, i.e. photos and messages for print PSAs. Participants discussed the various advertising options and NKDEP staff used the information to determine which concepts most successfully conveyed the NKDEP key messages. Participants also considered potential themelines for the campaign.

NKDEP staff selected two concepts based on the formative research and the combined results of the Wave I and Wave II focus group discussions. One concept focuses on the family and providing information to family members of people with kidney failure. The message that accompanies the family photo is, "The risks for kidney disease run in my family. Good thing awareness does, too." The second concept features an African American doctor since all focus group participants agreed that doctors are an important source of health information. The tagline that accompanies the photo of the doctor for the print PSA is, "Wait too long to talk about kidney disease and you could be waiting for a kidney." This message plays upon mild fear as an inducement to pay attention to a serious message. The program hopes that magazines, journals, and newsletters will use the materials.

NKDEP staff has also developed a consumer brochure and a fact sheet for PCPs as well as a fact sheet describing the pilot site initiative. The *NKDEP Community Action Toolkit* includes materials to help volunteers in the 4 pilot sites develop community outreach programs.

Community Pilot Sites

The Toolkit was taken to each of the 4 Pilot sites last October to aid in strategic planning efforts. The NKDEP team visited each site to bring Coalition members together. By January 2003 the Coalition sites had developed their program plans. NKDEP supports the Coalitions through these strategic planning meetings, development of program plans, PCP mailing, media training and technical assistance, NKDEP materials and a site-specific banner, NKDEP website and audiovisual materials.

Media Training

A consultant to NKDEP provided media training for 21 people in the 4 pilot cities. Local media input will be a major factor in the success of the campaign. NKDEP staff also provided a set of talking points for each spokesperson, press kits, press calls and NIH press releases and media advisories.

The PCP Mailing

In response to suggestions at last year's Steering Committee meeting, NKDEP staff mailed introductory materials to PCPs in all 4 pilot sites, so that they would be aware of

the campaign. The mailing included: Dear Colleague Letter, *PCP Targets* fact sheet, consumer brochure, information on "How to Document the Care of Your Complex Patient" (developed with the Baltimore Coalition) and a response postcard that went out with the PCP mailing. (A copy of the PCP mailing was distributed to attendees). The "Dear Colleague Letter was signed by Tom Hostetter and a Co-Chair from each respective city. The returned "bounce back" cards have shown a positive response to the mailing.

The NKDEP Website

NKDEP staff created a Community Pilot Sites section on the NKDEP website. Staff hope that coalition members will make use of this section to share information with each other including a program plan for each city. Coalition members from each city have a page to display their program plan, to highlight success stories and media coverage, to share an event calendar for the year and to list coalition members and member organizations.

Audiovisual Materials

NKDEP has also produced a PCP slide presentation and is working on radio PSAs, and radio scripts to be read live and a video. The slide presentation is available on CD and is also on the website. The video will be an educational video for use in dialysis units, churches, health fairs and PCP offices. It targets family members of people with kidney failure.

III. PRESENTATIONS COALITION UPDATES

Atlanta Coalition

Janice Lea, MD, Coalition Co-Chair who is also a nephrologist from Emory University provided an update on her site's activities. She showed an impressive list of organizations aligned with her Coalition in Atlanta. One of her Coalition's general strategies has been to tag their message to on-going activities. Any event with a health-related issue is a place for them to get involved. They are also involved in events they specifically designed for NKDEP such as their kick-off event at Grady Hospital on May 14th. This hospital caters primarily to African Americans. The NKF and AKF also participated in this event as did Ortho-Biotech and other supporting groups. They distributed information on kidney disease at the event. The NKF did screenings (KEEP Screenings-Keep Your Kidneys Healthy). Seventy-five people were screened. These were patients with hypertension, family history of CKD or diabetes who did not know they were at risk for KD. Another 100 people got information but were not screened. The newspapers also came to the event. Recently, the *African American Journal* published an article on "You Have the Power to Prevent Kidney Disease" mentioning NKDEP. Dr. Lea takes every opportunity to publicize the NKDEP message. Atlanta has done several radio interviews on the importance of being tested for KD. The Coalition has also set up church screenings working and will distribute the NKDEP materials at those screenings. Other channels of distribution of the materials include fire stations holding blood pressure screenings,

hospital taped messages that play when a caller is on hold, ADA church outreach efforts and church health fairs.

Atlanta's Physician Outreach efforts include local presentations to the Atlanta Medical Association, employers, residency programs, grand rounds, the Georgia Academy of Family Physicians, etc. The Coalition also plans to reach PCPs at the AKF meeting in August in Atlanta. Dr. Hostetter will speak there on CKD and Dr. Lea will speak on hypertension. In September the Coalition will participate in the NKF Nephrology Update. They will also be part of a one-day conference next March for PCPs at Emory and will distribute the PCP Targets during education sessions.

Media outreach activities include the previously mentioned radio interviews, work with local politicians and Tom Joiner, a talk show host as well as print PSAs. Tom Joiner's show is nationally broadcast and has a website. His show will post information about NKDEP on the show's website. Dr. Lea appeared on "Good Day Atlanta" with Alonzo Mourning. A newspaper article was also written on their presentation. Ortho Biotech arranged for them to appear together and also support NKDEP.

Baltimore Coalition

Jeffrey Fink, MD, Baltimore Coalition Co-Chair gave the Steering Committee an update on the Baltimore Coalition's efforts. The member organizations in this Coalition comprise a long list from universities and the Maryland Department of Health and Mental Hygiene to the ADA, a Baptist Church and the Urban League. The NKDEP Baltimore Coalition was one of the sponsors of the Community Health Awareness & Monitoring Program (C.H.A.M.P.) "*Health Freedom Walk: A Path To Wellness*". This 6K walk stopped at Historical Underground Railroad Stations throughout Baltimore and was designed to help Baltimore residents modify risk factors for cardiovascular disease. NKDEP messages were included in the training materials provided to the health advocates/trainers AKA "conductors" for the walk. These messages were repeated to the walkers during the 6 weeks of training that preceded the event. Future programs include church outreach, festivals and working with Baltimore City Community College to do an NKF KEY Screening. In conjunction with the local NKF affiliate, the Coalition has also participated in several mall-based screenings for hypertension, diabetes and KD. They identified many with early KD and glucose intolerance in this process.

Volunteers in the Baltimore coalition hope to make direct person-to-person contact with patients and family members in the dialysis units. They will play the NKDEP videotape and ask patients to deliver materials to family members. The dialysis unit is the key point of contact in the plan. It allows the Coalition to distribute materials at a low cost in a very efficient manner. The Coalition is also seeking funding from industry and other sources.

In the outreach efforts, the patient becomes the point of contact in the community. The brochure "How to Handle Your Complex Patients" speaks to PCPs and is a good tool to help physicians realize that the patient with early KD is complex. The fact sheet identifies the dimensions the PCP should explore when looking at a patient. The Coalition also attaches a note to hospital discharge summaries at Johns Hopkins (and is working to

implement this process at the University of Maryland) to make physicians more aware of patients who are at high risk for KD. They will also present a slide presentation to the Maryland Academy of Family Physicians. The Coalition plans to do radio interviews and get press coverage for its activities.

Cleveland Coalition

Steven Lovelace of HSI Hemodialysis Services, Inc. presented the plans for this Coalition. They, too, are partnering with many organizations such as the Kidney Foundation of Ohio, Inc., The Urban League of Greater Cleveland, Ohio Department of Health, etc. Their kick-off will be at an African American Picnic August 1-3. They are expecting 100 to 150 thousand people to attend. They are playing upon the family affair theme of the campaign and plan to ask the local media to help attract attention to CKD with a feature story, television and radio news shows, talk shows, PSAs and newspaper articles. They will have kidney patients who are part of the Coalition speak to the press. Like the other Coalition sites they plan to do community outreach, screening events and distribute materials. They will place ads on church vans.

To reach the PCPs they will participate in grand rounds in hospitals and conferences at community health centers. They also will place articles in professional association newsletters to appeal to PCPs.

In order to spread the message to dialysis centers they participated in the poster session at the Renal Network meeting. They will send a letter to dialysis units with the NKDEP video and materials. Their volunteers will target staff at dialysis units and their families. They will ask them to watch the video and hand out the materials. T

They will target older persons (over age 55) via the churches, senior centers, nursing homes and assisted living facilities. To reach the younger population they plan to use movie theatre stills viewed prior to the movie, to participate in an exercise simulcast and work site programs.

Jackson Coalition

John Bower, MD, Coalition Co-Chair and a community volunteer, provided meeting participants with an update on the activities at the Jackson site. He began by thanking Dr. Hostetter and his staff for the support they have provided to his site. He also acknowledged another Jackson Co-Chair, Brenda Dyson, whose efforts have made a tremendous difference. She herself has had two kidney transplants. The Jackson Coalition is participating in and planning efforts similar to those of the other Coalition sites. They did a Kidney Early Evaluation Program (KEEP) screening at the Jackson Medical Mall in March. They participated in a minority health fair in April. Other activities include grand rounds at the Medical Center, speaking at society meetings, other health fairs and diabetes events and biotech meetings. They are aligned with the Mississippi Chronic Illness Coalition as a separate section and work with their media. Among those with whom they have teamed are Baxter, the Urban League of Jackson and the Jackson Heart Study whose population is the same African American group who are at risk for both

CVD and KD. They are also working with patients in the renal care group at the Medical Center.

Brenda Dyson of Network 8, Inc. is an active member of the Jackson Coalition. She is also President of the Mississippi Sports Hall of Fame and is taking the NKDEP message to local athletes. The Coalition is also working with preachers in the area to disseminate information on KD. A resolution was passed in the Mississippi State Medical Association to endorse the concept of "Know Your Numbers" (the National High Blood Pressure Program slogan). Jackson is working with local media in ways similar to that of the other Coalition sites.

Dr. Hostetter closed this session. He summarized saying that these presentations are a sampling of the Coalition efforts. He asked Steering Committee members to send any ideas of additional activities to be incorporated in these efforts. NKDEP has this year to further hone the campaign materials prior to the national launch.

ROUNDTABLE REPORTS

Participants gave brief summaries of their current NKDEP-related activities. The American Society of Hypertension is trying to introduce the NKDEP materials into its current program. This requires tact and timing. They have chapters that are independently governed. The Washington/Virginia Chapter will submit a grant for NKDEP activities. On September 20 a full presentation of the NKDEP effort will be provided to the Executive Council. In Richmond a wide range of NKDEP-related efforts have been done with independently acquired funds. Consensus is building for this effort within the Society.

The Renal Physicians Association (RPA) is working on education of PCPs on CKD. The specialty areas know very little about CKD guidelines. The Quality and Accountability Committee of the RPA is involved in developing practical tools for information sharing between nephrologists and PCPs on laboratory values, etc.

The Society of General Internal Medicine focuses their KD efforts on the annual meeting. They are working on a KD pre-course prior to the meeting aimed at those teaching PCPs in medical schools.

The American Society of Transplantation representative describes his organization as representing the failure of KD education in a sense. They interact with NKDEP and advocate organ donation. Patients with normal renal function are potential donors. Those with kidney transplants hopefully have normal renal function that they want to protect and they want to be aware of KD in order to prevent it. They need to know the early signs of impending renal failure.

Dr. Hostetter commented that specialty groups such as the RPA and the transplant nephrologists have a big role in education.

The Indian Health Service (IHS) is improving standards of care for those with KD. The IHS has educators, nutritionists, etc. working on improving kidney care. Their basic approach is to build things into the system such as implementing the use of the MDRD equation to estimate GFR into their laboratory system. They learned quite a bit about what happens once GFR reporting is implemented. There are 1.5 million people in the system and when a creatinine is ordered for any patient over 16 a calculated GFR is reported. They are getting feedback now on this system and have ideas about where this ought to go in the future. The IHS also does education for PCPs, pharmacists and nutritionists. The Indian population is a defined one with a high risk of disease. Since the IHS has a system to deliver kidney care they can serve as a model and a lab to implement some of the things NKDEP is discussing.

The registered nurses sorority, Chi Eta Phi Sorority, Inc., have chapters that are very involved with the Coalition in Atlanta and Cleveland. Every year the chapters across the U.S. do their own health education. They are very active in grassroots activities like churches and the Essence Fest in New Orleans, distributing materials on maintaining health.

The Centers for Disease Control (CDC) fund health departments as one of the main foci. All 4 Coalition pilot sites have representatives from the CDC among their member organizations. State Health Departments are working on primary prevention campaigns and the ABC campaign. The CDC also has an Entertainment Education Initiative with tip sheets on health conditions for screenwriters in California. These are used in story lines. One was done on kidney disease and will be posted on the CDC website shortly. This allows the CDC to publicly disseminate accurate information on KD. Another arm of the CDC with Gary Myers, PhD is working with NKDEP on assay issues.

The American Academy of Physician Assistants (AAPA) is working on increasing knowledge of NKDEP and KD. They work closely with NKDEP to educate about diabetes and kidney disease. They have done continuing medical education (CME) credit sessions on this topic at their annual conference. The Chair of the National Diabetes Education Program spoke at their annual meeting and highlighted NKDEP in his talk. The AAPA also runs a Challenge Bowl annually for students and this year it included questions on kidney disease in the Bowl. They also met with Dr. Hostetter and the former Assistant Director of NKDEP last summer. They would like to do a national campaign and are searching for a partner to fund it. Dr. Hostetter added that if the Academy can increase awareness of reading routine tests that effort alone would be good.

The Centers for Medicare and Medicaid Services (CMS) are involved in quality improvement activities for both in- and out-patient care in the renal disease network program. Quality Improvement Organizations (QIOs) are partners with each of the 4 Coalition sites. Their Senior Clinical Advisor wants to have a conference call with the QIOs at the four sites to get an update on how the effort is working. This is an interesting time for quality improvement. Health care initiatives will be part of the next political election campaigns. There is potential for an infrastructure to be developed as it pertains

to clinical care and this could be plugged into the CMS system. Dr. Hostetter mentioned that NKDEP will facilitate getting the relevant QIOs together.

The Acting Director, Center for Quality Improvement and Patient Safety with the Agency for Healthcare Research and Quality reported that he testified recently on Capitol Hill on the growing rise in kidney disease and the lost productivity due to the disease. Some studies done in two cohorts have shown that the progression to ESRD has decreased but a scientific evidence base is needed. He emphasized that research is critically important in this area.

The American College of Physicians (ACP) is the largest subspecialty organization in the world and is comprised of physicians, residents and students. The College does not have a defined role in the NKDEP effort. However, its representative is working on ways to bring the NKDEP message back to his organization. Every medical sub-specialist is an internist. Half the ACP members are internists and internists have an interest in KD. In the last 3 years the Annals of Internal Medicine has had major articles on CKD and prevention. That publication can be used to get the message out. Each chapter has specific educational activities locally and these, too, can be utilized to distribute NKDEP materials at each chapter meeting. Since ACP reaches medical students it can affect change at that level too.

The Forum of ESRD Networks focuses on improving quality for patients. They have focused on end stage, not the conditions that precede end stage. There are 250,000 patients in dialysis units across the country who are prime targets for the NKDEP message, along with their families. The challenge for the ESRD Networks is to figure out how to appropriately utilize the networks for NKDEP. Dr. Hostetter commented that this group constitutes an "enriched group on dialysis" who could be missionaries for the NKDEP message.

The American Academy of Family Physicians (AAFP) has 90,000 members and constitutes the largest audience for NKDEP. However, the organization is cutting back on its partnerships with other organizations. Time is an issue and the AAFP at the national level does not want to listen to the message on KD. Dr. Cynda Johnson recommends that NKDEP work with the State Academy Chapters because they are strong and active. The NKDEP exhibits at the large AAFP annual national meeting have made a difference. Dr. Johnson has tried to appeal to constituencies that make a difference. She has reviewed the NKDEP messages designed for PCPs. She emphasized that it is very important to keep the messages clear, simple and consistent. She also writes articles on KD.

In the past year the American Academy of Nurse Practitioners (AANP) published a review article of the K/DOQI guidelines. They are going to have a presentation this month on CKD and KD. They are composed of group members, not chapters and half the membership is family nurse practitioners. They are considering using members from small towns as conduits to larger groups. A survey of members has shown that they like to receive clinical updates and patient education materials. Seventy percent of them use email and the internet and the organization will communicate with them electronically.

They also have a new Director of Communications who has a marketing background and will help them promote information from organizations such as NKDEP to members. There is a need to teach those in rural areas the importance of KD and the new recommendations.

A representative from The American Heart Association, Council on Kidney, gave a brief update of the Council's KD-related activities. There is a lay wing and a professional wing in the Association. The professional wing is more scientifically based. The Council has been more interested in recent years in getting involved in kidney disease. They are going to sponsor the fall meeting section on hypertension. Kidney disease and CVD have been big issues. Word is spreading that CKD has a big impact on hypertension and is an independent risk factor for CVD. There is more interest within the Association now in programs such as NKDEP. Information on NKDEP has been published in the Council's newsletter. The newsletter from the Kidney Council has been combined with those of the other Councils into one quarterly brochure. If one is a member of any Council, he/she will receive this brochure. Therefore, NKDEP can get exposure to every member of the AHA professional organization through this brochure. Dr. Hostetter added that the notion that CVD tacks with KD is new to many. KD is a risk factor for CVD along with elevated cholesterol.

The American Society of Pediatric Nephrology would like to broaden NKDEP's educational program to include screening of adolescents at high risk for KD. Many patients who present at later ages (in their 30s, 40s and 50s) probably had signs of KD at earlier ages. There is an epidemic of Type II diabetes and hypertension and the Society would be interested in partnering with the American Academy of Pediatrics in fighting KD.

A representative from the International Society of Hypertension in Blacks (ISHIB) updated the Steering Committee on ISHIBs activities. They have formed a Kidney Council; there is also a Diabetes Council. The Kidney Council has been charged with developing an agenda for the organization pertaining to advocacy and research for the lay public and for professionals to be used in their 5-year strategic plan. They also have plans to hold a course prior to the annual meeting with management with information on detection of kidney disease. They are also working with the National Kidney Foundation and the CDC giving grants to teachers of genetic medicine to identify markers of kidney disease. The Society has also developed tools to aid the PCPs in diagnosing and treating KD. They have developed practical tools to be used clinically that give adequate information at the point of service and can be downloaded. They have made a grid depicting ranges of serum creatinine by age and ethnic group to come up with an estimated GFR since most physicians and practitioners do not have access at this point to electronic means of calculating GFR. Hypertension is important and the Society is focused on that but the focus is being broadened to include experts from other areas that also contribute to CVD. The Society has published guidelines on treatment of CVD, meta syndrome, KD and hypertension. Dr. Hostetter added that hypertension continues to make the rate of ESRD climb in this country.

Staff members from the American Kidney Fund work with the Coalitions in Baltimore and in Atlanta. CKD is a new emphasis for the Fund. They have a new program, Minority Interventions in Kidney Disease (MIKE), which emphasizes outreach to the African American and Hispanic populations in Atlanta, Washington, DC, Chicago, and New York City. In addition, they have developed a brochure to distribute to PCP offices which also will be distributed at the annual meeting of Diabetes Educators in August.

The American Nephrology Nurses Association is trying to develop a special interest group on CKD. They are seeking funds to support this goal.

The National Kidney Foundation has been very active in the past year. Since the publication of the K/DOQI guidelines in 2000 the NKF has done outreach to the public and to PCPs on early detection of KD. The K/DOQI Guidelines can be downloaded from the website at www.kdoqi.org. The Foundation is spreading the word about CKD to PCPs through clinical meetings, media opportunities, public service announcements, local affiliates, KEEP screenings, insurance companies and government relations activities. One of the key meetings is the American Academy of Family Physicians. They distributed brochures and other materials at this meeting and developed a database of physicians who stopped by the NKF booth. They exhibit at many meetings throughout the country. Over 20,000 have participated in KEEP 2.0 screenings as of May 2003. Over 10,000 doctors are enrolled in the KEEP database.

The NKF launch of K/DOQI CKD Guidelines has generated 31 million media impressions in major media such as the New York Times and CNN. The NKF campaign featuring Alonzo Mourning and Sean Elliot generated awareness of KD among the public and PCPs. There have been 9,524,040 print impressions and 502,779, 400 broadcast impressions to date with the message: "Don't Let Kidney Disease Catch You Off Guard." NKF is also working with other groups such as the Medical Association of Georgia to adopt the NKF CKD Classification Guidelines as "Best Practice." They work with insurance companies and government organizations at the state level. The next steps include:

- launch advertising campaign
- kick off KEEP 3.0
- CKD e-newsletter to PCPs
- seek speaking and marketing opportunities at clinical meetings
- ongoing media relations

NKF is also working with managed care organizations. They launched a study in Pittsburgh with Coventry Health. There are 4000 PCPs in their organization who reach 200,000 in the Pittsburgh area. The laboratory will report estimated GFR in this study. They are also working with 3 laboratories in New York State to report eGFR.

NKF affiliates are involved with all 4 NKDEP pilot sites. They will hold symposia on CKD in Colorado, Illinois, New York, Georgia, Maryland, Michigan and Hawaii. They use government and medical organizations and grassroots efforts to reach PCPs. In Wisconsin they delivered 4,000 copies of their Guidelines and other materials. In South

Carolina they held a press conference with the Lieutenant Governor on the importance of CKD treatment and prevention. They launched a public service campaign. In addition to finding the K/DOQI Guidelines online, they also make available a downloadable GFR calculator and clinical action plans. The Guidelines will be sent out for review in August.

A representative from the American Dietetic Association expressed some concern that renal dieticians are not more prominently mentioned as partners with the Coalition sites. Renal dieticians can see CKD patients who are not on dialysis and the expense is reimbursable under Medicare and as such is covered by other insurance companies. She advocates integrating nutrition education more effectively in the pilot campaigns and asked that she be contacted if the sites need names of appropriate persons to participate in their areas. Atlanta does have a renal dietician representative as do most of the Coalition sites. The NKDEP information targeted at PCPs recommends getting nutritional counseling for KD patients.

A Medical Officer of the Health Resources and Services Administration told the Steering Committee that her organization wants to include NKDEP information in their materials. One of their goals is to decrease the number of organ donors and the need for donated organs. They will use messages consistent with the NKDEP program.

The Veterans Administration (VA) has implemented laboratory reporting of estimated GFR. Malnourished patients present a difficult group for estimated GFR. The New Haven VA is working with Yale on a telemedicine program for patients managing anemia (among other programs). Patients can dial an 800 number and get answers to their questions. They are then asked if they want more information on anemia. The VA calls them subsequently with more information and with a renal management survey. The VA may do more telemedicine in the system. This is an early attempt in KD. Patients can reach the VA and learn more about KD. The VA intranet system is an educational resource for patients and physicians with listings of guidelines for hypertension and vascular access management.

The American Association of Kidney Patients (AAKP) has pre-ESRD materials and has been involved in the prevention of KD for some time. They publish an e-newsletter (Kidney Beginnings), provide CKD awards to a physician and a patient at the annual AAKP meeting, and many chapters have held or are planning to hold a half-day seminar, "Finding Your Strength"

Dr. Hostetter closed this session saying that redundancy is good. All the organizations present want to learn from each other and keep in mind what others are doing.

NKDEP SURVEYS OF AFRICAN AMERICANS AND PCPS

Purnima Chawla, PhD, presented preliminary findings from the NKDEP surveys seeking baseline information on knowledge, attitudes and behaviors related to CKD among African Americans and PCPs. Analysis of the survey is not yet complete. There was no comprehensive dataset on attitudes toward KD, although some kidney testing data was

available. These surveys provide baseline information. A second survey will be done in one year to assess changes in attitude, behavior and knowledge due to the NKDEP program model. This original survey will provide formative data for practitioners and planners.

To conduct the survey, 2,017 phone interviews were done with African Americans aged 30+ in the 4 pilot sites (Atlanta, Baltimore, Cleveland, and Jackson) and in 3 control sites. There were approximately 400 contacts in each of the 4 pilot sites and 400 in the composite control site. They also faxed surveys to 665 PCPs.

Consumer Survey

The findings among consumers are as follows:

- Hypertension and diabetes are seen as major health problems with serious health consequences. Conscious, top-of-the-mind awareness of CKD as a health problem is low (3%).
- Very few respondents mentioned CKD as a complication of diabetes (17%) or hypertension (8%).
- Overall awareness of CKD is high. Ninety percent of those questioned have heard of CKD and 67% know ESRD patients. Ninety four percent think CKD is very or somewhat common.

Actual knowledge of CKD is very poor. More than half do not know what it is. Twenty-nine percent can name no risk factors. No single factor was named by more than 18% and only 2% mentioned family risk. Half can name no causes and many others have misperceptions. Two-thirds think there are symptoms such as pain, difficulty urinating or frequent urination. They are not aware it is a silent disease.

Personal risk perception is not aligned with actual risk. Fifteen percent see themselves at high risk yet 45% have one or more risk factors. Only a quarter of those at risk identify themselves as such. High-risk perception is due to diabetes, hypertension or family history. The reasons for low risk perception are not clear.

Even those who have been tested for KD do not understand the test. About 1/3 of the sample had been tested for CKD. Approximately half of the high risk people had been tested but about 2/3 could not identify the type of test used. Those who could identify the test said general blood or urine tests.

Most persons think CKD is preventable (mean of 6.8 on a scale of 0-10) and treatable (mean of 7.5 on a scale of 0-10) but they do not have a clear idea of prevention or treatment. About 1/3 did not know any ways to prevent or slow disease progression. No more than 1/3 mentioned any particular way to slow or prevent KD. General health habits such as good diet and drinking plenty of water were most often cited. About _ had discussed KD, 8% with their doctor and 7% with a friend or relative. There was no consistent message communicated to them by their doctors. Fourteen percent had encouraged a friend or a relative (8%) to get tested while 29% had seen information on KD, most often in the doctor's office, on TV or in a newspaper or magazine. Twenty-two people in the sample (1.1%) had CKD.

PCP Survey

The NKDEP PCP Survey was focused on understanding their attitudes and practices regarding KD and the kind of care they are currently providing. Seventy-percent of the sample were physicians and most were working in private practice. About 5% were working in community health clinics. They were fairly experienced and had a mean age of 46.

Most respondents (87%) see more than 200 patients per month. There is a fairly high incidence of hypertension and diabetes with half of the patient population having one or both. The ethnic composition of the patient population was about 1/3 African American. Doctors are aware of the risk factors for KD and virtually all say they emphasize the disease as a negative outcome of diabetes and hypertension. However, they may not discuss CKD often enough; only 46% said they discuss CKD always or frequently. They believe KD can be prevented and treated in most cases. Most follow the ADA position statement and/or JNC VI guidelines.

Other findings relate to actual clinical practice. Some key tests are not performed routinely for diabetes and hypertension patients. Less than 1/3 regularly use GFR and 46% say they do not use this index. Estimated GFR, therefore, is not consistently used as an indicator for KD. Even when doctors test for CKD they may not report the test result to the patient. Only half always discuss the test results and 13% discuss test results only when there is a problem. Doctors also report that they lack materials on KD. Only one third have sufficient materials. Brochures are most often used. About 2/5 say discussion of CKD is increasing while 29% say patient awareness is also up. KD-related tests are performed less often (e.g. dipstick for proteinuria is used by 87% of PCPs and 84% of patients receive it; spot urine albumin/creatinine ratio is used by 64% of PCPs and 68% of patients receive it).

Attendees had some questions for Dr. Chawla. One concerned clarification of PCP response. The physician response rate was poor. Initially phone calls were used, but finally NKDEP letters and faxes were sent. The final response rate was 40%. Consumers were contacted via random phone survey. There were many who did not want to respond. The hardest part of the survey was locating the right person to speak to on the phone. The government credibility behind the survey helped to get responses.

Dr. Chawla could not specifically say whether or not the questions asked PCPs to differentiate between calculating creatinine clearance and GFR. It is not clear whether or not PCPs understand that a calculated clearance differs from a creatinine clearance.

The consumer sample is biased toward females in households but is well distributed across age groups. However, the actual distribution between males and females has not yet been done.

This is a self-reported behavior survey. Self-report may differ from actual behavior. It was suggested that NKDEP measure what tests/treatment patients actually receive. There are databases that publish this information. Dr. Chawla said she would look at those databases. However, she added that the thinking behind this survey is that having documented what doctors are reporting they are willing to do shows whether or not there is a knowledge deficit. There is some information on what doctors are actually doing and the discrepancy between the actual behavior and the reported behavior can be measured and used for educational purposes. Although response rates were less than optimal they are relatively representative of the populations surveyed.

Dr. Chawla was asked if she could apply the data on perceived behavior to the actual practice patterns of this population. She responded that HIPAA constraint prevent this. The physician-meeting participants questioned the survey findings. They do not believe that 22% of doctors are getting 24- hour urines to test creatinine clearance. They do not think that findings reflect actual practice. Dr. Chawla responded that the survey is intended to show change. In the context of pre- and post-program interventions, it makes sense to be looking at these numbers. Dr. Hostetter commented that pre and post numbers are valuable in their own right. He added that NKDEP has some resources so suggestions for the post survey are welcome. He asked that those with suggestions approach members of the Evaluation Work Group.

UPDATE ON THE CKD INITIATIVE

Tom Parker, MD, Clinical Professor, University of Texas Southwestern School of Medicine and Medical Director of the Dallas Transplant Institute is a nephrologist known for organizing an instrumental meeting on quality in dialysis care. He was recently called upon to study CKD. He gave the Steering Committee an update on the CKD Initiative. He began by complimenting Tom Hostetter on his accomplishments and his restraint in grappling with this complicated issue. The Council of American Kidney Societies (CAKS) proposed the CKD Initiative. The president and president-elect of 6 kidney-related organizations that meet annually or semi-annually (ROA, ASN, NKF, AST, ASPN, PKDF), wanted to make sure that they do not work at cross-purposes with one another. These organizations decided they had no coordinated effort with regard to CKD. They wanted to have a meeting in Fall 2003 with 1000 persons to talk about the state of the science and what needs to be done to solve the current state of CKD. They perceived that the number and demographics of those with CKD are unknown and there is no method to identify either one. There are problems with creatinine, GFR, etc. There is also a diverse and uncoordinated approach to the problem. Some of those involved are NKDEP, the government, pharmaceutical companies, societies, etc. There is not a clear, unambiguous message on CKD as there is on cholesterol or hypertension, these groups thought. The science and the recommendations are not packaged in a manner to appeal to PCPs or nephrologists. Payors also do not seem to recognize the problem. There is no care model that PCPs like and use and there is insufficient awareness. These 6 organizations, therefore, formed a Steering Committee, but decided not to have the Fall 2003 meeting. They wanted to develop an infrastructure for a plan, and then present it to the public, to caretakers and to all interested parties. They felt a broader, more

comprehensive process such as a CKD Initiative was needed. The plan was to have an Initiative for one year, then hand-off the effort to existing agencies and societies that are already involved in this area. The Initiative would serve as a catalyst in this area. A stakeholder meeting was held February 25-26 in Washington, DC with 50 attendees including Dr. Briggs, Dr. Hostetter, clinical laboratories, Indian Health Service, universities, pharmaceutical companies, physicians, patients, nurses, dialysis providers, etc. Sponsors include the ASN, the NKF, the RPA and some pharmaceutical companies (Amgen, Ortho, Abbott, and Watson).

As the NKDEP Steering Committee is aware, millions-perhaps 15-20 million may have CKD or renal failure. There are high costs associated with CKD and manpower issues in treatment. Prior to the February 2003 meeting, the Initiative contracted with CWA Interactive Management and interviewed about _ of the participants. The process included establishing the following:

- barriers to solving the CKD problem
- a hierarchy of barriers
- solutions to the barriers
- a hierarchy of achievable solutions

In light of the discussion paper presented on improving CKD patient outcomes what barriers do the community of stakeholders face in ameliorating the CKD situation was the bottom line question. They came up with 85 barriers. To reduce and organize those barriers, they also asked if solving one barrier would lead to an easier solution to the next, etc. in the context of designing an action agenda for improving patient outcomes in CKD. Approximately 70% of the 50 participants had to agree on priority for a barrier.

The group agreed on the following priorities:

- To coordinate the many groups and have one group with a large mandate;
- To standardize and encourage reporting of GFR in support of NKDEP's recommendations;
- To develop simple guidelines for patients to understand the importance of screening and care (there is a need to market CKD);
- To determine a disease management model for caretakers;
- To develop a uniform definition of CKD among caretakers; and that
- K/DOQI is simply written but not simple enough.

An organizational tree came out of this research. There is no manpower on the tree. The 3 root issues are:

1. Evidence for effective therapy;
2. laboratory reporting of estimated GFR, and
3. development and distribution of guidelines for patients and providers.

The theory is that payors will spend less money if these recommendations can be implemented. Various components of this tree can be tackled. Awareness as a necessary task permeates the entire project. The project is to have a finite life and then disappear.

Secondary stakeholder messages include the following:

- urgency
- do not do primary research; do not reinvent what has been done
- package what already exists
- get the message across
- turn the project over to others

These secondary messages can be summarized:

- Develop a uniform definition.
- Build on existing programs and package the information simply.
- Develop clear and all encompassing yet crisp definitions and tailor the information to various stakeholders.

Tom Hostetter heads the Laboratory Reporting Committee. This complements the NKDEP/NIDDK program in this area to convince laboratories of the need to immediately begin reporting estimated GFR by 2004. The effort should be timed to market it with the other root issues and more robust testing and reporting should continue to be developed.

In terms of evidence for effective therapy the group decided to determine essential therapy to alter progression and comorbid conditions and it is necessary to develop a prioritization process for hierarchies of caregivers. All this needs to be packaged and marketed.

Existing guidelines, the group decided, need to be synthesized (e.g. NKF, RPA, NIDDK, ADA, etc.). Questions related to this part of the effort concern how this package should look and how best to deliver and market the guidelines.

In terms of clinical practice what disease management model is effective and convincing to patients? Clinical practice barely breaks even currently in caring for CKD patients. How should disease management be implemented clinically? How can the effort translate care to the clinical physicians at the encounter level?

In terms of payors, how can the effort get the attention and support of payors? The effort must demonstrate the best care models and therapies to payors.

The President of RPA is the Chair of the Caretaker Committee. He knows the caretakers are (e.g. PCPs, cardiologists, nephrologists, nurses) and how to market to them. There is also a need to educate and involve the caretakers.

This Initiative is not a big scientific effort nor is it intended to be one. The goal is to take what already exists and package it. The ability to simplify means eliminating what is

unnecessary so that the necessary can be heard. The solution may be to give the PCP 6-7 things that they need to know.

These committees were formed and were functioning well. A meeting was planned for early summer 2004 before this would be rolled out to the general public. The ASN and the NKF then decided to conclude the CKD Initiative and apportion the activities to various agencies and societies. A final report with suggestions for transferring categories to various agencies and societies is being drafted. A paper is being written with AJKD and JASN in 90 days. The idea is to synthesize the science, care models, guidelines and economics into a package that will increase awareness of the public and caregivers and then provide immediate tools while the science continues to be developed.

One of the recommendations of the CKD Initiative that will be in the final report is to develop a Committee of the Whole of those who should participate plus an additional 10-12 people who will all continue to push this effort forward, monitor it and continue to have various people talking with one another.

Meeting participants had some questions for Dr. Parker following this presentation. Will the group work on changing diagnostic coding? This was mentioned, Dr. Parker responded, but did not get sufficient weight to be acted upon. Manpower is another huge issue. The healthcare system will not have sufficient manpower for the next 10 years but the CKD problem can't wait that long.

Another issue raised by a participant is that CKD, at least in the VA system, is a disease most commonly found in old people. They usually have many things wrong so CKD is just one problem among many. The PCP does not pay much attention to CKD given the other problems. Maybe the message needs to be targeted for them? Dr. Parker responded that we have not done a good job of educating PCPs that a creatinine of 2 is among the many major problems of a particular patient but it is exacerbating all the other problems. Dr. Hostetter thinks that some of the things that need to be done cannot be done by a government sponsored agency like NKDEP. Efforts like this Initiative are therefore needed.

UPDATE ON KIDNEY DISEASE QUALITY INDICATORS

William McClellan, MD, MPH of the Georgia Medical Care Foundation, reviewed quality improvement efforts of The Centers for Medicare and Medicaid Services (CMS). CMS have Quality Improvement Organizations (QIOs). The ESRD Networks are contractors for CMS. Information can be found at: <http://cms.hhs.gov/esrd>. Information on dialysis facility comparisons can be found at: <http://www.medicare.gov/Dialysis/Home.asp>. Every dialysis center in the U.S. participates in the program. The Network provides information on how dialysis centers are caring for their patients. The system has been effective in documenting and influencing improvement in dialysis care in the U.S. NKDEP is developing a KD family history video. The use of this video can be monitored in the existing CMS system. NKDEP and CMS could work together. CMS can monitor the use of the video in the

dialysis centers through the Networks. Information on the U.S. Renal Dialysis Services (USRDS) can be found at: <http://www.usrds.org/>. Dr. McClellan wondered if NKDEP could help CMS foster similar initiatives to improve pre-ESRD care of Medicare patients.

There are several existing CMS/Network data sources for research on quality of pre-ESRD treatment by risk group. Risk groups include those with diabetes mellitus and those with CVD/HBP. Outpatient claims data and hospital chart review in CMS are being collected now. These data concern individuals with diabetes and CVD. From this data, patterns of care can be discerned to help see ways to deal with patients with CKD.

The QIO system has developed quality indicators for diabetes care. There are clear indicators such as HbA1c, dilated eye exam and quantitative urine protein analysis. The population selected to monitor is Medicare beneficiaries aged 65+ and Medicaid beneficiaries between the ages of 20 and 64. Diabetes patients with one hospitalization or two outpatient claims with ICD-9 code of 250.xx were selected in Georgia.

In Georgia, the data show that quality indicators are HbA1c, eye exam, lipid profile, urine test among diabetics for measurement of protein in the urine. It is hard in Georgia to find large numbers of diabetics who have annual tests for diabetic nephropathy. There is a worrisome gap in terms of quantitative urine testing annually. The survey is sent to physicians and state doctors who care for or treat 4-5 diabetics. This information could also be shared with NKDEP.

For patients with CVD they focus on earlier phases of CKD, primarily in diabetics. Patients with CVD have a high incidence of CKD, as this audience knows. They are a high-risk population for CKD and should be screened. The CMS Health Care Quality Improvement Program (HCQIP) selected hospitals in a state to study. The QIOs in CMS collect information on items relevant to CVD such as stroke, heart failure and AMI. That information is sent to hospitals in the state to improve the quality of care. An associated improvement due to this effort was documented and published in January in JAMA. The study looked at a representative sample to do a retrospective cohort study of heart failure and AMI. The patients were alive at discharge. Trained personnel abstracted charts. Data on demographics, clinical findings, lab reports, co-morbid conditions, etc. were abstracted. In assessing what Medicare patients with CVD look like from the nephrologist's perspective in the HCQIP data several things are clear. A retrospective cohort study taking random samples representative of all Medicare beneficiaries discharged from Georgia hospitals during 1998 reveals that there were 755 CHF patients and 709 AMI patients. The results show that among CHF patients (755 eligible patients; 665 in the analysis) in Georgia, many were older (mean age of 75.7 years and 60% women, 71% White) and met the definition of CKD by serum creatinine values. Anemia was highly prevalent (70% Hct < 40% and 14% had Hct < 30%). Twenty-eight percent of the sample (643 with CHF) had renal disease at discharge. Half of those were on an ACEi at discharge. Only about 10% survived to go on to dialysis. The AMI patients were younger (709 eligible patients; 559 in analysis; mean age 73.8 years; 49% women; 82% White). The Cockcroft-Gault equation was done to find CKD among them. CKD was highly prevalent: 48.7% of the men and 72.7% of the women. Anemia was also highly

prevalent: 54% with Hct < 40% and 6% with Hct < 30%. About 1/3 of them were sent home on an ACEi at discharge among those with no stated contraindication on their chart.

Dr. McClellan also reported on the proposal to establish a working group to develop a pilot HCQIP for CVD patients with CKD. The potential guideline-based quality indicators include:

- documentation of CKD
- ACEi at discharge
- treatment of anemia
- dietary protein restriction
- referral for vascular access assessment

The steps would be nationwide to confirm that patterns of care in Georgia conform to patterns elsewhere in the U.S. They would subsequently develop CQI tools for a hospital based CKD-QI initiative. They might do a pilot intervention to test their ideas.

There is also an ASM subcommittee on chronic diseases. NKF is doing state level of care that comes from the USRDS. They are available by request. There is a state of renal disease report by ethnic group done in the USRDS report. There is also a five percent sample of Medicare beneficiaries with CKD. However, that data is not releasable. Perhaps it would be available to NKDEP.

There were some comments following Dr. McClellan's presentation. There is a disparity between what was reported in the manuscript article analyzing CMS data in Georgia presented by Dr. McClellan and the NKDEP's PCP data. The NKDEP information is based on self-reports by physicians. This disparity reflects the fact that we all think we are better than we are. Another comment concerned the disparity of urine albumin to other measures. He said that only a small proportion of PCPs screen for diabetic nephropathy. Others never screen for it. In most rural communities he has found busy practices that hit on all four measures while some universities are providing inappropriate and inaccurate care. Dr. Hostetter commented that NKDEP could think about how to improve the quality of care in an interactive manner. NKDEP has formed a Patient/At Risk Work Group, a Professional Work Group, an Evaluation Work Group and there is a new Laboratory Work Group. They could add a Quality of Care Work Group. Those who are interested in joining this last Work Group should leave their names with him following this meeting. He will ensure that concrete proposals are provided.

NKDEP: NEXT STEPS, NATIONAL LAUNCH, LONG-TERM PRIORITIES

Elisa Gladstone, MPH, Associate Director of NKDEP, opened this session. She asked the participants to think about what NKDEP can do over the next year to prepare for the national launch. What else can be done to help the pilot sites achieve their goals? What else can NKDEP do at the national level to move the program forward? Suggestions included the following:

- There was consensus that just making significant progress in the areas NKDEP has already started such as the Laboratory Work Group initiatives would be sufficient. Perhaps tackling too many things would divert energy from the current plans.
- Another suggestion was that NKDEP support international reporting of estimated GFR with well-written materials to help people decide how to implement that reporting. Guidelines on implementing eGFR are also needed.
- Develop educational pamphlets to help doctors explain prediction equations.
- Implement coding changes so there is data in the future in medical records.

Note: the mechanism here is through the AMACPT Committee. The RPA is in the best position to pursue the coding changes. Doctors want to know how to bill for CKD tests. The CKD Initiative members like Dr. Tom Parker will also talk to RPA members to try to get this done. Information is also needed on what is allowable especially in view of the fact that terms such as "renal insufficiency" were removed from clinical practice. If coding changes, it will change behavior, some think, although others were skeptical about this point. Reimbursement is outside the scope of NKDEP, Dr. Hostetter commented. However, reinforcing the message can bring results.

- Tell PCPs that there is another inducement to stop smoking and to reinforce modifiable risk factors such as salt and protein intake, as per the MDRD Study.
- Get NKDEP materials into the National Board Exams and into the Medical School curriculae. Train early.
- Encourage research into surrogate markers to replace timed urine samples, especially one in the blood. Scientifically we are limited to checking for albumin in the urine.
- Use well-known political figures and athletes like Tiger Woods in PSAs to get the message across at the patient level. Has NKDEP defined the marketing awareness in order to understand what the response will be to the materials? Good nurse educators could move this process along since there seems to be a disconnect between what doctors said they said and what the patients said they heard. Patient buy-in is needed. Ms. Singer suggested that a literature search could be done and then something could be crafted and tested in one of the Coalition sites.
- Engage the American Association of Diabetes Educators and Community Health Centers. They combine health communications interventions with education intervention. It is reasonable to engage health systems on a community level.
- Continue to focus on high risk groups as in the Pilot program like family members. Encourage family members to get tested and distribute videos via the NKF and the ESRD groups. *Note: this is already being done. A decision was made not to focus on those under 18 years of age.*
- Assess the intervention by having dialysis facilities ask if the patient has a family history of KD and if a doctor has spoken to them about KD. That would be the next step in the family history initiative to target that group.
- Establish best practices using specific goals you want to achieve working at the pilot sites. Craft a tool or questionnaire to ascertain what the pilot sites have to teach everyone else in the country that would be valuable. Develop a continuing

- medical education (CME) module to put on the web to present best practices and other information on CKD.
- Broaden the effort to include adolescents, younger children and their caretakers.

There was a discussion concerning how to utilize dialysis units as conduits of information without using too much money and without overwhelming the unit personnel. There will be a Champion to spread the word in the unit. This does not cost money. Staff will run the videos and volunteers will play bingo, etc. with patients to spread the message. There may be other cost effective ways to reach patients like asking staff to wear buttons asking if they have asked their family members to be tested.

Steering Committee members offered the following means of communicating with dialysis patients:

- NKF has a newsletter that goes out to all dialysis units and could be used to spread NKDEP messages.
- The AHA can also disseminate this message to recipients of its newsletter.
- ESRD Networks also has a patient newsletter.

Another suggestion was to target other groups at risk such as Hispanics and transplant patients. The risks are the same between races, diabetes, hypertension, and obesity. Make the message broader and then display it in appropriate locations to reach the targeted populations.

PCPs should only screen high-risk patients for kidney disease. One step forward is that the JNC now lists CKD as a risk factor for CVD.

Perhaps NKDEP could begin to act upon the suggestion to target other groups as well. Culturally appropriate materials are needed so that the message does not become: "This is a Black disease." It should be like the diabetes education program in which all the messages are the same in terms of cause and treatment. Dr. Hostetter agreed and said that once NKDEP reaches this group (African Americans) they can cheaply move the materials to other groups. This is a good launch pad to reach other audiences. Another attendee commented that the message should be that the heart disease and vascular disease associated with CKD will kill you; many more die with CKD than from it. The public and PCPs need to be educated on this. CKD does not naturally progress to ESRD. Participants mentioned the need to develop a universal consult form.

IV. CONCLUSION

Dr. Hostetter thanked attendees for their participation. He appreciated seeing them and working together in person. The minutes of this meeting will be published. He also reiterated his appreciation to the Coalitions for coming and reminded all to call NKDEP with any further suggestions.

V. ATTACHMENTS

1. Agenda
2. List of Participants