

**NC IOM TASK FORCE ON CHRONIC KIDNEY DISEASE**  
**January 22, 2007**  
**NC Hospital Association**  
**10:00am-3:00pm**

**ATTENDEES**

*Task Force/Steering:* Joel Bruce, Ann Bullock, Celeste Castillo Lee, Jennifer Cockerham, Sam Cykert, Shirley Deal, Laura Edwards, James Fleming, Linda Gross, Deidra Hall, Donna Harward, Nancy Henley, Bill Hyland, Jim Keene, Chip Killian, Ann Lefebvre, Denise Michaud, John Middleton, Marcus Plescia, Janet Reaves, Leanne Skipper, John Smith, Linda Upchurch

*Interested Persons/Staff:* Jacqui Brett, Patrick Buffkin, Leighann Sauls, Kimberly Alexander-Bratcher, Jennifer Bonds, Kristen Dubay, Thalia Fuller, Mark Holmes, Kiernan McGorty, Pam Silberman

**WELCOME AND INTRODUCTIONS**

**Marcus Plescia, MD, MPH**

*Co-Chair*

Chief, Chronic Disease and Injury Section  
NC Division of Public Health  
Department of Health and Human Services

**Leanne Skipper**

*Co-Chair*

Chief Executive Officer  
National Kidney Foundation of  
North Carolina

Dr. Plescia introduced himself and welcomed the Task Force members to the meeting. He thanked everyone for their willingness and eagerness to participate in the Task Force because chronic kidney disease affects so many North Carolinians. The members of the Task Force introduced themselves and the organizations they represent.

**LEGISLATIVE CHARGE**

**Pam Silberman, JD, DrPH**

President & CEO

NC Institute of Medicine

Dr. Silberman welcomed the Task Force members on behalf of the NC IOM. She also provided information on the history and work of the NC IOM. She explained that the NC General Assembly requested the NC IOM form this Task Force with the help of the NC DHHS.

Dr. Silberman reviewed the five parts of the charge of the Task Force:

1. Reduce the occurrence of chronic kidney disease by controlling the most common risk factors, diabetes and hypertension, through preventive efforts at the community level and disease management efforts in the primary care setting.

2. Educate the public and health care professionals about the advantages and methods of early screening, diagnosis, and treatment of chronic kidney disease and its complications based on Kidney Disease Outcomes Quality Initiative Clinical Practice Guidelines for chronic kidney disease or other medically recognized clinical practice guidelines.
3. Educate health care professionals about early renal replacement therapy education for patients (including in center dialysis, home hemodialysis, peritoneal dialysis as well as vascular access options and transplantation) prior to the onset of end-stage renal disease when kidney function is declining.
4. Make recommendations on the implementation of a cost effective plan for prevention, early screening, diagnosis, and treatment of chronic kidney disease and its complications for the State's population.
5. Identify current barriers to adoption of best practices and potential policy options to address these barriers.

## **OVERVIEW OF THE PROBLEM**

**Linda Upchurch, MBA, MHA**  
Renal Consultant/Group Marketing  
Baxter Healthcare Corporation

Ms. Upchurch reviewed the costs and current trends in chronic kidney disease (CKD). She referenced articles in *Modern Medicine* showing that the cost of end-stage renal disease (ESRD) has increased nearly 60% to \$20.1 billion of Medicare's budget. Approximately 50% of diabetic patients have CKD, but may not know it. Another series of articles from the National Institutes of Health explained that 1/3 of adult diabetics have CKD, almost 6.5% of the population.

She explained that while costs are not the most important consideration, they indicate trends in CKD. The Center for Medicare and Medicaid Services focuses on clear rights and protections for patients. Of those with ESRD, 85% are covered by Medicare and 3-5% by Medicaid. Patients have a right to learn about information in a language they can understand and many patients are not receiving this information. The National Kidney Foundation defined different levels and standards of CKD including five stages of CKD, 585.1 – 585.5. Many patients and providers are not being given available information. According to ESRD network 6 data, only 25% of patients on dialysis recalled being given options of other therapies. A major problem is that 40% of patients present with urgent need for dialysis in less than one month. When focusing on urgent care, dialysis modality options may not be thoroughly reviewed. A recent *Disease Management* article suggests CKD-specific symptoms are best treated by nephrologists, but CKD-related symptoms are best treated by primary care providers.

In North Carolina, there are 10,000 people with ESRD, 9,000 on dialysis, and 1,000 successfully transplanted at this point. Of those on dialysis, 10% receive peritoneal dialysis and 90% use hemodialysis. Broad outcome studies show parity between the types of dialysis, and Ms. Upchurch described both processes. Most patients on

peritoneal dialysis are able to work and contribute in other ways. Hemodialysis patients must receive therapy 3 times a week. In North Carolina, the cost for delivering peritoneal therapy is \$10,000 less per patient-year at risk than hemodialysis. These data are about two years behind. Shriver Cleveland Clinic conducted a large study of 43,000 patients given thorough information on dialysis modalities and 50% reported that they would choose to be at home on peritoneal dialysis.

In North Carolina, there is an increased risk of disease depending on where you live. In the western part of the state, two neighboring counties have a difference of four times the relative risk. Ms. Upchurch suggested focusing the work of the Task Force on education across the state. Earlier identification and earlier education could decrease cost and social burden and increase patient satisfaction and standard of living.

**Comments/Questions:** The discussion that followed began with the different use of dialysis modalities across the state, by provider and payment method. It also was noted that when a patient first starts dialysis, the person is usually very ill and is given very little information about the ability to change modalities. Many patients are defaulting into hemodialysis rather than making an active choice. Some patients have limited support, decreased vision, and other problems that prevent in-home care. Often, patients start hemodialysis in the ER and continue that therapy rather than being given a choice to switch later. There are not peritoneal educators in each dialysis center that can offer and support informed patient choice. A provider explained that many of his patients are not choosing peritoneal dialysis because American culture focuses on providers doing things for patients rather than on patients doing things for themselves. In a rural clinic, many patients are stating that they do not want an everyday therapy, but rather one that is every third day. There is the possibility of explaining therapy as daily therapy regardless of type of therapy. Rather than supporting one type of dialysis or another, patients need the education to make informed decisions all along the process.

Disparities were also discussed. There are more African-American, Hispanic/Latino, and Native American patients with CKD. Both culture and genetics play a role; hypertension and diabetes are the largest risk factors. The Hispanic population may be less likely to receive dialysis due to Medicaid eligibility. The Eastern Band of the Cherokee Indians has the youngest CKD patient at 9 years old. Disparities also persist due the almost universal prevalence of diabetes in that community. Great programs have involved the community and tried to address the disparities. A warning was submitted that the stages are not experienced by all patients. African-American males usually progress directly from stage 1 to 4.

In putting forth issues, it is important to embrace the primary care community and patient populations. Reporting and testing for patients is another issue that needs to be addressed. Lab tests need to be added to the regular order form. There is a need for education (e.g., posters in clinics and hospitals) and common language so that everyone can understand about kidney disease and function.

## **AVAILABLE SERVICES FOR PEOPLE WITH CHRONIC KIDNEY DISEASE**

**Laura Edwards, RN**

NC Kidney/Epilepsy Program Coordinator  
NC DHHS Division of Public Health

Ms. Edwards explained the goals of the State Kidney Program. They include provision of preventative services for people at risk for ESRD and reduction of risk and consequences for people with ESRD by paying for some of their expenses. The new focus of the program is primary prevention. The two main components of the program are contracts with dialysis centers and purchase of medical care services. There are 157 dialysis centers in North Carolina, and the state program currently contracts with 14 of them.

The State Kidney Program has 1500-2000 current patients and can reimburse travel, medication, and emergency expenses. The maximum reimbursement is \$300 per patient per year, and the program has low eligibility levels.

Primary care providers may not have all the up-to-date information on patients with CKD. Access to some information is limited to nephrologists. Patients may have Medicare and/or Medicaid. Many patients use safety net providers, but access to providers is maldistributed across the state. A description of different safety net providers was given. The NCIOM report suggests that only 25% of the uninsured are seen by safety net providers.

Access to care is an important issue. Ms. Edwards described several examples of patient hardships including transportation, medication coverage, and continuity of health insurance. For medication, coverage varies between Medicaid and Medicare. The medication limit is waived under the State Kidney Program. Before a transplant surgery is scheduled, patients must have an acceptable plan for payment of rejection/antibiotic medication. Medicare coverage ends three years after transplant.

The future focus of the State Kidney Program is on a surveillance document describing the burden of CKD in North Carolina and statewide prevention.

**Comments /Questions:** The discussion that followed focused on program eligibility for Medicare and the need versus benefit of the State Kidney Program.

**INFORMATION FOR PEOPLE WITH CHRONIC KIDNEY DISEASE**

**Leanne Skipper**

Chief Executive Office  
National Kidney Foundation of North Carolina

Ms. Skipper explained that she was interested in establishing a framework for the work to be done by the Task Force. The National Kidney Foundation (NKF) is tackling CKD using the quote “put a fence on the cliff or an ambulance on the battlefield.” Prevention is the focus and the organization is making a concerted effort toward that end. Because

four of the five targets of the Task Force charge specifically focus on CKD, Ms. Skipper believes the effort of the group should be focused there.

A dollar value or quantification of CKD would allow the Task Force to have a significant effect on the state and the country. Ms Skipper discussed data from the *Journal of Managed Care Pharmacy*, “Resource Use in Patient Care Associated with CKD,” stating that CKD generated a quarter of a billion dollars in costs. Allen Gobe with Kaiser Permanente in San Francisco has released similar data on ESRD, hospitalizations, and death. She explained more CKD data is forthcoming.

Ms. Skipper discussed several programs and resources available through the National Kidney Foundation. The Kidney Early Evaluation & Prevention (KEEP) Program is a community-based education program focused on at-risk populations. It costs \$250/participant to provide urinalysis, blood draw, and consultation with nephrologists with personal recommendations. The program is being implemented by NKF affiliates across the country, including a partnership with UNC Kidney Center. A NKF brochure describes 5 stages of CKD using estimated glomerular filtration rate (eGFR). Serum creatinine-albumin may be a better predictor during the first stages. Monitoring these levels could promote better “kidney health” and postpone progression of the disease. The Kidney Disease Outcomes Quality Initiative (K-DOQI) guidelines are the gold standard and key education tool for primary care physicians. The organization is broadening its message from only nephrologists to include primary care providers. It is making pocket-sized information available.

Ms. Skipper noted that the American Journal of Kidney Data Annual Data Report excerpts will be available at the next meeting. The organization has a catalog of resources, including materials categorized by stage and some available in Spanish. The North Carolina affiliate is considering placing “know your score before you press your floor” in all state elevators in recognition of Cherie Berry, the North Carolina Commissioner of Labor, who cared for her husband who suffered from CKD for several years and whose signature is on all elevator certificates.

**Comments/Questions:** The discussion that followed focused on primary care provider and specialist interaction and strategies to help facilitate that relationship. Another discussion suggested that CKD management guidelines should be included in co-morbid disease guidelines. Comments regarding the importance of identifying key partnerships and relationships in communities and across the state and the importance of focusing on kidney health rather than kidney disease were also noted. March is National Kidney Month and March 8<sup>th</sup> is World Kidney Day. An NKF representative will ring the bell at the national stock exchange that day.

#### **GAPS IN KNOWLEDGE AND SERVICES**

**Donna Harward**

Director of Education

UNC Kidney Center

Ms. Harward explained that gaps in knowledge and services are rooted in failures of communication. The parties involved in the process of prevention and early intervention include at-risk citizens, primary care providers, sub-specialists, private insurers, and the Centers for Medicare & Medicaid Services. Coresh et al reported only 25% of those diagnosed with CKD reported awareness of weak or failing kidneys, and only 30% of North Carolina Medicaid patients in 2003 who were seen in emergency rooms with acute kidney episodes were seen by a health professional for kidney-related problems within the two months prior to the emergency room visit.

The UNC Kidney Center's Kidney Education Outreach Program (KEOP) has been implemented in 3 NC counties with high ESRD prevalence rates and expanding to 3 additional counties this month. Ms. Harward reviewed the prevalence of CKD risk factors for the citizens screened through November of last year: 69% with personal or family history of diabetes, 81% with personal or family history of hypertension; 39.3% qualified as obese; and 59% had microalbuminuria. A randomized telephone survey reflected some of the myths people believe about CKD and the lack of awareness about risk factors for CKD. Primary care, specialty providers, labs, and insurers also have gaps in awareness and services according to national research. There are significant costs incurred because of these gaps.

NC counties with high ESRD prevalence rates tend to be more rural, have greater numbers of citizens in lower SES, higher percentage of Medicaid eligible citizens, larger numbers of under and uninsured citizens and health departments with fewer resources. The method of relaying information is very important for these targeted populations--it must be targeted and delivered in collaboration with community leaders and lay leaders. The UNC Kidney Education Outreach Program's educational outreach is based on three principles derived from the science of how people learn: assess preconceptions, provide new information (in appropriate format/level), and accommodates the need for metacognition (e.g., information should be given in a context that is useful and with opportunity to examine the new information in a relevant context.) KEOP activities are evidence-based, community-based, and outcomes-based. Each of the activities (focus groups, free screenings, follow-up outreach activities) has a role in bridging the gaps in citizens' awareness about the risk factors for CKD and the importance of early intervention. A reduction in the burden of kidney disease in North Carolina requires increased citizen and PCP awareness of the value of early diagnosis and intervention. This can be achieved through community-based, public awareness campaigns, integrated/coordinated health care teams, professional education, and integrated guidelines that promote cooperative and timely management.

*There was no presentation from Dr. Holmes at this meeting. His presentation will be done at the next meeting with health professions data system information on nephrologists and primary care providers.*

## **QUESTIONS AND DISCUSSION**

Dr. Silberman asked the members of the Task Force to list areas of interest for possible discussion at future meetings. The ideas included

- existing public service announcements and materials (NKF, KEOP, others)
- faith-based organizations, barbers/hair salons, etc. involved in CKD and their capacity
- billing and ICD-9 codes
- adolescent and young adult non-compliance and support
- North Carolina State Kidney Program broader risk factors (e.g., HTN & DM)
- national kidney program registry
- dialysis providers – CKD prevention & education
- professional engagement (e.g., HIV-related ESRD)
- specialists/organizations including barriers to screening for CKD in guidelines

Dr. Silberman explained that the next several meetings will focus on parts of the charge. She also encouraged members to contact the NC IOM with other ideas and thoughts that may come up along the way. She thanked everyone for their time and contributions.