

# NC IOM TASK FORCE ON CHRONIC KIDNEY DISEASE

September 20, 2007  
North Carolina Medical Society  
Raleigh, NC

## Meeting Summary

### ATTENDEES

*Task Force/Steering Committee:* Paul Bolin, Joel Bruce, Jennifer Cockerham, Sam Cykert, Shirley Deal, Annette DuBard, Thomas DuBose, James Fleming, Deidra Hall, Donna Harward, Jeffrey Hoggard, Bill Hyland, Cynda Johnson, Celeste Castillo Lee, Ann Lefebvre, Monica McVicker, John Middleton, Marilyn Pearson, Marcus Plescia, Barbara Pullen-Smith, Anne Rogers, Leanne Skipper, Linda Upchurch, Laura Edwards, Chip Killian

*Interested Persons/Staff:* Paige Fisher, Thomas Hoerger, Bill Hoskins, Bill Isley, Carolina Jennette, Susan Johnson, Amy McConkey, Billena Richardson, Denise Rouse, Nell Smith, Elizabeth Stoll, Virginia Wang, Pamela Wegienka, Kenneth Wilkins, 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  
10:15-11:00

### CKD BURDEN AND INTERVENTION PROJECTION MODEL

#### **Thomas J. Hoerger, PhD**

Senior Fellow in Health Economics  
Director, Health Economics and Financing Program  
Director, RTI-UNC Center for Excellence in Health Promotion Economics  
RTI International

Research Triangle Institute (RTI) is currently conducting two studies on CKD for the Centers for Disease Control and Prevention (CDC). The studies focus on estimating the cost of CKD by stage and developing a disease progression and cost-effectiveness model. Both studies are in progress, so final results are not yet available. Dr. Hoerger's presentation covered CKD costs and the cost-effectiveness of CKD interventions and what is being done in the RTI CDC studies. Traditional focus has been on end-stage renal disease (ESRD) because it is an acute condition with high rates of mortality and low quality of life and because it is covered by Medicare, which is extremely costly.

When examining the prevalence of CKD by stage, the prevalence at early stages is huge and narrows considerably at stage 4. There are relatively few people in stage 5, but it accounts for 50% of costs Medicare pays for CKD. It is difficult to estimate the cost by stage with nationally representative data. However, Smith et al. (2007) estimated costs by GFR for a large health maintenance organization. These costs need correction for age, sex, race, and other factors. It is possible, however, to estimate the cost of individual complications.

The data on cost is grouped into crude and adjusted categories. Crude costs do not control for age but focus on current expenditures and annual costs, not looking at downstream costs. The costs of complications include some that are causal (anemia) and some that are related to CKD (diabetes), while others may be caused by or correlated with CKD. In the adjusted costs without complications data, there is not a big difference between GFR values 60-89 and 30-59, but there is a bump at stage 4 (15-29). The data for adjusted costs with complications do not show big uptake until stage 4. That sample was not limited to people who were hospitalized. The data comparing adjusted costs with complications and ESRD costs show that \$60,000 per year for ESRD dwarfs the costs at other stages.

The US spends \$2 trillion on health care and the rate of spending has been going up faster in more recent years. According to the USRDS, ESRD costs \$35 billion a year. Thus, 1.6% of all health care expenditures are being spent on individuals who have reached stage 5. Expenditures on ESRD have been slowing. Other measures of burden (mortality, morbidity) include days of work lost per year and quality adjusted life years (QALY). There are not many days of work lost per year for stages 1 and 2; most are lost in stage 3-5. There are very few people in these national datasets that are at stages 4 and 5, probably because people in stages 4 and 5 have to quit their jobs. Only a very small percentage of people who go on dialysis have a job one year later. For QALYs, the data is from the literature and is not always controlled. Most studies do not look at stage 1 because QALYs are close to normal. There are less QALYs for stage 2 and a big loss at stage 5, but this loss cannot be completely disassociated from age.

The RTI Cost Study uses the National Health and Nutrition Examination Survey (NHANES), which is one of the only datasets with CKD prevalence. RTI is estimating future Medicare costs for individuals who receive GFR measurements in the NHANES by stage. The study will estimate work loss, come up with overall estimates of costs by

stage, and is likely to get results that are similar to but also different from Smith et al. The Smith research only looked at an under-65, non-Medicaid HMO population.

There are several basic questions in cost-effectiveness analysis. The first question is can we prevent people from reaching Stage 4 and Stage 5 since the mortality rates are high. The second question asks how much will it cost. It is important to think about the time pattern of costs. There will be high costs up front and benefits will accrue over years or decades. It is unlikely one study will produce enough good data because of the longitudinal nature of the question. The third question asks will the upfront costs of the intervention be offset by later reductions in complication costs. The answer is almost always no. If not, will the additional cost spent on the intervention be worth it in terms of benefits (QALYs) and are we getting good value for the money we spend on the intervention. With that in mind, it is important to look at non-financial gains. Dr. Hoerger explained that there likely will be savings on some of the complication costs, but the interventions are being paid up front and should be discounted for savings down the road. There will not be a reduction in spending on dialysis in years to come because people will be living longer on dialysis. It also will take a long time for prevention efforts to save costs, unless patients are sent home on therapy. It will require a paradigm shift in this country to pay for health, not disease.

The RTI approach is to build a simulation model of CKD disease progression and cost-effectiveness. A model is a systematic way to integrate and synthesize data from a wide variety of sources and may include epidemiology, clinical trials, costs, and QALYs. The study will follow people over time from age 30 until they die. They will follow what happens with and without the intervention. They will use a cost effectiveness measure of incremental costs and QALYs. If there are positive costs and positive outcomes, then they will look at benchmarks (e.g., <\$50,000 for a QALY or \$100,000 for a QALY). There are several basic model components; 1) individuals enter the model at age 30 and are followed through age 90 or death, 2) disease stages (normal, K/DOQI stages 1-5, death), 3) transitions between stages (depend on kidney disease, GFR declines with age), and 4) risk factors increase GFR decrement (diabetes, hypertension, and proteinuria), 5) stage increases probability of complications (i.e., coronary heart disease (CHD), stroke), 6) mortality depends on stage and complications (i.e., CHD and stroke, other causes of death, stage 5 mortality rates), and 7) costs depend on stage and complications.

The GRF decrement is described as how much GFR goes down each year. GFR tends to go down with age. According to Bouleware et al., the GFR decrement can be described based on risk factors. GFR goes down 1 point a year for no complications or proteinuria (defined as over 300), but there is quicker decline for people with certain conditions. Assuming stage 5 is around GFR 15, the person in the model would develop ESRD around age 75. If the GFR decrement could be slowed down, that would stall the onset of ESRD. The source of the data is clinical trials. A participant noted that aging is an abnormal process. There is a huge scatter in the data but the population is very heterogeneous, especially from 50-90 the data is not linear. As years pass, there are new developments and crises that cause variation between ages. The RTI team has

incorporated the differences between individuals but has not yet been able to build in variation between years.

The RTI study will compare two populations, one with and one without the intervention. Interventions slow GFR progression and have immediate impact on costs. The first intervention is screening. Patients will be screened for proteinuria followed by ACE or ARBs for detected individuals, to slow down the progression of CKD. There will be general and targeted screening, different types of screening tests, and different frequency of screening. Current insight shows that most individuals die before they reach Stage 5. The study will focus on what can lower mortality during Stages 3 and 4. One side-effect will be an increase on stage 5 incidence, which is good because people will be living longer. The cost-effectiveness of the intervention is likely to depend on age. The model uncertainty means sensitivity analyses are especially important. The RTI team recognizes the need for more interventions. The model will analyze an intervention to determine the cost, determine how it will affect care including earlier detection and the follow-up treatment will be provided, estimate its effect on GFR decrements, and generate cost-effectiveness estimates. The CDC is very interested in CKD surveillance, estimating the burden, and public health interventions. The burden estimates are useful for priority-setting, advocacy, and research needs. Cost-effectiveness modeling helps identify costs, benefits, and values of interventions and aids in resource allocation.

**Discussion/Questions:** The discussion that followed focused on the model. A participant noted that slowing progression to ESRD would lower ESRD costs but shift them to other complications. Another participant asked about a model that included other comorbidities including heart disease and whether attention to both diseases would result in significant savings. One participant suggested adjusting the current model for comorbidities of diabetes and heart disease because the current intervention will not affect whether patients live to ESRD. Another participant suggested retrospectively applying the model to determine if it predicts data that is already known. Lastly, an 80-year old dialysis patient suggested that we need to know when to stop interventions for people with ESRD and decide on a cutoff.

## **REPORT OF eGFR/LABORATORY WORKGROUP**

### **Thomas DuBose, MD**

Harrison Chair of Internal Medicine  
Wake Forest University School of Medicine

Dr. DuBose provided an overview of the work done by the eGFR/laboratory workgroup that met in August and has continued discussions. The eGFR workgroup strongly recommends automatic reporting of eGFR values on all creatinine determinations by clinical laboratories in NC. Given concerns about the precision of current estimating equations (such as the MDRD formula) for eGFR values above 60 mL/m, the workgroup recommends that, following common practice, all eGFR values greater than 60 mL/m be reported as “>60” rather than denoting the calculated value. Additionally, eGFR values

should be automatically computed on all creatinine determinations by clinical laboratories in North Carolina. Hospital and commercial clinical laboratories should include a calculated eGFR on all patient laboratory data that includes measurement of the serum creatinine. Payers and insurers should require that all creatinine laboratory reports for their members and dependents include eGFR. If the preceding recommendations are insufficient to make automatic eGFR reporting standard practice throughout the state for all laboratories within one year, the General Assembly should consider altering General Statutes to require all creatinine laboratory reports to include eGFR values. The wording could be changed to laboratories currently not reporting should, so that the text will emphasize that we want them to do it voluntarily. There should also be a disclaimer that a value greater than 60 may be abhorrent.

**Discussion/Questions:** The discussion that followed focused on formulating a strong statement that would encourage voluntary participation. A participant suggested not making labs that are already pro-active change. Labs will not need to reconfigure their output data fields. Another recommended an educational piece directed to providers that includes understanding eGFR lab results. The observation was made that the problem is populating the other formula fields to generate the outcome. Carolina Renal Care could send out a query to ask all multi-physician practices whether they are receiving lab results. The NC Hospital Association could collect the information from their membership. The NC Division of Public Health could work on a system to monitor it. Another participant noted that state labs have no relationship with private labs. Another person recommended that LabCorp could help pull data on the number of labs automatically reporting eGFR. A participant urged that the group needs to specify steps that would be taken before approaching the legislature and define success (e.g., percentage of labs reporting, partnering with agencies, etc.) Another participant noted that it is important to have the major health care organizations across the state as partners in this effort. All the academic institutions are doing it, so the gap is with the small practices, but the hospitals might not reach all of them. Another participant explained that providers should not be able to opt out of automatic eGFR reporting.

## **CKD LEGISLATIVE UPDATES**

### **Caroline E. Jennette, MSW**

Social Research Specialist  
Kidney Education Outreach Program  
UNC Kidney Center

### **Linda Upchurch, MBA, MHA**

Former Renal Consultant  
Baxter Healthcare Corporation

Ms. Jennette explained that in 1972, kidney disease became the first chronic disease tied to Medicare. The Medicare ESRD Program was established through the Social Security Amendments of 1972. Since then the rates of ESKD have skyrocketed. The prevalence is slowing a little, but certain subgroups including African Americans and Native Americans are still increasing. Hemodialysis costs about \$70,000 a year and peritoneal dialysis costs \$20,000 less. The first year of transplant costs over a million dollars, but a normal year is \$25,000.

Current policy is meant to promote cost containment and quality of care for ESKD and CKD through various tools. The management of early CKD to slow progression to ESKD is achieved through public health and media campaigns, prevention and awareness of risk factors, clinical guidelines for screening, and pre-dialysis education. We need to focus on ESKD therapies that are less expensive includes better education on different treatment modalities which may improve quality of life and increasing organ donation and donor pool. Changing the payment structure of dialysis providers and nephrologists involves implementing pay for performance measures, composite rate increases, and changing bundling design for dialysis services.

The NC General Assembly has been very active in the CKD policy arena. In the 2006-2007 session, SL 2006-248: The Studies Act of 2006 called for the creation of a CKD Task Force to study the rate-setting methodology for state funded kidney dialysis. In the 2007-2008 Session, SL 2007-532: Organ Donation/The Heart Prevails clarified legal consent for organ donation with guidance from the Uniform Anatomical Gift Act 2006 update. It has been adopted by 19 states and is pending in 5 other states. It has an increased focus on personal autonomy in the donation process, clearer rules on the role of family, friends, and caregivers, and implementation of systems that make it easier for organ procurement organizations to look up potential donors.

Ms. Upchurch explained that the 110<sup>th</sup> Congress may result in an omnibus act because there are so many bills to consider and it is getting late in the session. Those bills that she discussed included HR710/S487: Charlie W. Norwood Living Organ Donation Act, S432/HR1245: Kidney Disease Educational Benefits Act of 2007, HR3282: Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2007, S691/HR1193: Kidney Care Quality and Education Act of 2007 (KCQEA), and H3162: The Children's Health And Medicare Protection Act (CHAMP). Lobbyists have

been spending a lot of money and creating a lot of activity. Some of the groups focused on kidney health are the Kidney Care Partners (covering patient advocates, dialysis professionals, care providers and suppliers), the Kidney Care Council (dialysis providers), the Renal Physicians Association (specific to public policy), the National Kidney Foundation, the American Association of Kidney Patients, the Renal Support Network Wellness & Education Kidney Advocacy Network (weKAN), the American Kidney Fund, DaVita Patient Citizens, Coalition of Patient Choice, Pharmaceutical Research and Manufacturers of America, individual companies, and other trade and professional organizations.

Ms. Upchurch further described some of the bills under consideration. HR710/S487 Charlie W. Norwood Living Organ Donation Act amended the National Organ Transplant Act to state that kidney pairs count as a viable transplant option and are not to be considered the transfer of a human organ for valuable consideration. HR3282 Comprehensive Immunosuppressive Drug Coverage for Kidney Transplant Patients Act of 2007 is a continuation of Part B Medicare coverage for transplant recipients not eligible for Medicare due to age or disability. Part B would only cover immunosuppressive drugs, but recipients would be responsible for Part B premium and deductible. After 36 months, these patients are not considered disabled and lose Part B coverage. They lose the ESRD label even though transplantation is not a cure. S432/HR1245 Kidney Disease Educational Benefits Act of 2007 includes 6 pre-dialysis educational classes reimbursed by Medicare. Educational sessions would include information on managing comorbidities, the prevention of uremic complications and each option for renal replacement therapy (peritoneal dialysis, home hemodialysis, hemodialysis, and transplant). Payment would be made by Medicare to dialysis facilities and not bundled with other services.

S691/HR1193 Kidney Care Quality and Education Act of 2007 (KCQEA) is written in two parts. Section 1: Improving Quality through Patient Education, Access, and Safety Initiatives includes CKD demonstration projects, ESRD self-management demonstration projects, Medicare coverage of kidney disease patient education services, blood flow monitoring demonstration projects, IOM evaluation and report on treatment modalities for patients with kidney failure, and required training for patient care dialysis technicians. Section 2: Assuring Quality of Care for Providers, Facilities, and Physicians That Provide Services to Individuals With ESRD Who Are Enrolled in Part B includes establishment of an ESRD advisory committee, updates for the Medicare Composite Rate for 2008, 2009, and 2010, a continuous quality improvement initiative in the Medicare ESRD program, and extension of Medicare Secondary Payer (MSP) from 30 to 42 months (only for larger health plans with over 100 participants).

The composite rate for dialysis was established in 1983. It pays for clinical and social services, equipment, supplies, some labs, and some drugs. It does not pay for injectible erythropoietin, vitamin D, or iron. In 2006, composite rate was \$130 per treatment. There is currently no annual update framework for the composite rate. Treatment has gotten more complex but has not brought down costs. In 2001, Medicare payments were 11% lower than the average facilities' costs to provide items and services included in the

composite rate. Medicare payments were 16% higher than facilities' costs for separately billable drugs. In 2006, these rates were adjusted to be paid at the average sales price (ASP) plus 6%. Payments are now focused on utilization and there is a lot of debate over hemoglobin levels for patients with kidney disease.

Erythropoiesis stimulating agents (ESAs) are a part of some patient treatment plans. Erythropoietin is made by the kidneys and helps stimulate red blood cells. ESAs increase red blood cell production, and can be given subcutaneously or through a vein, which is the most common. Target hemoglobin has averaged between 11-12 g/dl. Epogen was introduced in 1983 and Procrit and Aranesp followed. By 2004, spending for Epoetin therapy was the single largest Medicare drug expenditure and is the second largest source of dialysis facility income (22%). In 2005, total spending on Epogen was \$2 billion. There is concern over the lack of competitor products and much discussion of hemoglobin levels in both houses of Congress.

The main goal of H3162: The Children's Health And Medicare Protection Act (CHAMP) is to reauthorize the Children's Health Insurance Program (CHIP). It includes language from several bills that were previously discussed. It includes many provisions similar to KCQEA: CKD demonstration projects, pre-ESKD education without payment to dialysis facilities (only available to >65, leaves out disabled population), training for dialysis technicians, report on treatment modalities but the report will be done by MedPac instead of IOM, and MSP extension to 42 months but only for large employers (>100 employees). It is expected to save \$3 billion, but it supposes that patients are still working after two to three years of dialysis. The Senate side is SCHIP, but CHAMP is broader and pays for expansion by increasing the tobacco tax. The new House provisions include payment adjustment of ESAs to 102% ASP (currently at 106% ASP for large dialysis providers), an equalized composite rate for hospitals and outpatient facilities (hospitals would lose \$4), ESRD bundling to include more drugs and services and a MedPac report, bundling would pay 96% of total estimated payments if there were no bundling system (currently paying 100%), OIG study and report on EPO, and the establishment of a center for comparative effectiveness research.

As the session ends, advocates will push to get bills out of Committee including KCQEA and transplant coverage extension. There is increasing patient, caretaker, and provider participation in the advocacy process.

**Discussion/Questions:** The discussion that followed focused on the bills in Congress and how the Task Force can participate. A participant suggested that national initiatives need to expand the scope of ESRD networks and one of the presenters explained that they are adding language to 2728 about patient markers and patient education, but it is difficult to get data from before people became CKD patients. Another participant noted that CrownWeb is reporting software that is trying to look at a multi-disciplinary approach. A participant suggested that clinical performance measures could look at quality indicators of CKD. Another participant answered that Medicare controls the money and can only influence the ESRD population. If we want to look at CKD pay for performance (P4P), we need to look at national databases which do not include a lot of these measures.

It was suggested we talk with state experts about the progress of the Physicians Quality Reporting Initiative.

## **EDUCATION OF PATIENTS AROUND CHRONIC KIDNEY DISEASE: INFORMED DECISION MAKING**

### **Susan M. Johnson, RN**

Home Training Nurse Manager  
Independent Nephrology Services

Ms. Johnson has worked as a nurse in many different settings. She began her presentation with a patient case study. Within 9 years of being a CKD patient with diabetes, the patient should be self-managing. Instead he was in an in-care center and not active on a transplant list. Her presentation objectives were to provide an educational process, review barriers in the process, and review needed resources to implement the process.

The benefits of CKD education are saved health dollars, reduced hospitalizations, slowed progression of CKD, improved adherence to treatment, decreased need for urgent dialysis, improved functional status and quality of life, timely placement of appropriate access, and early selection of treatment modality. Ms. Johnson used the following quote to describe the impact of predialysis care: “Patients who participated in a multidisciplinary predialysis education program had fewer complications, ER visits, and hospitalizations. They also had fewer temporary catheter placements, shorter hospital stays, and reduced costs associated with initial dialysis.” The benefits of early referral are control of severe hypertension, lower prevalence of uremic symptoms, and avoidance of emergent dialysis therapy. Patients were more likely to choose a home therapy, more likely to receive renal transplant, and more likely to have satisfactory preparation and placement of dialysis access.

Informed consent is the basis for CKD education. It is a legal condition whereby a person can be said to have given consent based upon an appreciation and understanding of the facts and implications of an action. In this case, a medical action will change the patient’s life. The current system gets consent without providing critical information. Informed consent leads to self management. Empowering patients to self manage their medical condition improves outcomes not only for the patient but also for the health care system. The current education process at independent nephrology services at stage I includes no referrals. At stages II and III, the process includes providing informed consent, referral to a registered renal dietician, and referral to an in-house CKD class provided by Baxter’s Clinical Educator (50% participation of those invited), follow up, a visit with a nephrologist, and a visit with a Baxter educator. At stages III and IV, the process includes referral to a dialysis nurse to review modalities and discuss placement of access and follow up with a nephrologist and Baxter educator. This process could be improved with some modifications.

Ms. Johnson made several suggestions for improving the patient education process. In phase I education, GFR should be estimated yearly on all patients diagnosed with diabetes and hypertension. This test could provide early diagnosis for patients with GFR<60 by primary care providers and result in referrals to CKD programs. Initiating the education process requires early diagnosis. Education begins with an explanation of the staging of kidney disease including GFR, hypertension, diabetes (diet, medications), kidney function and disease process, and diet and medication compliance. The barriers to phase I are the lack of routine labs associated with kidney disease (GFR on all patients diagnosed with hypertension or diabetes), lack of referral to a nephrologist once diagnosed, lack of early diagnosis, lack of access to competent educators (currently no standards for minimum requirements measuring competency), lack of access to health care and primary care providers, and contributing patient factors. Patient factors include lack of confidence to ask questions, spirituality, compliance, values, education level, disease process, aging, lack of self management, trust in physicians, and lack of continuity of care within the health care system (free clinics, ER visits).

Phase II CKD education should include referral to a nephrologist once GFR is <40. Education is needed and should be mandatory. Patients already in CKD programs will automatically flow into phases as GFR declines. Patients need review of early education subjects (staging of kidney disease, hypertension and diabetes, kidney function, diet and medications, referral to renal dietician) and also need information on symptoms of kidney disease (like anemia, bone disease), modalities, emotional factors, and financial considerations (Who is going to pay for this? Who is paying now?). Barriers to phase II include reimbursement, lack of informed consent, lack of referrals from primary care, lack of access to competent educators, and contributing patient factors.

Phase III CKD education begins when GFR <30 and should include review of diet, medications, functions and symptoms of kidney disease, anemia management, bone disease, emotional factors (patients are grieving and not aware of it), and cost. This phase should emphasize and continue modality education, focusing on early access placement with each modality including hemodialysis, peritoneal dialysis, transplant (not a cure), and non-treatment (which might be better for older patients). The barriers to this phase include reimbursement, informed consent, contributing patient factors, lack of access to competent educators, and site for education.

In order to improve the patient education process, barriers must be removed and adequate resources must be provided. Education slows the progression of CKD. Happier patients live well with kidney disease. Reimbursement must use a cost effective approach. Informed consent is in the best interest of the patient, and the long term cost will pay off. We need to utilize programs already established and bridge the gap between physicians and referral groups. The resources needed to improve the process include reimbursement, competent educators (minimal competency, use of knowledgeable professionals), physician champions (primary care provider and early referrals for Phase I of CKD education), and public awareness through television, pharmacies, pharmaceutical venues, health fairs, wellness programs, insurance providers, dialysis providers, and conferences.

There are resources available through the collaboration of existing programs and available resources.

Educators must meet certain requirements in order to transform the patient education process. They must be competent as determined by minimal requirements. The use of multidisciplinary teams including physicians, nurse practitioners, registered dietitians, social workers, and registered nurses also provides great support for the education process. The education tools used by educators should be simple, include easy to understand materials (at the 4<sup>th</sup> grade level), assess individual patient needs, use patient mentors, and use visual tools like Dummie Tummies, access arms, videos, equipment (e.g., IV poles, carts for machines, and needles). The first time a patient sees the needles should not be when they are going to get stuck.

Ms. Johnson made some final suggestions about how to support the patient education process. All payers (including third party payers, private insurance companies, Medicare and Medicaid) should implement a reimbursement policy for CKD education. Medicare initiated the Medical Nutrition Therapy (MNT) benefit in 2002, an ideal plan to mirror for reimbursement of CKD education. Her closing thought was it is the educator's responsibility to answer patients' questions before they ask.

**Discussion/Questions:** The discussion that followed focused on eliminating barriers to patient education. One participant explained education has been implemented in Baxter clinics. Another participant suggested that the biggest barrier to choosing peritoneal dialysis is having a doctor on board. Only 40% of facilities offer peritoneal dialysis and only 25% of patients recall the option of peritoneal dialysis being offered. The majority of patients present in an emergency situation, but educators need people in the early stages of CKD to be educated about the difference. Certified diabetes educators not paid for by a peritoneal dialysis company should be teaching about the difference. Lastly, one participant noted that informed consent is consent to that treatment rather than consenting to understanding all the options.

## **PATIENT PERSPECTIVE ON NEEDS AND CKD EDUCATION**

### **Deidra Hall**

Founder, The Kidney Coaching Foundation, Inc.

### **Celeste Castillo Lee**

Administrative Manager, Interdisciplinary Programs  
Office of the Provost  
Duke University

Ms. Hall and Ms. Lee together have 25 years of transplant experience and 18 years of dialysis experience.

Ms. Hall was diagnosed at the age of 12. She was swelling a lot, went to pediatric nephrologists, used medication, and went into renal failure during her sophomore year of high school. Her patient education came early, she chose peritoneal dialysis, and went to school. She continued to have peritonitis caused by the catheter. She had a renal transplant from her mother and since 1994 has not had any problems. As a teenager, she needed to understand her disease to be able to explain to her doctors what happened at school. She went septic twice while she was at school, but it is possible to go to school and do activities. She urges that parents need to be taught that they can let their kids go. Social workers were important to coordinate care. It is possible to start a family, but patients need a doctor's support to do it. Ms. Hall started the Kidney Coaching Foundation for young people ages 12 to 21, to help them understand how to accomplish their goals. She explained that doctors need to treat the patient, not the numbers and not like textbook case.

Ms. Lee had an autoimmune disease that shut down her kidneys in 6 months. She used in unit hemodialysis that she gave herself and taught herself to use. The worst part for her was the liquid restriction and anemia. She had a renal transplant in 1986 from a non-living donor and lived with it for 10 years, but she began rejecting it after 6 years. She went back on hemodialysis and the transplant list, but it took longer than she had hoped. She went back to peritoneal dialysis, which she hated before when it was like a colostomy bag but now loved it because she could work and be normal. It is frightening for her to go into a dialysis unit now because it is dirty and cluttered. It makes her aware of health disparities and the big racial differences and cultural differences between dialysis centers and other treatment centers (e.g., cancer centers). It is important for patients to understand their options and it is important for doctors to take the time to help patients understand. Ms. Lee will be on hemodialysis for the rest of her life because her sensitivity skyrocketed after the transplant organ failed. She wants to help determine how to get everyone educated, informed, and not patronized. She was a fistula last patient and knows all the details about her dialysis. She suggested if patients can check their own hemodialysis machine, they may be able to not feel really bad after treatment.

After discussing their personal stories, they had a dialogue with the providers on the Task Force about patient information, when a patient will listen, various forms of education

material, what worked and did not work for them, and what questions providers would like patients to ask.

## **DISCUSSION OF RECOMMENDATIONS**

**Pam Silberman, JD, DrPH**

President & CEO

North Carolina Institute of Medicine

Dr. Silberman reviewed the proposed recommendations organized around a system of care which includes primary prevention, outreach and education, screening of high risk individuals, a regular source of care with a primary care provider, disease management, case management and quality improvement initiatives, nephrologists, and early education and preparation for kidney replacement therapy. The full list of potential recommendations is available in the presentation section of the website at [http://www.nciom.org/projects/kidney\\_disease/kidney\\_disease.html](http://www.nciom.org/projects/kidney_disease/kidney_disease.html).