American Society of Pediatric Nephrology

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January 26, 2016

The Hon. Johnny Isakson
131 Russell Senate Office Building
Washington, DC 20510

The. Hon. Mark Warner
475 Russell Senate Office Building
Washington, DC 20510

Dear Senator Isakson and Senator Warner:

On behalf of the American Society of Pediatric Nephrology (ASPN), I appreciate the opportunity to provide comments on the Senate Committee on Finance's Bipartisan Chronic Care Working Group Policy Options Document.

Founded in 1969, ASPN is a professional society composed of pediatric nephrologists whose goal is to promote optimal care for children with kidney disease and to disseminate advances in the clinical practice and basic science of pediatric nephrology. The ASPN currently has over 600 members, making it the primary representative of the pediatric nephrology community in North America.

ASPN is particularly interested in the policy options related to end-stage renal disease (ESRD) because, as you know, Medicare covers ESRD beneficiaries regardless of age. About one third of our pediatric ESRD patient population is covered by Medicare, while one third is covered by Medicaid, and the final third covered through private insurance. Although our patient population – encompassing both children and adolescents – is just a small portion of the full Medicare ESRD population, they are the most vulnerable. And although kidney transplantation is our best treatment for pediatric patients, there are still roughly 1,200 pediatric dialysis patients in the United States waiting for a transplant or for whom transplantation is not feasible. Therefore, the policy options related to ESRD will be instrumental to the care of children and adolescents. We offer the following comments:

I. Expanding Access to Home Hemodialysis Therapy

ASPN supports expanding access to home dialysis therapies. In fact, roughly half of our dialysis population receives home dialysis, primarily peritoneal dialysis. Pediatrics has always had a larger portion of its dialysis population on home therapies than the adult population.

We ask that the Working Group clarify the policy in question, however, as the specifics refer only to "home dialysis," not just "home hemodialysis." **ASPN supports expanding Medicare's qualified originating site definition to include free-standing renal dialysis facilities in any geographic area, and as such would include both home hemodialysis AND peritoneal dialysis**. Expanding access to different dialysis modalities is of the utmost importance. Patient and family choice leads to better quality of life and better health outcomes.

ASPN believes that there should be some safeguards in place for beneficiaries undergoing home therapies – specifically as an absolute minimum, a required in-person, face-to-face visit should occur every three months, however a once-per-month visit is ideal for our patient population. This is important to ensure that the nephrologist sees the patient in-person and assesses their health, including growth and developmental measures.

Additionally, we believe that with proper safeguards such as the one described above, the home could qualify as an originating telehealth site. Again, we have roughly half of our dialysis population taking advantage of home therapies, and we have been able to improve outcomes for those patients for whom this option makes sense. Due to pediatric nephrology workforce shortages and specifically lack of practicing pediatric nephrologists, in some states home dialysis is the only option. For example, pediatric nephrologists in Seattle, WA provide oversight and care of dialysis patients in Montana. Allowing either the facility or home to be an originating telehealth site would greatly improve the nephrologist's ability to provide care for these patients. While the pediatric nephrologist conducts clinics on a regular basis, the need for these families with young children to travel for hours is one that must be considered as well. Expanding the originating site options will allow these families to focus on the care of their child, rather than driving for hours.

II. Allowing End-Stage Renal Disease Beneficiaries to Choose a Medicare Advantage Plan

ASPN supports the proposal to allow ESRD beneficiaries to choose a Medicare Advantage (MA) plan, rather than the standard fee-for-service Medicare that they are currently forced to utilize if under the age of 65. Because Medicare provides coverage for ESRD patients regardless of age, those beneficiaries should have access to the same benefits and choice as other Medicare beneficiaries might have.

Regarding ensuring ESRD beneficiaries have the information to make an informed choice when deciding whether to enroll in an MA plan, ASPN urges the Working Group to ensure that the Centers for Medicare and Medicaid Services (CMS) gathers input from pediatric dialysis facilities – including administrators, nurses, social workers and pediatric nephrologists – to develop educational materials comparing the benefits, costs, etc., of current Medicare fee-for-server versus Medicare Advantage plans. This will ensure that those families wishing to enroll in an MA plan can reasonably consider all of their options. This population cannot be excluded from the process.

III. Developing Quality Measures for Chronic Conditions

ASPN again urges the Working Group to ensure that there is pediatric input in development of all quality measures. Specific to the questions under consideration by the Working Group, patient and family engagement for pediatrics is different from that for adults. The parents are often the primary caregivers for their children. Young children and infants cannot reliably assess their "satisfaction," but there are tools available that can be used to examine family engagement and caregiver satisfaction.

We also urge the Committee to look at pediatric nephrology as a model for shared decision-making. As noted above, half of children with end-stage renal disease are on home dialysis modalities, as opposed to roughly 10 percent of the adult population. Additionally, pediatric nephrologists have substantial experience with care coordination – often serving as the primary care provider for their patients. There are many lessons to be learned from our community.

IV. Increasing Transparency at the Center for Medicare & Medicaid Innovation

ASPN agrees with requiring CMMI to publicly report data related to models that affect a significant amount of Medicare spending, providers or beneficiaries, or to mandate a 30 day public comment period of all innovation models. Such reporting would go a long way to improving the transparency surrounding these programs. Public input into the process in a transparent manner is essential for these models to achieve their goals.

V. Immunosuppressive Drug Coverage Extension/Transplantation

Models of care that improve the quality of care and life for beneficiaries should be considered throughout this process. An important policy option not included in your document is that of extension of immunosuppressive drug coverage. ASPN is very supportive of extending immunosuppressive drug coverage for Medicare transplant recipients beyond the current limit of 36 months. As we previously noted, kidney transplant, particularly for pediatric patients, is currently the optimal treatment for ESRD. However, the current limit of 36 months is counterproductive. Without these drugs, children with kidney transplants can lose their life-saving transplants and be forced to initiate or resume dialysis, increasing Medicare costs substantially. Currently, the only Medicare beneficiaries eligible for lifetime coverage of transplant drugs are those who were and are eligible for Medicare because they are aged or disabled and whose transplant was paid for by Medicare.

Importantly, **the cost of transplant drugs per year is actually LESS than the cost of dialysis**. Although the Affordable Care Act's passage has helped allow those patients who might otherwise be on Medicare to have access to plans that would cover the cost of these expensive yet necessary therapies, ASPN believes that permanently expanding the immunosuppressive drug coverage through Medicare for the life of the kidney makes good policy sense, particularly for those who will fall through the cracks and may not have access to coverage via the Exchange. It is especially important to ensure that immunosuppressive drugs are available and affordable for the life of the kidney because even those patients with some prescription drug coverage through the Exchange can barely afford the cost of the other drugs they require, such as antihypertensives, anti-infectives, and others. In short, we urge the Working Group to consider the following policy: if an individual has Medicare coverage only because of ESRD, Medicare will pay for the immunosuppressive drug therapy for the life of the kidney, but NOT for immunosuppressive drug therapy for a transplant not originally paid for by Medicare.

Concluding remarks

Thank you again for the opportunity to provide comment on the Working Group Policy Options Document. We look forward to continuing to participate in this exciting process. Should you have any questions, please contact ASPN's Washington Representative, Katie Schubert, at kschubert@dc-crd.com or (202) 484-1100.

Sincerely,

Victoria F. Norwood

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President