August 29, 2013

Ms. Marilynn Tavenner  
Administrator, Centers for Medicare and Medicaid Services  
Department of Health and Human Services  
Hubert H. Humphrey Building  
Room 445-G  
200 Independence Avenue, SW  
Washington, DC 20001

Re: CMS-1526-P; Medicare Program; End-Stage Renal Disease Prospective Payment System, Quality Incentive Program, and Durable Medical Equipment, Prosthetics, Orthotics, and Supplies

Dear Ms. Tavenner:

On behalf of the Children’s Hospital Association, I appreciate the opportunity to comment on the proposed regulation for Changes to the End-Stage Renal Disease (ESRD) Prospective Payment System and Quality Incentive Program. The Association has concerns with the proposed 9.4 percent reduction in the base rate of the Prospective Payment System as it could have a significant negative impact on children’s hospitals and the children they serve.

Representing more than 220 children’s hospitals nationwide, the Association’s membership not only includes large, acute-care institutions, but also smaller specialty hospitals that treat a unique population of children with special health care needs. Children’s hospitals are a vital safety net for all children, treating uninsured, underinsured and publicly covered children across the country. Although children’s hospitals are less than 5 percent of all hospitals in the U.S., they account for 47 percent of all pediatric Medicaid admissions. Children’s hospitals serve the majority of children with serious illnesses and complex chronic conditions, including ESRD. Children’s hospitals rely on adequate reimbursement from public health care programs, including Medicare payments for ESRD, to ensure their ability to provide very specialized services for children.

Most pediatric-specific dialysis programs are located at one of the children’s hospitals represented by the Association, assuring these children the full range of pediatric supports and providers required to meet their unique and often challenging needs. For all of these dialysis programs, preserving and improving the quality of life for the children with ESRD they serve through the provision of high quality care is a top priority.

As you are well aware, the care needed by children with ESRD is different from that required by adults in a number of ways, including:

- Required intensive staff support to provide age-appropriate supervision and care to the growing child, many of whom experience cognitive or physical disabilities associated with pediatric ESRD
• Longer treatment times because of children’s inability to cooperate for long periods of time and the need to provide extra support for their adult caretakers
• Necessary support from ancillary pediatric personnel (i.e., dieticians, social workers and child life specialists) who can provide unique expertise on feeding problems, school requirements and interventions, early childhood development programs, and age-specific teaching and support
• The variety of specialized, expensive, size-appropriate equipment – including dialyzers, blood lines and catheters – necessary to provide dialysis to the broad spectrum ages/sizes of ESRD patients treated by these programs.

Given all of these clinical and practical differences in care, the actual cost of providing dialysis to a child is likely higher than for an adult patient. The Children’s Hospital Association has been working with seven children’s hospital-based dialysis programs for children with ESRD to better understand the cost of pediatric dialysis and the costs incurred in providing this care. At this point, the preliminary findings support the hypothesis that the current reimbursement under Medicare does not cover the cost of care provided to pediatric ESRD patients. The Association hopes to share the final findings with the Centers for Medicare and Medicaid Services (CMS) later this fall.

Because of the unique care pediatric ESRD patients require and our findings that demonstrate that Medicare does not currently cover the costs for pediatric dialysis, the Association has significant concerns about the net 9.4 percent cut to the base rate and the potential effects on access to high-quality dialysis care these cuts may represent for pediatric ESRD patients. We understand that CMS’ rationale behind the payment reduction is the decline in the cost and use of erythropoiesis stimulating agents (ESAs) since the black box warning was added to ESA labels. However, the Food and Drug Administration labeling change for ESAs was based on studies conducted on adult patients.

Before this payment reduction goes into effect for the pediatric ESRD population, the Association strongly urges CMS to carefully 1) reexamine the pediatric case mix adjustor and utilize updates of the Medicare cost reports from pediatric-specific providers to collect data for additional analysis of pediatric dialysis, and 2) examine pediatric ESA usage data to determine whether the same reduction in ESA use has also been seen in children undergoing dialysis. If there has not been the same level of reduction with pediatric patients, then the Association urges CMS to reconsider the proposal, especially in regards to children.

Again, thank you for the opportunity to comment on CMS’ proposed rule. We look forward to continuing this dialogue in the fall when the Association is prepared to share the results of our work that focuses on the cost of providing outpatient dialysis treatment to pediatric ESRD patients in children’s hospital-based programs. In the meantime, please contact either Sue Dull at sucdull@childrenshospitals.org or Liz Parry at liz.parry@childrenshospitals.org if we can provide any additional information.

Sincerely,

M. James Kaufman, PhD
Vice President, Public Policy