American Society of Pediatric Nephrology

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Dear Abby,

On behalf of the American Society of Pediatric Nephrology (ASPN), please accept my thanks for meeting with me and my colleagues to discuss our experiences educating members and their institutions on how to properly report pediatric data on their cost reports. As we shared, ASPN has endeavored to ensure that pediatric centers are reporting accurate and complete data to inform the future calculation of the Transitional Pediatric ESRD Add-on Payment Adjustment (TPEAPA). We greatly appreciate the time you and your team shared with us and your thoughtful attention to the challenges children's hospitals and independent dialysis facilities have encountered.

ASPN is grateful for the work that CMS did to develop the TPEAPA. As we discussed, the work, staffing, and supplies required to treat children with ESRD differ from those required to treat adults. There is consensus among our members, children's hospitals, and independent dialysis facilities that the costs to treat children are higher than those to treat adults. However, we are not confident that the data being reported to CMS accurately reflects this difference. As promised, we are sharing in writing the challenges that ASPN members have reported throughout this process to allow us to facilitate next steps as we work together to determine potential solutions.

Reporting for Hospital-Based Dialysis Units

Of the 1,000 to 2,000 children under 18 who receive chronic dialysis annually as treatment for ESRD, a majority are dialyzed in hospital-based units affiliated with children's hospitals. Texas Children's, Boston Children's, and Seattle Children's are three of the biggest centers in the county where children receive their dialysis and other care related to their ESRD.

ASPN has devoted time and resources to helping members identify the person responsible for Medicare cost reporting at their institutions and in understanding how their dialysis unit costs are acquired for the cost report. However, this has created its own set of challenges since the cost report applies to the entire hospital, and the dialysis unit represents a very small portion of the hospital's operations. While we are pleased to report that we have had success at the hospitals with large pediatric dialysis patient

populations, we have not been as successful across the board and cannot speak to if and how children's hospitals with smaller pediatric dialysis programs are reporting their data. Some hospitals have been willing to work with ASPN members to achieve more accurate reporting because they recognize this effort will improve care for this vulnerable population, but others have declined because of the significant administrative effort required to address a very small portion of their cost report.

The major challenge with appropriate reporting at all hospitals, regardless of the size of their pediatric dialysis programs, is that form CMS-2552-10 has not been updated to include specific lines to allocate pediatric-directed staff time. Staff time and resources are a primary driver for the increased cost of pediatric ESRD care since specialty trained nurses, social workers, child life specialists, and dieticians are needed to deliver care for this complex patient population. It is ASPN's understanding that few, if any, hospital-based dialysis units reported this information for calendar year (CY) 2023. After ASPN's efforts to emphasize the importance of reporting pediatric specific data on the current form, we believe that several large centers are likely to be reporting this information correctly for CY 2024, but we suspect that a significant accurate data gap will still exist.

Additionally, hospital-based units report challenges splitting the costs incurred among patients under 18 years of age and those older. Not all patients transition to the care of an adult nephrologist on their 18th birthday. In fact, some individuals remain in the care of a pediatric nephrology team into their early to mid-twenties because of their small size, neurocognitive limitations, and medical complexity stemming from co-morbid conditions typically cared for by pediatricians. Units do not separate out the costs—particularly for staffing—by patient age and have reported to us that it very difficult to separate the costs for patients under 18 from the total population treated in the dialysis unit. Another challenge is that some of the specialty trained staff are also providing non-dialysis patient care in the children's hospital, creating another challenge to appropriately allocate and report the staff time. Both issues may affect the accuracy of the staffing data reported.

Independent Dialysis Units

Independent dialysis units, including those run by the large dialysis organizations (LDOs), treat a much smaller segment of the pediatric ESRD population. As an example, DaVita only has five pediatric-specific units which treat 104 patients; they treat an additional 84 patients in mixed adult and pediatric units. These units, like hospital-based units, do not complete time studies to allocate costs between adult and pediatric units. Therefore, any data in the report is based on the ratio of adult to pediatric patients, calling into question the accuracy of their data. Additionally, it has been reported to ASPN members through conversations with the LDOs that the cost of supplies does not vary between children and adults because of their contracting mechanisms with suppliers, so that data is likely not reflective of actual costs for pediatric-specific supplies.

Next Steps

ASPN hopes that the information outlined in this letter provides helpful context on the challenges pediatric dialysis units face reporting accurate information to CMS. In follow up to our discussion, ASPN is working to identify the appropriate contacts for communications from CMS and the Medicare Administrative Contractors on this issue and will follow up with you separately once we have that list. We look forward to more conversations about additional actions that we can take together to ensure

that CMS has the information it needs to determine the next steps on TPEAPA and properly align pediatric payment with resource use. In the interim, please don't hesitate to contact me or Erika Miller, ASPN's Washington representative, at emiller@dc-crd.com.

Sincerely,

Meredith Atkinson
President