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Questions for the Record
House Committee on Energy & Commerce Subcommittee on Health
February 29, 2024
Hearing "Legislative Proposals to Support Patients with Rare Diseases"

The Honorable Robert Latta
1. By improving the process for enabling an out of state provider to enroll as a participating provider in the State Medicaid program for purposes of being reimbursed for treating children with deadly cancers like brain tumors, will these pediatric patients have a better chance of accessing state of the art care and clinical trials?

Enabling out of state providers to enroll as participating providers in all State Medicaid programs would allow children to enroll in the most relevant clinical trials for their medical condition, regardless of location. This change is essential to the care of children as most pediatric clinical trials, especially early phase trials, are only available at a limited number of hospitals. Each hospital has a different portfolio of trials.

The following is an example of the red tape experienced by one of our Iowa pediatric cancer patients. Our patient needed a liver transplant to treat their hepatoblastoma and to have the best chance for positive treatment outcome. The timing of this type of transplant is intricate and needs to be performed at a very specific time to be maximally successful. Our hospital does not provide this care, so we sought approval for our patient to travel out of state. The family really desired to have the treatment in Colorado where the care was offered and they had family to support them during this lengthy treatment. However, before Iowa Medicaid would approve the patient seek treatment in Colorado, they first had them receive care in Nebraska. The Nebraska treatment failed, and the patient was then allowed to seek care in Colorado. The out of state Medicaid provider enrollment and patient care approval paperwork that exists today took time and delayed the transplant.

The Honorable Gus Bilirakis
1. As medicine gets more personalized with innovative cell and gene therapies, how will the Accelerating Kids Access to Care Act help alleviate regulatory barriers to ensure these new innovations are available to rare disease patients that need it?

With implementation of the Accelerating Kids Access to Care Act pediatric patients diagnosed with rare diseases will have the best chance of receiving the most cutting-edge treatment at the children's hospital offering that care without having to experience the red tape that exists in our current Medicaid state system. In cases of rare disease, it is likely there will only be a few hospitals that offer the specialty treatment needed by the pediatric patient.

2. What are some additional ways we can reduce regulatory barriers beyond Medicaid, such as at the FDA or elsewhere in the health care system, to help pediatric rare patients?

Fixing prior authorization (PA)! Though there are federal policies aimed at fixing Medicare PA, that does not guarantee changes in the Medicaid system. A recent joint effort between the American Medical Association, the American Hospital Association, America's Health Insurance Plans, the American Public Health Association, BlueCross BlueShield Association, and the Medical Group Management Association generated a consensus statement on improving the PA process.

Five mutually agreed upon principles areas were identified as having the highest impact; selective implementation based upon providers' performance, regular program review, policy transparency with efficient communication, continuity of patient care, and systems automation. Critical to the successful implementation in pediatric oncology would be to incorporate best practices for the identification of standards of care which differ from other areas of medicine which cover more common disease states.

Much of what these associations agreed on is included in the Improving Seniors' Timely Access to Care Act (H.R. 3173/S. 3018). The legislation requires Medicare Advantage plans to establish an electronic PA program which provides real-time decisions in response to requests for items and services that are routinely approved in addition to other stipulations. Additionally, nine states have recently passed legislation that reforms the PA process in their jurisdiction, with more proposals introduced in 2024.

Lastly, in January 2024 the Centers for Medicare & Medicaid Services (CMS) finalized the Interoperability and Prior Authorization Final Rule, which set requirements for timeframes, denial reasons, metrics, and use of electronic measures(Services 2024). While this represents an enormous step in system-wide improvements, the impact on pediatric cancer care will likely be minimal given the percentage of pediatric patients who receive Medicare benefits. To ensure pediatric cancer patients and their healthcare providers similarly benefit, would require private policy and Medicaid changes as well which may require the assistance of disease specific and/or age specific advocates, so that children do not get left behind on these important changes.

The Honorable Larry Bucshon, M.D.
1. Do you think Medicare provider status and reimbursement of genetic counselor services would improve your patient care?

The short answer is YES, it will improve patient care. For example, University of Iowa Health Care and the Stead Family Children's Hospital have invested heavily in genetic counseling by employing twenty-four genetic counselors. Our physicians rely on genetic counselors as part of the care team to help more quickly identify genetic abnormalities, which in turn allows us as physicians to diagnose and treat our patients. The genetic counselors are also able to spend more time with the patients and their families to help them adapt to the medical and psychological issues that go along with a genetic diagnosis, which thereby enhances the care of our patients.

The lack of Medicare recognition of genetic counselors as providers and the resulting lack of reimbursement for genetic counseling services provided by genetic counselors prevents us from hiring more. Our Division of Pediatric Neurology is currently trying to figure out how to hire another genetic counselor to support our actively growing neurogenetics service for kids with intractable epilepsy, as these children often have a genetic cause for their epilepsy and require genetic testing and benefit from genetic counseling.

While most of my patients are not Medicare beneficiaries, many patients throughout the University of Iowa Hospitals and Clinics are. The hospital has limited resources, and the lack of reimbursement for genetic counselors in any area of our system presents a significant financial barrier in all areas, limiting the number of genetic counselors we can hire and support.

The lack of recognition also increases wait times for Medicare patients if they see a genetic counselor because a physician must supervise the genetic counselor. This requires coordinating clinic times to ensure a physician is present where the genetic counselor sees a Medicare patient. Medicare is the only payer where this supervision is necessary, as their licensure in Iowa does not require supervision for other insurers. Medicare recognition of genetic counselors would change this and improve the care not only for the kids and families at the University of Iowa, but for kids across the country.

Sincerely,

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