



September 6, 2018

The Honorable Michael Burgess
U.S. House of Representatives
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Gene Green
U.S. House of Representatives
Energy and Commerce Committee
2125 Rayburn House Office Building
Washington, D.C. 20515

Dear Chairman Burgess and Ranking Member Green:

We are writing to provide comments on the August 29, 2018 Discussion Draft of the Amendment in the Nature of a Substitute to H.R. 3325, the Advancing Care for Exceptional Kids Act, the ACE Kids Act. On behalf of our patients, families, and the clinicians who care for them, we thank you for your continued efforts to address the unique challenges children who have complex medical conditions and their families face in accessing needed health care.

Gillette Children's Specialty Healthcare (Gillette) has closely followed the genesis and evolution of this bill over the last several years and appreciates the opportunity to share our feedback. Although we are supportive of the goals of this bill, Gillette continues to have concerns about the framework of the ACE Kids Act and its very real potential to create more barriers to care for patients who have complex medical conditions and their families if the legislation were to be enacted.

Our history underscores our commitment to children who have complex medical conditions and their families. Gillette was created in 1897 as the nation's first state-created hospital dedicated to caring for children who have disabilities. We are an independent specialty hospital focused on the conditions of the musculoskeletal and neurological systems. Our providers' expertise in specialty care enables them to work in tandem with families, anticipating and meeting patients' needs. We work with each patient and family to identify individual goals and create proactive care plans to meet these goals. This partnership produces long-term and trusted relationships between families and care teams, as many patients have lifelong medical needs. Additionally, as many of the children Gillette serves qualify for Medicaid because of a disability, the percentage of our patients on Medicaid is one of the highest in Minnesota. In 2017, we also served patients from 42 states, including patients enrolled in Medicaid from 18 states outside of Minnesota. This is why the goals of the ACE Kids Act are of such importance to us.

While we recognize and are grateful for the many of the improvements made to the ACE Kids Act over the last several years, including most notably some that we have suggested, we continue to have concerns and wish to offer a few targeted but essential modifications.

First, we continue to be concerned – as we have previously shared – that the legislation puts the hospital, and not the child at the center of care, and could be used to create

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exclusionary systems of care and barriers to patient and provider choice, thereby limiting access to specialty care. The bill may create financial or other incentives for a hospital to limit care to their own internal providers. Children who have complex medical conditions need to be able to see a specialist who is an expert in their condition, co-morbidities, age, and other factors. Health homes should be required to coordinate the care that best fits an individual patient's need with no incentives in place to limit referrals outside of a health home. Children who have complex medical conditions need to see a team of specialists and these specialists may not be located at the same hospital, system, or even in the same state. Although we do not believe this is the intent, the requirements for health homes in the current draft could limit a child's access to needed specialty care.

To ensure the ACE Kids Act does not create new, unintended barriers for these families to access this very specialized care, the language should be amended to emphasize that these specialty providers who focus exclusively on children with medically complex conditions can continue to serve as a care coordinator and participate in any created health homes. As such we request the following changes to the bill:

- 1) Add a few key words noted in bold on page two, lines 19-21, so the bill reads: "(1) coordinate prompt care for children with medically complex conditions, including access to pediatric emergency services, **triage services, or pediatric critical care services** at all times." This will ensure that teams of providers, specialty providers and other types of delivery systems that fit the bill's definition of a designated provider, but that may not operate their own emergency services (which are typically available at a hospital-setting), are included. Further it protects family choice and the ability for them to have their medically complex child's care coordinated with a provider of their choice. This also aligns with the goal of care coordination and preventing unnecessary hospital and emergency room utilization.
- 2) Within part (h) of section 2 on page 13, add "**Nothing in this section shall be construed as limiting specialty care providers from being considered eligible to participate in all health homes created under this title.**" Such language would create a safeguard to prevent providers from being excluded from health homes or other unintended barriers or consequences that could limit specialists from providing for children who have medically complex conditions.

Second, there is scant data currently available with respect to children on Medicaid as a result of their disability, the providers who serve them and the process, gaps, and barriers their families experience in accessing needed care and treatment. Having this data and understanding how care is currently delivered is paramount before implementing a wide-reaching system change in Medicaid - incentivized by enhanced federal dollars - that could create unintended challenges. In the hearing on the ACE Kids Act on September 5, 2018, it was testified that "there is currently no national data available to inform our policies for children with medical complexity." We agree and support the data provisions in the ACE Kids Act, but strongly urge the Committee to make data gathering a precursor to the implementation of the health home model. We recommend the language be amended to:

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- Move section 3 to the beginning of the bill and require the data collected and presented in the MACPAC report be available at least 12 months prior to approval of any state plan amendment establishing such a health home. Data must come first, before creating any changes to Medicaid that could potentially adversely impact care to the most medically vulnerable.

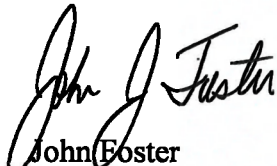
As a hospital exclusively dedicated for more than a century to serving children who are directly impacted by the ACE Kids Act, we again want to thank the authors, the Energy and Commerce Committee, and all staff working on this bill for your attention to these issues. Again, we note that although we do not believe this is the intent, the requirements for health homes in the current draft could limit a child's access to needed specialty care. We appreciate the opportunity to again express our concerns with the bill and to offer our recommendations to the latest version.

Thank you for your time and consideration. Should you have any follow up questions, want to meet or wish to discuss these issues with any of our patients or providers, please reach out to us at any time at (651) 578-5637.

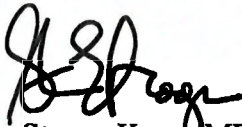
Sincerely,



Barbara Joers
President and CEO



John Foster
Chair, Board of Directors



Steven Koop, MD
Chief Medical Officer



Madeleine Gagnon, MD
Associate Medical Director, Pediatrics

CC: Chairman Greg Walden; Ranking Member Frank Pallone; Minnesota Congressional Delegation

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