July 6, 2016

The Honorable Cathy McMorris Rodgers United States House of Representatives 203 Cannon House Office Building Washington, DC 20515

Dear Representative McMorris Rodgers,

Seattle Children's delivers superior patient care, advances new discoveries and treatments through pediatric research and serves as the pediatric and adolescent academic medical center for Washington, Alaska, Montana and Idaho; the largest region of any children's hospital in the country. In 2015, Children's handled nearly half a million patient visits through specialized inpatient services, a large array of outpatient clinics, outreach visits to local health care organizations, on-call nursing consultations, and telemedicine.

Though our first priority is helping patients, we believe our role on behalf of our patients can also extend beyond the clinical setting and into the relevant policy arena. We were encouraged and grateful to hear that the Committee on Energy and Commerce's Subcommittee on Health would hold a hearing on one of our legislative priorities: the *Advancing Care for Exceptional (ACE) Kids Act.* Tomorrow's hearing is an important milestone that would not have been achieved without your leadership on the Committee. And while we have concerns with the current revised draft, we remain committed to working with you and your colleagues to improve and advance the bill toward final passage.

Specifically, it is important that future versions of this legislation support proven care coordination models and the data management systems required to maximize life-saving efficiency of care. Many Children's patients rely on an extensive team of experts for ongoing care. We, along with other children's hospitals and community physicians in our region, are dedicated to improving coordination of care to reduce the burden on families and improve outcomes and quality of life for children with complex conditions.

As it stands today, barriers to care coordination vary from state to state. A lack of comparative data on treatment approaches and outcomes consistently result in confusion and duplication of effort. This legislation has the potential to ensure that every child on Medicaid has a care coordinator, and that their provider team members in disparate locations are aligned on a plan of care based on evidence of success shown by comparative data from across the country.

This bill would also be strengthened by including more specificity in regards to the definitions of the population, identification of the specialized pediatric resources essential to the health home, and definition of the quality measures assessing health. Doing so would produce a more effective, targeted, and fiscally responsible draft.

We urge the Committee to consider using this legislative opportunity to define and establish adequate networks including highly specialized care for children with complex conditions, create a nationwide outcomes database to guide improved quality of care in the networks over time

and install a timeline for establishing and requiring consistent best practices for care across state lines.

Like you, we feel an urgency to work together and remove impediments to improved care for this very vulnerable population. Children's will always be a resource to hardworking public officials committed to improving the care and quality of life for children with complex medical conditions and their families.

Sincerely,

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