



Foundation to Eradicate Duchenne

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Joel Wood President

The Honorable Chuck Grassley
135 Hart Senate Office Building
Washington, D.C. 20510

The Honorable Michael Bennet
261 Russell Senate Office Building
Washington, D.C. 20510

The Honorable Joe Barton
2107 Rayburn House Office Building
Washington, D.C. 20515

The Honorable Kathy Castor
2052 Rayburn House Office Building
Washington, D.C. 20515

Dear Sens. Grassley and Bennet and Reps. Barton and Castor:

On behalf of the Foundation to Eradicate Duchenne, I am writing to express our support for S.428 /H.R.3325, The Advancing Care for Exceptional Kids Act of 2017 (The ACE Kids Act). We thank you for your leadership in introducing this bipartisan legislation to improve care for children with medical complexity on Medicaid.

Duchenne Muscular Dystrophy is the world's #1 lethal childhood genetic disorder and only affects boys and young men. Duchenne is a relentless disease that requires a complex set of treatments and constant vigilance on behalf of patients, their parents and the dedicated medical professionals who provide care. Due to the frequency and high cost of care, those battling Duchenne often rely on Medicaid for part or all of their medical care, and their parents act as de facto care coordinators.

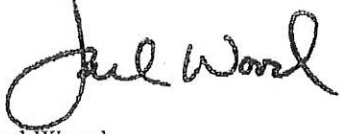
Children with complex medical conditions, like Duchenne, often see six or more specialists and a dozen or more physicians, and require care that takes them across state lines. Under the current Medicaid system, parents of children with multiple, life threatening disabilities struggle to coordinate the complex, multi-state care of their kids.

The ACE Kids Act advances an organized system of health care delivery for this unique population of children to ensure ready access across state lines and to reduce the burden on their families. Nationally designated children's hospitals networks created under the ACE Kids Act would employ national quality standards and coordinate care, both essential to improving quality and saving money. These networks would include the full range of acute, post-acute and primary care providers, with children's hospitals as anchors, and a focus on

outpatient care to ensure children get the care that they need in the most appropriate settings closest to home, while reducing hospitalizations and emergency room visits.

We believe ACE Kids Act can improve quality of care for the millions of children with medical complexity in Medicaid, while at the same time strengthening the program. The Foundation is happy to join the more than 20 national organization devoted to children's well-being that have already come out in support of The ACE Kids Act. Providing the best possible care for children with medical complexity enrolled in Medicaid is a national challenge that needs a national solution and requires Congress to act. We thank you again for introducing the ACE Kids Act and we look forward to working with you to advance this legislation in Congress.

Sincerely,

A handwritten signature in black ink that reads "Joel Wood". The signature is written in a cursive style with a large, looping initial "J".

Joel Wood

President & Founder

The Foundation to Eradicate Duchenne