May 28, 2015

The Honorable Fred Upton
Chairman
Committee on Energy & Commerce
2215 Rayburn House Office Building
Washington, DC 20515

The Honorable Frank Pallone
Ranking Member
Committee on Energy & Commerce
2322A Rayburn House Office Building
Washington, DC 20515

The Honorable Joe Pitts
Chairman
Committee on Energy & Commerce
Subcommittee on Health
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Gene Green
Ranking Member
Committee on Energy & Commerce
Subcommittee on Health
U.S. House of Representatives
Washington, D.C. 20515

The Honorable Diana DeGette
Committee on Energy & Commerce
U.S. House of Representatives
Washington, D.C. 20515

Dear Chairman Upton, Ranking Member Pallone, Chairman Pitts, Ranking Member Green and Representative DeGette:

On behalf of our nation’s children, thank you for your steadfast leadership in shepherding H.R. 6, the 21st Century Cures Act, through the Energy and Commerce Committee. We congratulate you for holding a successful markup with unanimous approval. We are especially grateful for the inclusion of key provisions to address the unique needs of pediatric populations, especially children with rare diseases. In particular, we support:

- Sec. 1021, which requires that as part of the development of its strategic plan, the NIH shall ensure that rare and pediatric diseases and conditions remain a priority;
- Sec. 1041, which authorizes an increase in the pediatric research loan repayment program to a maximum of $50,000;
- Sec. 1081, which includes strengthened language requiring the National Institutes of Health (NIH) to establish the National Pediatric Research Network;
- Sec. 1082, a sense of the Congress regarding a global pediatric clinical trials network; and
- Sec. 1083, which would help ensure appropriate age groupings are included in research studies involving human subjects.

We also support other provisions that impact pediatric populations, though not specifically targeted to pediatrics. We thank you for including:
• Secs. 1001 & 1002, which reauthorize the NIH and establish an innovation fund at NIH to support biomedical research through the funding of basic, translational, and clinical research; and

• Sec. 2001, which requires the Food and Drug Administration (FDA) to establish a structured framework for the meaningful incorporation of patient experience data into the regulatory decision-making process, including the assessment of desired benefits and tolerable risks associated with new treatments.

We commend your focus on advancing precision medicine. As you work with the Administration on the Precision Medicine Initiative, please emphasize the need for pediatric expertise and considerations as part of the process.

Thank you again for your efforts to advance biomedical research innovation for all Americans, including pediatric populations. We look forward to continued engagement with you and urge you to retain the key provisions referenced above as the legislative process moves forward.

Sincerely,

Children’s Hospital Association
Nemours Children’s Health System
The Children’s Hospital of Philadelphia