December 17, 2013

The Honorable Sherrod C. Brown
713 Hart Senate Office Building
Washington, DC 20510

Dear Mr. Brown:

On behalf of the 30 million Americans affected by the estimated 7,000 known rare diseases, approximately half of which affect children, the National Organization for Rare Disorders (NORD) thanks you for your leadership in ensuring the National Pediatric Research Network Act, included in the PREEMIE Reauthorization Act (S. 252), was passed by Congress on November 14 and signed into law by the President on November 27.

The National Pediatric Research Network Act will create a network and database of pediatric diseases, many of which are rare, to better coordinate pediatric research across the United States. NORD also hopes that the Pediatric Research Network will work closely with the NIH Office of Rare Diseases Research. Many of the 18 consortia are studying rare conditions and genetic disorders affecting children.

NORD is a unique federation of patient organizations dedicated to helping people with rare or “orphan” diseases. We are committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service. NORD supports a social, political, and financial culture of innovation that supports the basic and translational research necessary to create diagnostic tests and therapies for all rare disorders.

Thank you again for your continuing advocacy for the health and welfare of America’s children – our country’s most important asset. NORD looks forward to working with you in the future.

Sincerely,

Diane E. Dorman
Vice President