September 18, 2012

The Honorable Sherrod Brown  
United States Senate  
Washington, DC  20510  

Dear Senator Brown:

The National Organization for Rare Disorders (NORD) is writing in support of the National Pediatric Research Network Act (HR. 6163). We applaud your efforts to ensure that the National Institutes of Health (NIH) increase its attention to pediatric medical research. NORD is especially supportive of the increased focus on devastating rare pediatric diseases.

Without a coordinated research investment into the health and welfare of our nation’s children, thousands will continue to suffer. For instance, in a July 2010 editorial in Nature, the author states that twenty-seven percent of the individuals affected by one of the 350 most “common” rare diseases never live to see their first birthday. This is a national tragedy that must be addressed.

Once established, NORD hopes that the Pediatric Research Network will work closely with the Rare Diseases Clinical Research Network (RDCRN) currently administered by the Office of Rare Diseases Research at the NIH. Many of the 18 consortia are studying rare conditions and genetic disorders affecting children. Sharing knowledge will further the diagnosis and ultimate treatment for all children.

NORD represents the 30 million men, women and children affected by one of the 7,000 known rare diseases. Since 1983, we have served as the voice and advocate for the rare disease community to improve the lives of individuals with rare diseases by expanding access to life-saving care and furthering innovation for new therapies that treat rare diseases. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research and service.

The National Organization for Rare Disorders looks forward to the opportunity to work closely with you to ensure passage of this important legislation.

Sincerely,

Diane Edquist Dorman  
Vice President