LEADING THE
FIGHT TO
END DUCHENNE

July 30, 2012

The Honorable Sherrod Brown
United States Senate
713 Hart Senate Office Building
Washington, DC 20510

VIA ELECTRONIC DELIVERY

Dear Sen. Brown:

Parent Project Muscular Dystrophy, the largest advocacy organization fighting for therapies and a cure for Duchenne Muscular Dystrophy, is pleased to endorse the National Pediatric Research Network Act, which will help enhance federal support for pediatric research, including research into rare diseases like Duchenne.

The Duchenne community has witnessed first-hand the impact such a targeted commitment can have. As a result of the work of the Paul D. Wellstone Muscular Dystrophy Cooperative Research Centers, we have made significant progress in better understanding the disease, learnings that have helped develop potential therapies. Today, nearly 20 potential therapies for Duchenne are in clinical investigation, and several more are in earlier stages of development.

The National Pediatric Research Consortia Act will help advance pediatric biomedical research at all levels and expedite the pace of breakthroughs able to yield treatments and therapies for some of the most devastating conditions of childhood. The need is particularly acute since despite accounting for nearly 20 percent of the nation's population, the National Institutes of Health has historically invested a far smaller percentage of its budget to diseases and conditions that affect children and adolescents.

Your legislation will address these concerns by enhancing the national commitment to pediatric research across the board by providing the infrastructure – including training and support for younger investigators – that is needed to advance the field for decades to come. The bill authorizes the NIH to competitively select up to 20 pediatric research consortia, each of which would be comprised of multiple institutions and focused on a specific and high-impact basic research agenda. It would also require collaboration and resource sharing among the consortia to avoid duplication and maximize the return on investment pediatric medical research, and require that a subset of the consortia have a primary focus on pediatric rare disease research, including operation of clinical trials.

On behalf of all patients and families impacted by Duchenne Muscular Dystrophy, I thank you for your leadership on this legislation and offer our enthusiastic endorsement.

Sincerely,

Pat Furlong
Founding President and CEO

Parent Project
Muscular Dystrophy

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