



Make today a breakthrough.

March 8, 2021

The Honorable Chris Van Hollen
United States Senate
110 Hart Senate Office Building
Washington DC 20510

Dear Senator Van Hollen:

As the leading national organization that supports and advocates for children and adults with spinal muscular atrophy (SMA), a genetic neuromuscular disease, **Cure SMA is pleased to support your Keep Our Promise to America's Children and Teachers (PACT) Act** that would ensure that students with SMA and other disabilities receive a high-quality and appropriate education that meets their unique needs and prepares them for further education, employment, and independent living.

SMA is a progressive neurodegenerative disease that robs individuals of physical strength, taking away their ability to walk, eat, and breathe. SMA impacts 1 in 11,000 births in the United States and approximately 1 in 50 people is a genetic carrier for SMA. If both parents are SMA carriers, every child they have together has a 25 percent chance of being diagnosed with SMA, regardless of race, ethnicity, and gender.

The Individuals with Disabilities Education Act ([IDEA](#)) guarantees a free appropriate public education that meets the unique needs of students with disabilities. The landmark law established IDEA programs to assist states in delivering special education to school-aged children with disabilities ages 3 to 21 (Part B, Section 611), educational supports for preschool-aged students (Part B, Section 619), and early intervention services for infants and toddlers with disabilities (Part C). These programs help states and local educational agencies develop and maintain high academic achievement standards and provide educators and parents with the necessary tools to improve educational results for children with disabilities.

Bodhi, a 1st grade student with SMA, is excelling in school thanks in part to the rights, services, and protections available under IDEA. Because Bodhi was missing typical developmental milestones, his parents received an assessment and, later, accessed occupational and physical therapies through the early intervention program for infants and toddlers. When Bodhi turned 3, the family met with their school district's individualized education program (IEP) team to extend these therapies and to set educational goals as part of an IEP plan. His IEP goals included increased independence, ability to unzip his jacket and hang up his backpack, and transferring to and from his wheelchair. The school district assigned Bodhi a classroom paraprofessional to assist him with various activities like bathroom breaks, transfers, and navigating the playground during class recess. "They have completely included him in all school activities," said Bodhi's mom. "He plays and learns alongside his peers and they have integrated his therapies and goals in the classroom and within his regular class work. He loves school and rolls around like he owns the place!"

Unfortunately, not every student with SMA or other disabilities has the same positive experience of Bodhi and his family. **Many families struggle to get the educational supports and related services their student with SMA needs to receive a high-quality education.** Families with SMA have reported having to fight and take legal action to ensure their child with SMA receives an IEP and associated services. Cognitive development is usually not affected in children with SMA. However, children with SMA require assistance in school-related activities because of neuromuscular weakness that impairs their physical strength. School districts often point to budget restraints for their reason for limiting services or narrowing eligibility.

Under IDEA, the federal government pledged to cover 40 percent of the average per pupil expenditure for special education. However, the federal government has never fulfilled that commitment. Today, the federal government only covers approximately 13 percent of the national average per pupil expenditures. **The Keep Our PACT Act would fully fund IDEA on a mandatory basis, not subject to annual discretionary budget decisions.** Your legislation would finally meet the promise of IDEA and ensure that all children with disabilities, regardless of which state or school district they reside in, have the educational supports and related services they need to excel in school.

Cure SMA and our supporters across the country, including in Maryland, are pleased to support the Keep Our PACT Act. We look forward to working with you to get this important legislation signed into law. For more information, your staff can contact Maynard Friesz, Vice President for Policy at Cure SMA, at maynard.friesz@curesma.org or 202-871-8004.

Sincerely,

A handwritten signature in black ink that reads "K. A. Hobby".

Kenneth Hobby
President

A handwritten signature in black ink that reads "Maynard Friesz".

Maynard Friesz
Vice President of Policy & Advocacy