



Make today a breakthrough.

March 2, 2021

The Honorable Bob Casey
United States Senate
393 Russell Senate Office Building
Washington DC 20510

The Honorable Jerry Moran
United States Senate
521 Dirksen Senate Office Building
Washington DC 20510

The Honorable Tony Cardenas
United States House of Representatives
2438 Rayburn House Office Building
Washington DC 20515

The Honorable Cathy McMorris Rodgers
United States House of Representatives
1035 Longworth House Office Building
Washington DC 20515

Dear Senators Casey and Moran and Representatives Cardenas and McMorris Rodgers:

As the leading national organization that supports and advocates for individuals with spinal muscular atrophy (SMA), a genetic neuromuscular disease, **Cure SMA is pleased to support your ABLÉ Age Adjustment Act (S. 331/H.R. 1219) to expand the number of individuals with SMA and other disabilities who are eligible to open an Achieving a Better Life Experience (ABLE) account.**

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% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender.

The ABLE accounts that were created through the Achieving a Better Life Experience Act of 2014 have allowed individuals with SMA and their families to save for future expenses, such as housing, transportation, and health care, without jeopardizing their eligibility for Medicaid and other essential public services. In addition, the tax-advantaged savings accounts have allowed individuals with SMA to increase their financial stability and independence.

Currently, ABLE accounts are not available to all individuals with SMA and other disabilities. SMA Type 4 occurs in adulthood where symptoms often occur after 35 years of age. Because current eligibility for ABLE accounts is only for individuals whose disability onset occurred before age 26, individuals with SMA Type 4 are not able to benefit from this tax-advantaged savings account like individuals with other SMA types. Your legislation helps to address this challenge by increasing eligibility to include all individuals with disabilities whose age of disability onset occurs prior to age 46. This change is the right thing to do and will strengthen the ABLE program by increasing the pool of possible ABLE account holders.



Cure SMA and our supporters across the country strongly support the ABLE Age Adjustment Act (S. 331/H.R. 1219) and 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 and Advocacy 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