



Make today a breakthrough.

August 8, 2024

The Honorable Eric Schmitt
United States Senate
387 Russell Senate Office Building
Washington DC 20510

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

Dear Senators Schmitt and Casey:

As the leading national organization that advocates for individuals with spinal muscular atrophy (SMA), a genetic neuromuscular disease, **Cure SMA is pleased to support your Ensuring Nationwide Access to a Better Life Experience (ENABLE) Act.** Your bipartisan legislation (S.4539) would provide individuals with SMA and other disabilities with greater certainty around their financial futures and independence by permanently extending key ABLÉ account provisions.

SMA is a progressive neurodegenerative disease that attacks the nervous system and destroys muscles used for everyday living activities, such as walking, eating, and breathing. SMA impacts 1 in 15,000 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.

The SMA community applauded the creation of ABLÉ accounts through the Achieving a Better Life Experience Act of 2014. ABLÉ accounts allow individuals with SMA and other disabilities to save for future expenses, such as housing, transportation, and health care, without jeopardizing their ability to access Medicaid, caregiving services, and other essential public programs. Fashioned after the popular 529 college tuition accounts, an ABLÉ account is an easy-to-set-up, consumer-friendly option for individuals with disabilities and their families to set aside money for future living expenses. *"This account has given me a piece of mind, knowing that I have funds to cover an emergency or life event,"* said an employed **adult woman with SMA** who directly deposits money into her account from her paycheck. She is growing the account to purchase a new accessible van or a home. An **adult man with SMA** also sets aside money from his monthly paychecks. *"I take a portion of my work income to put toward my ABLÉ account. It's great for saving money, paying for hefty medical expenses, and just having some financial security."*

There is an annual contributions limit for ABLÉ accounts. Current law allows an individual with disabilities who is employed to contribute beyond the traditional yearly cap. However, this provision (known as ABLÉ to Work) is set to expire by the end of fiscal year 2025 along with a rollover provision and tax credit for individuals with disabilities who contribute into their own ABLÉ account. Your legislation would permanently extend these three provisions, which are key to promoting work and financial independence for individuals with SMA and other disabilities.



Cure SMA and our supporters across the country strongly support the ENABLE Act (S. 4539) 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. Hobby".

Kenneth Hobby
President

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

Maynard Friesz
Vice President of Policy & Advocacy