



Make today a breakthrough.

September 11, 2023

The Honorable Jimmy Panetta  
U.S. House of Representatives  
304 Cannon House Office Building  
Washington, DC 20515

Dear Representative Panetta,

As the leading national organization that represents individuals with a neuromuscular disease known as spinal muscular atrophy (SMA), **Cure SMA is pleased to support the Marriage Equality for Disabled Adults Act.** Your legislation will ensure that individuals with SMA and other disabilities can marry without fear of losing their federal benefits and health care.

SMA is a progressive neurodegenerative disease that robs individuals of physical strength and impacts their ability to walk, eat independently, and perform other essential functions of everyday life. Some individuals with SMA receive Social Security disability benefits through the Disabled Adult Child (DAC) program. These benefits are critical for independent living by assisting with basic living needs, such as food, clothing, and shelter. DAC eligibility can also include access to Medicare or Medicaid for health care, caregiving services, and medical equipment, such as power wheelchairs. **However, individuals with disabilities who receive DAC benefits can lose it all, simply for falling in love and getting married.** (Source: [Social Security Administration](#))

This discriminatory DAC policy has real consequences for individuals with SMA and other disabilities. *"We aren't allowed to have traditional love without losing life-saving health insurance and income,"* said a **woman with SMA** who transitioned from the Supplemental Security Income program to DAC when her father retired in 2018. The switch boosted her monthly benefit amount, providing her greater independence and financial security. *"I now have an accessible van and house with a living space for my 24-hour caregiver,"* she said. *"I am still poor, but I can live and survive."* Current law puts her independence, stability, and community living at risk if she gets married. *"Medically complex people would like to share their lives with others in loving situations without worrying about losing their healthcare or caregiver benefits. We want to love and be loved,"* she said. *"I feel discriminated against because of this rule."*

**Your Marriage Equality for Disabled Adults Act would remove this disability marriage penalty from existing law by allowing individuals with SMA and other disabilities to marry without losing their benefits and health care.** Cure SMA appreciates your leadership and efforts to end this discriminatory policy that is impeding the ability of individuals with SMA and other disabilities to marry and remain financially independent. The SMA community stands ready to help you pass this important legislation in the 118th Congress. Your staff can contact Maynard Friesz, Vice President for Policy and Advocacy at Cure SMA, at 202-871-8004 or [maynard.friesz@curesma.org](mailto:maynard.friesz@curesma.org) if they have questions or need additional information.

Sincerely,

Kenneth Hobby  
President, Cure SMA

Maynard Friesz  
Vice President of Policy, Cure SMA