



CURE SMA'S GREATER INDEPENDENCE AGENDA

Children and adults with SMA are achieving great things, from excelling at school, thriving in the workplace, and contributing to and participating in their community. Despite these personal achievements and advances in SMA treatment and care, individuals with SMA continue to face barriers in their everyday lives, from discrimination and inaccessible housing and transportation to obstacles in accessing healthcare, in-home care, and educational and employment-related supports.

Recognizing that state and federal policies impact nearly all aspects of life for those with SMA, Cure SMA is actively advocating for legislation and policy changes to help promote greater independence for all individuals with SMA. Cure SMA's Greater Independence advocacy agenda focuses on 5 key pillars:

- 1 ACCESS TO HEALTHCARE AND TREATMENT:** Cure SMA advocates for policies and programs that promote the development of new treatments to meet unmet needs of the SMA community, particularly for adults with SMA, and to ensure timely access to SMA treatments, therapies, equipment, and other health-related services.
- 2 TRANSITION TO ADULTHOOD:** Cure SMA supports policies and programs to improve the transition from youth to adulthood for individuals with SMA and their families, from expanding healthcare provider knowledge and evidence-based strategies to focusing on transition needs related to education, employment, and technology.
- 3 COMMUNITY LIVING:** Cure SMA advocates for policies and programs that promote independent community living for all individuals with SMA, including increasing access to affordable housing, accessible transportation, assistive technology, and in-home supports.
- 4 FINANCIAL INDEPENDENCE:** Cure SMA supports policies and programs that promote financial independence and economic self-sufficiency for all individuals with SMA by removing barriers to employment, increasing opportunities to save, and maintaining access to Medicaid, including through healthcare portability.
- 5 DISABILITY RIGHTS:** Cure SMA supports policies and programs that promote accessibility, equality of opportunity, and full integration and participation in all aspects of life for children and adults with SMA.

ADVANCING THE GREATER INDEPENDENCE ADVOCACY AGENDA

Individuals with SMA and their families and supporters of Cure SMA can help advance the Greater Independence advocacy agenda in Congress by becoming a Cure SMA Advocate and advocating for Greater Independence agenda priorities through the Cure SMA Advocacy Action Center.

Visit the Cure SMA
Advocacy Action Center



Sign up to be a
Cure SMA Advocate



Cure SMA Advocacy | 800-886-1762 | advocacy@cureSMA.org | cureSMA.org

Cure SMA is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.