

cure SMA Disability Rights Principles and Priorities

Despite the 1990 passage of the Americans with Disabilities Act (ADA), the United States has yet to fully live up to its mandate to eliminate discrimination against individuals with disabilities. While enormous progress has been achieved, the ADA's vision of equality of opportunity, full participation, independent living, and economic self-sufficiency remains out of reach for too some individuals with spinal muscular atrophy (SMA).

Cure SMA Disability Rights Principles and Priorities:

Cure SMA is committed to preserving and expanding the rights of individuals with SMA in all aspects of daily and community living. SMA community principles and priorities include:



Prevent the Weakening of the Americans with Disabilities Act: The ADA's nondiscrimination protections and enforceable accessibility standards remain vital and must be preserved and strengthened to help remove societal and institutional barriers for all individuals with SMA. *Cure SMA will oppose efforts to remove or weaken equal opportunity and nondiscrimination protections included in the ADA for individuals with SMA and other disabilities.*



Emphasize and Enforce Nondiscrimination Protections in Healthcare: Individuals with SMA should not be discriminated against in healthcare based on disability, including under national emergencies and pandemics or through quality-of-life formulas. *Cure SMA will support efforts to emphasize, clarify, and enforce protections in federal law that protect confidentiality of individuals with SMA and prohibits any discrimination in healthcare, including barriers to access treatments, medical devices, and other healthcare services.*



Strengthen and Enforce Physical and Electronic Accessibility Standards: Individuals with SMA should have equal opportunity to participate in and have access to all aspects of daily and community living. *Cure SMA will support efforts to promote and enforce accessibility standards in physical and electronic products, services, and locations to ensure full access for individuals with SMA and other disabilities.*



Protect Student Rights and Access to Accessible and Appropriate Education: Students with SMA should have full access to educational supports (i.e., accessible educational technology), learn alongside their peers, and not be subjected to discrimination in the classroom. *Cure SMA will support efforts to fulfill the federal mandate to provide all students with SMA with a free and appropriate public education that is least restrictive, meets their individual needs, and protects their rights.*



Require Disability Representation: Individuals with SMA should be represented or considered when agencies or policymakers consider changes to public services and programs that impact the SMA community. *Cure SMA will promote opportunities for individuals with SMA to serve on or provide feedback to governing boards or government agencies responsible for public programs and services that impact individuals with SMA and other disabilities.*