Cure SMA Advocacy Issue Survey

Thank you for your interest in the Cure SMA policy agenda. Your feedback will help inform Cure SMA as it continues to advocate for individuals with SMA and their families. Thank you in advance for sharing your feedback.

ISSUE CATEGORY RANKING

Cure SMA

Please rank each issue category in order of priority, with 1 representing your top priority and 10 representing your last priority. You may only use each rank number once. Thank you.
DISABILITY RIGHTS: Federal law mandates equality of opportunity, full participation independent living, and economic self-sufficiency for individuals with disabilities.
EDUCATION: Access to high-quality, inclusive education and educational supports are critical for individuals with SMA
EMERGENCY MANAGEMENT: Effective emergency preparedness and disaster response are a matter of life and death for people with disabilities.
EMPLOYMENT & FINANCIAL SECURITY: Employment is critical for individuals with SMA to achieve greater independence and economic self-sufficiency.
HEALTH CARE: Full and timely access to treatments and health care services greatly increase the health, well-being, and independence of individuals with SMA.
HOUSING: Architectural barriers and lack of affordable housing limit community living and independence for people with disabilities.
INDEPENDENT LIVING: Ensure access to in-home supports and community services to promote community living and independence.
SMA AWARENESS: Given spinal muscular atrophy is a rare disease, SMA awareness is limited among federal policymakers.
TECHNOLOGY: Technology devices and related technology can assist a person with SMA in education, employment, and activities of daily living.
TRANSPORTATION: Transportation remains a barrier for people with disabilities, impacting their ability to access services and to participate in their community.
OTHER:
COMMENTS Please feel free to share any additional information that may be relevant to the survey.
Thank you for your feedback!