

Effective emergency preparedness and disaster response are a matter of life and death for people with disabilities, including individuals with spinal muscular atrophy (SMA). Existing emergency response and recovery efforts often overlook or fail to effectively meet the needs of people with disabilities and older adults who may need accessible options and specialized assistance during an emergency evacuation.

### Cure SMA Emergency Management Principles and Priorities:

Cure SMA is committed to ensuring that emergency response and recovery plans in the United States meet the needs of individuals with SMA and other disabilities. Our principles and priorities in the 118th Congress include:



**Enhance Disability-Focused Emergency Preparedness Resources:** Emergency response and recovery efforts often overlook or fail to effectively meet the needs of people with disabilities, including individuals with SMA, who may need accessible options and specialized assistance during an emergency evacuation. *Cure SMA will support efforts, including dedicated technical assistance, resources, and disability-focused planning requirements, to improve emergency preparedness for people with SMA and other disabilities.*



**Support the Post-Emergency Needs of People with Disabilities:** Individuals with disabilities who are displaced from their home and community due to a natural disaster or other emergency must be supported to ensure they have full access to the services and supports they need to remain healthy and live independently. *Cure SMA will support efforts to ensure individuals with disabilities who are eligible for services and supports through Medicaid or other public programs are able to access those programs and services if they are forced to relocate to another state due to a natural disaster or national emergency.*



**Promote Disability Representation on Emergency Planning Boards and Committees:** Emergency response and recovery plans and efforts may lack knowledge and understanding of the needs of individuals with SMA and other disabilities in their community. *Cure SMA will support efforts to require that emergency planning boards and committees include members with disabilities or, at a minimum, collects the views and experiences of individuals with disabilities from their community as they develop and implement their emergency management strategies.*