

*Children and adults with spinal muscular atrophy (SMA) can experience unique and complex medical needs from complications associated with SMA, such as respiratory failure, difficulty swallowing, severe scoliosis, and upper and lower extremity contractures. In addition, individuals with SMA may require ongoing care, including therapies and equipment, to maintain their health and independence and for support in their activities of daily living. Federal programs (i.e., Medicaid) and laws (i.e., Affordable Care Act) have increased the ability for individuals with SMA to access essential care.*

## Cure SMA Healthcare Principles and Priorities:

Cure SMA is committed to expanding and improving access to healthcare for individuals with SMA and their families. SMA community principles and priorities include:



**Do No Harm:** Healthcare reforms and modifications to health-related programs should improve the lives of children and adults with SMA. *Cure SMA will view all proposals through the lens of whether the changes would benefit or harm individuals with SMA and their ability to access essential treatments and care.*



**Protect Individuals with SMA From Discrimination:** Individuals with SMA should not be discriminated against due to their SMA or related health conditions in accessing treatments and care that can help maintain and improve their health and independence. *Cure SMA supports the healthcare protections under current law that promote affordable access, prevents discrimination, and bans annual and lifetime limits. In addition, Cure SMA opposes efforts to ration care, under any circumstances, for individuals with SMA.*



**Promote Access to SMA Treatments:** Advances in medicine and science make it possible for individuals with SMA to halt the progression of the disease, improve function and muscle strength, and achieve unprecedented developmental gains. *Cure SMA will work to remove any barriers (i.e., utilization protocols) that take away from personal choices on treatment and care and will support the ability of individuals with SMA to access available treatments done in sequence or combination with other treatments.*



**Expand Home and Community-Based Services:** Individuals with SMA may utilize home-based care and related services and equipment to assist in their health and independence. *Cure SMA supports expansions of home and community-based services for individuals with SMA through Medicaid and other programs.*



**Expand Access to Comprehensive Healthcare:** All working-age individuals with SMA who rely on comprehensive healthcare and services available only through Medicaid should be able to gain Medicaid coverage without limiting their ability to work, earn, and save for their future. *Cure SMA supports federal and state efforts to guarantee access to Medicaid while not disincentivizing work and hampering financial independence.*



**Remove Healthcare Measurements That Minimize Patient Perspective:** Health-related decisions that impact individuals with SMA may rely on healthcare measurements that often discount or fail to accurately assess patient perspective. *Cure SMA does not support quality adjusted life year (QALY) or similar assessments that fail to accurately capture the perspective of individuals with SMA related to their health, quality of life, and independence.*