**SAMPLE MEETING REQUEST -** (personalize the highlighted sections before sending)

[Date]

The Honorable [First Name Last Name]

United States [Senate or House of Representatives]

[Address]

[City, State Zip]

Dear [Senator/Representative] [Last Name]:

Thank you for making your staff available to meet with me to discuss spinal muscular atrophy (SMA), a rare neuromuscular disease, and the caregiving needs of the SMA community.

As I described to [Name of staff person(s) you met with], I am a [person/parent of a child] with SMA, a neuromuscular disease that impacts the muscles used for activities such as breathing, eating, crawling, and walking. As highlighted in Cure SMA’s national caregiving report, many individuals with SMA rely on a paid or family caregiver to assist with getting out of bed, transferring into wheelchairs, and performing other regular daily activities.[**Repeat your/your child’s caregiving needs in a sentence or two. For example, “As an individual with SMA type 2, I depend on a caregiver to get out of bed every morning.”]**

Accessing caregiving services is far too challenging for [me/ my child] and other individuals with SMA. Thank you for considering the caregiving needs and recommendations of the SMA community, which include:

* Strengthening the direct care workforce through increased Medicaid HCBS investments,
* Removing eligibility barriers for accessing caregiving services, including asset and income limits,
* Promoting Medicaid coverage portability among states, and
* Incentivizing Medicaid waiver best practices, including paying family caregivers and offering caregiving services for individuals with disabilities who work and earn above traditional Medicaid levels..

I appreciated the time I had with your office to share my experience. Thank you for considering my views. Your staff can contact me or Cure SMA ([advocacy@curesma.org](mailto:advocacy@curesma.org)) if you have any questions or need additional information about the priorities of the SMA community.

Sincerely,

[Your First Name Last Name]

[Your Address}

[Your City, State Zip]

[Your Phone]

[Your Email]