**INSTRUCTIONS**

* **Send your meeting request at least 3 weeks prior to your recommended meeting date.**
* **Use the “Find Officials” search bar located on Cure SMA’s** [**Advocacy Action Center**](https://www.curesma.org/advocacy-action-center/) **to find and email of your Members of Congress**
* **Use Cure SMA’s State Fact Sheets, located on Cure SMA’s** [**Advocacy Web Page**](https://www.curesma.org/cure-sma-advocacy/#state-fact-sheets)**, to tailor the letter with state-specific data.**
* **Refer to Cure SMA’s DIY Video on** [**How to Set Up A Congressional Meeting**](https://www.youtube.com/watch?v=QZ8bpRGsoD0) **for additional guidance on requesting a meeting. And once the meeting is scheduled, please view the** [**How to Structure a Congressional Meeting**](https://www.youtube.com/watch?v=0CnkRfJUj8M) **to assist you in organizing your meeting.**
* **Contact** [**advocacy@curesma.org**](mailto:advocacy@curesma.org) **if you have questions at any point during your congressional outreach.**

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

[Date]

The Honorable [First Name Last Name]

United States [Senate or House of Representatives]

[Congressional Member’s Address]

[City, State Zip]

Dear [Senator/Representative] [Last Name]:

As your constituent and a supporter of Cure SMA, a national organization that represents individuals with a rare neuromuscular disease known as spinal muscular atrophy (SMA**)**, **I write to request an in-person or virtual meeting** to discuss SMA and the SMA community’s legislative priorities.

SMA is an inherited neurodegenerative disease that affects the motor nerve cells in the spinal cord and impacts the muscles used for activities such as breathing, eating, crawling, and walking. SMA impacts 1 in 11,000 births in the U.S. If both parents are SMA carriers, every child they have together has a 25% chance of being diagnosed with SMA, regardless of race, ethnicity, and gender. [**Include 1-2 sentences describing your connection to SMA. Bold-face the type. Consider adding a statistic from your state’s fact sheet]**

SMA was once the leading genetic cause of infant death. Today, thanks to past research and policies supported by Congress, there are multiple SMA treatments that are helping to slow or stop symptoms associated with SMA. However, because these treatments do not cure or reverse muscle loss and motor function decline, significant unmet needs remain for children and adults with SMA across all ages and disease types. I am writing to request a meeting with you and/or staff to [insert the [advocacy issue](https://www.curesma.org/cure-sma-advocacy/#advocacy-toolkit) you want to discuss during the meeting. For example, **“***I am writing to request a meeting with you and/or staff to discuss the caregiving challenges of the SMA community. Individuals with SMA often struggle to find and retain in-home caregivers to assist with everyday living activities, such as bathroom support, household duties, and transferring in and out of bed and into our power wheelchairs. In addition, many individuals with SMA only receive a fraction of the caregiving hours we need to maintain our health and independence.”]*

I know your schedule is very demanding. If you are unable to meet directly, I hope you will make available your staff to meet with me virtually or in-person to discuss SMA and the priorities of the SMA community. To arrange a meeting, your staff can contact me at [insert your phone number and email address]. Thank you for your consideration.

Sincerely,

[Your First Name Last Name]

[Your Address}

[Your City, State Zip]

[Your Phone]

[Your Email]