

EDUCATE CONGRESS ABOUT SMA DURING SMA AWARENESS MONTH

Meet with Your Congressional Office During August Recess

August is SMA Awareness Month. August is also a congressional recess month when your Members of Congress work in their states or congressional districts rather than in Washington, DC. These in-state work periods are great times for constituents, like you, to educate Members of Congress and/or their staff about issues important to them and the region.

Cure SMA encourages all Cure SMA advocates and supporters to use the August congressional recess to raise awareness about SMA and the unmet needs of children and adults living with SMA.

U.S. House Recess
August 1 to September 12

U.S. Senate Recess
August 8 to September 5

SMA AWARENESS MONTH – BOOK YOUR OWN MEETING (BYOM) RESOURCES

Members of Congress use congressional recesses to meet directly with constituents through meetings, events, and townhalls. This is a great time for individuals and families with SMA to arrange meetings with Members of Congress and/or their local office staff to develop or cultivate relationships with your representatives and to highlight the priorities of the SMA community.

SIX STEPS FOR SCHEDULING AUGUST MEETINGS WITH YOUR CONGRESSIONAL OFFICES

1. **INVITATION:** Email a formal letter requesting a virtual or in-person meeting with the Member of Congress and/or their staff.
(Note: send your request 3-6 weeks prior to your suggested meeting time.)

RESOURCES:

- **Find Your Member of Congress:** Access your Members of Congress and their district offices through the “Find Officials” tool on [Advocacy Action Center](#).
- **Meeting Request Letter:** Tailor this template letter to request a meeting with your congressional offices.

2. **REQUEST FOLLOW UP:** After one week, follow up your written meeting request with a phone call and/or a second email to inquire about your meeting request.

- During your follow-up, make clear that you are willing to meet with only staff if the Member of Congress is unavailable.
- Highlight that you are a constituent and that you want to meet in August because it is SMA Awareness Month

3. **SCHEDULE:** Arrange your in-person or virtual meeting.

- Be flexible given Members of Congress and their staff receive many meeting requests throughout the year, especially during August recess.

4. **PREPARE:** Make sure you are prepared before attending the meeting. Every success meeting should include: 1) a thank you for their time (& past support if you are away); 2) introduce yourself and your connection to SMA/Cure SMA; 3) educate about SMA and SMA in your state and SMA Awareness Month 4) Ask for their support of a SMA community/Cure SMA priority

RESOURCES:

- **State Fact Sheets:** Familiarize yourself with SMA in your state through your state’s Cure SMA fact sheet ([located in the Cure SMA Information Center](#))
- **Advocacy Request:** We recommend that you advocate for SMA research (see Cure SMA fact sheet). Alternatively, you could raise a different [Cure SMA priority](#).

5. **ATTEND:** This is the fun part, especially now that you are prepared for a successful meeting!

6. **MEETING FOLLOW UP:** Within one week of the meeting, send a follow up email to thank the Member of Congress (and staff if they were in the meeting) for their time in meeting during SMA Awareness Month.

- Attached the state fact sheet and Advocacy Request fact sheet if you haven’t shared already.
- Offer Cure SMA and yourself as resources on SMA or related issues.
- Also, please email Cure SMA Advocacy (advocacy@curesma.org) to share who you met with and how the meeting when.



If you have any questions related to any steps in the BYOM process, please contact Cure SMA Advocacy at advocacy@curesma.org

Cure SMA is a national organization that advocates for individuals with spinal muscular atrophy, a progressive neurodegenerative disease that robs people of physical strength, taking away their ability to walk, swallow, and breathe.

INSTRUCTIONS

- Send your meeting request at least 3 weeks prior to your recommendation meeting time.
- Use the “Find Officials” search bar located in the middle (right) of Cure SMA’s Advocacy Action Center to find the local office location and email of your Members of Congress
- Use Cure SMA’s State Fact Sheets, located on the bottom of Cure SMA’s Advocacy Information Center, to tailor the letter with state-specific data.
- Contact 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]

[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 while you are in the state for the August congressional recess 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.]

To commemorate SMA Awareness Month (August), individuals and families with SMA are meeting with their elected leaders throughout the month to increase knowledge about SMA and the issues facing the SMA community. Thanks to past investments and policies enacted by Congress, the SMA community now has multiple SMA treatments that are helping to slow or stop future degeneration associated with SMA. However, because these treatments do not cure or reverse disease symptoms, significant unmet needs remain for children and adults with SMA across all ages and disease stages. As a Member of Congress, you can help address this unmet need by supporting additional rare disease research and programs.

I know your schedule is very demanding, especially when you are in the state during a recess. If you are unable to meet directly, I hope you will make available your local staff to meet with me virtually or in-person. To arrange a meeting, your staff can contact me at **[insert your phone number and email address].**

Thank you for your consideration. I look forward to updating you and your office on recent SMA progress and the ongoing needs of individuals with SMA and their families.

Sincerely,

[Your First Name Last Name]

[Your Address]

[Your City, State Zip]

[Your Phone]

[Your Email]

**CLICK HERE TO DOWNLOAD A
WORD DOC AND PERSONALIZE
THE CONTENT**

