

State and federal officials make decisions on policies and programs that affect the SMA community. Legislators and their staff need to hear from you to ensure these policies and programs are responsive and reflective of your needs. Sharing your personal experience with SMA is extremely important and can be the catalyst for change.

RULES OF ENGAGEMENT

- No matter your method of contact, have an ask ready for your legislator. You must tell them what you want them to do—like cosponsor a bill or vote in opposition or support of a certain bill.
- If your legislator disagrees with you, let them know your concerns and how this would affect you, your family, and community negatively. Use your story to back up your point.
- Be prepared with statistics and facts to back up your story for why it is important to support or oppose a certain bill.
- Be respectful while describing your passion and why you care.
- Offer them resources for SMA. You can find the SMA fact sheets for each state on Cure SMA's Advocacy webpage at <https://www.curesma.org/advocacy/>.

PHONE CALLS

- Call your legislative office when an issue is being heard in committee, especially if your legislator serves on the committee discussing the issue. If the legislator is unavailable, ask if there is a staff person who oversees the issue (i.e., healthcare) you are calling about. If no one is available, leave your information and ask for the appropriate person to call you back.
- Before you place a call, practice your story and ask beforehand to make sure you are brief, specific, and to the point. To help with this, create talking points ahead of time so you stay on track.
- Be sure to identify yourself as their constituent. If asked, be prepared to give your name, address, and the organization you represent (if any).
- If reaching out about an existing law or bill, give the bill number, subject, and sponsor. Give your position on the law or bill and explain why that is your position.
- At the end of the call, remember to thank them for their time.

PERSONAL VISITS

- Contact your legislator's office and make an appointment for an in-person meeting with their scheduler or office coordinator. Let them know that you would like 15-30 minutes to discuss your issue. Be mindful of their busy schedules and respectful of their time.
- Accept an appointment with the appropriate staff member if the legislator is unavailable. If you do not have an appointment, there may be no one available to meet with you.
- Make the most of the time you have with your legislator or staffer. Always practice your story and ask beforehand and allow time for questions at the end.
- If you don't have the answer to a question or are unsure, say so and follow-up later. The Policy and Advocacy Team at Cure SMA is here as a resource, so please reach out.
- At the meeting, feel free to ask to take a photo with the legislator or staffer. If they are agreeable, share it on your social media using the hashtag **#CureSMA**.
- Follow-up after the meeting with a thank you note or letter. Thank and remind your legislator or staffer what you talked about and the actions you asked them to take. Include any answers to questions you were unable to answer during the meeting. If you took a picture, include that as well.

LETTERS OR EMAILS

- When constructing a letter or email, it is important to remember to be concise and identify the issue up-front and how it impacts you.
- Include your name, address, email, and telephone number.
- If you have multiple issues that you would like to address, please send separate letters or emails for each one.
- Invite your legislator to contact you to speak with them about your position on a certain issue or bill. Request a reply from them that states their position on the certain issue or bill.

QUICK TIPS



Power in Numbers. Your personal advocacy can be amplified when you encourage others to join the cause. Calls, emails, or in-person meetings from multiple people on an issue will resonate with and get the attention of your elected officials and their staff.



Communicate Regularly. In addition to the thank you follow-up, look for other ways you can keep your elected official (and their staff) updated during the year about key milestones related to your SMA experience or through invitations to local Cure SMA activities.



Targeted Follow-Up. Elected officials who receive large volumes of constituent calls and letters may be unable to respond to all constituent inquiries. If your outreach requires a response (i.e., an event invitation), be persistent—yet respectful—with your follow-up correspondence.