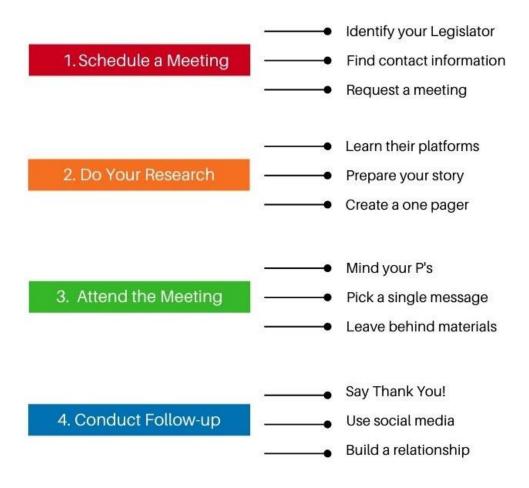
Updated: 9/24/2020



How to Meet with Your Legislator A Guide for Sickle Cell Advocates

This guide provides sickle cell advocates with the information you need to schedule, conduct, and follow up on successful meetings with legislators.

With a little planning and preparation, you can hold impactful meetings with lawmakers. Your personal story is the most powerful tool you have to ensure lawmakers create health care policies that address the needs of people living with sickle cell disease. Follow these four steps to influence the legislative process and build relationships with your lawmakers and their staff.



Step 1:

Schedule a Meeting

- Use Sick Cell's "State Advocacy Tool Map" to find your members of Congress.
- Determine whether your legislator will be in Washington D.C. or in their home office. It will often be easier to schedule a meeting with your legislator when they are on recess (not in D.C.), though most accept meeting requests while in session. (The average member of Congress is home 40 weekends a year, and while at home, lawmakers tend to have more time to spend with advocates and are less distracted by their duties in D.C.).
- To request a meeting, go to your senator/representative's website and find a "Connect" or "Contact us" menu.
- Many legislators give you the option of mailing or emailing a meeting request.
- Be sure to identify that you are a **constituent** (a voting member of the community they represent).
- Schedule well in advance.
- If you have not heard back about your request after about a week, it is fine to call the office to follow-up.
- If the lawmaker is unavailable, ask to meet with the member of their staff who works on health care issues. While meeting with the lawmaker is helpful, meetings with staffers is also beneficial. These staffers are used to taking meetings and then passing on important information to the lawmaker.

Sample Meeting Request Letter

Dear Senator/Congressman/Congresswoman [NAME],

As one of your constituents and a dedicated ambassador for Sick Cells, I am contacting you today to request a meeting with you and your staff to discuss several issues central to our mission, my life, and the lives of countless children and adults living with sickle cell disease and sickle cell trait.

I thank you for your support of [NAME OF INITIATIVE] that brought positive change to our community by [WHAT IT DID]. Sickle cell disease remains one of the most prevalent, yet underfunded and understudied, diseases in this country and I hope you will join us in our efforts to improve the lives of so many.

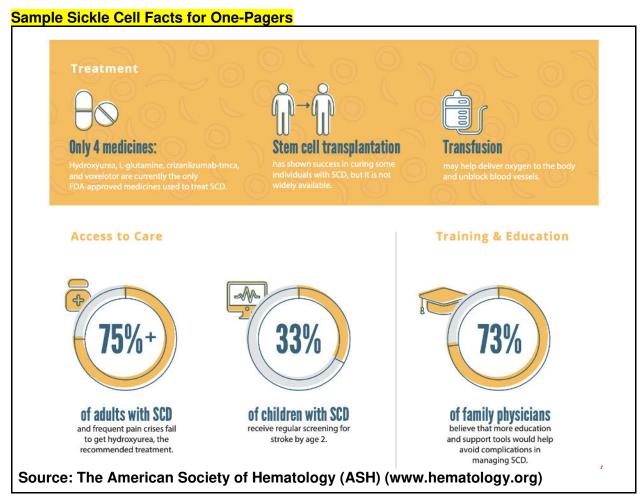
I am available on [DATES] at [TIMES] to meet at your [LOCATION] office to speak with you about these issues. I can be reached at the email or phone number listed below. I look forward to our meeting.

Sincerely, [FIRST NAME LAST NAME] [ADDRESS] [EMAIL] [PHONE NUMBER]

Step 2:

Do Your Research

- Get to know your Legislator. Research the legislator and write down notable ways
 they have contributed to the sickle cell cause (or to a related cause). Visit the lawmaker's
 website, Facebook page, or Twitter feed to see recent statements and positions on
 health care.
- Prepare your personal story. The most effective tool you have is your personal story.
 Prepare and practice talking about your personal story with sickle cell and the impact it has had on your life. Sharing your experiences helps people understand why you are advocating.
- Know your facts. Have a couple facts about sickle cell disease written down, and include your sources. Find ways to simplify complex ideas.
- **Gather materials.** Contact Sick Cells or another sickle cell advocacy organization and ask for talking points or upcoming legislative priorities.
- **Create a "one-pager"** that summarizes the story you want to tell and provides helpful statistics or figures. Ensure you include your contact information.
- **Confirm the meeting.** Try to call the office the day before to confirm the meeting is still on. (Don't email your confirmation; you won't get a response back in time.)



Step 3:

Attend the Meeting

• Mind Your P's:

- Be Punctual. Get to your appointment on time to ensure you don't miss the opportunity.
- <u>Be Professional</u> and dress formally. You're not at a job interview, but you want to look composed and like you are taking this meeting seriously.
- <u>Be Patient</u>. Do your best to extend compassion and patience if your legislator is running late. Their schedules can be unpredictable.
- **Be Prepared** and bring any materials or one-pagers you plan to leave behind with them. Silence your phone right before you meet.
- Be Personal and friendly. Even if you do not agree with the legislator politically, your issue could still be important to them.

_	they are interested in meeting you. Where are you from? What is your
	they are interested in meeting you. Where are you from? What is your profession? How are you connected to the SCD community?
_	•
	Tell your SCD Story. Using your personal story can help put a human face on a
	complex, rare disease. Use your story to spark emotion, start conversation, and
_	create change.
	State your Purpose. Have one or two key priorities ready to discuss with your
	legislator and encourage action from your legislator.
	Ask them if they have any questions for you. This can be a good chance to let
	them engage with the story you have shared.
	Write down important information. Feel free to bring a notebook and pen with
	you to write down specific ideas, questions, or information during the meeting.
	Thank your legislator! Thank the person you're meeting with for their time and
	try to reference something their office has done that positively impacted the
	sickle cell community.
	Leave materials. Be sure to leave any "one-pager" materials with facts about
	SCD and key priorities related to a specific issue. Also, bring a business card or
	include your contact information on the leave-behind materials.
	Ask to take a photo. Take a photo with the lawmaker or staff at the end of your
_	meeting to share on social media.

Step 4:

Conduct Follow-up

- Say Thank You! It's a good idea to have a thank you note with you so you can write it right after, while the details are still fresh.
- **Follow-up on Items**. Sometimes your meetings will result in action or further communication. You may also get a question that you were unable to answer, so you can tell the lawmaker that you will follow up.
- Use social media. We encourage you to talk about your time meeting with your lawmaker on social media. Use the hashtag #SCDadvocates and tag Sick Cells, as well as your lawmaker's official account after your meetings.
- Share with other advocates. Report back to Sick Cells so we can learn from your experience and help inspire other advocates to do advocate, too.
- **Thank yourself!** A lot of work went into making this meeting happen, so please give yourself credit. This is really important work that you are doing for SCD.
- Then, repeat! It is important to build a relationship with your legislators by scheduling frequent meetings. Don't worry, advocating gets easier with practice! Like other experiences in life, you will find that these meetings aren't so intimidating once you've experienced them a few times.

Sample "Thank You" Post on Social Media



Special Considerations During COVID-19

While COVID-19 has brought many challenges, it is still important for advocates to engage with lawmakers. Below are some tips to consider for "virtual fly-in" meetings with your legislators.

- **Follow all the steps above.** Meeting virtually is similar in many ways and requires the same amount of preparation and research.
- They will usually set up the meeting. Often their office will send you the invitation and select the meeting platform.
- **Find somewhere quiet**. Find a place where you won't be interrupted and that is away from louder noises.
- Use a computer, if possible. If you have a computer available, it is usually easier to use that for your meeting so you have a bigger screen and better video quality.
- Have a neutral background. Avoid busy rooms where people may be walking around. If
 you're uncomfortable showing your home, see if the platform you're using has a virtual
 background option. (See virtual background instructions for <u>Zoom</u>, <u>Google Meet</u>, <u>Microsoft
 Teams</u>, and <u>Skype</u>.)
- Wear headphones. Wearing headphones can help avoid common issues like echoing or distorted sound.
- Make sure there is enough light. Make sure the room you're using for your meeting has enough light so the video quality is good and they can see you.
- **Don't multitask.** It's tempting to get things done while you're on a video call and your email and social media are sending you notifications, but you want to be sure to remain focused and present.

Navigate to other resources:

Your 5-Minute Story | Sickle Cell Facts | The Importance of State-Level Advocacy

This guide was created by Sick Cells in collaboration with the Sick Cells' Ambassador Program. Ambassadors are sickle cell advocates that are dedicated to changing the landscape of sickle cell disease and driving legislative agendas forward at every level of government.

For more information, visit <u>sickcells.org/ambassador-program</u>.