



The Importance of State-Level Advocacy

A Guide for Sickle Cell Advocates

State-level advocacy is a great way to bring meaningful action and awareness for sickle cell disease much closer to your home. Almost everything related to sickle cell treatments, clinics, and research can be traced back to policy, and building state-level support is an important step to making widespread positive change.



"If it's not in policy, it's not going to happen."

- VELVET BROWN-WATTS

FOUNDER-CHAIRPERSON:
SUPPORTERS OF FAMILIES WITH SICKLE CELL DISEASE, INC.

Putting together a policy agenda for state advocacy can seem challenging, so we've made this step-by-step guide that will help prepare you to impact decisions being made by your state and local governments. Check out our other policy and legislative resource guides:

- "How to Meet with Your Legislator" Meeting Guide for specifics on scheduling and attending meetings with legislators
- "Build Your 5-Minute Sickle Cell Story" for tips on how to tell your story effectively to decision-makers
- "Sickle Cell Disease Fact Sheet" to start gathering data you can use in your advocacy and storytelling

Why Become Involved in State Policy?

- ❖ **It's a chance to tell your personal story.** Telling your story will humanize SCD, especially for someone who may not know much about it. It's a chance to say how the state policy is helping SCD patients and what needs are still unmet.
- ❖ **Every state has different laws and policies for SCD.** You have the power to change what happens in your state, and often this means bringing awareness to how SCD looks in your town, city, county, and state as a whole.
- ❖ **State and local governments can have a more prominent role in decision-making than the federal government.** Some decisions made at the local level can have dramatic effects on how and where people in your community live and receive care.

Step 1

Set a Legislative Agenda

- **A legislative agenda** is an outline of what the Senate/House of Representatives in your state will be focusing on during that year. It will tell you the policy issues they have chosen and who will be involved. You can create one for yourself that outlines what YOU (or your organization) will focus on and who you need to get involved.
- **Identify an issue.** In your case, this will most likely be related to SCD, such as research funding, data monitoring, Medicaid coverage, etc.
 - What are the priority issues and possible solutions?
 - Be clear about what the problem is and evaluate potential solutions.
 - The best solutions are ones that can satisfy other stakeholders' interests too, or "bundle" a number of priorities into one solution.
 - Are there any successful efforts that can be used to model a similar legislative agenda in your state?
 - Similar advocacy efforts that have been led in other states or by other disease-advocacy organizations can serve as examples when planning a similar effort in your own state or for your own cause.
 - Have you talked to the key players in your policy issue?
 - Who are the voices in your area that stand out to you? Think of patients, caretakers, doctors, researchers, and others who are familiar with SCD and support positive change.
 - Can you identify one decision-maker who will be a champion for your cause?
 - Every cause needs a champion. Find someone that is willing to invest personally and feels compelled to join the cause.

Step 2

Build Relationships

- Do you have the relationships that are needed?
 - What kinds of contacts and relationships do you already have? This can be with dedicated sickle cell advocates, nonprofits, or government employees that can help amplify your voice.
 - A great place to start is to make contact with the legislative aide or assistant, which is an assistant to your senator or representative.
 - Find your senator or representative with our [state advocacy map](#) and search their website for location and contact details.
- **Meet with people who can help.** Find out who key decision-makers are in your state. It doesn't necessarily have to be a legislator; many people can help make your voice heard. Here are some ideas:
 - Legislators
 - State Medicaid Department
 - State Department of Health
 - Department of Health and Human Services
 - Department of Mental Health
- **Identify legislative leadership.** Committee chairs and ranking members play a key role in the legislative process and can—and should—be targeted in advocacy efforts.
- **Most importantly,** find out who in those departments works on sickle cell issues and programs. Finding this out may be as easy as Googling “State Department of Health sickle cell disease.”

Step 3

Move the policy-making process

- **Passion is GREAT, but you need to build your advocacy skills.** Starting with passion is the best way to start. Now, you have to channel your passion into educating others and raising the voice of the sickle cell community.
- **Bring data.** The first step is finding data and facts to clearly define the issue and motivate others to join your cause. Useful data may include:
 - The number of people with sickle cell in your state
 - The cost of sickle cell care in your state
 - Allocated funding and resources for sickle cell programs
- **Trust your data source.** Before using data, make sure it's from a trustworthy organization. Always cite the source of your data so that decision-makers can access it themselves. Never make a claim that the data doesn't support. Trustworthy sources may include:
 - [Centers for Disease Control](#)
 - [Department of Health and Human Services](#)
 - [American Society of Hematology](#)
 - Local department of public health

- Local sickle cell clinics or research centers
- **Build your “policy squad”.** Get support from other organizations in your area so you can cite them as supporters of your advocacy work. Ideally, they will be leaders or well-known orgs in the community, such as:
 - Local sickle cell advocacy organizations
 - Legislative Black Caucus
 - Latinx organizations
 - Children’s Hospitals
 - Sickle cell clinics or research centers
- **Establish goals.** Work with your “policy squad” to set objectives carefully. This will help you know if you’re on-track to accomplish your legislative agenda.

Step 4

Create Action

- **Schedule Meetings.** Begin to meet with other organizations, individuals, and legislators who can help you share your story and the story of SCD patients everywhere. See the “How to Meet with Your Legislator” Meeting Guide to plan a formal meeting with policymakers.
- **Stay informed.** Keep your legislators and “policy squad” informed about the issues and what actions you expect each of them to be working on. On the flip side, you should also stay informed on what’s happening in your state and if any upcoming bills or debates are pertinent to your legislative agenda.
- **Follow-up.** Continue building those relationships! The way to demonstrate that you are serious about your cause is to continue asking until you get action.
- **Media Coverage.** Getting media coverage can help raise your public profile, position yourself as an expert, and recruit more support for your cause. Take the time to research the right local journalist or media outlet, and identify what’s “newsworthy” when crafting your pitch.

Navigate to other Sick Cells Resources:

[Meet Your Legislator](#) | [Your 5-Minute Story](#) | [Sickle Cell Facts](#)

This guide was created by the Sick Cells’ Ambassador Program in collaboration with community activist, Velvet Brown-Watts

Velvet L. Brown-Watts, is the Founder-Chairperson of Supporters of Families with Sickle Cell Disease, Inc. Supporters (as it is affectionately known) is a community-based Oklahoma nonprofit organization that has assisted families living with sickle cell diseases since 2004. For more information, visit <https://sicklecelloklahoma.org/>

The Sick Cells’ Ambassadors Program is a network of sickle cell advocates dedicated to changing the landscape of sickle cell disease and driving legislative agendas forward at every level of government. For more information about the program, visit sickcells.org/ambassador-program.