



SPINA BIFIDA
ASSOCIATION

Advocacy 101

2023 Teal on the Hill

February 26, 2023

To build a better and brighter future for all those impacted by Spina Bifida

What is Lobbying?

- All lobbying is advocacy, but not all advocacy is lobbying
 - We advocate for a cause, i.e., the Spina Bifida community; we lobby for a discrete policy goal, i.e., increased funding for the National Spina Bifida Program
- Lobbying = Direct contact with government officials to influence specific policy decisions
 - Principal purpose is to influence legislation
 - Specific piece of legislation referenced, even if not currently proposed, i.e, Fiscal Year (FY) 2024 Labor/HHS Appropriations Bill
- Your constitutional right
 - There aren't many activities that are explicitly protected in the Bill of Rights, but lobbying is right there in the First Amendment
 - "Congress shall make no law...abridging the right of the people...to petition the Government for a redress of grievances."

Myth 1: “Elected officials know what they want to do. They don’t listen to people like me.”

- You are someone with first-hand knowledge of Spina Bifida. You are the authority.
- Data and statistics don’t tell a personal story. Your personal story will get the attention of elected officials and their staff and will leave a lasting impression.
- Elected officials are more likely to listen to you – you are the expert.
- You never know when an issue will resonate with the Member of Congress or his/her staff.
- You can’t let elected officials off the hook. If they don’t hear from you, then they will think your issue is not important.

Myth 2: “My concerns are not being discussed right now by elected officials.”

- Maybe no one is writing or calling about those concerns.
- The Spina Bifida community can help elevate an issue to the local, state, or national agenda by communicating to your elected officials.
- Sometimes it takes a grassroots movement to garner attention from policymakers.

Myth 3: “I am the opposite party of my elected official, so I don’t think they will care what I think.”

- Do not worry about your party affiliation; just identify yourself as a constituent (someone who lives in the district or state the Member of Congress represents).
- Tell your story about what life is like living with Spina Bifida. This is the only qualification you need for your views to be treated with respect.
- And you may be surprised when the Member or Staffer shares that they know someone with Spina Bifida. That’s not a partisan experience!

Myth 4: “I have written before and didn’t get a response. It doesn’t matter.”

- It absolutely makes a difference.
- Regular contact is essential. “The squeaky wheel gets the grease.” Nowhere is this adage truer than with elected officials. Policymakers often claim that the reason for their inaction on matters is they aren’t “hearing (enough) from folks back home” on the issue.
- One person or a small group of dedicated people can result in the development of policy and law.

Remember....

- Be confident that you can articulate the issues and influence the outcome
- You are the subject-matter expert who can provide much needed knowledge on a topic
- Your meetings helps Members and their staff cut through the noise and focus on your issue
- To enjoy your meeting!

Authorization v. Appropriations

Types of Legislation

- Authorizing – creating new programs or extending or modifying existing programs
- Appropriations – 12 “checks” the Congress “writes” every year to fund the government

Getting ready for your visit

Objectives of a visit

- Establish who you are and why you're there
- Establish/maintain rapport with member office
- Secure the "ask(s)"
- Serve as a resource on issues that matter to people with Spina Bifida

Architecture of a visit

- Who you are (name and title)
- Where you're from
- What you want (asks)
- Why you want it (rationale)
- When do you need it done (timing)
- How you can help (offer to be a resource)
- Thank yous

Know your audience



Member of Congress

Visitors may not realize how highly overscheduled Members are; they average 70-hour weeks when in D.C., often achieved by double-booking meetings



Chief of Staff

Visitors may not expect how often chiefs are in communication with a Member; the tight bond means that chiefs are often delegated to speak for Member to constituents



Legislative Director

Visitors may not expect that LDs tend to be specialists in the policies of the committees on which Member serves; they may focus less on other areas



Legislative Assistant

Visitors may not expect that LAs are very young; their average age is under 29



Legislative Correspondent/Staff Assistant

Visitors may not expect that LCs and SAs tend to be even younger than LAs, often recent college grads

Because members of Congress are often running from meeting to meeting to vote, staffers will often have more time to devote to a meeting, and be more capable of affecting any takeaway

It is not uncommon for Members to show up halfway through a meeting or leave part of the way through

Meetings are most often scheduled with and run through one or more of these staffers

LCs and SAs may join in meetings as a junior staffer or note-taker

Tricks of the trade

Do:

- Introduce yourself
- Thank the member/staff
- Provide real world anecdotes
- Keep it local
- Stay focused
- Make “the ask”

Don't:

- Be late
- Just read from a statement
- Be argumentative
- Talk politics or campaigns
- Forget to follow up

Remember...

- Capitol Hill staff are overwhelmingly young, overworked, and juggling a million issues at once
- As a person connected to Spina Bifida, you are their best resource
- Use this dynamic to your advantage!
- Be confident in your ability to articulate the issues and influence the outcome
- You are the subject-matter expert that can provide much needed knowledge on a topic
- Your visit helps Members and their staff cut through the noise and focus on your issues
- Enjoy your meetings!



**SPINA BIFIDA
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