

ADVOCATING WITH PURPOSE

A Capitol Hill Readiness Session

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DISCLOSURES

- I am an independent patient advocate.
- I am not a policy analyst.
- I do not have a degree in political science.
- I have no financial relationships, affiliations, or conflicts of interest related to the content of this presentation.

Federal Budget Status



Where Are We Now

FY 2025 is being funded through a Continuing Resolution (CR) expiring Sept. 30, 2025.

H.R. 1, the “One Big Beautiful Budget Act” (OBBBA) passed the House but has not gone before the full Senate for a vote yet.



What This Means

Proposed budget cuts in the OBBBA are not yet law and the Senate is likely to make more changes.

The final version of the OBBBA could dramatically reshape health research, funding, and access to care starting Oct. 1, 2025.



Why It Matters

Administrative changes are already impacting currently approved funding and programs.

The OBBBA as it is currently written will set deep funding cuts into law, with effects that will be felt well beyond FY 2026.



WHY MEETINGS MATTER

▶ **Constituent Influence**

Direct constituent interactions influence lawmakers' decisions

▶ **Relationship Building**

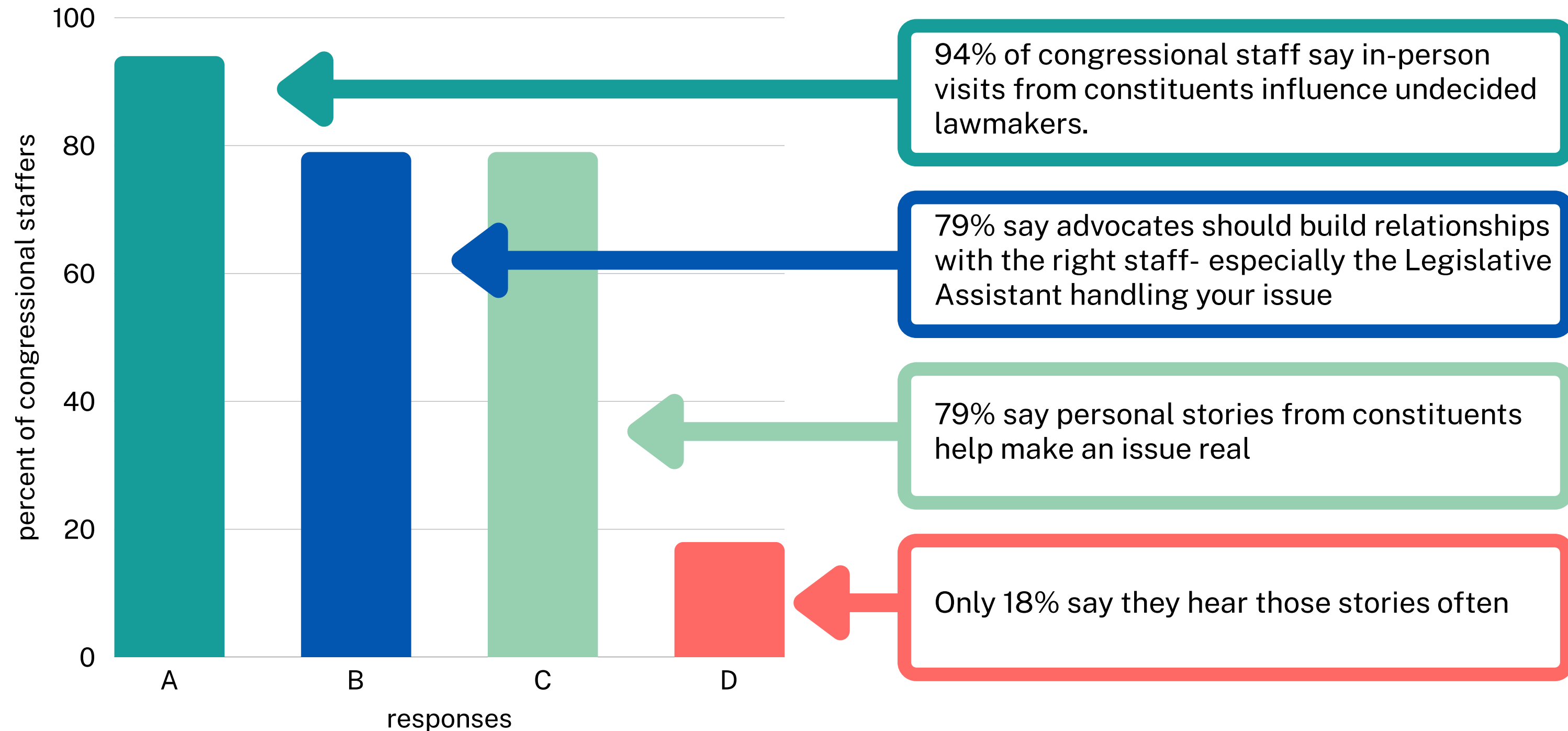
Lawmakers place a high value on citizens who have built relationships with them

▶ **Power of Personal Stories**

Citizen advocates who provide personal testimony are more influential and contribute to policy-making



Influence Of Advocacy Strategies On An Undecided Member/Senator



MEETINGS DON'T NEED TO FEEL INTIMIDATING



Meetings are often with a legislative staffer and not the congress member



Staffers can spend more time with constituents, listening to personal stories



They know we are constituents and not professional lobbyists and aren't experts in government and legislation



Preparation before your meeting will help you feel more comfortable

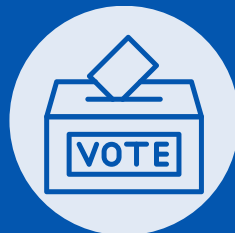
KNOW YOUR LEGISLATOR



Basic Information



Voting Record



Policy Priorities



Press releases and public statements



Parts of An Advocacy Message



Problem

Briefly describe the problem



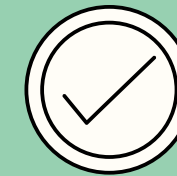
Impact

How it affects many people or communities



Personal Story

How it personally affects you or your family



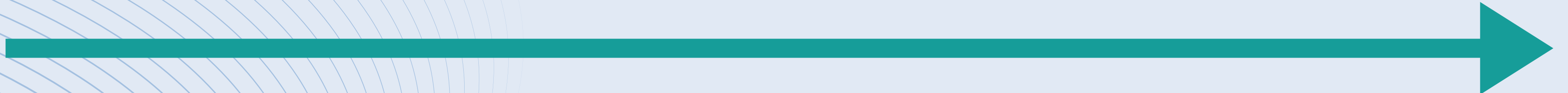
Solution

Propose a clear and actionable solution



Ask

Make a specific, measurable request



Personal Story Basics

- ▶ **Grab audience attention**
- ▶ **Make it a 2-3 minute movie trailer**
- ▶ **Share with passion & conviction**
- ▶ **Relate your story to others**
- ▶ **Support the ask**

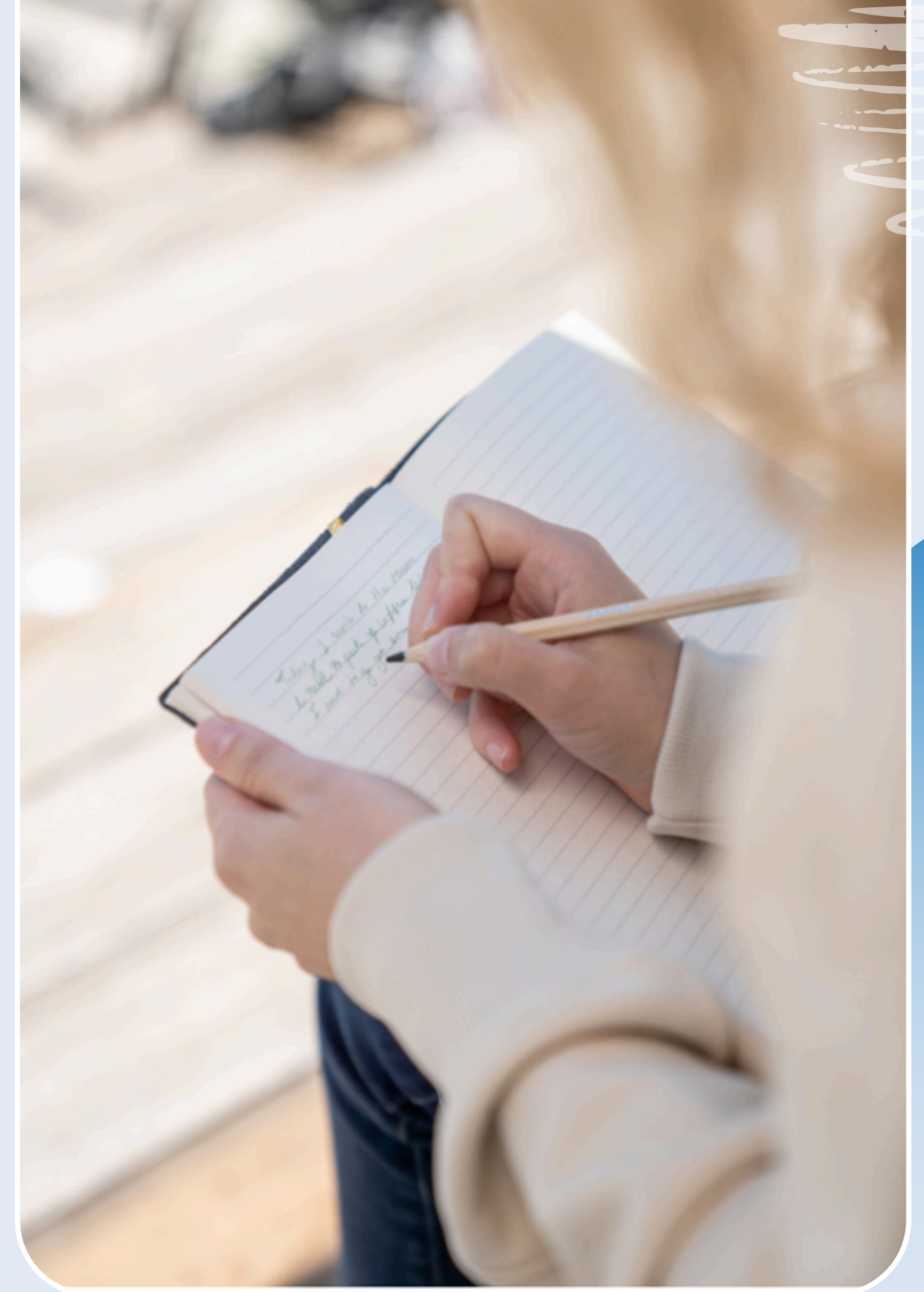
Tell your story...



YOUR PERSONAL STORY

One of the most important things you can do is make an **emotional connection** with your legislator or their staff. Your personal story can show the representative how their legislation affects real people, their constituents, and those who vote for them.

- ✓ Stories are more memorable than facts.
- ✓ Stories can change current legislation
- ✓ Share more details in follow up emails



Fine Tune Your Story

Time Yourself

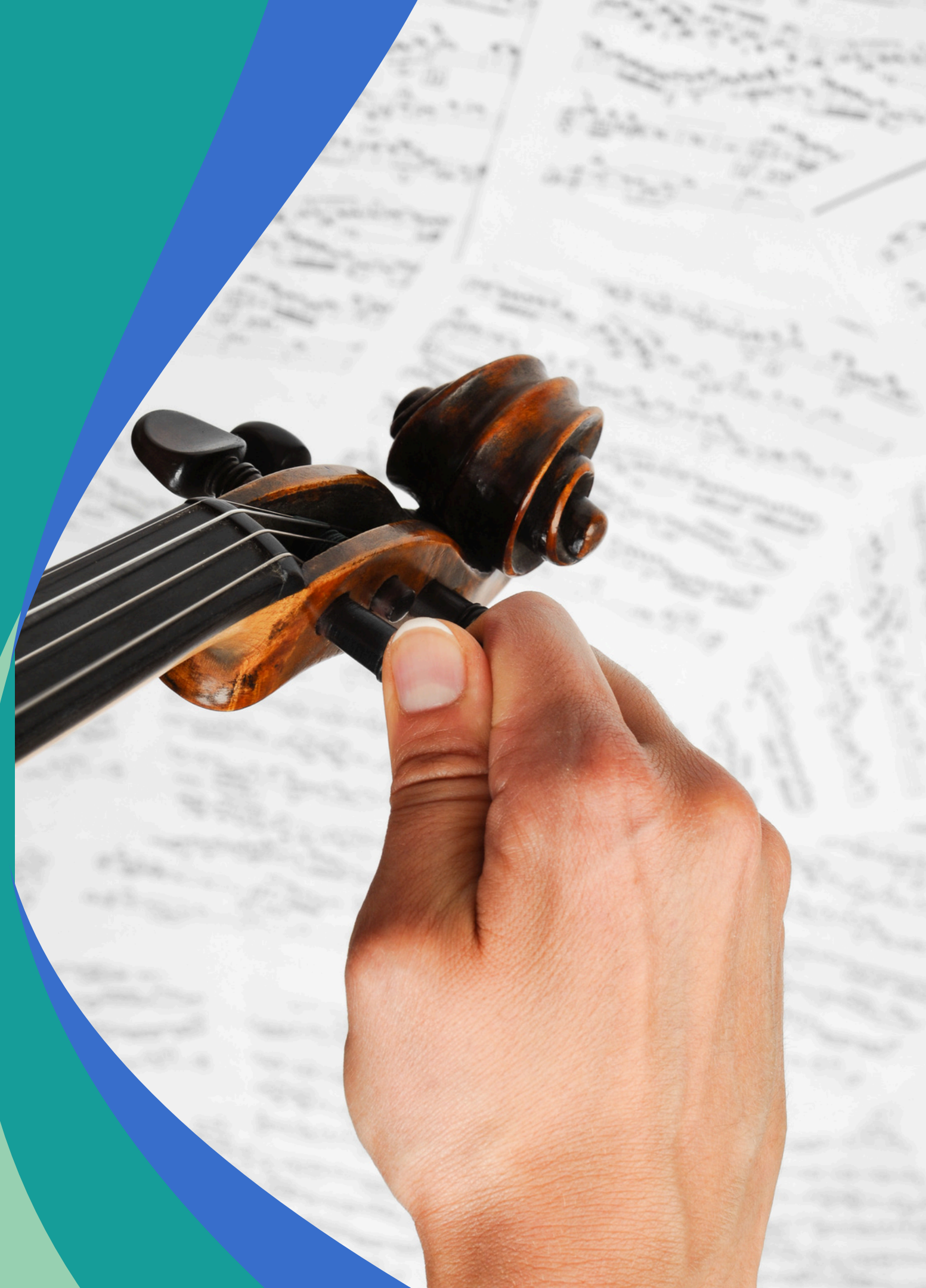
2-3 minutes — this keeps it concise and impactful. Save the details for your follow up.

Don't Memorize

Let your story flow naturally. Use a note card with bullet points to help. This allows you to make eye contact.

Practice, Practice, Practice

Practice sharing your story. Their feedback will help you refine your delivery and enhance clarity.



PREPARATION- PRESENTING THE ASK



BE SPECIFIC & DIRECT

The more specific the ask, the easier it is to make it achievable and measurable.



MAKE IT ACHIEVABLE & MEASURABLE

It should be realistic and attainable enabling follow up.



ASK QUESTIONS

Will they support your ask?
Why or why not? What hurdles are in the way.



RESPOND TO ROADBLOCKS

Find solutions to roadblocks stopping lawmakers from supporting your ask.

Protecting Access to Healthcare

Medicaid Cuts Summary

- Among the **largest components** of the FY 2026 reconciliation proposed cuts.
- Congressional Budget Office estimates show **\$800–880 billion in federal Medicaid cuts** over ten years, averaging.
- Combines **policy barriers** (work rules), **financing reductions** (provider tax caps), and **administrative hurdles**.
- Projections predict a **loss of coverage for 2.3–10.3 million people**, depending on which provisions persist.



Protecting Access to Healthcare

Medicaid Asks

- **Safeguard Medicaid, CHIP and other vital healthcare programs**
- **Oppose Medicaid Work Requirements and Administrative Barriers**
- **Preserve and Fully Fund Medicaid Expansion & Maintain Federal Matching Rates (FMAP)**
- **Protect Home and Community-Based Services (HCBS)**



Protecting Rare Disease Research



HHS & NIH Summary

- **HHS cuts are the single largest**, in dollar terms, and will deeply affect public health, research, prevention, and healthcare programs.
- **Cuts to the NIH, CDC, FDA**, and related agencies would slow or stop critical research and impact people living with rare diseases.
- The **Office of Rare Diseases Research (ORDR)** and **Rare Diseases Clinical Research Network (RDCRN)** are folded into general NIH operations. The **Agency for Healthcare Research and Quality (AHRQ)** will be absorbed by the Office of Strategy and the budget “**eliminates patient-centered outcomes research**” (**PCORI**).
- Budget cuts at the federal level will have a ripple effect **causing nongovernmental entities to lose funding** and grind to a halt.



Protecting Rare Disease Research

HHS & NIH Asks

Oppose Cuts to HHS, the CDC, and FDA Proposed in H.R. 1 or Other Reconciliation Bills

Fully Fund the NIH and Key Research Agencies such as NINDS, AHRQ, and PCORI in FY 2026

Support Dedicated Funding for Rare Neurological Conditions

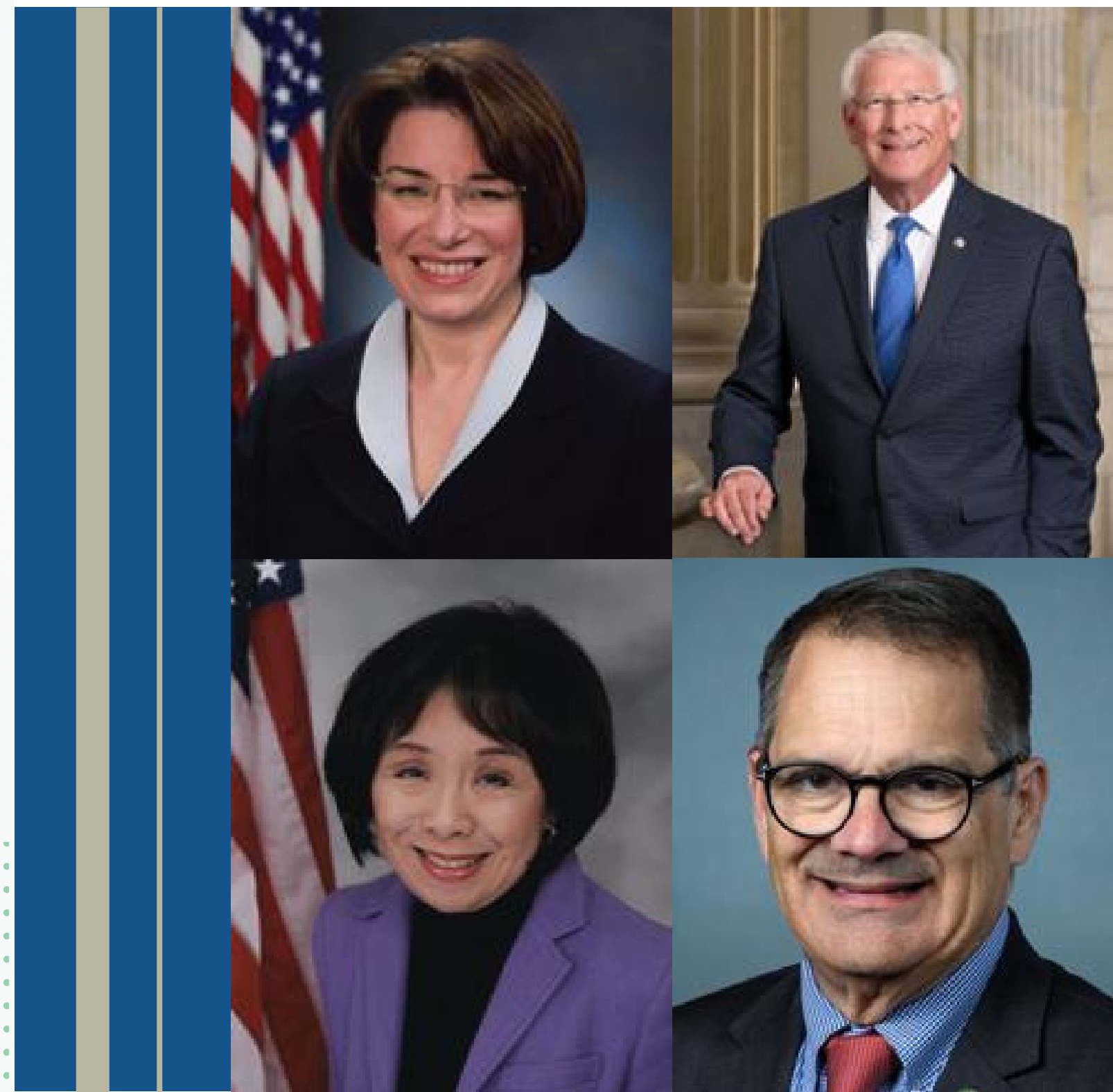
Urge Strengthening of Rare Disease Programs at NIH



Rare Disease Congressional Caucus

RDCC Summary

- The RDCC allows members of Congress to **voice constituent concerns, collaborate on ideas, and build support for legislation** that will improve the lives of people with rare diseases.
- The caucus works to **advance legislation and education** regarding specialized and rare health issues and diseases, and to promote patient advocacy.
- People with rare diseases often wait years for a diagnosis, travel long distances to see specialists, and face barriers to treatment due to **limited research and FDA-approved options**.
- Rare diseases aren't rare. There are nearly **11,000 rare disease** with **one in ten Americans** living with a rare disease. **More than half are children and 95% of rare diseases have no approved treatment.**



Rare Disease Congressional Caucus

RDCC Ask- Join The Caucus

It Show Support For Bipartisan, Bicameral Efforts to improve diagnosis, treatment, and equity for those with rare and complex conditions.

It Show Support For Robust Investment In Rare Disease Research and FDA programs like orphan drug development.

Demonstrate Dedication To Legislation that expands research funding, protects patient access to care, and ensures policies reflect the needs of rare disease patients and families.

Caucus Briefings Are Four Times A Year



THE ART OF THE ASK

The "ask" is the heart of any advocacy campaign, outlining what advocates are hoping to achieve.



Use Moral Framing

Ask lawmakers to consider their role in a broader moral or ethical context.



Appeal to Legacy or Values

Connect the issue to something they care about or want to be remembered for.



Focus The Blame

Focus the "blame" on the entity or system and highlight the power of individual responsibility.

DIFFICULT CONVERSATION TIPS

01



Stay Calm and Professional

Do not get defensive or argumentative. Stay calm and professional.

02



Pivot to Shared Values

Pivot the conversation to shared values to keep the conversation positive and constructive.

03



Acknowledge Their Concerns

Validate concerns by acknowledging their reservations or competing priorities respectfully.

04



Offer More Information

Follow up targeted towards their priorities may make a difference.

05



Keep the Door Open

Always thank them for their time and express your willingness to work together.

06



Follow Up Afterwards

Stay in touch over time, as positions can shift and relationships can grow

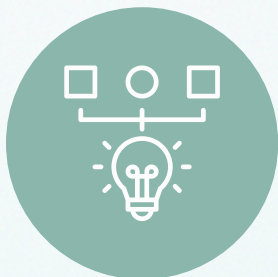
Meeting Timing



**Shows Respect For
Everyone’s Time**



**Builds Credibility &
Professionalism**



**Ensures Your
Message is Heard**



**Keeps the
Meeting Focused**

SPEAKER	APPROX. TIME	TOPIC
	30 sec. to 1 minute	Initial greetings and thanks to lawmaker/staff. Ask how much time for the meeting. Ask to take a photo at the end.
	1 to 2 minutes	Introduce the BJCSF and individuals in the meeting. Give name, city/state you are from, and conditions you have.
	1 to 2 minutes	Present the problem and Introduce asks to be brought up during meeting. Include the impact.
	2 to 3 minutes	First personal story
	2 minutes	First Ask
	2 to 3 minutes	Second Personal Story (if time available)
	2 minutes	Second Ask
	2 to 3 minutes	Questions and discussion
	1 to 2 minutes	Wrap up of asks and thank you--mention successful recent legislation. Tell them we will send a follow-up email.

Remember To...



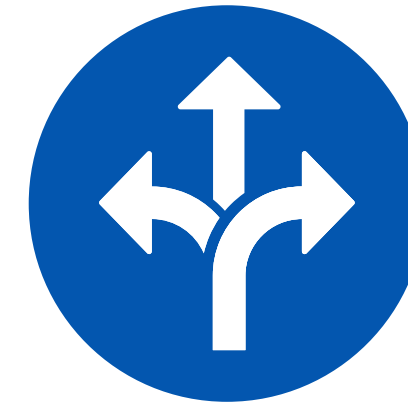
**Put Your Phone
On Silent**



**Professional Dress
Comfortable Shoes**



Be On Time



Be Flexible



**Remember To Get
A Group Photo**



**Bring a
Notepad & Pen**



**Stick To Your
Talking Points**



**It's Okay To Say
"I Don't Know"**

A Few Don'ts

DON'T

be discouraged if someone isn't on the same page

DON'T

assume they are familiar with your issue or legislation

DON'T

be afraid to ask their position on an issue

DON'T

argue politics. Set aside your differences.

Building A Relationship With Your Lawmaker

► Foundation

Meetings are a building block to developing a relationship with your Congressman

► Access

Meeting with the staff can facilitate a relationship with your representative

► Momentum

The Bobby Jones CSF meetings are only one part of building that relationship

► Recognition

Building relationships allows lawmakers to recognize and consider our concerns





Those who do not speak give others
the power to decide for them.

You don't have to be an expert to be a credible advocate. When we choose silence, we leave our future to be shaped by those who don't carry our burdens and don't know our pain. Your voice has the power to open doors for yourself and for every person who can't be in this room but needs your voice to carry their message.