

IDENTIFYING AND REACHING YOUR ELECTED OFFICIALS

When new legislation is introduced in Congress, it is done so by a U.S. Representative(s) or Senator(s) who sponsors — and supports — the proposed policy.

Once a bill is introduced, advocacy is a critical tool that constituents can use to provide feedback, urge their federally elected representative to demonstrate support for the legislation, and even ask their elected official to sign on as a co-sponsor.

If you are not sure who your federally elected representatives are, we can help. Based on where you live, you have one representative in the U.S. House and two Senators.

To find them, you can use these resources:

- You can search for your elected official in the House of Representatives or Senate on [Congress.gov](https://www.congress.gov)
- U.S. House of Representatives allows you to find your Representative based on your [zip code](#).
- The U.S. Senate allows you to search based on the [state where you live](#).

Throughout this toolkit, elected officials are referred to as a Member of Congress (MOC) or member. As you conduct your outreach, use their formal title such as Congressman, Congresswoman, or Senator.

It is always best to start your Congressional outreach with the MOC that represents you. But you can also reach out to a MOC to whom you are connected for another reason. As you reach out, it's important to customize your outreach to that MOC.

There are a few things to consider, such as:



Party Leadership

The [Senate](#) and [House of Representatives](#) have majority party and minority party leadership committees. If the member you are reaching out to holds a leadership position, garnering their support can go a long way in getting additional members to take note.



Committee Assignments

The [Senate](#) and [House of Representatives](#) have specific committees with their own jurisdiction on various legislative priorities. If your MOC sits on one of the committees that could shepherd legislation through both Chambers, it's critical that they hear from constituents on why they should support the legislation.

MOCs and their staff make time to hear from constituents (that's you!) and consider their perspective when deciding what legislation to support. There are several ways you can engage your elected official — detailed in the Outreach Tactics section below — but the key thing to remember is to keep your ask clear, concise, and simple.

ENGAGING ELECTED OFFICIALS AND THEIR STAFF

While elected leaders are ultimately the ones casting their vote for or against a piece of legislation, they can't take every meeting themselves. To maximize their reach, they lean heavily on their staff. Staff inform the MOC of policy specifics included in legislation and keep a pulse on what constituents think about proposed legislation.

We recommend that you begin your outreach by connecting with your MOC's staff, using their influence to set the stage for engagement with the representative directly.

Here is what you should know about the staff roles in an elected official's office.

Chief of Staff

Every member has a Chief of Staff. They are the highest-ranking staff in a congressional office. This person acts as the member's right-hand person. They help drive the office's policy and communications strategy, attend meetings on behalf of the member, and have oversight of state and D.C. staff.

Schedulers

They are the gatekeeper to the member's calendar and are often the person sorting and prioritizing constituent meetings, event requests, travel, and coordinating time spent in D.C. and back in their home state.

Legislative staff

Every member has a dedicated group of staff who handle specific policy portfolios. They are led by the legislative director and the team can include legislative assistants/aides and legislative correspondents.

Communications staff

Members have a dedicated communications staff led by the communications director/press secretary who develops the office's media and communications strategy, manages media contacts and requests, and acts as the spokesperson for the member.

District/State staff

Each member will have an office(s) in their home district/state. Staff based in home state offices are focused on constituent services and organizing

Washington D.C. staff

A member's staff in D.C. is primarily focused on policy and advancing the member's legislative agenda. They do facilitate constituent meetings with D.C. based staff and the member (time permitting) and liaise with state staff on constituent issues.

Who should you reach out to in a member's office?

- If you personally know someone who works for a MOC, you can reach out to them directly. Sometimes having a personal connection will expedite your ask or your contact can connect you to the appropriate staffer more quickly.
- If you want to share your support for a piece of legislation or raise a policy priority, reach out to a **legislative staffer or district/state staff**.
- If you want to invite your MOC to an event, reach out to their **scheduler**.

There is not one best way to reach your MOC and their staff. You can call the member's state or D.C. office, email a staff member directly, send an email through the member's website, or submit a meeting/scheduling request via the member's website.

You can view a short video on best practices when meeting with legislators from the National Organization of Rare Diseases (NORD) [here](#).

AMPLIFYING YOUR ASK

Outside of direct federal elected official/staff outreach, it's important to consider the broader 'sphere of influence' around elected officials and how that overlaps with your connections in the community. You can amplify your ask by leveraging those connections to reach your federal elected official through influential voices at the local and state level.

Relationships you might lean on to help create a surround sound of support could include:

- Relationships with other federally elected officials outside of your district or state
- Local elected officials including mayors, city council members, alderman etc.
- Local business leaders, small business owners, or representatives from community-based organizations
- State and local SCD groups and other healthcare advocacy groups
- SCD families and advocates who want to get involved
- Connections to local media outlets and journalists

Here is how you can plug them in to advocate for legislative change:



Ask them to call their elected officials



See if they are interested in speaking with the media or submitting an opinion piece to their local news outlet



Have them send a letter or email to their elected official



Ask them to spread the word about the legislation to their network



Encourage them to post on social media



Ask a reporter to write a story or produce a news segment on SCD and how federal action can impact the lives of patients

By tapping your broader network of contacts, you can help create a wrap-around messaging effect highlighting the importance of legislation. It is impactful when a MOC hears from a multitude of voices from diverse backgrounds. This is an effective way to break through the crowded landscape — making sure that this bill becomes a priority to your representative.

MESSAGING BEST PRACTICES

The policy landscape is crowded. There are many other patient advocacy groups. Elected leaders need to hear from you so they can truly understand the experience of patients with SCD — as well as what they can do to improve care and quality of life for SCD patients.

Your story is powerful. It helps others relate to the experience of SCD, even if they might not be familiar with or have had previous experience with it. Creating that understanding with elected officials and their staff is critical to making change.

Here are some tips to help you tell your story effectively when communicating with your elected official or their staff:

- Make it personal
- Keep it short and sweet
- Emphasize the importance of supporting policies that advance SCD research and care
- Don't worry if you get asked a question about a complex policy issue or you are unsure of the correct answer — just tell them that is not something you can answer and pivot back to your story and message
- Policymakers want to know about your experience and perspective. Sharing a personal story is one way to reinforce your experience or knowledge about SCD

Once you have shared your story and emphasized the importance of federal action when it comes to SCD, wrap up with a **call to action**. Ask your elected official to co-sponsor the federal legislation you are advocating on behalf of.



FOLLOWING UP WITH ELECTED OFFICIALS

Once you have engaged your elected officials and their staff, it is important to stay in touch with their office so that they continue to hear about the policy priorities that constituents, like yourself, care about. Touching base with your elected officials regularly is a good way to ensure SCD issues stay on their radar.

Here are a few ways you can follow up with your elected officials:



Leave behind materials

Whether you are meeting with an elected official or staff member in person, virtually, or at an event, you can bring or send materials such as a fact sheet about a piece of legislation or other policy topic so that the MOC and their staff can refer to information you might have discussed with them.



Send a thank you note

Within a few days of meeting with an elected official and/or their staff, you can send a note to the person you met with, thanking them for their time and reminding them about the key policy priorities discussed in the meeting.



Schedule a follow up meeting

As you monitor the status of legislation, you can get back in touch with an elected officials office to set up a follow up meeting. Try to touch base by phone with an elected official or key staff once a quarter to discuss specific policy priorities and help strengthen the relationship.



Earned media

Submitting an opinion editorial (op-ed) or letter to the editor (LTE) in your local paper is another way to elevate policy priorities with your elected officials as well as within the local community. Best practices on using earned media are in the following section of this toolkit, including tips on writing content to share with media.



Social media

Engage with your elected officials through social media where individuals in your network can also join in on the conversation. Best practices on using earned media and social media are in the following section of this toolkit, including tips on writing content to share with media and crafting social media posts.

Full links for websites mentioned in this toolkit:

- Congressional elected official search: <https://www.congress.gov/members/find-your-member>
- U.S. House of Representatives elected official search: <https://www.house.gov/representatives/find-your-representative>
- The U.S. Senate elected official search: <https://www.senate.gov/senators/senators-contact.htm>
- U.S. House of Representatives party leadership: <https://www.house.gov/leadership>
- U.S. Senate party leadership: <https://www.senate.gov/senators/leadership.htm>
- U.S. House of Representatives committee assignments: <https://www.house.gov/committees>
- U.S. Senate committee assignments: <https://www.senate.gov/committees/>

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