



BUILDING RELATIONSHIPS WITH CONGRESS MEMBERS

Angie Hott meets with West Virginia
Senator Joe Manchin during the
2017 Parkinson's Policy Forum.

PHOTO CREDIT: JOE SHYMANSKI

Establishing relationships with elected officials is the foundation of advocacy. While this can seem intimidating, it's actually quite easy! Policymakers want to know their constituents and better understand voters' concerns. By reaching out regularly, you can develop a rapport and educate these individuals on what it's like to live with Parkinson's.

It's also critical to make connections with the staffers who work on health issues because they advise legislators on policies related to research funding and access to care. Lawmakers rely on their staff to inform them of what's important to their constituents.

There are many ways to develop and maintain relationships. Different people have different styles; some want to take

time to compose an email and others prefer to pick up the phone. Still others want to show up on their Congress member's doorstep. Choose what works best for you and what you feel comfortable doing. The most important thing is to find a way to tell your story.

The following tips can help you get started.

Do Your Research

Regardless of the communication you prefer, make sure you are sending the right message to your member of Congress. You can do some quick research online, either on the Members' website, your local media or on the internet. If you are talking about a specific issue, see whether the member of Congress has supported or opposed the issue in the past. You do not want to ask a member to cosponsor legislation that they are already signed onto. You can look up legislation online at www.congress.gov. Try to determine whether or not the member of Congress has made any comments related to the issue you will be talking about, or even Parkinson's disease in general.

Sending Letters

Writing your Congress members is an effective way to make your priorities known. Legislators want to hear from their constituents so they can take their needs into account as they make policy decisions. Because you have first-hand experience with Parkinson's disease, you can encourage your lawmaker to look to you as a resource for information policies impacting people with PD and their families. Because of security screening on Capitol Hill, it is recommended that you send physical letters to the district office or send an email. You can send an email through the members' congressional website or the **Contact Your Policymakers** section of The Michael J. Fox Foundation website. When writing letters, consider these tips:

- Keep it simple and only discuss one or two issues
- Avoid abbreviations
- Be courteous
- Remind the office that you are a constituent and a member of the Parkinson's community
- If you are using the template on the Foundation website, personalize with your own story



Making Telephone Calls

Another way to engage with members of Congress is by calling their offices. Lawmakers record how many calls they get on a particular policy or bill (so if no one answers the phone, be sure to leave a message!). When the phone is ringing off the hook because constituents want to express their views on a piece of legislation, the staff takes note. When contacting your member by phone, it may be helpful to:

Plan ahead. Before you call, use the talking points and educational handouts in this toolkit to brainstorm what you'll say. And, feel free to use the sample script at the end of this section.

To find your member's phone number, visit **advocate.michaeljfox.org**. Each legislator has an office in Washington, D.C. and one or more district offices in their home state. If you are calling to speak about federal research funding, use the number for the D.C. office.

Identify yourself. State your name, and make it clear that you are a constituent and a member of the Parkinson's community. Ask to speak to the staffer who handles health issues. If this individual is unavailable, leave a message.

Stay on topic. Use the talking points in this toolkit to guide your call. If you are speaking about a specific bill, be sure to mention the bill's full name and bill number so the staffer knows what you're referencing.

Ask for a written response. Leave your contact information so the staffer can update you with the member's position or any action taken. Remember that lawmakers receive many calls, though, and a response could take six weeks or more.

Be courteous. Regardless of where your policymaker stands on the issue(s) you're discussing, always be polite and patient.

SAMPLE TELEPHONE SCRIPT

My name is _____ and I am from _____ (city/state).

[Add one sentence about your personal connection to PD.]

[Provide two to three sentences about the specific issue you want them to know more about. Here is an example:]

I'm calling to ask Representative/Senator _____ to support funding for three agencies and programs that are critical to furthering Parkinson's research.

These include the National Institutes of Health, the Department of Defense Parkinson's Research Program, and the National Neurological Conditions Surveillance System at the Centers for Disease Control.

Thank you so much for your support!



Personal Meetings

Meeting with your lawmakers in person allows you to share your story face-to-face. It gives members and their staff an opportunity to ask questions and have an in-depth conversation about the matters important to you.

Visiting with your legislator while they are in your home state (called an in-district meeting) is often more effective than a Capitol Hill meeting. Washington, D.C. offices are hectic and fast-paced, meaning lawmakers have very limited time to spend with constituents. Visits conducted in the districts frequently last longer, leaving more time for you to share your story. Members travel back to their states and hold meetings during recess periods (times when Congress is not in session and elected officials conduct business at home). You can view all recesses on the 2019 congressional calendar (found on page 10). You'll notice that members are in their districts very often!

If you're not able to conduct an in-person visit or prefer not to, that's okay! Choose the advocacy option that works best for you. Here are some tips for meeting with your legislators:

Invite other advocates. If there are other Parkinson's policy advocates in your area, invite them to participate in the meeting. This can show the congressional offices that there are many of us within the community and can incorporate more voices.

Schedule an appointment. Many members of Congress have electronic meeting request forms on their websites or you can call the office directly to ask for an appointment. During recess, members' calendars fill up very quickly. Look to make your request four to six weeks before your targeted meeting date.

The scheduler will ask you about the purpose of your visit. Tell them the issues you will discuss, keeping it to two to three issues at most. Members always bring a staffer to constituent meetings, so by sharing your issues ahead of time you ensure the person working on health and research topics will be present. In many cases, the legislator will not attend the appointment and you'll be told you're meeting with a staffer. Speaking with staff is just as important as speaking with a member because they play a significant role in shaping the lawmaker's policies.

Determine what you'll say. Use the talking points and educational handouts available to you to plan what you'll say in your meeting. Review these documents several times so you feel comfortable speaking on these topics. Print the handouts to bring to your appointment and leave with you remember and/or their staff. It is recommended that you also send them before your meeting to help ensure a more robust conversation.

Be patient. Lawmakers and their staff often have very tight schedules. It's not uncommon for the member to be late or for your meeting to be interrupted, and you may speak in the hallway or while walking between rooms. If prolonged standing or walking is too difficult, though, speak up. They'll work to find alternative arrangements for your meeting.

Remain flexible. Prepare to meet with your elected official or their staff. Treat both with equal respect. If the member arrives in the middle of the appointment, continue the conversation and allow them to ask questions if needed. If you discover your legislator is not able to join the meeting, don't be discouraged. Remember educating staffers on your needs is critical.

Tell your personal story. No one is in a better position to educate lawmakers on Parkinson's than those who are living with it every day. Sharing your experiences will help your member understand how public policies impact the PD community.

Stay focused. Keep your conversation limited to one or two policy issues and be specific about the positions you'd like your legislator to take. Have your key requests organized so you can present them concisely.

Follow up. After the meeting, send a thank you not to the member of Congress and to the staffer. Also make sure you reiterate the ask from the meeting and provide any follow-up materials that may have been requested during the meeting.



Attending Town Halls

Because members of Congress can be very busy, scheduling an individual meeting may be difficult. Another place to engage with them is at scheduled town halls. At these large public forums, lawmakers can hear from a number of their constituents at once and present their positions on hot-button issues (or not so hot). Social media engagement, including posting quotes from your legislator and pictures of the event, is acceptable and often encouraged.

As a result of COVID-19, many Congressional offices have transitioned to only hosting tele-town halls. Many times, these meetings are about specific topics or geared towards a geographic area for the district. They are still a great opportunity to build the relationship with the office. If relevant, have a question prepared at the start of the town hall so that you can tell staff and get in line early.

To find town halls in your area, you can visit your members' website and social media profiles, join their mailing list and check your local news outlets. The Town Hall Project (townhallproject.com) also maintains a calendar of events across the country.

When attending a town hall, follow these steps:

Prepare a question. Review the talking points and educational handouts available to you. Then, think of a question you'd like to ask your member about a particular policy issue. Keep your question brief as you may not get much time to ask your question. For a tele-town hall, you may have to submit your question in advance.

Bring your story. Adding just a sentence or two about why the topic is personally important to you can really make an impact. If you're comfortable, you could share that you are there because you or your loved one has Parkinson's. Tie your experience to what you're asking for.

Be respectful. Town hall meeting discussions can get heated. Remain calm and polite when speaking to your legislator, their staff and other attendees.

Go in groups. There is power in numbers. Ask your community members to attend with you. Every single person doesn't have to ask a question, but a large show of support from more constituents can make an impression.

Find staffers. Everyone will want to talk directly to their member but speaking to the right staff person can be just as effective. Staff do the background work on an issue before bringing a recommendation to their boss. Building a relationship with your member's staff is essential to your ongoing advocacy work.

Leave educational handouts. Print out educational handouts and give them to your legislator or a staffer after the meeting. These will be helpful resources for the office to refer back to when it comes time for the member to vote on the issues. You also should ask for the staffer's email address so you can communicate. You can email materials to a staffer if you attend a tele-town hall.

Promise to follow up — and then do it. Reinforce your presence and comments by email or phone shortly after the town hall meeting. Lawmakers and staff conduct hundreds of events when they're in their home districts. It's important to remind them of who you are and what you're asking for.

