



# PARKINSON'S ADVOCACY TOOLKIT

A Guide to Making Your  
Voice Heard in the Public  
Policy Process

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

2021 EDITION

PHOTO CREDIT: JOE SHYMANSKI



# *Dear Advocate,*

Whether public policy and advocacy work are second nature or you're just getting started, you can be an effective advocate. You already have the most important and valuable tool you need: your personal story. No one understands the ins and outs of Parkinson's disease (PD) better than those who live with it every day. By translating those experiences to policymakers, you can play a critical role in shaping legislation that affects the PD community.

The Michael J. Fox Foundation (MJFF) is dedicated to finding a cure for PD and ensuring the development of improved therapies for those living with the disease today. But drug development and approval alone isn't enough. This is just one of our Foundation's three policy priorities, along with furthering Parkinson's research and safeguarding access to health care and support services. And to achieve all of our shared goals, a robust and coordinated advocacy effort is key.

There are many different ways to advocate. This toolkit is full of resources designed to bring you up to speed on current Parkinson's policy issues and show you how to take action on them. No matter what you decide to do — meet with your lawmaker in person, advocate on social media and/or write about Parkinson's-related policy issues in traditional media outlets — it's important to speak up for yourself and the Parkinson's community.

Our collective voice can influence policies that have the potential to affect people with Parkinson's and their loved ones. We look forward to advocating with you.

Sincerely,

The Michael J. Fox Foundation Public Policy Team

**P.S.** If you have any questions, don't hesitate to reach out to us at [policy@michaeljfox.org](mailto:policy@michaeljfox.org)



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# **BUILDING RELATIONSHIPS WITH CONGRESS MEMBERS**

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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.

## How to Tell Your Story

Whether communicating with a congressional office, the media or posting on your personal social media, it is important to talk about experience with Parkinson's and how it relates to your everyday life — that is what we mean when we say “tell your story.” Sharing your story puts a very real face on the issues that are important to our community, and it helps legislators understand how their actions and votes impact their constituents living with Parkinson's disease. Your experience has value.

**Be brief.** Whether in writing or presented in a meeting, you want to be brief in sharing your story. The human attention span is not a long one, and it is getting shorter.

**Tell a story.** Thanking about your favorite book or movie, every great story has characters and a challenge that they must overcome. Who are the people in your story? What is their challenge?

**Have the possibility of a happy ending.** Everyone, especially politicians, want to be part of a happy ending. Share how the listener can be part of the solution in your story.

**Avoid acronyms or jargon.** While the government and medicine are both full of acronyms and jargon, it is still important to avoid using it in your conversations. Not everybody knows every acronym or advancement, especially about medical issues. Offer an explanation when you introduce a new technical term.

**Be different.** Every person with Parkinson's has a unique experience. Share what makes your connection and experience different.

**Write it down.** We can all get carried away when sharing a story — especially a very personal one. It can help to write it down before hand to make sure you have all of the important points — and that all of the points included are necessary. When crafting your story remember to:

- Begin with the story in mind
- Set the stage
- Include a challenge and obstacle that is preventing our hero/heroine from reaching success
- Finish with a hook to keep the listener wanting more



# 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](http://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](https://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 [Issue]*

*August 2021 Issue: H.R. 3321/S. 1670, the Credit for Caring Act.*

*Sixty-two percent of people with Parkinson's disease receive care from a care partner, which is often a working family member. This legislation supports working family care partners by offsetting the cost of care expenses.*

*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 the Congressional calendars online at [www.majorityleader.gov/calendar](http://www.majorityleader.gov/calendar) and [www.senate.gov/legislative/2021\\_schedule.htm](http://www.senate.gov/legislative/2021_schedule.htm). 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](https://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. A question may be as simple as "A bill to support family care partners has been introduced by giving a nonrefundable tax credit. Sixty-two percent of individuals with Parkinson's disease receive care from a care partner. Will you cosponsor and support this legislation?"

**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 to 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.



A photograph of Joe Narciso and his daughter standing in front of the United States Capitol building. Joe is seated in a wheelchair, wearing a dark suit, a striped tie, and glasses. He has a name tag on his lapel. His daughter is standing next to him, wearing a light-colored patterned dress and a matching cardigan. Both are smiling at the camera. The background shows the iconic dome and columns of the Capitol building under a clear sky. An American flag is visible on a pole to the right. A police officer is partially visible in the background on the right side.

# USING SOCIAL MEDIA

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Joe Narciso and his daughter attend meetings on Capitol Hill during the 2017 Parkinson's Policy Forum.

PHOTO CREDIT: JOE SHYMANSKI



**When it comes to advocacy, social media platforms, such as Facebook and Twitter, can be powerful tools. Many of your lawmakers, other advocates and policy groups are active on social media. Using your computer, tablet or smartphone, you can inspire others, engage with the advocacy community and interact with elected officials.**

Your personal social media account, whether that's on Facebook, Twitter or another site, is the best place to feature your advocacy work online. Through your own network of contacts, you can exert a tremendous amount of influence and drive progress.

Each social platform has its strengths. Facebook is particularly good for getting others to sign on to petitions, email their lawmakers and participate in local events, like town halls. You also can post educational information about Parkinson's policy-related topics. Twitter is an ideal space for sharing images of meetings with your lawmakers. It also allows you to speak with your elected

officials by tweeting at them directly. And you can make a particular tweet more visible to users by including a certain hashtag. (#Act4PD is used for Forum and other advocacy efforts.) Remember, tweets can be no more than 280 characters so Facebook may be better for those with a talent for prose!

You may be active on other social networks, too. You can use Instagram and Snapchat to post a photo or short video when you're at an advocacy event or town hall. It's not necessary to be active on every platform. If you only use one or two social media sites, that's okay. Try to choose at least one that you enjoy and log on to regularly!

## Create Your Own Post

Posting on social media is a key way to give your followers more insight into what policy issues matter most to you, highlight PD-related policy news or get the attention of your elected officials. (Sample Facebook and Twitter posts are included in this section. It is easy to update these sample posts to show support for legislation. Remember to include a bill number and a very brief explanation of what the legislation will do to support the Parkinson's community.

### Facebook

- Keep your message concise when writing about a petition or piece of legislation.
- Point out specifically what interests you about what you're posting and encourage your friends to get involved.
- You can always link to **advocate.michaeljfox.org**, the Foundation's advocacy page. Here, individuals can send lawmakers pre-drafted emails or compose their own notes. After you contact your lawmakers, send the link to your friends and family and encourage them to take action

#### Sample Facebook posts:

- I'm supporting federal research funding to advance new treatments and a cure for Parkinson's. Join me by contacting your lawmakers and taking action here: [\[include link here\]](#)
- Approximately 1 million Americans are living with Parkinson's disease. I contacted my lawmakers to advocate for federal research funding. Join me: [\[include link here\]](#)
- I advocate to help advance new treatments and a cure for Parkinson's. It's important that our policymakers hear directly from us, the PD community: [\[include link here\]](#)
- Parkinson's disease costs the U.S. \$52 billion per year. Let's tell our policymakers that robust federal research funding can help lower these costs: [\[include link here\]](#)



## Twitter

- To tweet at a member of Congress, be sure to include their Twitter handle in your post. Use the search box in the top right corner of Twitter to find your lawmaker's page. You'll see a button under their profile picture that says "Tweet to [lawmaker]."
- If your member's handle is the first thing in the tweet, add a period (.) in front of it to ensure all of your followers can see your post. Tweets without the period will be sent directly to lawmakers and won't be visible to all users.
- Use the hashtag #act4PD in Parkinson's public policy-related tweets.
- Attaching a short video to your tweet is a great way to engage with your elected officials. Here is a sample script you could use:

*My name is \_\_\_\_ and I am from \_\_\_\_ (city/state).*

*[Include 1-2 sentences about your connection to PD.]*

*I'm asking 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!*



A tweet from Chad Moir, a Parkinson's fitness expert from Massachusetts.

## Sample tweets:

- .@[lawmaker's handle] Support research funding in FY20 for @NIH, @CDCgov and @DeptofDefense for the approximately 1 million people in the U.S. living with #Parkinsons. #Act4PD
- #Parkinsons disease costs our country \$52 billion per year. Federal research funding can help lower Parkinson's health care costs. @[lawmaker's handle], it is imperative that you support research this year!
- Thank you @[lawmaker's handle] for supporting the #Parkinsons community by making sure research funding remains a federal priority. You are pushing us closer to a #cure. #Act4PD (Note: you can use this tweet to thank a lawmaker who recently voted in support of research funding.)
- I advocate to help advance new treatments and a cure for #Parkinsons. It's important that our policymakers hear directly from the PD community. Take action with me here: [include link here] #Act4PD (Note: use this to tweet at fellow advocates.)



Steve Pritchett, a person with Parkinson's from Indiana, advocates for federal research funding in a video sent to his lawmaker through Twitter.

**Looking for inspiration?** Search for tweets featuring the "act4PD" hashtag on Twitter to see how your fellow advocates are taking action! You can find their posts at [twitter.com/hashtag/act4pd](https://twitter.com/hashtag/act4pd).





# Support an MJFF Post

The Foundation's Facebook page and Twitter account are frequently updated with information about policy issues affecting people with Parkinson's and their loved ones. We keep our eye on Washington so when new proposals are introduced and bills move through Congress, we can deliver the latest news. By supporting one of these posts, you can spread the word about Parkinson's disease and public policy.

When an MJFF Facebook or Twitter post resonates with you, there are a number of different actions you can take to respond.



## Facebook

(facebook.com/michaeljfoxfoundation)

1. **Act.** Many posts link to pre-drafted emails you can send to your members of Congress on a particular policy issue. Click on the post to take action through the Foundation's website.
2. **Share.** The "Share" button allows you to place an MJFF post on your own timeline where your friends can see it.
3. **React.** Hover over the "Like" button and select from the options to express how you feel about a post.

## Twitter

(twitter.com/michaeljfoxorg)

1. **Act.** Some posts direct you to pre-drafted emails that can be sent to elected officials. Click on the bit.ly link to take action through the Foundation's website.
2.  **Share.** The "retweet" button at the bottom of the post allows you to share an MJFF tweet from your own account so your followers can see it.
3.  **React.** Click the "like" button to indicate your support for a post.







# USING TRADITIONAL MEDIA

Advocates attend meetings  
on Capitol Hill during the 2017  
Parkinson's Policy Forum.

PHOTO CREDIT: JOE SHYMANSKI

# Write Letters to the Editor, Op-eds and Blogs

While social networking sites can seem ubiquitous, don't forget about the ways in which traditional media (e.g. newspaper, television, radio) can further your advocacy goals. Print publications provide a host of opportunities for you to share your story and explain the needs of people with PD and their loved ones. In letters to the editor, op-eds and blogs, you can call attention to important policy issues and educate the public. Submitting these pieces to a news outlet is easy, and when reporters craft a story they will often pull directly from what you send them. When writing, remember to:

- **Highlight your personal story.** Readers want to hear how Parkinson's has impacted *your* life.
- **Include Congress members' names.** State the names of your legislators, as well as where they stand on the issue you're covering. Congressional offices keep records of articles that mention their member. And, if you've previously met with your lawmaker, this will help them remember your visit.
- **Add facts.** Language from the educational handouts in this toolkit may support your letters, op-eds and blogs.
- **Review submission guidelines.** Each media outlet is different. Be sure you understand word limits and submission processes before you begin developing your pieces. You can search for news outlets in your state by visiting [onlinenewspapers.com](http://onlinenewspapers.com). Verify the outlet's guidelines and contact info on their website.

If a reporter reaches out to you to request an interview related to your advocacy work, the Foundation communications team can provide support. Contact us at [policy@michaeljfox.org](mailto:policy@michaeljfox.org).

## Letters to the editor

These short commentaries (typically about 250 to 300 words) can be in support of or opposition to a newspaper editorial, or detail your thoughts in relation to a recently published article. Consider these tips:

- **Find something to respond to.** Choose an article you'd like to comment on that's directly relevant to the Parkinson's community. Your letter can be in response to the article in general or a specific issue within it.
- **Share your position.** Be able to simply state that you agree, disagree or have something new to add.
- **Establish yourself as credible.** Note your experiences with Parkinson's disease and advocacy to lend authority to your voice.

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Letter to the editor  
by Kevin Kwok, a person  
with Parkinson's from  
California, published  
in the San Francisco  
Chronicle in 2017.

### Parkinson's disease advocacy

I have Parkinson's disease and, with The Michael J. Fox Foundation, just returned from meetings in Washington, D.C., with the offices of Sens. Dianne Feinstein, Kamala Harris, House Minority Leader Nancy Pelosi and Rep. Mark DeSaulnier. We had productive conversations about safeguarding federal research funding, the need to maintain policies that allow patients access to high-quality, affordable care and the critical importance of increasing support for our nation's caregivers.

At present, there are no cures for Parkinson's disease, but we have hope and energy, both for living well with this disease today and preventing it for future generations. Being able to meet with the offices of each of these elected officials reaffirmed that my voice as a patient matters and gives me continued faith in the American system. I am grateful for the chance to advocate for these important issues, and I will continue to speak out on behalf of the Parkinson's community.

*Kevin Kwok, San Francisco*





## Op-eds

These pieces should be persuasive and detail your thoughts and expertise on a particular topic. They often focus on current events or issues relevant to a particular community. Op-eds usually are around 750 words. This framework can help guide your writing:

- **Start with a hook.** Find a current event or news story that makes your op-ed relevant and compelling. (You can do this in the first sentence.)
  - Examples: Yesterday a bill was introduced that...; April is Parkinson's Awareness Month; Last week the president gave a speech on...
- **State the problem and how you'd fix it.** What's the issue and what do you recommend to make it better?
- **Be persuasive.** Use evidence and your experiences with PD to convince the reader you have the right solution.
- **Finish strong.** Reiterate your proposal and issue a call to action.
  - Examples of calls to action:
    - Contact your members of Congress at [advocate.michaeljfox.org](https://advocate.michaeljfox.org).
    - Sign up at [michaeljfox.org/advocacy](https://michaeljfox.org/advocacy) to join the MJFF email list and receive communications about relevant policy issues.

## Blog posts

You can publish blogs in many places, including online news publications, your own personal webpage and other websites. They're typically more informal than letters to the editor and op-eds and usually run about 500 words. As you compose your blog, remember to:

- **Keep it personal.** Use a compelling anecdote to illustrate the issue and attract readers.
- **Use visuals.** A picture really is worth a thousand words. Photos, images or graphics can bring your story to life. Cite the source if you didn't create the visual yourself.
- **Make your case.** Your experiences with Parkinson's disease and your role as an advocate can lend credibility to what you're saying.
- **Incorporate a call to action.** People should know what to do next after reading your blog. Examples:
  - Contact your members of Congress at [advocate.michaeljfox.org](https://advocate.michaeljfox.org).
  - Sign up at [michaeljfox.org/advocacy](https://michaeljfox.org/advocacy) to receive emails about relevant policy issues.
- **Ask others to share.** Encourage readers to re-post your blog, especially on social media.



Personal blog of Maria de Leon, a person with Parkinson's and retired movement disorder specialist from Texas.







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