



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

2019 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



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2019 POLICY ISSUES

Steve and Nancy Hovey attend meetings on Capitol Hill during the 2017 Parkinson's Policy Forum.

PHOTO CREDIT: JOE SHYMANSKI

PLURIBUS

Summary and Talking Points

The Michael J. Fox Foundation established three priority areas in which to focus our public policy efforts: furthering Parkinson's research, advancing therapy development and approvals, and safeguarding access to care and support services.

Within each of these broad categories, there are many specific policy issues of importance to our community. These vary from year to year as the political environment in Washington, D.C. shifts and the priorities of people with PD and their loved ones change.

Currently, we are focused on securing robust federal funding for several programs and agencies that further Parkinson's research.

The following talking points can be used to write emails to lawmakers, prepare for phone calls and meetings, brainstorm town hall questions, formulate social media posts, and draft articles for local newspapers or blogs. The educational handouts in this toolkit can be printed for individual or town hall meetings.

The below information was accurate at the time this toolkit was published. However, legislation on these topics is constantly shifting. Visit michaeljfox.org/policyblog for updates on these issues.

Federal Research Funding

Where Are We Now?

Over the coming months, Congress must set funding levels for Fiscal Year (FY) 2020, which will run October 1, 2019 to September 30, 2020.

During these negotiations, legislators will decide how much money to allocate to the government agencies and programs involved in Parkinson's research. While the president has expressed an interest in cutting this funding, lawmakers from both parties have shown their support for science. In fact, they increased federal research funding in the FY 2019 budget.

At the time this toolkit was released, Congress was in the initial stages of setting funding levels for FY 2020 but had not passed a final spending plan. Use these talking points to encourage members to continue supporting research investments.



Talking Points

Strong federal funding for the government agencies and programs involved in biomedical research is of the utmost importance to the Parkinson's community.

- **Currently, there is no treatment** to slow, stop or reverse the progression of Parkinson's disease, nor is there a cure.
- **PD affects nearly 1 million people in the United States, and it costs the country at least \$26 billion per year.** Because age is the greatest risk factor for Parkinson's, these numbers are expected to rise as the population gets older and more individuals are diagnosed with the disease.
- **Investing in biomedical research** now will further the development of new treatments and a cure, improving quality of life for people with PD, and helping individual families and the government save money in the long run.

Urge your Congress members to support the following funding levels in FY 2020:

- **\$5 million for the National Neurological Conditions Surveillance System (NNCSS) at the Centers for Disease Control (CDC)**

- The NNCSS gathers vital information related to age, race, sex, geographic location and family history from people living with neurological diseases, including Parkinson's. Currently, researchers don't have access to this important data, which can inhibit scientific progress.
- The NNCSS does the following:
 - Provides scientists with comprehensive data to refine and target their research, which could lead to better knowledge of complex neurological diseases, new treatments and a cure

- Builds a foundation for understanding many factors, such as variances in diagnoses among men and women, and people living in different geographic regions
- Makes it easier to properly allocate health care resources
- Congress first gave the CDC money to implement the NNCSS in FY 2019. It's critical that lawmakers continue to support funding for this system in FY 2020 and beyond.

- **\$25 million for the Department of Defense (DoD) Parkinson's Research Program (PRP)**

- Funding for the PRP has decreased in recent years (from \$25 million in FY 2010 to \$16 million in FY 2019) and should be restored.
- This program studies how events in the line of service, such as toxin exposure and traumatic brain injury, may lead to the development of Parkinson's in our nation's service members and veterans.
- An estimated 80,000 veterans are living with Parkinson's today. Research into PD's service-related links is critical to support these individuals, as well as future military generations who may be affected by the disease.

- **\$41.6 billion for the National Institutes of Health (NIH)**

- The NIH is the largest public funder of Parkinson's research, investing an estimated \$177 million in the disease in 2018.
- The agency supports foundational research that furthers our understanding of PD and lays the groundwork for the development of new therapies.
- The NIH is able to fund only 12 percent of the grants it receives, leaving 88 percent of scientific ideas unfunded.



Congressional Caucus on Parkinson's Disease

Talking Points

Caucuses are formed by members of Congress to provide a forum for issues or legislative agendas. At the end of any meeting you hold with your lawmaker, ask them to show their support for the PD community by joining the Caucus. (A list of current members can be found on the MJFF website.) Membership will allow them to learn more about the needs of people with PD and care partners.

- **Two senators and four representatives lead the Caucus:** Senators Johnny Isakson (R-GA) and Debbie Stabenow (D-MI); and Representatives Gus Bilirakis (R-FL), Hank Johnson (D-GA), Peter King (R-NY) and Carolyn Maloney (D-NY).
- **The Caucus supports** federal research funding, champions Parkinson's policy priorities, introduces PD-specific legislation and hosts educational briefings.
- **Being a member of the Caucus** is a way to show your support for constituents living with Parkinson's disease and stay informed on issues impacting our community.
- **Members of Congress who are interested in joining the Caucus should email** Shayne Woods (shayne.woods@mail.house.gov) in Rep. Bilirakis' office or Alex Graf (alex_graf@stabenow.senate.gov) in Senator Stabenow's office.





EDUCATIONAL HANDOUTS

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

PHOTO CREDIT: JOE SHYMANSKI

Support Federal Funding for Parkinson's Disease Research

Parkinson's disease (PD) affects nearly 1 million Americans. Currently, there is no treatment to slow, stop or reverse the progression of the disease, nor is there a cure. PD is estimated to cost our country at least \$26 billion per year. Robust and reliable federal research funding is imperative to drive scientific progress and lower Parkinson's health care costs, relieving the burden on Medicare, Medicaid and the Department of Veterans Affairs (VA).

Please support these FY 2020 funding levels:

National Institutes of Health (NIH):
\$41.6 billion

Department of Defense (DoD)
Congressionally Directed Medical Research
Program (CDMRP) for Parkinson's disease:
\$25 million

Centers for Disease Control and Prevention
(CDC): **\$5 million for the National
Neurological Conditions Surveillance
System (NNCSS)**

NIH

As the largest public funder of Parkinson's disease research, the NIH invested an estimated \$177 million in PD in FY 2018.

- NIH research has led to groundbreaking PD treatments that have been used across a spectrum of disorders.
- Every dollar of NIH investment generates two dollars in local economic growth; NIH funds research at universities and institutions in all 50 states.

DoD CDMRP

This is the only Parkinson's-specific government-funded research program.

- It aims to understand the military service-related links to PD, such as toxin exposure and traumatic brain injury.
- Funding for this program decreased from \$25 million in FY 2010 to \$16 million in FY 2019. Restoring funding is critical for the estimated 80,000 veterans currently living with PD, as well as service members and veterans who may be affected and are not yet diagnosed.

CDC

The NNCSS will collect data to inform PD research and health care priorities.

- This system will gather vital patient information related to age, race, sex, geographic location and family history. This will lay the groundwork for targeted medical research and better health care planning, reducing future costs for people with Parkinson's and the government.
- The CDC will work efficiently to create the surveillance system by pulling information from existing sources, such as Medicare, Medicaid and VA databases, as well as state and local Parkinson's registries.
- The NNCSS was funded by an amendment in FY 2019. It's critical that this system is included in future appropriations bills.

Please contact Brittany Meyer at bmeyer@michaeljfox.org for more information.

Join the **Congressional Caucus on Parkinson's Disease**

The Congressional Caucus on Parkinson's Disease increases lawmakers' awareness of issues impacting the Parkinson's community, including the latest developments in health care-related legislation and medical research. The Caucus supports federal research funding, champions Parkinson's policy priorities, introduces Parkinson's-specific legislation and hosts educational briefings.

Two senators and four representatives lead the Caucus: Senators **Johnny Isakson** (R-GA) and **Debbie Stabenow** (D-MI); and Representatives **Gus Bilirakis** (R-FL), **Hank Johnson** (D-GA), **Peter King** (R-NY) and **Carolyn Maloney** (D-NY).



Johnny Isakson

U.S. Senator Johnny Isakson, who announced his own Parkinson's diagnosis in June 2015, said, "Co-chairing the Congressional Caucus on Parkinson's Disease holds special meaning for me. I'm honored to have the opportunity to help inform Congress about Parkinson's impact on patients, caregivers and society and to offer a glimpse at the important role investing in research can play in managing and working to cure the disease."



Carolyn Maloney

"I am proud to serve as co-chair of the Parkinson's Disease Caucus, which advocates for strong funding for medical research and helps raise awareness about this disease. We have successfully secured hundreds of millions of dollars for life-saving research through the Department of Defense Parkinson's Research Program. With about 1 million Americans living with Parkinson's, the caucus is firmly committed to supporting patients, families and caregivers."

Please support Americans living with Parkinson's disease by joining today!

Contact **Shayne Woods** (shayne.woods@mail.house.gov) in Rep. Bilirakis' office or **Alex Graf** (alex_graf@stabenow.senate.gov) in the office of Sen. Stabenow.

ABOUT PARKINSON'S DISEASE

Parkinson's disease (PD) is a chronic, degenerative neurological disease that affects one in 100 people over age 60. It is estimated to cost our country at least \$26 billion per year. Currently, there is no treatment to slow, stop or reverse the progression of PD, nor is there a cure. Existing Parkinson's treatments are limited in their ability to address symptoms and remain effective over time. There is no diagnostic test for Parkinson's, so the rate of under-diagnosis can be relatively high, but it is estimated that nearly 1 million people in the United States are living with PD. Motor and non-motor symptoms can include (but are not limited to) resting tremor, stiffness and slowness of movement, as well as depression, sleep disorders and cognitive impairment.

Please contact Brittany Meyer at bmeyer@michaeljfox.org for more information.



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 and sharing your story, 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

When emailing, calling or meeting with your members of Congress and their staff, it's important to talk about your experience with Parkinson's and how it relates to your everyday life — that's 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.

Below, three advocates share examples of how they've told their story to lawmakers. Feel free to use these as a starting point to begin crafting your own narrative, which you can employ when advocating in person, over the phone or in writing.

Dan Kinel, New York: *“I was diagnosed with Parkinson's disease at 43, when my sons were six and eight. It hit me like a ton of bricks. What would my future and the future of my family be like? When I finally got up and dusted myself off, I realized that the most effective way to help myself, pursue a PD-free future for my children and reduce the ever-growing societal impact of the disease was to engage in research. I do this both as a clinical trial participant and as an advocate of research funding. I know my lawmakers are looking out for the best interests of our citizens. Congress has the power to devote government resources to finding a cure and improving people's lives. Allocating resources to fight PD is an investment in our collective futures that is urgently needed.”*

Leslie Peters, Colorado: *“My mother-in-law had PD and my husband has young-onset Parkinson's disease. My husband and his mom grew up in Allentown, Pennsylvania, which is highly industrial. I feel there is a possible genetic component and environmental component to their PD. Recently, my oldest daughter developed a tremor. Doing all I can to advocate for research funding and scientific progress is the most important thing in the world to me. New research helps us know if others in my family will be at risk for Parkinson's. In the past few years, scientists have made significant strides understanding the genetic aspects of PD, but there's still work to do. This is not the time to slow or stop this critical work.”*



Israel Robledo, Texas: *“I was diagnosed with Parkinson’s disease when I was 42. With no family history, it came as quite a shock and it took me a while to come to terms with the diagnosis. I knew that I had to do something to help and decided to use my voice to advocate for health-related issues and increased research funding at the federal level. My medications, which were developed*

thanks to investments in research, do a good job of meeting my needs and helping me maintain a good quality of life. But that’s not the case for every person with PD because this disease affects each individual differently. The need for continued federal research funding is of the utmost importance because many patients need improved treatments to adequately manage their PD.”

Sending Emails

Emailing your Congress members is an effective way to make your priorities known. Legislators want to hear their constituents’ stories so they can take their needs into account as they make policy decisions. Because you have first-hand experience with the disease, you can encourage your lawmaker to look to you as a resource for information on policies impacting people with PD and their families.

Easily send a template email. You can quickly send legislators pre-drafted emails on important policy issues by visiting the Foundation’s advocacy page at advocate.michaeljfox.org. Here you will find an online tool that will allow you to contact your lawmakers in a matter of minutes. (Be sure you’re signed up to receive MJFF emails to be notified with an “Action Alert” when new issues are added.) All communications sent through this system are

automatically delivered to your elected officials’ health staffers. They read all constituent correspondence and convey your messages to their members.

Compose your own message. If you’d like to develop your own unique email, you can use the sample text below. Search your lawmakers’ websites to find online submission forms or email contact information.

Dear [\[member name\]](#),

I am writing today to ask you to support policies that benefit people living with Parkinson’s disease (PD) and their loved ones. PD affects nearly 1 million Americans and costs our country at least \$26 billion per year. It is the second most common brain disease after Alzheimer’s. Existing treatments are limited in their ability to meet patients’ needs. Currently, there is no cure.

[\[Insert one or two short paragraphs discussing your connection to PD and telling your personal story.\]](#)

[\[Tell your lawmaker what positions you’d like them to take on our issues. The talking points and educational handouts in this toolkit include sample language you can use.\]](#)

As your constituent and someone with first-hand knowledge of PD, I can provide valuable insights on living with the disease. I would be happy to speak with you further about the ways Parkinson’s impacts patients, care partners and families.

Feel free to reach out to me at any time. I look forward to staying in touch with you on these topics.

Sincerely,

[\[Your name\]](#)

[\[Contact information\]](#)



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 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).

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!



Meeting in Person

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 17). 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:

Before the Meeting

Schedule an appointment. Locate your lawmaker's in-district office(s) by visiting advocate.michaeljfox.org and using the lookup tool. You should schedule a meeting in the district office closest to you. Many officials have electronic meeting request forms on their websites or you can call the office directly to ask for an appointment. During recesses, members' calendars fill up very quickly. Look to book several weeks in advance.

The scheduler will ask you about the purpose of your visit. Tell them you'd like to discuss research funding. 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 the health 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 in this toolkit 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 your member and/or their staff.

During the Meeting

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.



Be honest. It's okay if you don't know the answer to a question. Offer to figure it out and get back to the staffer.

Keep politics out of it. Your lawmaker may not support the issues you cover in your meeting, but they could be your ally on future topics. Do not discuss elections or campaign support, and respect the member's political views.

Say thank you and leave educational materials.

Express your gratitude and leave copies of the educational handouts so the office can review the issues again. Take the staffer's business card so you can stay in touch. Members don't give out their personal email addresses; you'll keep in touch with them through their staff.

After the Meeting

Follow up. There are many ways to share your thanks after a congressional meeting. You can send an email to your lawmaker and their staff summarizing the issues you discussed and expressing your gratitude for the visit. (If helpful, you can use the template message below.) Or, you can tweet at your member and thank them for their time. Legislators are often eager to take pictures with their constituents during meetings, so feel free to ask for a shot and then attach it to your tweet! And, if you prefer traditional mail, you can always send a handwritten note (just be aware that it may be delayed due to congressional security measures).

Dear *[staffer name, add the member if they joined your meeting]*:

Thank you for the opportunity to meet on *[date]* to talk about policies impacting the Parkinson's disease (PD) community. I appreciate your consideration of these issues.

As discussed during our meeting, I ask you to please support these funding levels in FY 2020:

- Centers for Disease Control and Prevention: \$5 million for the National Neurological Conditions Surveillance System
- Department of Defense Congressionally Directed Medical Research Program for Parkinson's disease: \$25 million
- National Institutes of Health: \$41.6 billion

[Add a few sentences here about your personal connection to the disease and the impact it has on you and your loved ones.]

[If the member or staffer asked for more information, wanted to speak to someone at the Foundation and/or planned to discuss an issue with their colleagues before giving an official position, be sure to follow up on these points here.]

It was a pleasure meeting with you. Again, thank you for taking the time to speak with me. I look forward to staying in touch with you on these topics.

Sincerely,

[Your name]

[Contact information]

Let MJFF know. Please complete a debrief form by visiting surveymonkey.com/r/congressionaldebrief to let the Foundation know how your meeting went. This will help MJFF identify which members of Congress currently support our policy issues, as well as other lawmakers we can further educate on the needs of our community.



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. Social media engagement, including posting quotes from your legislator and pictures of the event, is acceptable and often encouraged.

To find town halls in your area, you can visit your members' websites, join their mailing lists 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 in this toolkit. Then, think of a question you'd like to ask your member about a particular policy issue. The sample at the end of this page can help you get started. Keep your question brief as you may not get much time at the microphone.

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 PD. 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 larger 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. Before or after the town hall, approach a staffer and ask who's in charge of health care issues. Connect with the correct person, ask for their email address and follow up with more information.

Leave educational handouts. Print out the 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. Remember, legislators don't give out their personal email addresses; you'll communicate through their staffers.





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. Use the sample thank you language on page 15 to compose your message. (Edit as needed!)

Sample Town Hall Question

Thank you for the opportunity to ask a question. My name is ____ and I live in ____ (town/city). I am a person living with Parkinson's disease/have a loved one with Parkinson's disease. Currently, there is no cure for Parkinson's. We've had the same medication for decades. Drugs help some of my/my loved one's symptoms some of the time. I support and need research that can cure this disease. I'm grateful to Congress for increasing funding for the National Institutes of Health in Fiscal Year 2019. Will you support another increase in 2020?



2019 Legislative Calendar

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|  | House in Session Only |
|  | Senate in Session Only |
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|  | Federal Holiday |

| JANUARY | | | | | | |
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| 21 | 22 | 23 | 24 | 25 | 26 | 27 |
| 28 | 29 | 30 | 31 | | | |

| AUGUST | | | | | | |
|--------|----|----|----|----|----|----|
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| SEPTEMBER | | | | | | |
|-----------|----|----|----|----|----|----|
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| 29 | 30 | | | | | |

| OCTOBER | | | | | | |
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| NOVEMBER | | | | | | |
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| DECEMBER | | | | | | |
|----------|----|----|----|----|----|----|
| S | M | T | W | T | F | S |
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Courtesy of Rational 360



A photograph of a man and a young girl standing in front of the United States Capitol building. The man is seated in a wheelchair, wearing a dark suit, a light-colored striped shirt, and a striped tie. He has glasses and a friendly expression. The girl is standing next to him, wearing a light-colored patterned dress and a small bag, with her arm around his shoulder. The background shows the grand architecture of the Capitol, including its iconic dome and columns. The entire image has a warm, orange-toned overlay.

USING SOCIAL MEDIA

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. 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.)

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: [\[include link here\]](#)
- Nearly 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. at least \$26 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).

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!



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 at least \$26 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.



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/usstate/usatable. 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.

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.

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.
 - Sign up at michaeljfox.org/act 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.
 - Sign up at michaeljfox.org/act 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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