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 securing Parkinson’s research funding 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 — build a relationship with your lawmaker, 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 grassrootspolicy@michaeljfox.org.
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Steve and Nancy Hovey attend meetings on Capitol Hill during the 2017 Parkinson’s Policy Forum.

PHOTO CREDIT: JOE SHYMANSKI
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 drug 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.

This year, there has been much focus in Washington on health care reform and federal funding for medical research. It’s critical that Parkinson’s advocates speak up for accessible, affordable, high-quality health care and robust research funding to further new treatments and a cure.

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 author articles for local newspapers or blogs. The educational handouts on pages 8 to 14 go into further detail and 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 The Michael J. Fox Foundation website for updates on these issues.

Health Care Reform

WHERE ARE WE NOW?

In May 2017, the House of Representatives passed the American Health Care Act (AHCA), which, if signed into law, would have made significant changes to our health care and insurance systems.

Instead of adopting the AHCA, Republican leaders in the Senate decided to craft their own health care reform legislation, called the Better Care Reconciliation Act (BCRA), but it did not have enough support to pass and was not voted on. Both the AHCA and BCRA contain provisions that could have negatively impacted the Parkinson’s community.

At the time this guide was published, the Senate was still debating its next steps. Some senators were considering an option to “repeal now, replace later.” This would allow legislators to pass a bill to repeal the Affordable Care Act (ACA), or Obamacare, but it wouldn’t go into effect for two years. Congress would use that time to develop a new health care reform proposal to replace the ACA. However, it’s unclear what the replacement would look like. Another option was to amend the BCRA and bring it up for a vote. Both of these scenarios would result in health care changes that could harm people with PD and their loved ones.
TALKING POINTS

Comprehensive care is a key component of life with Parkinson’s disease. No matter where Congress is in the health care reform process, urge your lawmakers to keep patient needs at the center of their efforts. Ask officials to consider these guidelines when they vote on legislation:

• **Do not discriminate against people with pre-existing conditions.** Every person living with Parkinson’s has a pre-existing condition. Laws that allow insurers to charge higher premiums based on health status will significantly raise expenses for our community. PD already costs a patient an estimated $26,400 a year.

• **Safeguard Medicare and Medicaid.** Eighty percent of PD patients rely on Medicare for basic health care needs, and up to one-third of these individuals also are eligible for Medicaid.

• **Do not raise costs for older Americans.** As the average age at diagnosis of Parkinson’s is around 60, the disease impacts a substantial number of older individuals.

• **Cover wide-ranging health care benefits.** People with Parkinson’s rely on a broad scope of services to meet their needs, including, but not limited to, access to medical specialists, physical, occupational and speech therapy, and medications and surgical procedures.

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**Federal Research Funding**

**WHERE ARE WE NOW?**

Over the coming months, Congress must create a budget for Fiscal Year (FY) 2018, which will run October 1, 2017, to September 30, 2018.

During the budget negotiations, legislators will decide how much money to allocate to the government agencies and programs involved in Parkinson’s research and drug development. 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 2017 budget.

At the time this toolkit was released, Congress was in the initial stages of setting funding levels for FY 2018 but had not passed a final budget. 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 and drug development 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 an estimated 750,000 to 1 million** people in the United States, and it costs the country an estimated $19.8 to $26.4 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 the FY 2018 budget:

- **A $2 billion increase for the National Institutes of Health**, the largest public funder of PD research.
- **$5 million to implement the National Neurological Conditions Surveillance System at the Centers for Disease Control and Prevention** to gather data on how many people are living with Parkinson’s disease, who they are and where they are located. (This system was established by the 21st Century Cures Act but is not yet funded.)
- **$20 million for the Department of Defense Parkinson’s Research Program**, which investigates the military service-related links to PD, such as toxin exposure and traumatic brain injury.
- **$2.8 billion for the Food and Drug Administration**, which people with PD rely on to bring life-changing treatments to market.

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**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.

- **The Congressional Caucus on Parkinson’s Disease** is made up of lawmakers from both the House and Senate who seek to increase awareness on Capitol Hill about PD issues.
- **The Caucus supports** federal research funding, champions Parkinson’s policy priorities, introduces PD-specific legislation and hosts educational briefings.
- **Legislators can join the Caucus** by emailing the contacts listed on page 14.
Advocates attend meetings on Capitol Hill during the 2017 Parkinson’s Policy Forum

PHOTO CREDIT: JOE SHYMANSKI
KEEP PATIENTS AT THE CENTER OF HEALTH CARE REFORM

Comprehensive care is a key component of life with Parkinson’s disease (PD). Being able to access health services, see a specialist, and pay for medications and treatments isn’t just about symptom management; it can impact a person’s disease course and quality of life. As Congress works to reform our health care system, patient needs should be the driving force behind any changes. This is critical to providing top-level care and ensuring optimal outcomes.

Please keep these tenets in mind as you consider health care legislation:

1. DO NOT DISCRIMINATE AGAINST PEOPLE WITH PRE-EXISTING CONDITIONS.

Because every person living with Parkinson’s has a pre-existing condition, laws that allow insurers to charge higher premiums based on health status will significantly raise expenses for our community. According to a 2016 study commissioned by The Michael J. Fox Foundation, an individual with Parkinson’s spends an estimated $26,400 a year on their care. That’s a lot of money for the average American household, and it underscores the need for affordable, non-discriminatory health coverage that spreads costs across a large, diverse population.

2. COVER WIDE-RANGING HEALTH CARE BENEFITS.

People with Parkinson’s rely on a broad scope of services to meet their needs, including, but not limited to, access to specialists, physical, occupational and speech therapy, and medications and surgical procedures. Revisions to existing law that reduce the number of benefits a plan must cover will make it more difficult and expensive for individuals to live well. Similarly, current law that says insurers cannot cut off coverage when a patient’s medical claims reach a certain limit should be maintained.

3. SAFEGUARD MEDICARE AND MEDICAID.

Eighty percent of PD patients rely on Medicare for basic health care needs, and up to one-third of these individuals also are eligible for Medicaid. Changes in law that reduce funding for these programs, restrict benefits or make it less attractive for physicians to care for enrollees will add to the economic burden of Parkinson’s.

4. PREVENT OLDER AMERICANS’ COSTS FROM RISING

As the average age at diagnosis of Parkinson’s is around 60, the disease impacts a substantial number of older individuals. The Parkinson’s population will see its health care expenses rise if insurers are allowed to charge people in higher age brackets significantly more than younger Americans.

Accessible, affordable, high-quality coverage is an absolute necessity for people living with Parkinson’s disease. It is imperative that Congress keeps patient needs at the forefront of the health care reform process.

Please contact Ted Thompson at tthompson@michaeljfox.org for more information.
SUPPORT FEDERAL FUNDING FOR PARKINSON’S DISEASE RESEARCH AND DRUG DEVELOPMENT

Parkinson’s disease (PD) affects an estimated 750,000 to 1 million Americans. Currently, there is no treatment to slow, stop or reverse the progression of the disease, nor is there a cure. Existing treatments are limited in their ability to address patients’ symptoms and to remain effective over time.

As the world’s largest nonprofit funder of Parkinson’s research, The Michael J. Fox Foundation (MJFF) is dedicated to finding a cure and ensuring the development of improved therapies for people living with Parkinson’s today. MJFF’s investments are a complement to, rather than a substitute for, federally funded research. Robust and reliable federal funding is imperative to drive progress in drug and device development from basic research through FDA approval.

NIH
As the largest public funder of Parkinson’s disease research, NIH invested $152 million in PD research in FY16.
- NIH supports basic research to better understand and diagnose PD, and develop new treatments.
- Every dollar of NIH investment generates two dollars in local economic growth; NIH funds research at universities and institutions in all 50 states.
- The economic burden of PD in the United States is $119.8 to $26.4 billion per year, and this is expected to grow as the population ages. Research toward new therapies has the potential to save future health care costs.

CDC
The National Neurological Conditions Surveillance System at the CDC, authorized by the 21st Century Cures Act, will collect data to inform PD research and health care priorities.
- There is no accurate and comprehensive information about the number of people with neurological diseases, including Parkinson’s. This slows the progress of research and drug development.
- This system will gather demographic and geographic data, which will promote targeted medical research and health care planning.

FDA
The FDA ensures the safety and efficacy of therapies and medical devices that improve quality of life for people with PD.
- The PD community depends on the FDA to move potential therapies through an efficient, rigorous review and approval process.
- In the last few years, the FDA has approved several new symptomatic therapies for Parkinson’s disease. A number of additional treatments are in late-stage clinical testing or approaching FDA approval. These are signs of progress, but there is still work to be done.

DoD CDMRP
This is the only Parkinson’s-specific government-funded research program.
- The program aims to understand the military service-related links to Parkinson’s disease, such as toxin exposure and traumatic brain injury.
- Funding for this program decreased from $25 million in FY10 to $16 million in FY17. Restoring funding to at least $20 million 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.

Please contact Brittany Meyer at bmeyer@michaeljfox.org for more information.
As the world’s largest nonprofit funder of Parkinson’s research, The Michael J. Fox Foundation (MJFF) is dedicated to finding a cure and ensuring the development of improved therapies for people living with Parkinson’s today. But we cannot do it alone. **Congress must support funding for the National Institutes of Health (NIH) and place the agency on a path for steady, predictable growth.**

**NIH Research Supports New Treatments and a Cure for Parkinson’s Disease**
- Approximately $152 million of FY16 NIH funding was directed to Parkinson’s-related research.
- Currently, there is no therapy to slow, stop or reverse the progression of Parkinson’s disease (PD), nor is there a cure. Existing treatments are limited in their ability to address patients’ medical needs and to remain effective over time.
- NIH research has led to groundbreaking PD treatments that have been used across a spectrum of disorders. For example, deep brain stimulation was developed to help relieve symptoms of Parkinson’s disease, and it is now being tested in neuropsychiatric conditions, such as dementia and treatment-resistant depression.

**NIH Invests in the U.S. Economy and Local Communities**
- The economic burden of PD in the United States is an estimated $19.8 to $26.4 billion per year, and this is expected to grow as the population ages. Research toward new therapies has the potential to save future health care costs.
- NIH funds research in all 50 states; every dollar of funding generates two dollars in local economic growth.
- NIH research grants support more than 400,000 jobs across the country.

**Reduced NIH Funding Impedes Progress**
- Funding has not kept pace with inflation and NIH purchasing power is down nearly 20 percent since 2003. In 2016, NIH was only able to fund 12 percent of investigator-initiated grants, leaving 88 percent unfunded.
- Investing in NIH research on the front end to develop innovative therapies and cures can lower back-end costs, relieving the burden on Medicare, Medicaid and the Department of Veterans Affairs.
- Patients and the medical community deserve stable and reliable funding that allows for research progress and supports innovative projects that bring us closer to cures.

Please increase the NIH budget by at least $2 billion in FY18.

Please contact Brittany Meyer at bmeyer@michaeljfox.org for more information, including NIH and MJFF funding in your state.
RESTORE FUNDING FOR PARKINSON’S RESEARCH AT THE DEPARTMENT OF DEFENSE

Why Is Research Funding Necessary?

• The Department of Defense (DoD) Parkinson’s Research Program is the only government-funded research program specifically dedicated to Parkinson’s disease (PD).

• Military service members often are exposed to toxins and other external stressors, such as traumatic brain injury, which research has correlated with an increased risk of Parkinson’s.

• Currently, there is no treatment to slow, stop or reverse the progression of Parkinson’s disease, nor is there a cure.

• 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.

• These investigations will lead to a deeper understanding of the underlying disease process and pave the way toward new treatments and a cure.

What Are the Program’s Goals?

To identify and understand risk factors associated with PD (such as chemical exposures, psychological stress and traumatic brain injury) in order to prevent or delay the onset of symptoms, as well as advance the development of new treatments.

In recent years, program funding has significantly decreased (from $25 million in FY10 to $16 million in FY17). Reinstating funding at previous budget levels will ensure scientific progress important to our nation’s service members can continue.

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

Please restore funding for the DoD Parkinson’s Research Program to $20 million in FY18.
FUND THE CDC’S NATIONAL NEUROLOGICAL CONDITIONS SURVEILLANCE SYSTEM TO INFORM RESEARCH AND HEALTH CARE PRIORITIES

Accurate and Comprehensive Data Is Critical

The National Neurological Conditions Surveillance System at the Centers for Disease Control and Prevention (CDC), authorized by the 21st Century Cures Act, will gather vital patient information related to age, race, sex, geographic location and family history. This system will:

- Provide scientists with comprehensive data to help refine and target their research, which could lead to better knowledge of complex neurological diseases, new treatments and a cure.
- Build a foundation for understanding many factors, such as clusters of diagnoses in certain geographic regions, differences in the number of men and women diagnosed with neurological diseases, and variability in health care practices among patients.
- Assess the needs of those with neurological diseases on a deeper level, thereby allowing for future health care planning.

The CDC will work efficiently to create the surveillance system by pulling information from existing sources, such as Medicare, Medicaid and Veterans Affairs databases, as well as state and local Parkinson’s disease registries.

Why Create a Surveillance System?

We do not currently have accurate and comprehensive information on how many people are living with Parkinson’s disease, who they are and where they are located. This lack of core knowledge makes it difficult to assess potential environmental triggers and other patterns of the disease. The absence of this data also slows Parkinson’s research and drug development and makes it hard to properly allocate health care services.

The total economic burden of Parkinson’s disease in the United States is estimated to be $19.8 to $26.4 billion per year, and is expected to grow as the population ages. Research toward new treatments has the potential to save future health care costs.

By supplying $5 million per year for a surveillance system, we can begin to lay the groundwork for research that will lead to new therapies and health care services allotments that will improve quality of life for people with neurological diseases.

Congress has already authorized $5 million per year from FY18 to FY22 for the system, but the funds have not yet been appropriated. Please provide the CDC with this funding so the National Neurological Conditions Surveillance System can be implemented.

Please contact Brittany Meyer at bmeyer@michaeljfox.org for more information.
ENHANCE SUPPORT FOR THE FOOD AND DRUG ADMINISTRATION

The U.S. Food and Drug Administration (FDA) Is Essential to Cures

• The FDA assures the safety and efficacy of drugs, medical devices and biological products. Before a therapy can be made available to the public, the FDA reviews and, if appropriate, approves it. Prior to FDA approval, new therapies undergo years of extensive clinical trial testing.
• In recent years, Congress has given the FDA additional responsibilities, but has not provided the increased funding or necessary staff for successful implementation.
• The Parkinson’s community depends on the FDA to move potential therapies through an efficient but rigorous review and approval process and bring life-changing treatments to market.
• It is imperative that Congress boost resources for the FDA so this important agency can continue its work.

The FDA and Parkinson’s Disease (PD)

• Currently, there is no therapy to slow, stop or reverse PD progression, nor is there a cure. Existing treatments are limited in their ability to address symptoms and remain effective over time.
• In the last few years, the FDA has approved several new symptomatic therapies for Parkinson’s disease. A number of additional treatments are in late-stage clinical testing or approaching FDA approval. These are signs of progress, but there is still work to be done.
• The Parkinson’s therapeutic development pipeline is incredibly robust, but the FDA is overburdened and the review and approval process is at times stifled due to limited resources.

Please support $2.8 billion for the FDA in FY18 so it can move safe and effective treatments into patients’ hands.

The research and development pipeline is currently a lengthy and iterative process of winnowing thousands of potential treatments down to a small number of compounds that prove safe and effective in treating human disease. Discovery is largely funded by public sources such as the National Institutes of Health and the Department of Defense; clinical research is largely funded by industry.

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.

ABOUT PARKINSON’S DISEASE

Parkinson’s disease (PD) is a chronic, degenerative neurological disease that affects one in 100 people over age 60. 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 patients’ symptoms and remain effective over time. There is no diagnostic test for Parkinson’s, so the rate of under-diagnosis can be relatively high. The disease costs our country an estimated $19.8 to $26.4 billion per year. An estimated 750,000 to 1 million people in the United States and more than 5 million worldwide 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 support Americans living with Parkinson’s disease by joining today!

Contact **Christina Parisi** (Christina.Parisi@mail.house.gov) in Rep. Maloney’s office or **Jordan Bartolomeo** (Jordan_Bartolomeo@isakson.senate.gov) in the office of Sen. Isakson.

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, you can develop a rapport and educate these individuals on what life with Parkinson’s disease is like.

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 congressman’s doorstep. In Parkinson’s, speech and mobility can be affected, so choose what works best for you and what you feel most comfortable doing. The most important thing is to find a way to tell your story.

The following tips can help you get started.

**Sending Emails**

Emailing your Congress members is a great 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.

You can easily send your legislators pre-drafted emails or compose your own message. Learn more about important policy issues at [advocate.michaeljfox.org](http://advocate.michaeljfox.org).

Then, use the online tool on this page to send your elected officials an email.

All communications sent through this system are automatically delivered to your lawmakers’ health staffers. They read all constituent correspondence and convey your messages to the members.

If you’d like to start your own email from scratch, you can use the framework below.

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**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 an estimated one in 100 people over age 60. 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 on pages 3 to 14 include sample language you can use.]

As your constituent and a person in the Parkinson’s community, I would like to offer myself as a resource to you and your staff on PD-related issues. As someone with first-hand knowledge of this disease, I can provide valuable insights on living with PD.

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. And when their 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 on pages 3 to 14 to brainstorm what you’ll say. It may be best to focus on one policy issue that matters most to you.

To find your member’s phone number, visit advocate.michaeljfox.org. (Use the lookup tool at the top right of the page.) Each legislator has an office in Washington, D.C. and one or more district offices in their home state. Call the district office closest to where you live.

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 prepared talking points on pages 3 to 6 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.

Meeting in Person

Meeting with your legislators is a great way 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.

Lawmakers schedule constituent meetings in Washington, D.C. and in their district offices during recesses (times when Congress is not in session and members go back to their home states). You can view all recesses on the 2017 congressional calendar (found on page 21). During the summer of 2017, the House will be in recess from July 31 to September 4 and the Senate will be in recess from August 14 to September 4.

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 elected officials:

BEFORE THE MEETING

Schedule an appointment. Locate your lawmaker’s offices in Washington, D.C. and their home state. (Visit advocate.michaeljfox.org and use the tool at the top right of the page.) To organize a meeting on Capitol Hill, contact the Washington, D.C. office. To schedule a meeting at home, contact the district office closest to you. (There may be more than one in your state.) Many officials have electronic meeting request forms on their websites or you can call the office directly to ask for an appointment.

The scheduler will ask you about the purpose of your visit. Tell them you’d like to discuss access to health care and 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 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.

During recesses, members’ calendars fill up very quickly. Look to book several weeks in advance.

**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 Parkinson’s makes prolonged standing or walking too difficult for you, 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 on pages 8 to 14 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.** Email the staffer you met with to thank them and your member again. If helpful, you can use the following template email. Be sure to edit the content so it references the specific issues you covered during your appointment.

**Determine what you’ll say.** Use the materials on pages 3 to 14 to decide what positions you’d like your legislator to take on the issues. Review these documents several times so you feel comfortable speaking on these topics. Print the educational handouts to bring to your appointment and leave with your member and/or their staffer.
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 2018:

- National Institutes of Health: $2 billion increase
- Food and Drug Administration: $2.8 billion
- Department of Defense Congressionally Directed Medical Research Program for Parkinson’s disease: $20 million
- Centers for Disease Control and Prevention: $5 million to implement the National Neurological Conditions Surveillance System

I also ask you to keep individuals with Parkinson’s in mind as you reform our health care system. People living with the disease need accessible, affordable, high-quality care. Do not vote for any health care reforms that discriminate against those with pre-existing conditions, affect people’s ability to access Medicare and Medicaid programs, raise costs for older Americans or cut comprehensive benefits.

[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/2017congressionaldebrief 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 great 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 on pages 3 to 14. Then, think of a question you’d like to ask your member about a particular policy issue. The samples below 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 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 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 documents on pages 8 to 14 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 stay in touch. Remember, legislators don’t give out their personal email addresses; you’ll stay in touch 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 19 to compose your message. (Edit as needed!)

**SAMPLE TOWN HALL QUESTIONS**

**Federal research funding**
Thank you for the opportunity to ask a question. My name is XX and I live in XX 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 by $2 billion in the last budget. Will you support another increase in the 2018 budget?

**Health care reform**
Thank you for the opportunity to ask a question. My name is XX and I am from XX town/city. I am living with Parkinson’s disease/have a loved one with Parkinson’s disease. Both the American Health Care Act in the House and the Better Care Reconciliation Act in the Senate will harm people with pre-existing conditions, including Parkinson’s. Will you reject health care reform proposals that would raise costs and cut benefits for people with chronic diseases?
2017 Legislative Calendar

January

February

March

April

May

June

July

August

September

October

November

December

For more information, contact: Johanna Derlega | 202-628-8533 | jderlega@thehill.com
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 results.

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 and videos 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 140 characters so Facebook may be better for those with a talent for prose!

You may be active on other social networks, too. On Instagram and Snapchat, you can 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!

Support an MJFF Post

A quick and easy way to continue your advocacy in this digital age is to support one of The Michael J. Fox Foundation’s social media posts about public policy. MJFF’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 that 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.

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**Create Your Own**

You also can design your own posts. This is a great 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 at the end of the 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.
- Link to advocate.michaeljfox.org, the Foundation’s advocacy page. Here, individuals can send lawmakers pre-drafted emails or compose their own notes.

**Sample Facebook post on federal research funding:**

Urge your lawmakers to increase federal research funding to advance new treatments and a cure for Parkinson’s disease. We need robust funding for the government agencies and programs that support this work. Visit The Michael J. Fox Foundation website to learn more about this issue and send your members of Congress an email on the topic: advocate.michaeljfox.org.

**Sample Facebook post on health care reform:**

Members of Congress are debating changes to our health care and insurance systems. It’s critical that they hear directly from our community about what is important to our care and well-being. Tell lawmakers that they must not make any changes that raise costs or cut benefits for people living with Parkinson’s. Learn more about this issue and contact your legislators on The Michael J. Fox Foundation website: advocate.michaeljfox.org.
**TWITTER**

- To tweet at a member of Congress, tag them using the @ sign (Shift+2), then search for their name. You also can write or comment directly on their page.
- Add a period (.) in front of an @mention to ensure all of your followers see certain tweets.
- Use the hashtag #act4PD in Parkinson’s public policy-related tweets.

**Sample Twitter posts on federal research funding:**

.@[Lawmaker’sHandle] support funding in FY18 for #NIH, #CDC, #FDA and #DoD #act4PD
.@[Lawmaker’sHandle] please support a $2 billion increase for @NIH in FY18 to further Parkinsons research #act4PD
.@[Lawmaker’sHandle] support $20 million for the #DoD #Parkinsons research program in FY18 to benefit service members & veterans

**Sample Twitter posts on health care reform:**

.@[Lawmaker’sHandle] please ensure access to affordable coverage for those with #chronicconditions #ProtectOurCare #Parkinsons
.@[Lawmaker’sHandle] #ACA replacement must maintain affordable health coverage #ProtectOurCare #act4PD
.@[Lawmaker’sHandle] please support the affordability & stability of health care costs for all patients #ProtectOurCare #act4PD

A tweet from Chad Moir, a Parkinson’s fitness expert from Massachusetts.
Advocates attend meetings on Capitol Hill during the 2017 Parkinson's Policy Forum.
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.

When writing letters, op-eds and blogs:

• **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 on pages 8 to 14 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 constructing your pieces.

### 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 published by Kevin Kwok, a person from California living with Parkinson’s, in the San Francisco Chronicle.**

**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*

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### 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.

### ONE FINAL THOUGHT…

A simple action you can take today is to ask your local publication to post on their calendar about upcoming support group meetings, fundraisers and PD events. These calendars are usually printed in the outlet’s paper or featured on their website. Encourage any new contacts you meet to get involved in Parkinson’s advocacy work!