

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



PARKINSON'S POLICY PRIORITIES

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

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 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 issues shift as the political environment in Washington, D.C. shifts and the priorities of people with PD and their loved ones change.

The talking points on the following pages 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 document 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?

Every year, Congress must set funding levels for the fiscal year which runs from October 1 to September 30 of the following calendar year.

During these negotiations, legislators decide how much money to allocate to government agencies and programs involved in Parkinson's research. While there is bipartisan support in Congress for biomedical research funding, we continue to work to educate members about Parkinson's disease and the need for research funding every year.

To learn more about how you can help advocate for Parkinson's research funding, go to www.michaeljfox.org/contact-your-policymakers to view the latest action alerts you can send your members of Congress.



Federal Policy Support

Talking Points

Use these talking points to help guide you in writing emails, preparing for phone calls and meetings, creating social media posts and other outreach and advocacy activities.

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.
- **Parkinson's affects 1 million people in the United States, and it costs the country \$52 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 people are diagnosed with the disease.
- **Investing in biomedical research and supporting federal policies now** will further the development of new treatments and a cure, improving quality of life for people with Parkinson's, and helping families and the government save money in the long run.

Urge your members of Congress to support the following initiatives:

- **Increased Access to Mental Health Care**
 - At least half of all Parkinson's patients may experience clinical depression, anxiety or other mental health issues. Depression and anxiety may emerge prior to the more classic motor symptoms of Parkinson's. These issues can complicate other symptoms and affect long-term outcomes.
 - Fortunately, therapy and counseling are effective treatment options for depression and anxiety. These treatments can also alleviate other symptoms and help people remain in the workforce, contribute to their family life and live independently.
- **Out-of-Pocket Spending Cap for Medicare Part D**
 - According to the American Counseling Association, there are more than 120,000 licensed mental health counselors in the U.S. Licensed mental health counseling services are not covered, and therefore not reimbursed, through Medicare. Ninety percent of Parkinson's patients receive health care coverage through Medicare and have no coverage for these providers.
 - The Mental Health Access Improvement Act of 2019 (S. 286/H.R. 945) takes an important step in addressing the shortage of mental health providers throughout the U.S. by providing coverage for licensed mental health counselor services under Medicare. Please support this Act so that people with Parkinson's have access to much-needed mental health resources.
- **Out-of-Pocket Spending Cap for Medicare Part D**
 - Prompt and affordable access to medications is vital to patients' ability to maintain their quality of life and independence.
 - Ninety percent of people with Parkinson's obtain their insurance coverage through Medicare, but Medicare Part D doesn't have an out-of-pocket spending cap, which presents challenges.
 - People with Parkinson's have no financial limit to what they may have to spend to obtain life-changing prescription drugs throughout the year. They can't plan or prepare financially. For those who obtain coverage through non-Medicare commercial insurance plans, there is a single out-of-pocket maximum for all covered services, so they can predict their out-of-pocket spending.



- Parkinson’s patients who surpass the catastrophic threshold are responsible for five percent of all additional pharmaceutical drug costs. As the costs of pharmaceuticals continue to rise, the financial strain increases for beneficiaries with Parkinson’s who rely on prescription drugs to function.
 - People with Parkinson’s may also have other diseases and conditions, resulting in out-of-pocket spending that impacts their ability to adhere to their prescription drug protocols.
 - Implementation of an out-of-pocket spending cap for Medicare Part D will provide people with Parkinson’s and their families predictable annual financial obligations and the ability to maintain their quality of life and independence.
- **Ban Toxic Herbicide**
 - Congress is considering legislation (H.R. 3817) that would eliminate paraquat (a toxic herbicide) in the U.S. More than 30 countries around the world — including China and the European Union — have already banned paraquat. Now, it’s time for the U.S. to eliminate this dangerous chemical.
 - The purpose of this act is to protect Americans and guard the safety of our communities by eliminating the use of paraquat in the U.S. This legislation has been years in the making, and it is time for Congress to ban paraquat once and for all.
 - Research shows that paraquat greatly increases the risk of a person developing Parkinson’s disease. Recurring exposure to paraquat can damage brain cells and lead to heart failure, kidney failure, liver failure and lung scarring. Ingesting large quantities leads to likely death, with no remedy or cure.
 - Paraquat is dangerous to Americans who work in food and agriculture, but also to everyone who eats food treated with it, as there can be paraquat residue on fruits, vegetables and the soil.



Congressional Caucus on Parkinson's Disease

Talking Points

Use these talking points to help guide you in writing emails, preparing for phone calls and meetings, creating social media posts or other outreach activities.

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 Sen. Stabenow's office.





EDUCATIONAL HANDOUTS

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

PHOTO CREDIT: JOE SHYMANSKI

Support Federal Policies for Parkinson's Disease

Parkinson's disease (PD) affects 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 \$52 billion per year. Robust and reliable federal policies are 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).

Out-of-Pocket Spending Cap for Medicare Part D

Ninety percent of people diagnosed with Parkinson's obtain their insurance coverage through the Medicare program. But Medicare Part D doesn't have an out-of-pocket spending cap, which presents challenges. People with Parkinson's have no financial limit to what they may have to spend to obtain life-changing prescription drugs throughout the year. Prompt and affordable access to these medications is vital to patients' ability to maintain their quality of life and independence. Please support an out-of-pocket spending cap for Medicare Part D.

Increased Access to Mental Health Care

Licensed mental health counseling services are not covered, and therefore not reimbursed, through Medicare. This means the 90 percent of Parkinson's patients who receive health care coverage through Medicare have no coverage for these providers.

Please support the Mental Health Access Improvement Act of 2019 (S. 286/H.R. 945), which takes an important step in addressing the shortage of mental health providers throughout the United States by providing coverage for licensed mental health counselor services under Medicare.

Ban Parkinson's-causing herbicide

Rep. Nydia Velázquez (D-NY) has introduced legislation (H.R. 3817) that will ban paraquat, a toxic herbicide that has been linked to causing Parkinson's disease.

For more information, or to co-sponsor the bill, please contact Monica Garay (monica.garay@mail.house.gov).

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. With 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 \$52 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 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 Aaron Polacek at apolacek@michaeljfox.org for more information.



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH