

# Advocacy 101 & the National Plan to End Parkinson's Act



PMD Alliance April Support Group Leader Roundtable  
April 3, 2023

  
THE MICHAEL J. FOX FOUNDATION  
FOR PARKINSON'S RESEARCH

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# Advocacy 101

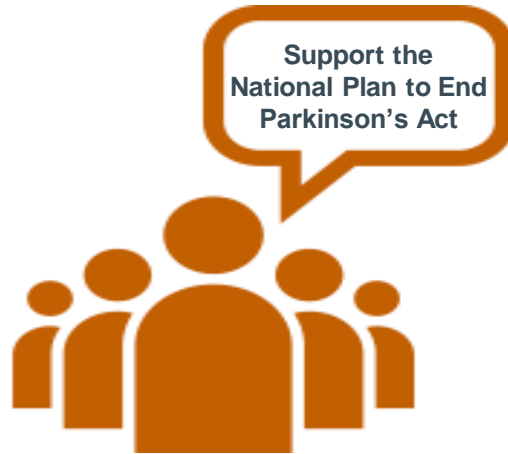
## The National Plan to End Parkinson's Act

### How to Get Involved

# Advocacy 101



Policy advocacy is the public support for or recommendation of a specific cause or policy.



# Advocacy 101



## Parkinson's Advocacy Toolkit

# Advocacy 101



Advocacy is public support for or recommendation of a specific cause or policy.



# Advocacy 101



Explaining **what cause or policy you care about** and **why it is important to you** are the most important parts of policy advocacy.

# Advocacy 101



**Advocacy is not...**



# Advocacy 101



## Tips & Tricks

# The National Plan to End Parkinson's Act



First-ever legislation solely devoted to ending Parkinson's

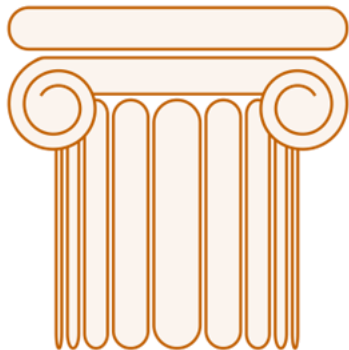
When passed, this bipartisan bill will:

- Unite the federal government in a mission to prevent and cure Parkinson's
- Alleviate financial and health burdens on American families
- Ensure those living with Parkinson's have access to care

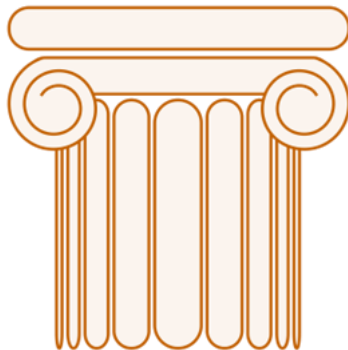
# The National Plan to End Parkinson's Act



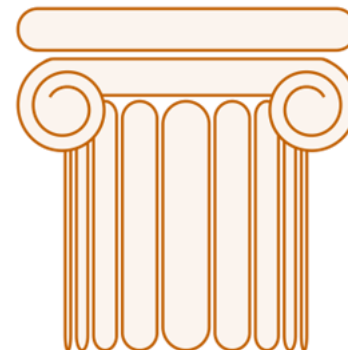
**Fund research  
toward a cure**



**Improve access  
to care**



**Identify mechanisms  
for prevention**



# The National Plan to End Parkinson's Act



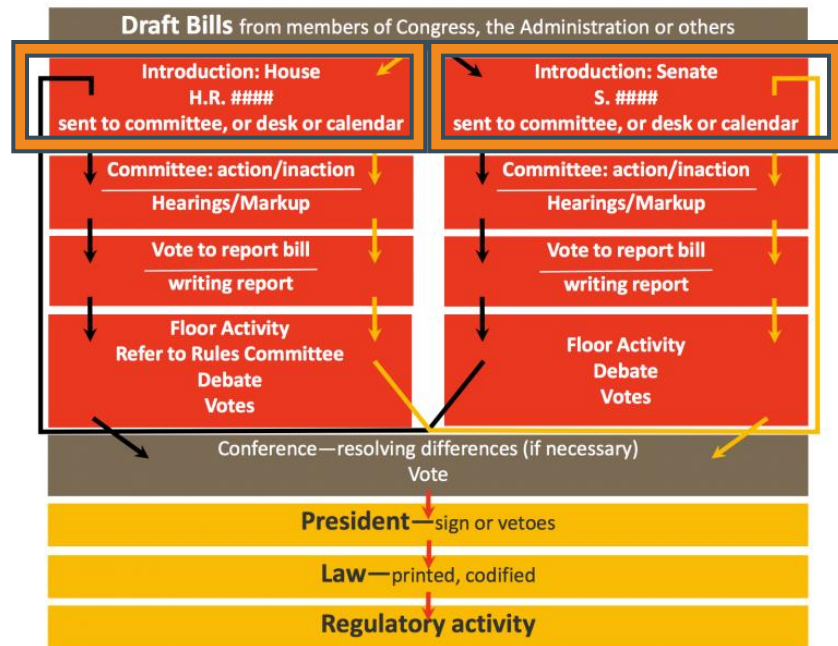
## House of Representatives

- [H.R.2365](#)
- Led by Representatives Gus Bilirakis (R-FL-12) & Paul Tonko (D-NY-20)
- 10 co-sponsors (of 435)
- Committee on Energy & Commerce

## Senate

- [S.1064](#)
- Led by Senators Shelley Moore Capito (R-WV) & Christopher Murphy (D-CT)
- 8 co-sponsors (of 100)
- Committee on Health, Education, Labor, & Pensions (HELP)

# The National Plan to End Parkinson's Act



## The Legislative Process

# The National Plan to End Parkinson's Act



- ❑ Direct lobbying
- ❑ Grassroots & Grasstops
- ❑ Coalitions
- ❑ Public relations

# How to Get Involved

A screenshot of a web browser displaying the Michael J. Fox Foundation website. The page is titled "Advocate for the National Plan to End Parkinson's Act". The navigation bar includes "My Official", "National Plan", "Federal Advocacy", "State Advocacy", "More", and "Sign Up". The main content area is divided into two columns. The left column contains the title "Advocate for the National Plan to End Parkinson's Act", a paragraph of text, and three blue links: "Call Your Members of Congress", "Write Your Members of Congress", and "Share With Friends and Family". The right column is titled "Share Your Story" and contains a form with the following fields: "Title" (with a sub-field "First Name"), "Last Name", "Email", "Address (Please select the drop-down option)", "Connection to PD" (with a sub-field "Select..."), and "Military Experience".

Advocate for the National Plan to End Parkinson's Act

The National Plan to End Parkinson's Act (H.R.2365/S.1064) has been reintroduced in Congress as the first legislation that will unite the federal government in a mission to prevent and cure Parkinson's. We need your help to get it passed!

[Call Your Members of Congress](#)

[Write Your Members of Congress](#)

[Share With Friends and Family](#)

No one understands Parkinson's like you do, and your personal story will go a long way in convincing Congress to prioritize support for Parkinson's research.

### Share Your Story

If you are comfortable sharing your story with us for our records, please attach below. We may use your story for our communications and/or policy efforts.

Title  First Name

Last Name  Email

Address (Please select the drop-down option)

Connection to PD

Military Experience

## National Plan Action Center

# How to Get Involved



## Co-sponsor the National Plan to End Parkinson's Act

The National Plan to End Parkinson's Act (H.R.2365/S.1064) is bipartisan, no-cost legislation that will, for the first time, unite the federal government in a mission to cure and prevent Parkinson's, alleviate financial and health burdens on American families, and reduce government spending over time.

### Policy Objective

The National Plan to End Parkinson's Act will create an advisory council comprising members of federal agencies that support research, care, and services for Parkinson's, plus patients, care partners, researchers, clinicians, and other non-federal experts.

The advisory council will host meetings throughout the year and provide a report to Congress and the U.S. Secretary of Health and Human Services that contains evaluations of all federally funded programs related to Parkinson's. The report will also include recommendations on priority actions to prevent and cure Parkinson's, improve health outcomes, reduce the financial impact of the disease on patients and the federal government, and limit exposures to environmental triggers. The goal of the council is to ensure efficient and effective coordination among all federal entities with responsibility for managing, treating, and curing Parkinson's disease.

Parkinson's is the 2<sup>nd</sup> most common and fastest-growing neurological disease.

 More than 1 million people in the U.S. live with Parkinson's disease. **More than 110,000 are military veterans.**

 There are 90,000 new diagnoses each year in the U.S. That's 1 person every six minutes.

 **Parkinson's costs the U.S. \$52 billion every year.**

Half the annual cost is paid by the federal government. The other half is paid for by patients and their families.

**By 2037, the disease will cost the U.S. \$80 billion every year.**

We must end Parkinson's disease. The National Plan to End Parkinson's Act is the best way to start. Please co-sponsor this bill today.

### Lead Offices & Staff Contacts



#### House of Representatives

**Representative Gus Bilirakis (R-FL)** → Colleen Malloy White  
 [colleen.malloy.white@mail.house.gov](mailto:colleen.malloy.white@mail.house.gov)  202.225.5755

**Representative Paul Tonko (D-NY)** → Emily Silverberg  
 [emily.silverberg@mail.house.gov](mailto:emily.silverberg@mail.house.gov)  202.225.5076

#### Senate

**Senator Shelly Moore Capito (R-WV)** → Dana Richter  
 [dana\\_richter@capito.senate.gov](mailto:dana_richter@capito.senate.gov)  202.224.6472

**Senator Chris Murphy (D-CT)** → Marisa Salemme  
 [marisa\\_salemme@murphy.senate.gov](mailto:marisa_salemme@murphy.senate.gov)  202.224.4041



For more information about Parkinson's disease and its impact on your constituents, please contact Dustin Watson.  [dwatson@michaeljfox.org](mailto:dwatson@michaeljfox.org)  202.638.4101 x316

## National Plan One-Pager



# Co-sponsor the National Plan to End Parkinson's Act

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✉ [colleen.malloy.white@mail.house.gov](mailto:colleen.malloy.white@mail.house.gov) ☎ 202.225.5755

**Representative Paul Tonko (D-NY)** → Emily Silverberg  
✉ [emily.silverberg@mail.house.gov](mailto:emily.silverberg@mail.house.gov) ☎ 202.225.5076

### Senate

**Senator Shelly Moore Capito (R-WV)** → Dana Richter  
✉ [dana\\_richter@capito.senate.gov](mailto:dana_richter@capito.senate.gov) ☎ 202.224.6472

**Senator Chris Murphy (D-CT)** → Marisa Salemme  
✉ [marisa\\_salemme@murphy.senate.gov](mailto:marisa_salemme@murphy.senate.gov) ☎ 202.224.4041



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# How to Get Involved



## Frequently Asked Questions

# How to Get Involved



**Call Your Members of Congress**



**Write Your Members of Congress**



**Share with Friends and Family**

# How to Get Involved



Hello! My name is \_\_\_\_\_, and I am calling from \_\_\_\_\_, \_\_\_\_\_.

I am calling to ask \_\_\_\_\_ to co-sponsor the National Plan to End Parkinson's Act.  
It is bill number H.R.2365/S.1064.

The National Plan to End Parkinson's Act is bipartisan, no-cost legislation that would create an advisory council to bring together the federal government and Parkinson's community to focus on ending Parkinson's.

I am asking \_\_\_\_\_ to show their support for the Parkinson's community by co-sponsoring the National Plan to End Parkinson's Act.

I am happy to answer questions about my experience with Parkinson's disease, and I would appreciate a response once \_\_\_\_\_ has decided whether to co-sponsor the bill.

Thank you for your time today.

# Take Action Today



- ❑ Email or write a letter to your members of Congress
- ❑ Call your members of Congress
- ❑ Invite your members of Congress and their staff to join your support group meeting, boxing class, or community event
- ❑ Find and attend a local townhall and other events to share information about the National Plan to End Parkinson's Act



# Questions?



THE MICHAEL J. FOX FOUNDATION  
FOR PARKINSON'S RESEARCH

# Thank You

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 [@michaeljfoxorg](https://www.instagram.com/michaeljfoxorg)

 [michaeljfox](https://www.youtube.com/michaeljfox)