

# Advocating for Parkinson's Policies

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*Director of Advocacy*



The Michael J. Fox Foundation for Parkinson's Research

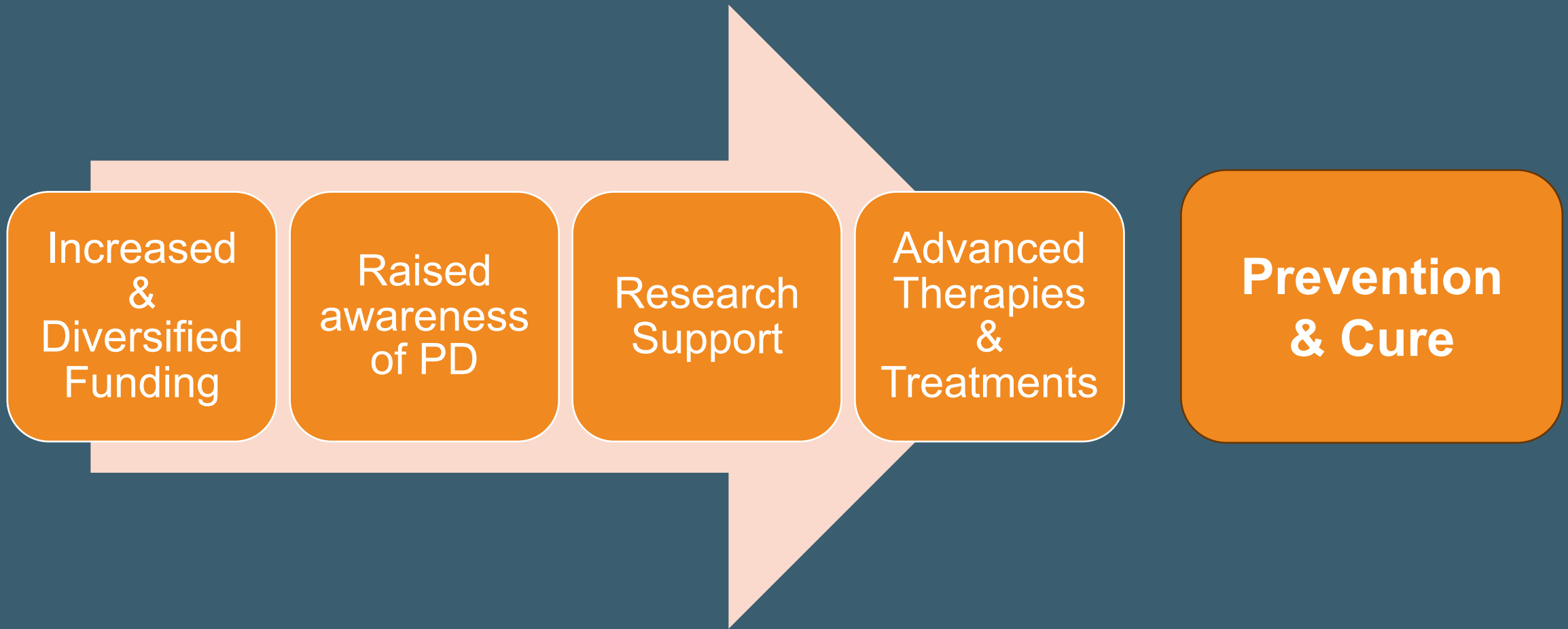
# Our Mission & Model

The Michael J. Fox Foundation is dedicated to finding a cure for Parkinson's disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.

- Founded in 2000 by Michael J. Fox
- Funded more than \$2 billion in Parkinson's research around the globe
- Supported more than 3,200 projects by academics, biotech and pharma
- 88 cents of every dollar raised goes directly to research



# Why We Advocate



# How We Advocate

AUDIENCES
PD COMMUNITY
PROVIDERS & RESEARCHERS
FAMILY & CAREGIVERS
SUPPORTERS
ELECTEDS/TL
CORPORATE PARTNERS



**Recruitment**



**Training**



**Engagement**

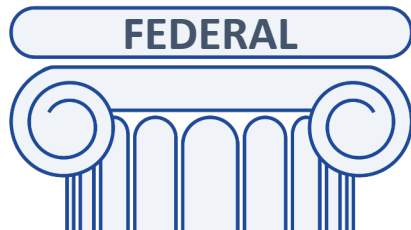


**Stewardship**

GOALS
RAISE AWARENESS
EDUCATE LAWMAKERS
STORYTELLING
CONSTITUENT SUPPORT
RELATIONSHIP BUILDING
THOUGHT LEADERSHIP

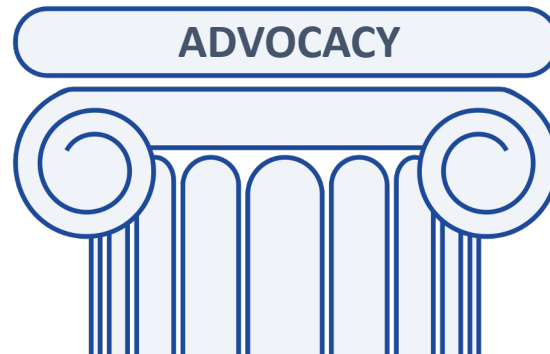
# MJFF Legislative Priorities

- + National Plan to End PD
- + PD Research Funding
- + PPMI
- + Caregiving/Long Term Care
- + Access to Care
- + Environmental Risk Factors



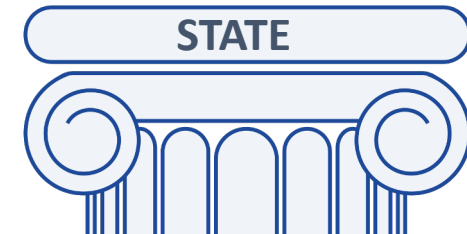
**Works with Congress and relevant Federal agencies to advance PD research, increase funding & improve well-being of PD Community**

- + Grassroots
- + Grasstops
- + Relationship Building
- + Outreach



**Supports Policy work by working directly with PD advocates, recruiting, training and connecting to advocacy opps at Fed and State levels**

- + PPMI/State Research Funding
- + Neurodegenerative Disease Advisory Councils (NDACs)
- + Registries
- + Access to Care



**Works with State legislatures and agencies to support PD funding and research to directly impact the PD Community**

# Federal Priorities: Advancing Policies on Capitol Hill & Federal Agencies



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# National Plan to End Parkinson's Act

- National Plan to End Parkinson's Act (H.R.2365/S.1064) is the first federal legislation solely dedicated to diagnosing, treating, preventing and curing Parkinson's.
- Modeled after National Alzheimer's Project Act, this no-cost, bipartisan legislation would establish an advisory council tasked with creating and implementing a national plan to end Parkinson's.
- Council would regularly report progress to Congress.
- Comprised of federal agencies, people living with Parkinson's, care partners, researchers, clinicians and other experts.



# National Plan Update

- House passed National Plan in December 2023, now awaits Senate vote
- Nearly **1,000** advocates held more than **400** meetings with Congressional offices
- More than **200** members of Congress have cosponsored National Plan
- **TELL THE SENATE: Advance the bill and urge Senate HELP committee consideration and/or unanimous consent!**





# Funding Parkinson's Research

## PPMI: The Study That's Changing Everything



**PPMI has studied thousands of people across the globe.** Over 40,000 volunteers share data with PPMI through its online platform, and more than 2,500 participants have tests and share biological samples at each of the 50 participating medical centers in 12 countries.



**PPMI has assembled the world's most robust repository of Parkinson's data and biological samples,** which it shares with scientists to speed breakthroughs. The dataset has been downloaded by researchers over 17 million times.



**In 2023, PPMI scientists validated a biological test for Parkinson's with an astonishing 93 percent accuracy.** For the first time, the test can objectively and reliably detect abnormal alpha-synuclein proteins — a hallmark of Parkinson's disease — in a living body. This discovery, which comes in the form of a spinal fluid test, is one of the most prominent breakthroughs in brain disease research of the past decade.

# Federal Funding for Parkinson's



**The Department of Defense's Parkinson's Research Program**, one of the only government-funded programs dedicated to Parkinson's



**The Centers for Disease Control and Prevention's National Neurological Conditions Surveillance System** tracks epidemiology of Parkinson's in U.S. to better understand & ID patterns



**The Department of Veterans Affairs' Parkinson's Disease Research, Education, and Clinical Centers** serve veterans with Parkinson's through education, research & clinical care

# State Priorities: Advocating in the States



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# 2023 State Wins

- **Five** states passed legislation to create Parkinson's research registries (MD, MO, NE, NV, OH)
- Over a **dozen** state legislatures introduced legislation to expand health care coverage for biomarker testing
- Nearly a **dozen** states introduced bills to extend protections against discrimination based on genetic test results



# 2024 State Priorities



Funding Parkinson's Research



Creating Parkinson's Research Registries



Increasing Access to Biomarker Testing



Expanding Genetic Testing Protections



Access to Care



Environmental Transparency

# What Can You Do?

## Storytelling

- Send Letters
- Call lawmakers
- Attend Meetings
- Media (op-eds, LTEs, blogs)
- Social Media
- Videos

## Relationship Building

- Log relationships
- Attend Townhalls
- Testify at Hearings
- Invite lawmakers to support groups/boxing classes

## Digital Advocacy

- Action Alerts
- Info Emails
- Surveys, Petitions

## KEY RESULTS

**RAISE  
AWARENESS**

**EDUCATE  
LAWMAKERS**

**CHALLENGE  
PERCEPTIONS**

**DISPLAY  
SUPPORT**

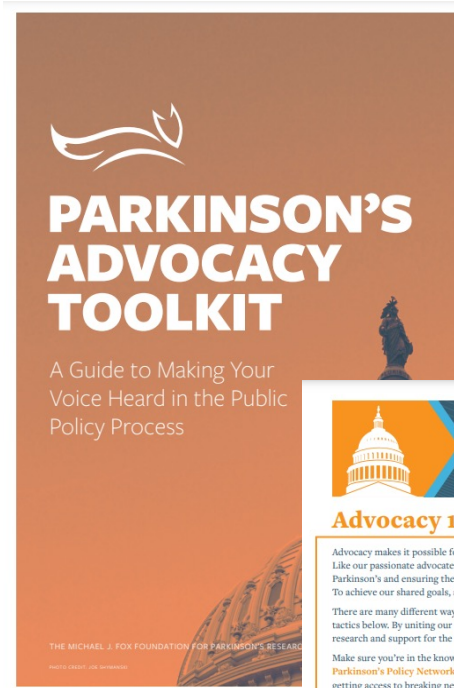
**BUILD  
RELATIONSHIPS**

**BECOME SME**



# Advocacy Resources

- Action Center
  - Fed Policy 1 pagers
  - State Policy 1 pagers
  - Action Alerts
- Tools & Resources
  - Elevator Pitch Worksheet
  - Advocacy 101
- Relationship & Interaction Logger
- Advocate Training Sessions
- Upcoming Events



**PARKINSON'S ADVOCACY TOOLKIT**

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

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Home Federal Policy State Policy More Hello, Amy!

Contact Congress! Share Your Story! 2023 State Wins

Members of Congress We want to hear from you how Your advocacy resulted in major

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**Advocacy 101**

Advocacy makes it possible for people and organizations to challenge perceptions and beliefs, garner support around critical policy relationships with key decisionmakers. Use the worksheet below to plan with your legislator so you can feel confident and prepared when the time comes.

**Advocacy Tactics**

**Building Relationships**

- Keep track of relationships with elected and appointed officials
- Meet with members of Congress or state law
- Provide personal testimony at Congressional hearings
- Attend or participate in town halls and issue briefings

**Grassroots Engagement**

- Attend an MJFF Hill Day or State Advocacy Day
- Participate in a digital action campaign through MJFF's Policy Network
- Share your own Parkinson's story with decisionmakers
- Recruit advocates for Parkinson's Policy Network

**Outreach**

- Traditional Media
  - Write an op-ed or letter to the editor
  - Share your experience in media interviews
  - Tell your story at a press conference or media event
- Social Media
  - Post an action campaign to your social media
  - Thank or ask your members of Congress to cosponsor a bill
  - Share your story via a short video

**Legislative Meeting Worksheet**

Meeting with a government official gives advocates the opportunity to present their perspectives and concerns, challenge perceptions and beliefs, garner support around critical policy relationships with key decisionmakers. Use the worksheet below to plan with your legislator so you can feel confident and prepared when the time comes.

- 1. Introductions**  
Go around the room and have each person introduce themselves. Your introduction should include your name, your role, and where you are from. Conclude the introductions with the phrase "I'm here to support Parkinson's research."
- 2. Advocate Stories**  
Each advocate shares a 3-5 minute version of their Parkinson's story as it relates to the policy ask. MJFF staff will connect advocate stories to the main policy ask and provide information on what their office can do to support members of the Parkinson's community. The legislative ask will also include how the legislation in question will impact the Parkinson's community.
- 3. Legislative Ask**  
MJFF Policy staff will connect advocate stories to the main policy ask and provide information on what their office can do to support members of the Parkinson's community. The legislative ask will also include how the legislation in question will impact the Parkinson's community.
- 4. Questions**  
Address any questions the legislator or staff may have. If the staff asks a question just say that you will follow up with that information after the meeting. This is an engaging with the legislator's office!
- 5. Leave-Behind Information**  
Designate one advocate to hand over a folder of additional information about the change as it relates to Parkinson's disease. If this is a virtual meeting, MJFF staff will provide the information.
- 6. Thanks**  
Everyone will thank the member of Congress and/or the legislative staff for taking the time to meet with advocates.
- 7. Feedback and Follow-up**  
Provide MJFF with your meeting feedback and of any need for follow-up with the legislator's office thanking them for their time and to the matter expert.

**How to Create an Elevator Pitch**

An elevator pitch is a short advertisement about you and your connection to Parkinson's that can be told in the time it takes for a short elevator ride (roughly 30 to 60 seconds or 75 words). Stories help invoke empathy, challenge perceptions and put a human face to complex issues. Your story needs to be clear, concise and conversational in order to be impactful. By sharing your story, you can help lawmakers better understand how policy solutions can improve quality of life for the Parkinson's community.

This worksheet will help you formulate your elevator pitch. It can be used in many settings, especially during meetings or conversations with legislators and their staff.

**Part I: Introduce yourself**

- Ex. My name is NAME and I'm from PLACE. I work as WORK/ I am retired.

Write your introduction here.

**Part II: Explain your connection to Parkinson's disease.**

- I was diagnosed with PD in XX.
- My family member/friend was diagnosed with PD in XX.
- I am a member of the medical community.
- I am a clinical researcher.

Write about your PD connection in 2-3 sentences here.

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Please direct advocacy inquiries or questions to Amy Becker, Director of Advocacy

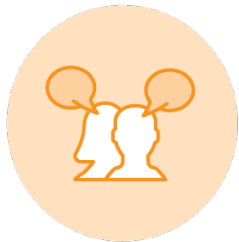
# Ways to Get Involved: Join Us



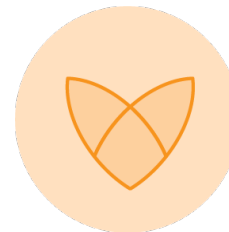
**Public Policy:** Advocate for Parkinson's Policies at [michaeljfox.org/advocacy](https://michaeljfox.org/advocacy)



**Team Fox:** Join grassroots fundraising efforts at [teamfox.org](https://teamfox.org)



**Buddy Network:** Connect with new friends, share tips and build relationships at [parkinsonsbuddynetwork.org](https://parkinsonsbuddynetwork.org)



**Participate in a Clinical Trial:** Find the right trial for you at [michaeljfox.org/join-study](https://michaeljfox.org/join-study)



# Ways to Get Involved: Learn More



**Webinars:** Join free, live panel discussions monthly and on-demand at [michaeljfox.org/webinars](https://michaeljfox.org/webinars)



**Ask the MD:** A movement disorder specialist discusses Parkinson's research and care through blogs and videos at [michaeljfox.org/ask-md](https://michaeljfox.org/ask-md)



**Podcasts:** Hear from scientists, doctors and people with Parkinson's at [michaeljfox.org/podcasts](https://michaeljfox.org/podcasts)

Questions, consultations & inquiries:

[Policy@michaeljfox.org](mailto:Policy@michaeljfox.org)



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# Thank you



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