

# PUBLIC POLICY AND PARKINSON'S DISEASE

Supporting patients and care partners through advocacy.

THE MICHAEL J. FOX FOUNDATION FOR PARKINSON'S RESEARCH

# RESEARCH AND POLICY UNITE AT THE MICHAEL J. FOX FOUNDATION

As the world's largest nonprofit funder of Parkinson's disease (PD) research, 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.

Because decisions affecting the scope of publicly funded PD research, the regulation of new drugs, and the quality and availability of patient care are made by our nation's lawmakers and government agencies, a joint focus on research and public policy is critical.

The Foundation pursues its policy goals through many avenues, including a Parkinson's Policy Forum in Washington, D.C. where patients, care partners and legislators unite to discuss pressing issues; a national grassroots advocacy network that calls, emails and meets with lawmakers year round; and close collaboration with the federal agencies that further Parkinson's research and help individuals access care.

## What Is Parkinson's Disease?

Parkinson's disease is a chronic, degenerative neurological disease with no known cure. The motor symptoms of tremor, rigidity and slowness are only half the experience; non-motor aspects include depression, sleep disorders and cognitive impairment, among many others. Available treatments address only some of these symptoms and can lose efficacy over time.

Estimated number of Americans living with Parkinson's

60

The average age at diagnosis, but some get PD at 40 or younger

#### 60,000 People diagnosed with the disease each year

## 1 IN 100

People over the age of 60 affected by Parkinson's disease

# \$52 BILLION

The estimated amount Parkinson's costs our country each year, with \$25 billion in costs to the federal government



MICHAEL J. FOX WITH REP. STEVE SCALISE AND REP. GUS BILIRAKIS

## OUR KEY POLICY PRIORITIES

In the last decade, the state of Parkinson's disease drug development has evolved significantly.

More potential treatments are entering clinical testing and approaching Food and Drug Administration approval than ever before. Additionally, with age the greatest risk factor for Parkinson's, there is an urgent need for better treatment options as the population grows older and more individuals are diagnosed with the disease. The community also requires support services to improve quality of life now, such as comprehensive Medicare and Medicaid coverage, Social Security Disability Insurance and veterans benefits.

With these goals in mind, the Foundation established three policy priorities:

#### **Further Parkinson's Disease Research**

Increased federal research funding and greater resources for scientists can advance breakthroughs that could lead to new treatments and a cure.

#### **Support Drug Development and Approvals**

Amplifying the patient voice in conversations with drug makers, insurers and government regulators can help bring effective, affordable therapies to market.

#### **Safeguard Access to Care and Support**

Resources such as government benefits, therapy services and emerging technologies can help improve well-being and symptom management.



BILL CLINCH AND KEVIN KWOK



AMY VOHS, MARIA L. DE LEON, MD, VERONIQUE ENOS KAEFER, DARRELL VOHS, MELANIE LOCKHART, ISRAEL ROBLEDO

## YOUR VOICE IS POWERFUL

No one understands Parkinson's disease better than those who live with it every day. When people with PD and their loved ones share their stories with lawmakers, they play a critical role in shaping legislation that affects our community.

Anyone can become an effective advocate. It can be as simple as picking up the phone or sending an email to your U.S. senators or representative to let them know how their vote will directly affect you or a family member. Or, you can meet your policymakers in person and connect on social media. There are many options; it's important to find the one that works best for you.

## VISIT ADVOCATE.MICHAELJFOX.ORG TO:

- » Learn more about current policy issues
- » Download a comprehensive advocacy toolkit
- » Contact your members of Congress
- » Read the latest policy news on the MJFF blog

## INTERESTED IN DOING MORE?

Learn about additional ways to engage at michaeljfox.org.

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