

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 \$19.8 - \$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.

Call to Action

Submit an FY18 programmatic request to support the following agencies and programs:

National Institutes of Health (NIH): **\$36.1 billion**

Food and Drug Administration (FDA):
\$2.8 billion

Department of Defense (DoD) Congressionally Directed Medical Research Program (CDMRP) for Parkinson's disease: **\$20 million**

Centers for Disease Control and Prevention (CDC):
\$5 million to implement the National Neurological Conditions Surveillance System

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.



THE MICHAEL J. FOX FOUNDATION
FOR PARKINSON'S RESEARCH

FURTHER SCIENTIFIC BREAKTHROUGHS BY INCREASING FUNDING FOR THE NATIONAL INSTITUTES OF HEALTH

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 – \$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.

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.

Congress has already authorized \$5 million per year from FY18 – 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.**

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 – 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 allotments of health care services that will improve quality of life for people with neurological diseases.

ENHANCE SUPPORT FOR THE FOOD AND DRUG ADMINISTRATION

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

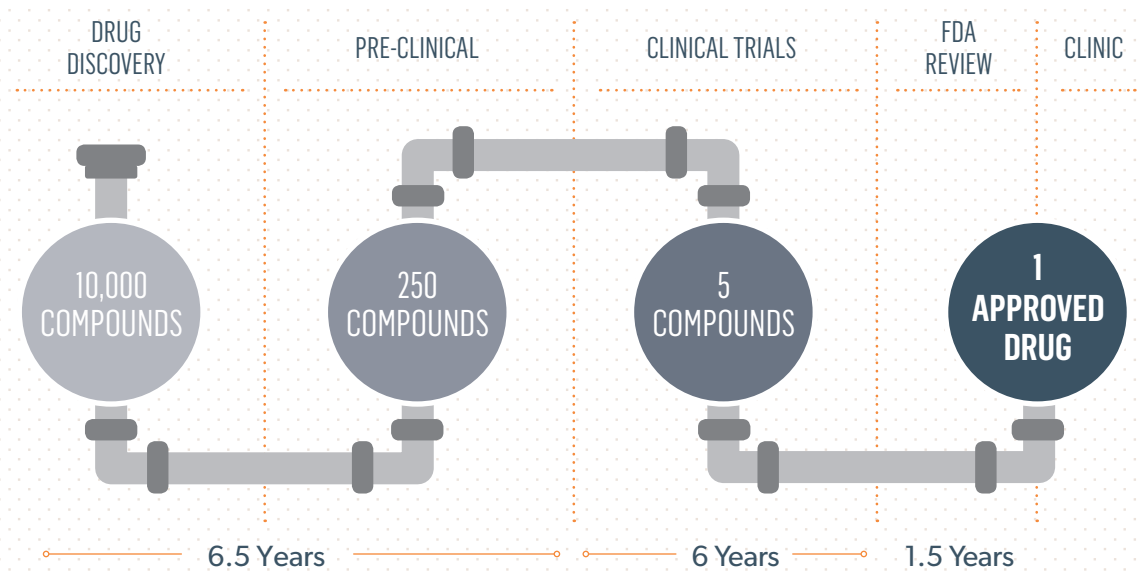
- The FDA assures the safety and efficacy of drugs, medical devices and biological products. Before a therapy can be made available to the public, the FDA reviews and, if appropriate, approves it. Prior to FDA approval, new therapies undergo years of extensive clinical trial testing.
- In recent years, 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.



Source: FasterCures

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

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.

Please restore funding for the DoD Parkinson's Research Program to \$20 million in FY18.

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.

YEARLY APPROPRIATIONS FOR THE DOD CONGRESSIONALLY DIRECTED MEDICAL RESEARCH PROGRAM FOR PARKINSON'S DISEASE

