

PARKINSON'S POLICY FORUM

March 19–21, 2018 · Washington, DC

HILL DAY REQUESTS AND TALKING POINTS

We are thankful to Congress for supporting increased access to care by including these provisions in the February spending bill:

- A permanent exceptions process for the Medicare therapy cap,
- A commitment to close the Medicare Part D donut hole in 2019, rather than 2020,
- An expansion of telemedicine services under Medicare, and
- Repeal of the Independent Payment Advisory Board, which would have made harmful cuts to Medicare.

These changes are critical to helping people with Parkinson's disease (PD) manage their disease and access necessary care.

Support funding for the National Neurological Conditions Surveillance System and the federal agencies that further Parkinson's research.

- The 21st Century Cures Act created a national registry at **the Centers for Disease Control and Prevention** (CDC) to gather demographic information on neurological diseases but it was never funded. It's critical that the CDC receives the money needed to fully implement this database.
- The **National Neurological Conditions Surveillance System** will:
 - Provide scientists with comprehensive data to 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 variances in diagnoses among men and women, and people living in different geographic regions, and
 - Make it easier to properly allocate health care resources.
- It is estimated that nearly **1 million people** in the United States are living with Parkinson's disease and it costs our country almost **\$26 billion per year**.^{*} By furthering PD research and care, this system will help patients and the government conserve future costs.
 - ^{*}This number includes health care and medical costs; lost wages due to patients and/or care partners needing to reduce work or leave a job; long-distance travel to see a neurologist or movement disorder specialist; home modifications; adult day care; personal care aides.

- In addition to the surveillance system, funding for agencies that conduct medical research must remain a top federal priority:
 - Funding for the **Department of Defense (DoD) Parkinson's Research Program** has decreased in recent years and should be restored. This program studies how events in the line of service, such as toxin exposure and traumatic brain injury, and genetics may lead to the development of Parkinson's in our nation's service members and veterans.
 - The **National Institutes of Health (NIH)** supports approximately \$169 million in Parkinson's research. Its work is vital to the development of treatments to slow or stop the progression of the disease. Currently there is no cure for PD, and we urgently need one. The NIH's work can help make this happen.

Please support these funding levels in Fiscal Year 2019: **\$5 million** to implement the National Neurological Conditions Surveillance System at the CDC; at least **\$38.4 billion** for the NIH; **\$20 million** for the DoD Parkinson's Research Program.

Join the bipartisan, bicameral Congressional Caucus on Parkinson's Disease.

- 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 great way to show your support for constituents living with Parkinson's disease and stay informed on issues impacting our community.
- Email Shayne Woods (shayne.woods@mail.house.gov) in Rep. Bilirakis' office or Alex Graf (alex_graf@stabenow.senate.gov) in Senator Stabenow's office to join.