

Empire State Plaza Lit Orange for Parkinson's Disease Awareness

SENATOR BRAD HOYLMAN-SIGAL AND ASSEMBLY MEMBER AMY PAULIN April 4, 2024

ISSUE: PARKINSON'S DISEASE, PARKINSON'S, NEW YORK STATE CAPITOL



Paulin, Hoylman-Sigal and The Michael J. Fox Foundation attend lighting to advocate for passage of their legislation to establish a Parkinson's Disease Registry which could benefit 65,000+ NYers currently living with Parkinson's

NEW YORK — The Empire State Plaza will be illuminated orange tonight to celebrate the beginning of Parkinson's Disease Awareness Month. **Assembly Member Amy Paulin, State Senator Brad Hoylman-Sigal** and representatives from The Michael J. Fox Foundation (MJFF) for Parkinson's Research will be present at the lighting. Together they are calling for the passage of their legislation to establish a state Parkinson's Disease Registry (A5803/S4674),

which passed the State Senate today, to provide for the collection of data on the incidence and prevalence of Parkinson's disease (PD). The registry will help expand understanding of PD and advance research towards prevention, treatment and an eventual cure.

A registry of people with Parkinson's would help researchers identify high-risk groups, detect prevalence patterns among the New York population, and uncover disparities in treatment in marginalized communities. Currently, ten other states, including California, already have such a registry.

Assembly Member and Health Committee Chair Paulin said: "Illuminating the Capitol orange shines a light on the extraordinary efforts of the many researchers, doctors and advocates who are working to win the battle against Parkinson's Disease. I'm proud to sponsor the Parkinson's Disease Registry bill to help in the fight. The more data we can give to researchers, the better they can direct their efforts to find a cure and more advanced therapies for Parkinson's. I thank State Senator Hoylman-Sigal for his partnership on the bill, and thank The Michael J. Fox Foundation for their staunch advocacy. Tonight we're lighting up the Capitol and the fight against this disease!"

Senator Brad Hoylman-Sigal said: "Tonight, the New York State Capitol Building shines orange in honor of Parkinson's Awareness Month. Parkinson's disease is the second most common and fastest-growing neurological disorder in the world. It currently impacts approximately 65,000 New Yorkers. Today, the Senate passed our bill (S.4674A/A5803) with Assembly Member Paulin establishing the New York Parkinson's Disease Registry to facilitate the collection and utilization of PD data so we can measure the incidence and prevalence of the disease and provide vital contributions towards Parkinson's research. I'm extremely grateful to The Michael J. Fox Foundation for Parkinson's Research for helping us craft this

important legislation. Together we can provide hope to PD patients by advancing research and innovation to better prevent, diagnose, treat and ultimately cure Parkinson's."

"The Michael J. Fox Foundation launched with one goal: to end Parkinson's disease," said Ted Thompson, MJFF Senior Vice President of Public Policy. "As New York commemorates Parkinson's Awareness Month, we are reminded of the ongoing need to further educate the public on Parkinson's disease, and advocate for the resilient community we are proud to represent. We look forward to continuing our work with policymakers, clinicians and researchers to support the more than 65,000 New Yorkers currently living with Parkinson's, their families and caretakers."

Barbara Zimmerman, MJFF advocate, said: "Passing this bill and creating the registry for Parkinson's is just as important to the individuals battling Parkinson's as it is for future generations. This bill is monumental in enabling us to understand the factors that will someday lead us to discover the root cause and hopefully a cure. My family, the approximately 65,000 New Yorkers and their families presently facing Parkinson's disease, and the future patients will be helped by this bill."

Parkinson's disease is a progressive neurological disorder that causes unintended and uncontrollable movements and affects the lives of nearly 1 million Americans. The U.S. spends \$52 billion annually on Parkinson's treatment, and in New York alone, the direct and indirect costs to care total \$3.3 billion each year. Research shows that the prevalence of Parkinson's disease has doubled over the past 25 years, yet much remains a mystery about this currently incurable disease.

"Creating a Parkinson's registry in New York would help expand researchers' understanding of the disease in order to ultimately improve the lives of those impacted," **said Paulin**. "California, Maryland, Missouri, Nebraska, Nevada, Ohio, South Carolina, Utah, Washington, and West Virginia already have a statewide Parkinson's registry. I hope that we can soon add

New York to the list and contribute to the development of therapies, treatments and eventually a cure of the disease."

RELATED LEGISLATION

2023-S4674A

- Introduced
- o In Committee Assembly
 - o In Committee Senate
- o On Floor Calendar Assembly
 - o On Floor Calendar Senate
- o Passed Assembly
 - Passed Senate
- Delivered to Governor
- Signed By Governor

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Establishes a state Parkinson's disease registry

February 13, 2023

Signed by Governor

Sponsored by Brad Hoylman-Sigal

Do you support this bill?