



In December 2023, the Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act. (HR 2365) passed the House by a vote of 407-9!

This legislation will unite the federal government in a mission to prevent, treat and cure Parkinson's disease and related diseases. **Now, we must focus on passing the Senate companion bill, S. 1064**, so the bill will advance to the President's desk to be signed into law.

Progressive supranuclear palsy (PSP), corticobasal degeneration (CBD) and multiple system atrophy (MSA) are specifically named in this bill, marking an extraordinary move in increasing awareness and support to these otherwise often under-recognized diagnoses.

PSP, CBD and MSA are considered "atypical Parkinsonian" diseases due to overlap with certain symptoms of Parkinson's disease. However, unlike Parkinson's disease, they are rare, there is currently very little research and there are no disease-modifying treatments. People usually wait years for a correct diagnosis, while dealing with significant and worsening movement and cognitive symptoms, due to a lack of familiarity among healthcare professionals. Patients are only offered symptom management and face an average life expectancy of 7.5 years. Congress can help improve the quality of life of those impacted by PSP, CBD and MSA and make progress on research and ultimately find a cure.

S. 1064 is bipartisan, no-cost legislation that will create an advisory council to coordinate federal efforts around the Parkinsonian diseases and report annually to Congress on the progress made to end the diseases. It has the potential to:

- Dramatically increase federal research funding;
- Develop more effective pathways for treatments and cures;
- Improve early diagnosis;
- Spark new and improved models for patient care;
- Create standards and measures of prevention;
- Alleviate financial and health burdens on families;
- Address health disparities in diagnosis, treatment and clinical trial participation;
- Enhance public awareness of the diseases.

CurePSP is a member of the Unified Parkinson's Advocacy Council, in collaboration with the Michael J. Fox Foundation. Together we endorse the National Plan to End Parkinson's Act, but we need your help to prioritize it.

To learn more about PSP, CBD and MSA, visit
www.curepsp.org

For more information on the legislation, contact
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