Jay Bhattacharya, MD, PhD
Director
National Institutes of Health
9000 Rockville Pike
Bethesda, Maryland 20892

August 21, 2026

Re: National Plan to End Parkinson's Request for Information (RFI) Strategy (Notice Number: NOT-NS-26-039)

Dear Dr. Bhattacharya,

The Alzheimer's Association and the Alzheimer's Impact Movement (AIM) appreciate the opportunity to respond to the National Plan to End Parkinson's Request for Information (RFI) Strategy.

The Alzheimer's Association is the leading voluntary health organization in Alzheimer's care, support, and research. The Alzheimer's Impact Movement, a separately incorporated advocacy affiliate, is a nonpartisan, nonprofit organization and works to make Alzheimer's a national priority.

Regarding research on Parkinson's disease dementia (PDD) and related neurodegenerative parkinsonisms, there are many outstanding questions about these forms of brain disease, including causes of dementia. Investment in research will be required to pursue all avenues toward diagnostics and therapeutics. Specifically, the National Institute on Neurological Disorders and Stroke (NINDS) should consider investment in:

- longitudinal cohorts spanning Parkinson's Disease (PD), PDD and dementia with Lewy bodies (DLB), with deep cognitive phenotyping;
- biomarkers capable of detecting alpha-synuclein, amyloid, tau, and vascular co-pathology in the same individuals;
- research identifying which co-pathologies determine cognitive decline and treatment response;
- harmonization and interoperability of PD and Alzheimer's disease research cohorts/data resources;
- clinical trials that characterize rather than automatically exclude participants with relevant co-pathology;
- research into mechanisms underlying cognitive impairment and dementia in PD; and
- greater integration of Alzheimer's Disease Research Centers (ADRCs) and Parkinson's-focused research centers/networks.

Such investment is also critical to the larger neurodegenerative space. More than 50 percent of people diagnosed with Alzheimer's dementia who were studied at ADRCs had mixed dementia and in community-based studies, the percentage is considerably higher.[1] For instance, we now understand that many individuals with Alzheimer's

[1] Alzheimer's Association. (2026). *2026 Alzheimer's Disease Facts and Figures*.

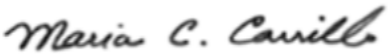
may also have DLB, which may impact their ability to respond to treatment. The National Plan should simultaneously recognize the distinct needs of individual Parkinsonian and Lewy body disorders and establish cross-disease research priorities addressing shared biology, co-pathology, biomarkers, cognitive impairment, and dementia. The National Institute on Neurological Disorders and Stroke should promote integration and interoperability between Parkinson's-focused research networks and existing ADRCs and related dementia research infrastructure, particularly for studies of cognitive impairment, Lewy body disease, and mixed neurodegenerative pathology. The National Plan should also explicitly support multimodal biomarker characterization of co-pathology in clinical trials and therapeutic development. Investing in our understanding of mixed etiologies will strengthen the field overall.

With regard to care and services for Parkinson's disease and related neurodegenerative parkinsonisms, we note that these conditions can present very differently and have distinct implications for both individuals living with a diagnosis and their care partners. Some symptoms overlap between pathological states. For instance, although PDD and DLB share many clinical and pathological features, their clinical presentation and diagnostic frameworks differ. In DLB, cognitive impairment occurs before or concurrently with parkinsonism, whereas PDD is diagnosed when dementia develops in the setting of established Parkinson's disease. These differences can have important implications for diagnosis, clinical management, research enrollment, and support for patients and care partners. Therefore, we suggest that NINDS explicitly recognize the distinct and overlapping features of PD, PDD, DLB, and other related parkinsonian disorders. Without making these distinctions, it may be difficult to fully recognize and address the unique needs and experiences of people living with the full spectrum of related disorders and their care partners.

Finally, people living with PD, PDD, DLB, and related disorders—including individuals with cognitive impairment, dementia, or suspected mixed pathology—and their care partners must be included in every aspect of the Plan's development and implementation. This includes understanding the co-pathologies at work biologically, the impact of their clinical symptoms, the progression they experience, their responses to treatments, and beyond.

Thank you for the opportunity to comment. The Alzheimer's Association and AIM would be glad to serve as a resource to NINDS as it considers these important issues and how they relate to individuals living with Alzheimer's and related dementias. Please contact Laura Thornhill, Director, Regulatory Affairs, at 202-638-7042 or lthornhill@alz-aim.org if you have questions or if we can be of additional assistance.

Sincerely,



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