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Advisory Council on Parkinson's Research, Care, and Services
National Institutes of Health (NIH)
6001 Executive Boulevard
Rockville, MD 20852

Subject: Public Comment on National Institute of Neurological Disorders and Stroke; Notice of Meeting – Published Document: 2026-10117 (91 FR 29504)

Dear Members of the Advisory Council on Parkinson’s Research, Care and Services (ACPRCS),

On behalf of CurePSP, we congratulate the ACPRCS members and thank HHS and NIH for implementing the *Dr. Emmanual Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson’s Act*. As the Council begins its work, we urge it to ensure that atypical parkinsonian diseases, specifically progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and multiple system atrophy (MSA), are intentionally included throughout the National Plan. We are encouraged by the Council’s commitment to moving this effort forward and support a timely and transparent process that includes ongoing stakeholder engagement, regular public updates, and the identification of investments needed to improve prevention, diagnosis, treatment, care, and cure for all parkinsonian disorders.

CurePSP is the leading nonprofit organization dedicated to advancing the awareness, care, and cure for three rapidly progressing neurodegenerative diseases: PSP, CBD, and MSA. Through research investments, educational initiatives, support resources, advocacy efforts, and the CurePSP Centers of Care, a growing network of reputable medical institutions, we work to improve diagnosis, treatment, and health outcomes for this complex patient population.

PSP, CBD, and MSA, along with dementia with Lewy bodies and vascular parkinsonism, are often collectively referred to as “atypical parkinsonian disorders.” While they share some clinical features with Parkinson’s disease, they are distinct with different symptom profiles, disease trajectories, and treatment responses. Yet, patients with PSP, CBD, and MSA frequently receive a misdiagnosis of Parkinson’s disease because of overlapping symptoms and limitations in current diagnostic tools. Significant delays to clinical diagnosis can leave patients and families without a clear path forward, such as a lack of appropriate care plans, disease-specific resources, or opportunities to participate in clinical research, all of which can contribute to poorer health outcomes and diminished quality of life. With no FDA-approved treatments currently available for PSP, CBD, or MSA, timely and accurate diagnosis is especially critical.

For these reasons, we encourage the Council to view the inclusion of atypical parkinsonian disorders as an opportunity to strengthen outcomes across the entire Parkinson’s community.

CurePSP respectfully requests the Council consider the following priorities in its initial workplan:

1. **Ensure that the National Plan implementation explicitly includes atypical parkinsonian disorders- PSP, CBD, and MSA.**

Strategies across the federal landscape, such as research initiatives, data collection, and public awareness, should consistently account for PSP, CBD, and MSA alongside Parkinson’s disease. At the same time, these conditions must be recognized as distinct neurodegenerative disorders with unique clinical characteristics and care needs. Unfortunately, atypical parkinsonian disorders are often absent from publicly available data, educational resources, and assessments of disease burden and care needs.

The National Plan should capture the full spectrum of parkinsonian disorders and promote improved identification, reporting, and analysis of data related to PSP, CBD, and MSA to better inform federal planning, resource allocation, research priorities, and patient services. As an early work product, the Council should identify unmet needs and the investments required to improve prevention, diagnosis, treatment, care, and cures across the parkinsonian disease continuum.

2. **Advance research that recognizes both shared and distinct scientific opportunities.**

There is an urgent need to understand pathological similarities, distinctions, and overlaps across PSP, CBD, and MSA, Parkinson’s disease, and other neurodegenerative diseases. Research in this space is essential to unlocking insights into disease mechanisms, identifying shared and distinct biomarkers, tracking disease progression, and accelerating therapeutic development that will benefit patients, families, clinicians, and researchers.

As part of this effort, the Council should identify research gaps, unmet needs, and opportunities that can help guide a long-term federal strategy for advancing scientific discovery, improving patient outcomes, and delivering new treatments and cures.

3. **Prioritize methods for earlier and more accurate diagnosis.**

For many people affected by PSP, CBD, or MSA, a primary pain point is not just living with disease but obtaining the correct diagnosis and information. Misdiagnosis and diagnostic delays derail access to appropriate care, limit participation in clinical trials, and slow treatment development.

Targeted investments in education and training across the care continuum, diagnostic tools, biomarkers, specialized care, and referral pathways can help close these gaps and improve the accuracy of detecting both Parkinson’s disease and atypical parkinsonian disorders. Since diagnosis is a cornerstone of effective clinical care, research participation, and treatment development, sustained investments in improving diagnostic accuracy should be a core objective of the National Plan.

4. **Ensure specialized access to care and caregiver support.**

Unlike Parkinson’s disease, PSP, CBD, and MSA bring debilitating symptoms, including dysphagia, loss of speech, and regular falls, earlier on in the disease course. Patients experience limited benefit from therapies developed for Parkinson’s and generally face a more rapid disease progression. Families assume significant caregiving responsibilities while navigating health and long-term care systems that are ill equipped to support their needs.

The Council should ensure that critical resources such as specialized access to care, essential therapies and equipment, caregiver support, palliative care, and community-based services are incorporated in the National Plan. Existing models like CurePSP’s Centers of Care network demonstrate that coordinated specialty care can meaningfully improve outcomes for patients and families facing complex neurodegenerative diseases. The Council should look to and build upon such models in shaping the National Plan and identify actionable recommendations with resources and investments needed to improve access to high-quality integrated care while reducing barriers that prevent patients and families from obtaining needed services and support.

As the Council begins this historic effort, CurePSP remains a partner and resource alongside the broader Parkinson’s community. We encourage the Council to maintain momentum, engage stakeholders throughout the process, and deliver clear and actionable recommendations that improve research, care, and quality of life for all people affected by parkinsonism. The National Plan should also provide a roadmap for the investments needed to address current gaps and accelerate progress towards better treatments and cures.

By ensuring that PSP, CBD, and MSA are represented from the outset, the Council can build a comprehensive and effective national strategy that will improve the lives of all impacted by parkinsonism. Thank you for your consideration and for your service.

Sincerely,

Kristophe Diaz, PhD
Chief Executive Officer
CurePSP