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Subject: Public Comment ahead of the November 9 Meeting of the Advisory Council on Parkinson's Research, Care, and Services (ACPRCS)[1]

Dear ACPRCS Members,

On behalf of CurePSP, thank you for the opportunity to provide comments to the ACPRCS.

The National Plan to End Parkinson's efforts provides an important opportunity to bring federal agencies, researchers, health care providers, industry, nonprofit organizations, and people with lived experiences together around shared goals for Parkinson's disease and related neurodegenerative disorders (PDRD), including progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and multiple system atrophy (MSA). As the Council moves from identifying priorities toward developing recommendations, the challenge is increasingly one of implementation: how to translate broad priorities into coordinated national action, measurable progress, and accountability.

CurePSP supports ambitious national goals across the entire PDRD community that advance research, diagnosis, treatment, care, services, and quality of life. These include earlier and more accurate diagnosis; deeper understanding of disease biology and development of effective treatments; stronger research tools and infrastructure; timely access to specialized, coordinated care; a knowledgeable workforce equipped to recognize and manage these diseases; support for care partners; fewer financial and coverage barriers to essential services; and better identification and reduction of disparities in research and care. As these priorities are translated into the National Plan recommendations, CurePSP encourages the ACPRCS to establish an implementation approach that maximizes opportunities for shared progress across PDRD, while ensuring that no population within the National Plan's scope is left behind.

[1] https://www.ninds.nih.gov/news-events/events/november-2026-advisory-council-meeting-parkinsons-research-care-and-services

Translate PDRD inclusion into clear, actionable, and measurable recommendations

As recommendations are developed, the ACPRCS should ensure that populations within the scope of the National Plan are meaningfully reflected in the actions proposed. This does not require every recommendation to separately address or name every disorder. Rather, recommendations should make clear when an action is intended to benefit PDRD broadly, when a shared approach requires adaptation for specific populations, and when an important need or opportunity requires targeted action.

Explicitly naming PSP, CBD, MSA, or another condition is essential when it clarifies the scope of a recommendation, identifies a distinct unmet need, or creates accountability for implementation. Ultimately, meaningful inclusion should be measured by whether priority needs are addressed and outcomes can be assessed, not by how often individual diseases are named.

Establish a consistent framework for cross-disease and disease-specific action

The ACPRCS will repeatedly confront questions about what can be learned across diseases and when disease-specific expertise, evidence, or investment is necessary. These should not be treated as competing approaches.

Cross disease perspectives can identify shared challenges, transferable solutions, and opportunities to leverage common infrastructure. Disease-specific expertise is equally important when differences in biology, clinical presentation, disease trajectory, available evidence, or implementation could materially change the conclusions being reached. One should not substitute automatically for the other.

CurePSP encourages the ACPRCS and federal and non-federal partners to apply a framework when developing recommendations and investments in research, care, services, and supports:

- Share when expertise, evidence, infrastructure, programs, or solutions are genuinely transferrable across disorders.
- Adapt when an underlying opportunity or need is shared, but disease-specific characteristics affect how an approach should be designed or implemented.
- Invest specifically when an important unmet need or scientific opportunity cannot be adequately addressed through a common approach.

For example, a recommendation to improve earlier and more accurate diagnosis across PDRD could support shared investments in clinical education, diagnostic tools, and referral pathways; adapt those approaches to account for differences in clinical presentation and disease trajectory; and identify targeted research or implementation needs where evidence or validated tools remain insufficient for particular disorders.

Similarly, a recommendation to improve access to coordinated care could advance shared workforce development and multidisciplinary care models while accounting for differences in progression rates, prognosis, treatment needs (e.g., care plan prioritization, safety, rehabilitation), symptom prevalence and severity (e.g., communication, cognition, autonomic), and care partner experiences that may require adaption or targeted federal action.

These examples illustrate how a single recommendation can advance shared PDRD goals

without assuming one approach will work identically for every population. Shared research infrastructure, data resources, workforce initiatives, care-delivery models, benefits, and community-support programs should be leveraged, but their applicability to different diseases should be evaluated rather than assumed. Where a recommendation, program, or investment is intended to serve PDRD broadly, there should be a deliberate assessment of what is truly shared, what requires adaptation, and what may otherwise be missed.

Recognize the broader value of related disorders across both care and research

Population size alone cannot measure the value of attention to an individual disorder. National priorities should weigh disease burden alongside unmet needs, opportunity for scientific advancement, and relevance to the question being asked. Studying related disorders can sharpen our understanding of heterogeneity among PDRDs, improve diagnostic precision, distinguish shared from disease-specific mechanisms, and yield tools that benefit the entire field.

Recent research demonstrates why this matters. In a 2026 global cohort study of parkinsonian disorders, researchers found substantial complexity across clinical diagnoses, underlying pathology, genetics, and co-pathologies among parkinsonian disorders. Importantly, diagnostic overlap was not limited to the less prevalent disorders.[2] Some individuals clinically diagnosed with PD had PSP, MSA, or other primary pathology at autopsy. These findings reinforce the value of developing National Plan recommendations that recognize both the shared and distinct needs across PDRDs.

The same principle applies to care, services, and supports. Different disease trajectories can expose gaps in diagnostic pathways, care coordination, rehabilitation, coverage, and other systems that may also inform improvements for the broader PDRD community.

Federal strategy should therefore weigh both the needs of individual disease populations and the potential for experience or investment in one population to generate knowledge, infrastructure and models with broader value. Intentional inclusion of related disorders does not compete with progress in PD. When strategically designed, it strengthens the research and care systems serving the entire PDRD community.

Set clear expectations and accountability for public-private partnerships

Public-private partnership can address challenges that no individual federal agency, company, research institution, or nonprofit organization can solve alone. As the ACPRCS considers the role of these collaborators, it should also recognize that partnership is a mechanism for achieving National Plan objectives, not an outcome in itself.

Federally supported partnerships should have clearly defined objectives, partner roles and responsibilities, measurable milestones, realistic timelines, and mechanisms for assessing and reporting progress. When expected milestones are missed, partners should reassess priorities and approaches.

People living with PDRD and their care partners should be integral participants in the design,

[2] Wu, L. Y., Du Toit, T., Georgiades, T., Stafford, E. J., Levine, K., Fang, Z. H., ... & Morris, H. R. (2026). Pathology and genetics in a global cohort of Parkinsonian Disorders. JAMA neurology. https://jamanetwork.com/journals/jamaneurology/article-abstract/2850075.

implementation, and evaluation of these partnerships. Their lived experience provides essential insights into unmet needs, practical barriers, and outcomes that matter in daily life, helping ensure that research advances, care models, and other partnership activities are relevant, accessible, and responsive to the populations they are intended to serve. Meaningful engagement should extend beyond consultation to opportunities that can inform priorities, decisions, and measures of success.

These expectations are particularly important for partnerships intended to serve multiple diseases or populations. Expanding the stated scope of an initiative or adding organizations to a partnership does not alone demonstrate meaningful integration. Multi-disease partnerships should articulate how the populations within their scope are expected to contribute to and benefit from the work, where shared approaches provide value, and where disease-specific gaps remain.

As the National Plan is implemented, the ACPRCS should encourage regular assessment of whether federally supported partnerships are producing outputs that advance identified national priorities and reach the populations they are intended to serve.

From inclusion to implementation

As the ACPRCS develops its first recommendations and establishes a foundation for the future of the National Plan, CurePSP encourages it to adopt an approach that:

1. Identifies opportunities for shared action and investment across research, care, services, and supports
2. Incorporates disease-specific expertise and adaptation where differences could materially affect outcomes
3. Supports targeted investments when priority needs or opportunities cannot adequately be addressed through shared approaches
4. Establishes clear objectives, roles, milestones, and measures of success for public private partnerships that have federal investments
5. Enables the Council, federal agencies, and the public to assess whether implementation is producing meaningful progress across the populations the National Plan is intended to serve.

This approach will maximize the value of federal investments, strengthen collaborations, reduce unnecessary duplication, and ensure that related disorders and the people living with them are meaningfully reflected in the National Plan's implementation. A National Plan for PDRD succeeds if it delivers for everyone within its scope. CurePSP looks forward to continuing to work with the ACPRCS and other partners toward that goal.

Sincerely,



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