Parkinson's Foundation

June 22, 2026

Dear Advisory Council on Parkinson's Research, Care, and Services (ACPRCS) Members,

Thank you for the opportunity to comment ahead of the inaugural meeting of the ACPRCS. The Parkinson's Foundation is pleased to submit the following priorities developed in close consultation with the community and based on our 60 years of experience, which we hope you will take into consideration on behalf of the 1.1 million people living with Parkinson's Disease (PD). The National Plan to End Parkinson's provides a catalytic opportunity to increase national attention and investment through a coordinated, government-wide effort to prevent, treat and cure PD. Success will depend on sustained federal follow-through — planning, reporting, interagency coordination, and accountability.

1. **Produce an estimate of the investments needed to prevent, diagnose, treat, and cure Parkinson's as a core deliverable — scaled to meet the growing economic burden of the disease. This should be a clear, evidence-based assessment with defined assumptions and phases so Congress can right-size appropriations and the nation can build a long-term strategy.**

Parkinson's is the fastest-growing neurodegenerative disease, with 90,000 new people diagnosed each year. Yet there is no clear cause, no cure, and too many people experience delayed diagnoses and uneven access to quality care.

Parkinson's disease and atypical parkinsonisms impose an escalating burden on patients, families, health care systems, and the economy, totaling an estimated $82.2 billion in economic costs in 2024.[1] In contrast, federal investment in Parkinson's research in 2024 totaled less than 1% of this economic cost, with NIH funding remaining effectively flat since fiscal year (FY) 2021. Meanwhile, research costs have increased, eroding the value. Adjusted for inflation, funding in FY 2026 for Parkinson's research is almost 20% below FY 2021 funding.

Given the urgent need for increased investment to accelerate scientific discovery, the Parkinson's Foundation and other patient organizations have called for an initial investment of $600 million annually in funding for PD research at NIH to narrow the funding gap. We know an infusion of resources can kickstart the plan based on the results seen when resources were increased in the early years of the National Alzheimer's Project. NIH spending on Alzheimer's research increased nearly 4.5-fold from $631 million in FY 2015 to $2.87 billion in FY 2020, significantly expanding research capacity that led to breakthroughs for patients. Based on this precedent, a reasonable target for federal Parkinson's research funding is at least $1.5 billion annually by 2032.

While these are starting points for research funding, an evidence-based roadmap to fully address unmet needs in Parkinson's research, care and prevention will help Congress develop a long-term funding strategy. We urge the Council to consult with experts in health economics to identify the specific level of investment necessary to fully address the unmet needs. Experts should consider:

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[1] https://www.parkinson.org/blog/research/economic-burden-2024

- the economic burden of disease, both direct medical costs and indirect costs of lost income and unpaid caregiving,
- the cost of bringing new treatments capable of slowing or halting disease progression to scale, with a particular focus on the challenges facing drug development for neurodegenerative conditions, including a near 100% clinical failure rate for disease-modifying treatments,
- necessary investment to educate health care providers on ways to better identify, diagnose, and treat PD and its symptoms, and
- resources needed to identify and reduce preventable toxic exposures linked to PD— this should include both research to better understand risk and regulatory action for substances where scientific evidence has already established a link, like paraquat. While states can, and have, taken action to ban dangerous substances like paraquat, only through EPA cancellation can protections cover all Americans.

2. **Prioritize improving quality of life for those living with Parkinson's disease and their families across the lifespan, including people with young-onset and older adults. The report should include actionable recommendations that improve access to high-quality care and reduce financial burdens.**

While Parkinson's prevalence is increasing, there is a growing shortage of neurologists. Fewer than 10% of people with PD receive care from a movement disorders specialist, and the majority of people with PD have limited access to the rehabilitation and mental health services that are essential to managing the disease.

With these challenges in mind, in September 2025 the Parkinson's Foundation convened the National Roundtable on Parkinson's Care and Innovation, which brought together people living with PD and professionals across disciplines to lay the groundwork for the work of the Council.[2] Four high-impact national PD care recommendations were identified that we hope the Council will take and develop:

- Build community clinician capability to manage PD, leveraging movement disorder expertise, training, and education.
- Develop a sustainable, integrated care model that improves care coordination and patient outcomes.
- Define the minimum clinical dataset to support care coordination across settings for people with PD.
- Prioritize patient-centered technologies that are clinically relevant and scalable.

In addition to these priorities, we encourage the Council to focus on identifying solutions for some of the most pressing access and affordability issues that make navigating the health care system particularly challenging for people with PD. Areas we suggest focusing on generating recommendations to help strengthen care systems and alleviate financial burdens include:

- Coverage gaps and common pain points: while some needs are well established, including limited or financially prohibitive long-term care coverage and utilization

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[2] https://www.parkinson.org/sites/default/files/documents/Care-Innovation-Patient-Centered-Agenda.pdf

management improperly restricting access to medically necessary care, a landscape analysis across Medicare and commercial health plans could help identify common areas where additional guardrails may be necessary to ensure access without burdensome delays, or new policy that may be needed to expand coverage of best practice care like rehabilitative services and exercise.

- Provider workforce: a combination of factors drives provider shortages leading to long appointment wait times and unreasonable travel distances to receive care. In addition to models to extend provider capacity, consider changes that may need to be made to the training pipeline and underlying causes of workforce shortages including graduate medical education structure, access to post-graduate student loans, reimbursement policies, telehealth continuity, panel sizes, and administrative burdens leading to provider burnout.

- Clinical trials: a shift toward decentralized clinical trials can make it easier for more people living with PD to benefit from potential research advances. Consider what additional incentives may be necessary to increase uptake of patient centered approaches to clinical trials like integration with local providers, home visits, and increased used of digital-health technologies.

- Financial wellbeing: beyond traditional coverage, consider out-of-pocket costs and lost income of participating in clinical trials, disability support, and tax policies that can help offset the significant economic burdens families face after a diagnosis.

3. **Finally, while we are encouraged by the fast action of the Council to schedule the first meeting and begin formal work, under P.L. 118-66, the first annual report was due January 2, 2026. In order to stay on track, we urge the ACPRCS to produce the first annual report within one year. This approach ensures the Council has sufficient time to produce high-quality work while remaining accountable to the public. We encourage regular public updates and transparency throughout.**

We look forward to working together to chart a course to end Parkinson’s disease and positively change the lives of those impacted by PD.

Sincerely,

Andi Lipstein Fristedt
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