



June 22, 2026

Jordan Gladman, Ph.D.  
Deputy Executive Officer  
National Institute of Neurological Disorders and Stroke  
National Institutes of Health  
Bethesda, MD 20892

**Subject:** Public Comment on National Institute of Neurological Disorders and Stroke; Notice of Meeting

Dear Dr. Gladman:

The American Parkinson Disease Association (APDA) is a nationwide grassroots network dedicated to improving the lives of those living with Parkinson's disease (PD). Founded in 1961, APDA has raised and invested more than \$313 million to provide services and educational programs, elevate public awareness about Parkinson's disease, and support innovative research.<sup>1</sup> On behalf of the more than 1 million people in the U.S. living with Parkinson's disease, APDA applauds the establishment of the Advisory Council on Parkinson's Research, Care, and Services (ACPRCS) and appreciates the opportunity to provide public comment in advance of the Council's inaugural meeting.<sup>2</sup>

The National Parkinson's Project, described in the National Plan to End Parkinson's Act (P.L. 118-66), provides the ACPRCS with an opportunity to address significant challenges faced by people living with Parkinson's disease. These challenges include securing appropriate diagnosis and treatment of Parkinson's disease, as well as determining the research investment necessary to secure advances in treatment that not only improve symptoms and slow disease progression but ultimately result in a cure. APDA urges the ACPRCS, in partnership with the Parkinson's disease community, to commit to executing the following actions to meet the National Parkinson's Project objectives as described in P.L. 118-66:<sup>3</sup>

### **1. Establish an Annual Report Work Plan with a 1 Year Project Timeline**

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<sup>1</sup> <https://www.apdaparkinson.org/about-apda/>

<sup>2</sup> <https://www.federalregister.gov/documents/2026/05/20/2026-10117/national-institute-of-neurological-disorders-and-stroke-notice-of-meeting>

<sup>3</sup> <chrome-extension://efaidnbnmnnibpcajpcglclefindmkaj/https://www.congress.gov/118/plaws/publ66/PLAW-118publ66.pdf>

The National Plan to End Parkinson's Act (P.L. 118-66) required the first annual report to assess the Nation's progress in preparing for, and responding to, the escalating burden of Parkinson's by January 2, 2026.<sup>3</sup> As the ACPRCS develops the work plan for the first annual report, APDA urges the ACPRCS to establish a 1-year timeline to develop the report to ensure a high-quality product while simultaneously remaining accountable to the public and Congress. The report should include clearly identified tasks and subtasks, with measurable goals, reasonable deadlines, and clear implementation leads to ensure the report results in real progress for the Parkinson's disease community.

## **2. Estimate the Financial Investments needed to Prevent, Diagnose, Treat, and Cure Parkinson's disease**

Parkinson's disease is the second most common neurodegenerative condition in the US<sup>4</sup>. The current estimated economic burden for the nearly 1 million individuals in the US with Parkinson's disease or Atypical Parkinsonism (AP) is \$82.2 billion, 30% of which is associated with direct medical costs, 32% indirect medical costs, 22% non-medical costs, 10% disability benefit costs, and 7% out-of-pocket costs not currently covered by insurance. By 2045, it is estimated that the PD/AP population in the US will increase to 1.7 million individuals and result in an estimated economic burden of \$112.4 billion.<sup>5</sup>

Costs associated with Parkinson's disease have risen faster than previously projected, suggesting a need to identify effective fiscal investments that reduce costs while improving the quality of life for people with PD.<sup>4</sup> While the federal government has made investments in Parkinson's research through the National Institutes of Health (NIH), the Department of Defense, the Department of Veterans Affairs, and other federal entities, Parkinson's research in 2024 totaled less than 1% of the economic cost associated with the disease. Despite an increase in prevalence and incidence of PD, NIH funding has remained effectively flat since fiscal year (FY) 2021, while research costs have increased. If adjusted for inflation, funding in FY2026 for Parkinson's research is almost 20% below FY2021 funding.

Given the urgent need for effective fiscal investments in PD research, the APDA urges the ACPRCS to develop a report that provides a comprehensive assessment of the level of public investment required to meaningfully reduce the burden of Parkinson's disease and accelerate progress toward prevention, improved treatments, and a cure. ACPRCS should establish transparent, reproducible, evidence-based estimates of investments needed in both basic science and translational research to improve early and accurate diagnosis, advance development of disease modifying and symptomatic therapies, and accelerate scientific discovery toward disease prevention and cure.

The final report should recommend the following: a national, annual investment target; short-, medium-, and long-term investment goals; priority funding categories; and metrics for evaluating

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<sup>4</sup> <https://www.apdaparkinson.org/what-is-parkinsons/>

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[https://www.michaeljfox.org/sites/default/files/media/document/MJFF%20Lewin%20Economic%20Burden%20of%20PD%202024%20Full%20Study%20Report%20FINAL\\_CLEAN\\_20260217\\_FOR%20UPLOAD.pdf](https://www.michaeljfox.org/sites/default/files/media/document/MJFF%20Lewin%20Economic%20Burden%20of%20PD%202024%20Full%20Study%20Report%20FINAL_CLEAN_20260217_FOR%20UPLOAD.pdf)

progress. At a minimum, any investment modeling should consider disease prevalence and incidence, demographic trends, inflation, research success probabilities, and adoption of emerging technologies. Specific areas of interest for investment may include biomarker development, therapeutic development, precision medicine, clinical trial infrastructure, data sharing and registries, environmental and genetic risk factor research, and prevention-focused research initiatives.

An evidence-based estimate for public investments in Parkinson's disease research, that is commiserate with the growth in prevalence and incidence, costs of care, and current economic impact, is critical to inform the federal appropriations process.

The American Parkinson Disease Association and other Parkinson's disease organizations recommend an initial investment of \$600 million annually in NIH research funding. 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 which led to scientific breakthroughs. Based on this precedent, advocate organizations believe a reasonable target for federal Parkinson's research funding is at least \$1.5 billion annually by 2032.

### **3. Explore Development of an Innovative Care Model to Improve Health Outcomes and Reduce the Costs of Parkinson's disease**

Services critical to improving the lives of those with Parkinson's disease, such as care coordination, exercise as medicine, medication management, caregiver support, and others may not be appropriately reimbursed or covered in the current Medicare Fee for Service System due to the additional time and resources that may be required to provide care longitudinally over the duration of the disease.<sup>6</sup> In 2025, an expert roundtable of people living with Parkinson's disease, movement disorder specialists, former federal agency leaders, and others developed the nation's first patient-centered agenda to improve PD care. The national roundtable identified the development of a sustainable, integrated care model that improves Parkinson's disease care coordination and patient outcomes as one of four solutions to transform care. Researchers suggested that stakeholders explore feasibility of expanding existing value-based payment models, such as the Guiding an Improved Dementia Experience (GUIDE) Model, to Parkinson's disease and other neurological conditions.<sup>7</sup>

Development of a Parkinson's disease specific innovative care model aligns with Congressional interest in improving health outcomes and the quality of life for people living with Parkinson's disease, as well as reducing the financial burden experienced by many families, as described in the National Plan to End Parkinson's Act (P.L. 118-66).<sup>3</sup> The ACPRCS should recommend the development of a sustainable, integrated care model for Parkinson's disease that addresses Congressional interest in pursuing transformative healthcare delivery initiatives that improve quality of care and reduce financial burden.<sup>4</sup>

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<sup>6</sup> chrome-extension://efaidnbnmnnibpcajpcglclefindmkaj/https://healthpolicy.duke.edu/sites/default/files/2025-04/Care%20Models%20for%20Parkinsons%20Disease\_FINAL.pdf

<sup>7</sup> <https://www.parkinson.org/sites/default/files/documents/Care-Innovation-Patient-Centered-Agenda.pdf>

#### **4. Promote Public Transparency through Public Engagement**

The ACPRCS should engage people living with Parkinson's disease throughout each phase of the Council's work, including the evaluation and prioritization of federally funded initiatives in Parkinson's research, prevention, diagnosis, treatment, clinical care, and institutional-, home-, and community-based programs. People living with Parkinson's disease are invaluable resources who can lend lived experience to the identification of ways to reduce the financial burden of Parkinson's disease, improve health outcomes and quality of care, and address environmental triggers and underlying factors contributing to Parkinson's disease. Across ACPRCS activities, NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency with the public.

Again, we appreciate the opportunity to provide written comments in advance of the Council's inaugural meeting. In summary, APDA seeks the establishment of a 1-year deadline for the first annual report, an estimate of the financial investments needed to accelerate Parkinson's disease research, the development of an innovative care model specifically designed with the Parkinson's disease community, and the promotion of public transparency through public engagement. APDA is eager to support the work of the Council to realize the aims of the National Parkinson's Project and to collectively address the pressing priorities of the Parkinson's disease community.<sup>3</sup> If you have any questions or require additional information please contact Emma Plourde, APDA Director of Health Policy, at [eplourde@apdaparkinson.org](mailto:eplourde@apdaparkinson.org) or 202-763-6801.

Sincerely,



Leslie A. Chambers  
President & Chief Executive Officer  
American Parkinson Disease Association