October 26, 2026

Dear Members of the Advisory Council on Parkinson's Research, Care, and Services:

The National Parkinson's Project represents a monumental opportunity to improve coordination, accelerate progress, and drive meaningful change for millions of Americans impacted by Parkinson's disease and related disorders (PDRD). We are grateful for your time, expertise, and commitment as well as the opportunity to share comprehensive input from the Parkinson's community.

Congress passed the National Plan to End Parkinson's Act (P.L. 118-66) to help fundamentally change the trajectory of a disease that impacts millions of American families and is growing at a rapid pace. As the Council develops recommendations for the plan, we urge you to pursue policy recommendations that improve outcomes for people and families affected by Parkinson's today while also advancing long-term progress in research, prevention, care, and services. To help inform your efforts, we have identified priority outcomes and objectives, organized according to the six statutory objectives outlined in the Act.

We, the undersigned PDRD organizations, believe the following goals match the magnitude of the challenge before us and hope they will be reflected in the Council's deliberations and plan:

- Remove barriers to essential treatment, lower out-of-pocket costs, and provide patients and families with the financial support and navigation assistance they need.
- Strengthen the Parkinson's care workforce, expand access to timely diagnosis, and make high-quality, coordinated care the standard for every patient.
- Ban substances linked to increased risk of Parkinson's Disease and related disorders (PDRDs) and invest in the interventions and treatments that slow, stop and prevent disease progression.
- Ensure that every American with Parkinson receives care that meets the highest standard of quality and safety, including Medicaid, Medicare and those receiving Veteran's services.
- Track environmental and occupational triggers to inform regulatory and public health action.
- Commit to a sustained federal research investment, backed by a dedicated budget process, that advances understanding of PDRDs, modernizes clinical trials, and builds a robust treatment pipeline.

We offer these goals as a starting point for discussion and refinement as the Council develops recommendations that are bold, actionable, evidence-based, and informed by the lived experiences of people with Parkinson's and their families. Across all six goals, we urge the Council to apply a set of four foundational principles that reflect the need for meaningful, lasting progress. First, the Council's recommendations should include **scaling and sustaining federal investmen**t to match the scope and urgency of Parkinson's disease across research, prevention, care, services, workforce development, and infrastructure, including through a dedicated budget process for Parkinson's disease investments. There needs to be a focus on **strengthening coordination and shared capacity** across federal agencies and sectors to reduce fragmentation, maximize resources, and accelerate progress. In order to measure progress there needs to be an **interoperable data infrastructure** to improve data collection, disease surveillance, and tracking. And throughout all of the work should be a **transparent implementation framework** with designated leads, clear timelines and milestones, measurable outcomes, and regular public progress reporting to ensure accountability.

We appreciate the Council's commitment to this important effort and stand ready to serve as a resource as you develop the National Plan to End Parkinson's. We look forward to partnering with you to ensure the Plan reflects the needs, priorities, and experiences of the Parkinson's community and drives meaningful progress for the PDRD community.

Sincerely,

American Parkinson Disease Association

Brian Grant Foundation

CurePSP

Dallas Area Parkinson Society

Davis Phinney Foundation

Friends of Parkinson's

Hawai'i Parkinson Association

Houston Area Parkinson Society

Kirk Gibson Foundation for Parkinson's

Lewy Body Dementia Association

Life Spark Jewish Center for Parkinson's

Michigan Parkinson Foundation

Mission MSA

Neuro Challenge Foundation for Parkinson's

Northwest Parkinson's Foundation

Parkinson & Movement Disorder Alliance

Parkinson Association of Alabama

Parkinson Association of Central Florida

Parkinson Association of Northern California

Parkinson Association of the Carolinas

Parkinson Association of the Rockies

Parkinson Foundation Western Pennsylvania

Parkinson Resource Organization

Parkinson Support Center of Northern Nevada

Parkinson Voice Project

Parkinson's Connect

Parkinson's Foundation

Parkinson's Resources of Oregon

PD Alliance of Wisconsin

PD Avengers

Power for Parkinson's

Power Over Parkinson's

Southwest Parkinson's Society

The Michael J. Fox Foundation for Parkinson's Research

Wisconsin Parkinson Association

Parkinson's Community Priorities for the National Parkinson's Project

The attached priorities are organized according to the six statutory mandates outlined in the National Plan to End Parkinson's Act (P.L. 118-66)[i] and are intended to inform the development of recommendations for the National Plan to End Parkinson's.

Statutory Mandate: Develop recommendations to reduce the financial impact of Parkinson's on families living with Parkinson's.

Parkinson's Community Desired Outcome: By 2035, reduce the financial hardship experienced by people living with Parkinson's disease and related disorders (PDRD) and their care partners through affordable and more equitable access to essential care, services, and supports, workplace accommodations, and policies that strengthen long-term economic security.

- Address coverage, cost-sharing, and utilization management policies that create inappropriate barriers to recommended PDRD care and treatments including access to medications, devices, rehabilitative care, evidence-based exercise, and other supportive and nonpharmacologic services.

- Expand tax relief for caregiving, home improvements, and other accessibility needs through tax credits and tax incentives.

- Reduce out-of-pocket costs associated with long-term service and support and improve and expand Medicare home health services coverage.

- Improve timely access to disability benefits and health coverage by fast-tracking review of disability claims, reducing Medicare waiting periods, and aligning VA presumptive eligibility policies with scientific evidence.

- Develop coordinated benefit, employment, and disability navigation support.

Statutory Mandate: Develop recommendations to improve health outcomes for, and the quality of life of, individuals living with Parkinson's.

Parkinson's Community Desired Outcome: By 2035, ensure timely and accurate diagnosis and access to high-quality, coordinated, person-centered care and supportive services that optimize health, function, independence, dignity, and quality of life for people living with Parkinson's disease.

- Strengthen the Parkinson's care workforce by expanding Parkinson's-specific education and training across providers, increasing neurology and movement disorders training opportunities, improving diagnosis and management skills among frontline clinicians, expanding access to rehabilitative therapies, and aligning Graduate Medical Education funding with current and projected workforce needs.

- Expand timely access to healthcare services to manage motor and non-motor symptoms of PDRD by reducing wait times for specialty care, making Medicare telehealth flexibilities permanent, supporting interstate licensure portability, and developing hub-and-spoke models that connect specialists with community providers.

- Advance comprehensive, person-centered care by supporting integrated, interprofessional care models; expanding access to care navigation services and precision medicine services; addressing motor and non-motor symptoms and overall well-being; integrating palliative and end of life care; and promoting continuous quality improvement.

- Strengthen support for care partners and families by increasing access to in-home respite services and other programs that reduce care partner burden and promote long-term well-being.

- Improve access to precision medicine and personalized care by ensuring coverage for genetic counseling and related services that can inform treatment, care planning, and research participation.

Statutory Mandate: Develop recommendations to prevent Parkinson's, ameliorate symptoms, and slow or stop progression.

Parkinson's Community Desired Outcome: By 2035, effective mitigation efforts are in place to reduce environmental and toxic exposures that lead to the development of neurodegenerative diseases, and more people living with Parkinson's benefit from medical and non-medical interventions that prevent disease, reduce symptoms, and slow or stop progression.

- Coordinate increased research investment across and within Federal agencies to better understand modifiable risk factors and occupational exposures.

- Strengthen exposure monitoring, transparency and public awareness for known environmental and toxic risks.

- Eliminate use of toxic substances that contribute to PD, including TCE and similar solvents on military installations and paraquat, by optimizing federal regulatory tools and pathways to suspend use or ban substances linked to serious health risks.

- Accelerate the development and validation of diagnostic tools, biomarkers, data infrastructure, regulatory readiness and clinical trial infrastructure to enable earlier diagnosis, improve trial readiness, and support the development of therapies that slow, stop, or prevent Parkinson's disease progression.

Statutory Mandate: Develop recommendations to improve the quality of care provided to beneficiaries with Parkinson's who receive coverage through a federally funded health care program, such as the Medicare program under title XVIII of the Social Security Act or the Medicaid program under title XIX of such Act.

Parkinson's Community Desired Outcome: By 2035, beneficiaries with Parkinson's who receive coverage through federally funded healthcare programs have access to high-quality, person-centered care that improves outcomes, reduces avoidable complications, supports independence throughout the disease course, and is aligned with best practices.

- Develop a coordinated, longitudinal Parkinson's Medicare care model, which may include adapting the Guiding an Improved Dementia Experience Model to support people with Parkinson's and their care partners.

- Increase access to comprehensive, multidisciplinary Parkinson's care by strengthening Centers of Excellence, expanding the VA PADRECC network, and supporting evidence-based integrated care approaches across health systems.

- Improve care quality and safety in clinical settings by incorporating Parkinson's screening into preventive care visits and implementing hospital and skilled nursing facility protocols to address medication timing/accuracy/contraindications, swallowing assessment, and other Parkinson's-specific care needs.

- Promote earlier identification and proactive management of Parkinson's disease through enhanced surveillance of at-risk populations, including veterans with exposure-related risk factors, and policies that reflect current scientific evidence regarding disease risk and latency.

Statutory Mandate: Develop recommendations to research the association between environmental triggers and Parkinson's to help reduce exposure to potential triggers.

Parkinson's Community Desired Outcome: By 2035, environmental and occupational factors associated with Parkinson's are better understood, monitored, and mitigated, resulting in stronger evidence to inform prevention strategies and public policy, reduced exposure to potential risk factors, and ultimately fewer new cases of Parkinson's disease.

- Evaluate known and emerging environmental hazards and translate evidence into regulatory, clinical, public health, workplace and policy action, including banning substances proven to contribute to Parkinson's disease while advancing risk communication and strategies to reduce harmful exposures.

- Increase and sustain research investments to support coordinated environmental research that connects population studies, exposure science, biological mechanisms and prevention.

- Strengthen data and surveillance to improve how Parkinson's and environmental exposures are tracked, including identifying and monitoring populations with known or elevated exposures over time to support earlier detection, intervention and access to care.

- Advance prevention and risk reduction by identifying modifiable environmental risk factors, implementing interventions to mitigate exposure, and evaluating the impact of interventions over time at reducing disease risk and improving health outcomes.

Statutory Mandate: Develop recommendations to research and better understand the underlying factors contributing to Parkinson's.

Parkinson's Community Desired Outcome: By 2035, increased federal investment in Parkinson's disease research funding, via a dedicated budget process, that will accelerate scientific discoveries that deepen understanding of the biological, genetic, environmental, and clinical factors underlying Parkinson's, leading to the development of therapies that prevent, slow, stop, or reverse disease progression and ultimately enable a cure.

- Establish a sustained and transparent federal research investment strategy with clear funding targets, priority areas, and measurable goals across basic, translational, and clinical research to accelerate progress toward better preventing, diagnosing, treating, and curing Parkinson's disease.

- Define disease biology to advance understanding of the biological, genetic, environmental, and clinical factors that contribute to PDRD and their progression. Support research on biomarkers, precision medicine, and disease staging to enable earlier, more precise diagnosis and prognosis.

- Support diverse and rigorous treatment pipelines that address different disease mechanisms, stages, and symptoms, including therapies that slow, stop, or prevent disease progression.

- Modernize clinical trials and expand participation by improving clinical trial tools, designs and networks while reducing barriers to participation, supporting more representative enrollment and expanding community-based and remote research options.