August 21, 2026

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Advocacy Organization
Responding on behalf of Parkinson's Foundation
Executive Vice President and Chief Strategy and Policy Officer

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

Thank you for the opportunity to provide input as part of the request for information (RFI) to inform the National Plan to End Parkinson's. The Parkinson's Foundation makes life better for people with Parkinson's disease (PD) by improving care and advancing research toward a cure. The scope and reach of our work are broad: in 2025 alone 364,739 people received specialized care from one of our Global Care Network sites and more than 500,000 people were treated by providers who completed one of our accredited courses. Forty-four scientists and 92 community programs received Parkinson's Foundation grant funding and staff at 93 senior living communities across 25 states received expert training as part of our Community Partners in Parkinson's Care Program. Since launching our landmark genetics study, PD GENEeration, more than 35,000 people living with PD have received genetic testing and counseling at no cost. 356,400 people have received information and resources from our toll-free Helpline since 1998. In addition to insights from across these programs, more than 624 people living with PD and 148 care partners have shared with us their top priorities for the National Plan, which we have incorporated throughout this response.

As we have worked to compile our response to this request for information (RFI), we sought to tie together the statutory requirements from the Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act (as enacted by Pub. L. No. 118-66) for ACPRCS reports and Parkinson's Foundation goals, shared by other community organizations, for each of those areas with the specific prompts for research and care. We would be happy to talk in more depth on our programmatic work that informs these recommendations.

Research

Parkinson's research is at an inflection point – we are closer than ever to disease modifying therapies yet adjusted for inflation the real value of federal investment in PD research at NIH is almost 20% below Fiscal Year 2021 funding. We urge you to set ambitious goals for funding to seize the scientific opportunity. Based on precedent and progress from the National Alzheimer's Project, a reasonable target for federal Parkinson's research funding within the first five years of the Plan is at least $1.5 billion annually. While the Parkinson's Foundation and many of our partners are committed to investing in Parkinson's research, federal research funding provides the foundation, scale, and long-term commitment to public benefit that no individual private organization can match. In addition, funding must be paired with a focus on making research work better for patients in order to truly accelerate progress.

42 U.S.C. § 280n(e)(4)(C)(vi): Research and better understand the underlying factors contributing to Parkinson's

Parkinson's Foundation Goal: By 2035, increased federal investment in Parkinson's disease research funding 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.

Relevant RFI Prompts:

- Barriers and challenges to participating in the research process including clinical trial participation
- Ways to accelerate the development of safe and effective treatments to prevent, slow, or stop Parkinson's disease and related disorders, or ameliorate symptoms and improve quality of life

New and more effective treatment options depend on completion of clinical trials, yet common structural barriers limit participation, delaying trial completion and subsequent new drugs. Making it easier for more people to participate in research has the dual benefit of alleviating individual participant burdens while accelerating the pace of discovery. Research has found the burden of traveling to a clinical trial site is one of the most common reasons for declining or discontinuing participation in a clinical trial. Lengthy travel times for those in rural communities, mobility limitations, time off work, and care partner obligations all make it more difficult for individuals with Parkinson's to participate in trials. Out-of-pocket costs and a lack of clarity around when and how financial compensation can be provided are also significant barriers. In addition to cost-sharing obligations, clinical trial participants often face significant non-medical expenses like transportation, lodging, childcare, and meals that are not covered by insurance or trial sponsors.

Evidence from our Research Advocates program and newly launched PD Trial Navigator confirms these common financial and logistical barriers. Additional barriers we have identified include the disconnect between clinicians and research, resulting in limited clinician referral into trials, and overly strict eligibility criteria for many of the trials currently in the pipeline. We hear often from the community that they want to participate in research and help advance science, but the eligibility criteria are too narrow and they are often ineligible. Given that many of the comorbidities that are exclusion criteria for trials (e.g., obesity, hypertension) disproportionately affect communities of color, current status quo research design often furthers inequities.

Through our programs we have found the PD community is eager to participate in research when opportunities are accessible and meaningful.

Recommendations:

- Include robust research investment needed to sustain a pipeline of research talent and a roadmap to reach at a least $1.5 billion in annual federal research funding
- Ensure research investments are paired with investment in infrastructure to support expanded decentralized clinical trials and regulatory clarity on how data from digital health technologies can be used as clinical trial endpoints
- Better integrate clinical trials with practicing clinicians and leverage electronic health records
- Provide personalized assistance navigating clinical trials
- Make community-based clinical trial participation the default through use of digital health technologies, telehealth, and provider home visits
- Modernize the regulatory framework for digital health technologies to facilitate remote trials
- Increase coverage of out-of-pocket costs of participating in clinical trials and clarity of guidance for allowable compensation

Trial enrollment and ongoing participation challenges are leading reasons for research delays. Sustaining a strong research infrastructure and making clinical trial participation more accessible will make trial completion easier, ensure results more closely reflect the full Parkinson's community, and accelerate the development of safe and effective treatments.

42 U.S.C. § 280n(e)(4)(C)(v): Research the association between environmental triggers and Parkinson's to help reduce exposure to potential triggers

Goal: 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.

Relevant RFI Prompt:

- Research on the association between environmental triggers and Parkinson's disease and related disorders to help reduce exposure to potential triggers

We still do not know exactly what causes Parkinson's disease, but scientists believe that a complex interaction between genes and environmental factors play a role in determining if, and when, a person may develop PD. The extent to which each factor is involved varies from person to person. From the work of PD GENEration we know that only around 13% of people have a known genetic link to Parkinson's disease. From both animal and epidemiological models we know that exposure to certain chemicals like the pesticide paraquat, and solvents trichloroethylene (TCE) and perchloroethylene (PCE) are strongly linked to developing PD, but the complexity of long latency periods and mixed exposures across the life course are a challenge for evidence generation.

We know that many of these exposures kill the same brain cells that are lost in Parkinson's disease. We know enough today to take key regulatory action, like banning paraquat, but more

research is needed to know the universe of potential toxic exposures and to fully understand the mechanism of action, potential exposure thresholds, and real-world multiple exposure modeling.

Research across the federal government, including the National Institute of Environmental Health Sciences (NIEHS) and the National Center for Environmental Health (NCEH) at the Centers for Disease Control and Prevention (CDC), has been pivotal to our understanding of some of the most dangerous exposures but is chronically underfunded. Less than 1% of NIH Parkinson's research funding is spent on understanding environmental links to neurodegenerative diseases. To change the trajectory of future Parkinson's cases and move toward a framework of prevention, significantly higher investment is needed in research to examine the association between environmental exposures and PD.

Recognizing this gap, in 2025 the Parkinson's Foundation and University of Florida Norman Fixel Institute for Neurological Diseases convened a two-day workshop bringing together leading clinicians, researchers, and experts to advance understanding of strategies for preventing Parkinson's and related disorders. A summary of the findings from that convening, including necessary regulatory and policy actions for moving toward primary prevention, are available and will be published in the journal *npj Parkinson's Disease.*[1] As a result of findings from this work, Parkinson's Foundation has funded an initial round of grants to support a portfolio of basic science research focused on the relationship between paraquat and other environmental toxicants and Parkinson's disease to inform evidence-based policy decisions.

Recommendations:

- Dedicated, increased federal investment to better understand and mitigate environmental contributors to Parkinson's disease
- Coordinated effort to bridge the gap between academic research and regulatory risk assessment frameworks
- Federal focus on translational research to communicate potential harmful exposures

Better understanding the underlying causes and environmental triggers of Parkinson's disease will help move us toward a future where it is possible to not only slow or stop progression but to ultimately prevent PD.

42 U.S.C. § 280n(e)(4)(C)(iii): Prevent Parkinson's, ameliorate symptoms, and slow or stop progression

Parkinson's Foundation Goal: By 2035, effective mitigation efforts are in place to reduce environmental and toxic exposures that lead to Parkison's, and more people living with Parkinson's benefit from medical and non-medical interventions that prevent disease, reduce symptoms, and slow or stop progression.

Relevant RFI prompts:

[1] https://www.nature.com/articles/s41531-026-01437-1

- Ways to accelerate the development of safe and effective treatments to prevent, slow, or stop Parkinson's disease and related disorders, or ameliorate symptoms and improve quality of life
- Ways to improve early diagnosis of Parkinson's disease and related disorders

As noted previously, robust research investment and making it easier to participate in clinical trials are two necessary elements to accelerate progress toward disease modifying treatments to slow or stop progression, and dedicated research to understand harmful exposures and the connection to PD are necessary for prevention.

Once we understand the underlying causes we can move to act on the evidence. In order to support earlier diagnoses and connection to effective treatments, we need clinically useful diagnostics and a well-resourced, modern FDA. To mitigate and prevent harmful exposures, we need systematic monitoring and reporting of known risks.

Recommendations:

- Fund research into biomarkers for diagnosis and diagnostic technologies
- Ensure adequate FDA staffing and expertise to support regulatory guidance and review of innovative diagnostic tools
- Strengthen exposure tracking, monitoring systems, and public reporting for known chemical risks like TCE and PCE
- Optimize federal regulatory tools to end the use of toxic substances that contribute to PD
- Increase public awareness and education about potential environmental risk factors and locations including right-to-know notifications for occupational exposures and Superfund sites

The urgency around research is clear. In our community survey 94% of respondents placed treatments that can slow, stop, cure or prevent Parkinson’s among their top two priorities.

Care

Increased research investments and understanding of underlying causes of Parkinson’s disease will lead to more treatments and enable earlier detection and diagnosis. For this to meaningfully benefit individuals living with Parkinson’s, there needs to be an underlying infrastructure in place that makes it possible for every person to access expert, coordinated and affordable care wherever they live.

We know there is significant work to do deliver on this vision. While Parkinson’s prevalence is increasing, there is a growing shortage of neurologists and an acute shortage of movement disorder specialists, neurologists with specialized extra training in Parkinson’s and other motor conditions. Additionally, the majority of people with PD have limited access to the rehabilitative and mental health services that are essential to managing the disease.

While Parkinson's care looks different depending on age of diagnosis, across the care continuum, and as a person progresses with the disease, the Parkinson's Foundation has identified five principles of quality care that will improve outcomes, mitigate risk of preventable harm, and reduce costs across the care continuum:

- Timely diagnosis—prompt, accurate diagnosis
- Comprehensive treatment – comprehensive approach that includes early referrals to supplemental therapies, medications, non-pharmacological interventions, and surgical options
- Medication management—timely medication administration, proper dosing and avoidance of contraindicated medications to optimize health outcomes and minimize symptom deterioration
- Person- and Family-Centered Care—care tailored to an individual's needs via a shared decision-making process focused on individual goals, unique disease progression, quality of life and care partner engagement
- Team-Based Care—coordinated care delivered by an interprofessional workforce equipped with PD knowledge, experience, and training

The five principles are core to our care work and our recommendations for the Council. As previously shared, the Parkinson's Foundation convened the National Roundtable on Parkinson's Care and Innovation in 2025, bringing together people living with PD and professionals across disciplines to lay the groundwork for ACPRCS work.[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

Meeting care needs will require both expanding the provider workforce and equipping current providers who care for people with Parkinson's with expertise, while addressing navigation, cost, and access challenges for patients.

42 U.S.C. § 280n(e)(4)(C)(ii): Improve Health Outcomes and Quality of Life

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

Relevant RFI Prompts:

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

- Gaps in clinical care and services for people living with Parkinson's disease and related disorders
- Barriers and challenges to receiving care and services for Parkinson's disease and related disorders
- Ways to improve care and service delivery

With only 660 practicing movement disorder specialists in the United States, there is a significant shortage relative to the 1.1 million Americans living with PD. Research published in 2023 found that more people with Parkinson's receive no care at all (11%) than those who receive care from a movement disorder specialist (9%). The majority of people with PD receive their care from a general neurologist or primary care providers, which include physicians, nurse practitioners (NPs), and physician assistants (PAs) ("community clinicians"). Community clinicians typically have less experience with and expertise in treating PD, and therefore diagnosis and care management can pose significant challenges. That same research also found that few Medicare beneficiaries with PD receive recommended services such as physical, occupational, or speech therapy.

In practice, the shortage of specialists and limited Parkinson's specific training for community clinicians can mean difficulty finding Parkinson's expertise and long wait times for appointments. Leading up to this RFI, the Parkinson's Foundation surveyed the community to hear directly where the most significant challenges were. 36% of the 873 survey respondents reported difficulty finding a provider with Parkinson's expertise or getting an appointment. Among rural respondents, 46% reported the same challenge. This mirrors both published research and what the Parkinson's Foundation's Helpline data show. The toll-free Helpline is staffed by a team of 13 health professionals providing real-time support 50 hours a week. On average there are roughly 1,500 cases a month and navigating care is a major unmet need—approximately one-third of Helpline interactions focus on connecting people to care, resources, and support services.

To help address provider gaps, Parkinson's Foundation has programming to both help equip providers with expertise and build the future pipeline of providers. Recognizing that the average student at leading nursing schools was receiving less than one hour of dedicated Parkinson's disease education, Parkinson's Foundation launched the Edmond J. Safra Nurse Educator Program to help prepare the next generation of nurses for the growing population of people with Parkinson's disease. This train-the-trainer model has equipped 330 nurse educators with PD knowledge and tools, collectively reaching an estimated 26,000 nursing students annually. Another model is Parkinson's Foundation Team Training, a 3-day in-person interprofessional program designed for healthcare professionals working in the PD community to improve Parkinson's care. Through this unique training model participants have reported increased confidence and knowledge in caring for people with Parkinson's disease. Based on the learnings from the training, participants have integrated mental healthcare into clinic visits, added non-motor screenings and assessments, and instituted interdisciplinary clinic days to include neuropsychology, OT, PT, speech therapy, and neurology in one day. And finally, to help build the pipeline of Movement Disorder Specialists, the Parkinson's Foundation launched a

Neurology Residents Program to introduce neurology residents to Parkinson's disease through the Parkinson's Foundation immersive, interprofessional Team Training program. While more than 500,000 people have received Parkinson's care informed by Parkinson's Foundation training, the work is scalable and there is more work to be done to reach the full care continuum.

Recommendations:

- Equip practicing clinicians throughout the care continuum, and faculty educating future clinicians, with Parkinson's specific training
- Build in opportunities, and consider requirements, for neurology and Parkinson's specific rotations or practicum in medical school, nursing, and physician assistant training
- Update Graduate Medical Education funding and policy to align with current and projected care needs and geographical gaps with a focus on supporting movement disorders fellowships for neurologists and advanced practice practitioners
- Establish Parkinson's specific hub-and-spoke models, like Project ECHO, that help bridge gaps between specialists and community clinicians
- Make Medicare telehealth coverage flexibilities permanent
- Incentivize medical licensure flexibility and interstate compacts to make it possible to provide telehealth care across state lines
- Establish full provider status for occupational therapists to ensure Medicare recipients have access to needed health services
- Provide coverage of genetic counseling
- Fund dedicated care navigators for people living with Parkinson's
- Encourage integrated, interprofessional, comprehensive care clinics

42 U.S.C. § 280n(e)(4)(C)(i): Reduce Financial Impact of Parkinson's on families living with Parkinson's

Parkinson's Foundation Goal: By 2035, reduce the financial hardship experienced by people living with Parkinson's disease and their care partners through affordable access to care and services, stronger caregiver support, workplace accommodations, and policies that help offset the direct and indirect costs of the disease and strengthen long-term economic security.

Relevant RFI Prompts:

- Impact of Parkinson's disease and related disorders on the physical, mental, social, and financial health of individuals living with these diseases and their caregivers and communities
- Ways to reduce the financial impact of Parkinson's disease and related disorders

Beyond direct medical considerations, Parkinson's disease is profoundly financially disruptive to individuals and their families. Research released this year found that the total economic burden of Parkinson's disease in the United States in 2024 was estimated to be $82.2 billion.[3] Some of the most significant changes at an individual level were in non-medical costs, which more than

[3] https://www.parkinson.org/sites/default/files/documents/2024-parkinsons-economic-burden-study.pdf

doubled in the past decade with the average person with PD paying $15,614 in non-medical expenses in 2024. This includes an average $4,675 in out-of-pocket expenses not covered by insurance such as counseling, supplies, and therapeutic activities as well as major contributors to economic burden, like housekeeping services, financial and legal planning services, and accessible home purchase expenses.

Nearly 40% of people living with Parkinson's relied on unpaid care partners. More than 20% of those care partners retired or worked fewer hours and 34% canceled or missed their own routine health care visits. Indirect costs, which include the loss of wages or earnings due to the reduced ability to work attributable to PD (reduced hours, sick time spent, etc.) were also calculated. Taken altogether, the non-medical and indirect cost burden on people living with Parkinson's and care partners was $40,290 per person in 2024, up 58% from the 2017 amount of $25,558. This amount is greater than similar costs of other conditions such as diabetes, which had reported a total indirect cost per person with diabetes of $4,500 in 2022. For people diagnosed with young-onset Parkinson's disease financial burdens can be particularly pronounced given the career disruption, lost wages, and potential premature retirement.

In order to address financial health and reduce financial burdens, the National Plan must address more than just the cost of health care.

Recommendations:

- Ensure full coverage of proven rehabilitative care, including exercise
- Create dedicated tax credits for caregiving
- Establish tax incentives and financial assistance for home modifications and accessibility needs
- Formalize a Medicare respite care benefit
- Begin to drive coordinated action for Long Term Care coverage – explore successful models and funding mechanisms being used in other states and countries
- Streamline prior authorization, tiering exceptions, and coverage appeals processes to help reduce out-of-pocket health care expenses
- Increase access to paid family leave, social security, and VA disability benefits

42 U.S.C. § 280n(e)(4)(C)(iv): 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 Foundation Goal: By 2035, beneficiaries with Parkinson's who receive coverage through federally funded healthcare programs have access to coordinated, high-quality, person-centered care that improves outcomes, reduces avoidable complications, supports independence throughout the disease course, and is aligned with the evidence base.

Relevant RFI Prompts:

- Disparities in Parkinson's disease presentation, outcomes, care, service delivery and access
- Ways to improve care and service delivery

Medicare is the primary health coverage for around 90% of individuals with Parkinson's and an additional subset are dual-eligible beneficiaries who also have Medicaid coverage. Additionally, more than 110,000 veterans with Parkinson's receive care through the Department of Veterans Affairs (VA). Given these large concentrations, leveraging federal health programs at scale has the power to transform care delivery for people with PD.

People with Parkinson's, care partners, and clinicians need a flexible, evidence based, integrated care model that can be adapted to a variety of settings and resources. While variability in resources across the U.S. poses a challenge for care coordination, particularly in rural areas, Medicare driven care models, programs and requirements can help bridge some of those gaps.

Various federal funding streams, including Medicare and Medicaid, also support hospitals. Given that nearly one-third of people with Parkinson's are hospitalized each year, this nexus provides an opportunity to improve care and reduce harm through policy. Whether unexpected or planned, a hospital visit puts a person with PD at significant risk of avoidable complications that can lead to longer hospital stays, more severe PD symptoms, and increased costs. An estimated 1 in 6 people with Parkinson's will experience avoidable complications in the hospital, often related to issues with medication management, mobility, and dysphagia.

Recommendations:

- Expand the Guiding an Improved Dementia Experience (GUIDE) Model to include Parkinson's Disease, or pilot a Medicare integrated care model for Parkinson's based on the lessons learned from the GUIDE model
- Grow the Parkinson's Disease Research, Education, and Clinical Centers (PADRECC) network so that all veterans have access to care at a Center of Excellence
- Formalize early collaboration between the Food and Drug Administration (FDA) and Centers for Medicare and Medicaid Services (CMS) to help minimize duplication, improve regulatory predictability, and prevent delays in coverage of FDA approved breakthroughs
- Invest in implementation and delivery science research, including longitudinal outcomes assessments to evaluate interprofessional care
- Include Parkinson's screenings in Welcome to Medicare and annual wellness visits
- Incentivize hospital and skilled nursing provider education and policies to prevent medication administration delays—missing medication windows can cause symptoms to suddenly and severely flare up
- Require evaluation of swallowing ability within first 24 hours of hospitalization—dysphagia is often underrecognized and can occur without overt clinical signs like choking during a hospital stay. Aspiration pneumonia tied to swallowing difficulties is the leading cause of death among people with PD

One rural survey respondent captured the access challenge clearly: *"I travel nearly 3 hours to my neurologist twice a year. It took 9 months to see him for my first appointment."* Experiences like this underscore the need for the National Plan to provide leadership toward better access to high-quality Parkinson's care.

The National Plan provides an unmatched opportunity to transform Parkinson's disease research and care and improve the lives of those living with Parkinson's. While the work of the Council will unfold over several years, we hope you use this as a framework to guide the work and identify incremental opportunities for progress. Many of the recommendations we have highlighted throughout are ripe for more immediate action and the first annual report will provide a chance to start to chart the course. We are grateful that the work and schedule of the ACPRCS thus far reflects the urgency of need. It is incredibly important that urgency is sustained with an initial annual report released within a year of the first council meeting that:

- Defines the federal investment needed to change the trajectory of Parkinson's, in both care and research, including how that estimate was developed and a roadmap for reaching it.
- Identifies actionable steps to improve access, affordability and quality of care across the lifespan, with clear responsibilities and measures of progress.
- Drives coordinated action on a framework to prevent Parkinson's, connecting research on risk factors to actions that reduce preventable risk.

Thank you for your service and we look forward to continuing to work together.

Sincerely,

Andi Lipstein Fristedt
Executive Vice President, Chief Strategy and Policy Officer