

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

Public Comments — June 29, 2026 Meeting**172 Comments | Through June 23, 2026 |****#001 Benzi Kluger, MD, MS, FAAN** | Received: April 10, 2026

To Whom It May Concern:

I am writing to provide a comment/suggestion for the Advisory Council on Parkinson's Research, Care, and Services (ACPRCS). I applaud this effort and think it is about time we addressed Parkinson's and related disorders at a national level given its high prevalence and significant impact on the lives of patients and their families.

A concern that I have in the mission "for an integrated national plan to prevent, diagnose, treat, and cure Parkinson's, ameliorate symptoms, and slow or stop progression" is that care per se is not mentioned and that the language used is entirely biomedical. While biomedical treatments (and hopefully one day a cure) are important, this does not address the total pain of Parkinson's and related disorders for patients and families which also includes psychosocial, spiritual, existential, and practical concerns. Even within the realm of the biomedical, there are many issues which are currently not well-addressed that affect a majority of people living with Parkinson's including dementia, pain, mood disorders, and fatigue.

Palliative care is an approach to improving the quality of life for people living with serious illness and their families that focuses on addressing medical symptoms, psychosocial issues, spiritual concerns, and planning for the future. While traditionally associated with cancer and end-of-life care, it is now recognized that palliative care can be helpful for a wide-range of illnesses and across the disease journey starting at diagnosis. Notably, there is specifically a growing body of literature demonstrating the high rates of palliative care needs in Parkinson's and related disorders, as well as randomized controlled trials demonstrating the effectiveness of palliative care approaches in improving patient and family-centered outcomes. While it may take years (or decades) to advance biomedical treatments to slow or stop progression, there is much we can do today to improve care.

A related concern is that the field of movement disorders has traditionally avoided discussions of end-of-life care. It is still common to hear neurologists state that people "die with Parkinson's and not of Parkinson's" despite the fact that the CDC ranks PD as the 10th leading cause of death in individuals over age 65. I think the ACPRCS should address this issue. There are many gaps in end-of-life care for people with Parkinson's and significant evidence that people with Parkinson's face excessive suffering, hospitalizations, and institutionalization near end-of-life because of failures of our healthcare system to acknowledge and address mortality and related issues.

In my roles as the founding president of the International Neuropalliative Care Society (and current past president), a neuropalliative care researcher, physician, and friend to many people with Parkinson's and related disorders I hope that you will give due consideration to these concerns. If there is anyway I can help serve ACPRCS in any of my roles, please feel free to reach out to me. I would also be happy to make a few remarks or answer questions at the inaugural session.

Sincerely,

Benzi Kluger, MD, MS, FAAN
Past President, International Neuropalliative Care Society
Julius, Helen and Robert Fine Distinguished Professor of Neurology
Director, Palliative Care Research Center
Director, Neuropalliative Care Division
University of Rochester Medical Center

#002 George Ackerman, PhD, JD, MBA | Received: April 10, 2026

George Ackerman, PhD, JD, MBA
TogetherForSharon®

In memory of my mother, Sharon, to advocate for awareness & hope for a cure for Parkinson's Disease.
PO Box 480041, Delray Beach FL 33448

To: The Advisory Council on Parkinson's Research, Care, and Services,
Re: Public Comment in Memory of Sharon – Urgent Need for Parkinson's Resources and Support
Date: 4/10/2026

I submit this comment in memory of my mother, Sharon, who lost her battle with Parkinson's disease. While she is no longer with us, her memory lives on through my advocacy and in the work so many of us continue every day. I ask that as you guide policy and recommendations, you carry forward not only the needs of those currently battling Parkinson's, but also the voices and stories of those we have lost. They must never be forgotten.

My family's experience revealed painful gaps in awareness, support, and resources—especially during the most critical moments of care. Even now, years later, I continue this fight, often feeling alone in navigating a system that should be better equipped to support patients and families.

There is an urgent need for:

- Greater access to resources and guidance for caregivers and families
- Improved education and awareness within healthcare systems
- Stronger coordination of care, particularly during hospitalizations
- Continued investment in research, policy, and community-based support
- Grief support for families who lost a loved one due to Parkinson's

No one should have to face Parkinson's disease in isolation. Families like mine need to know where to turn, how to advocate, and that they are not alone in this journey.

Please continue working toward meaningful change so that those living with Parkinson's today—and the families who stand beside them—receive the care, dignity, and support they deserve.

And please, ensure that those who have lost their battle are never forgotten.

Respectfully,
George Ackerman, PhD, JD, MBA

#003 Joanie Kahn-Rollins | Received: April 10, 2026

To whom it may concern,

I am writing to urge immediate action on the National Parkinson's Plan. I've been living with this disease since diagnosis in December of 2020. I have had Breast cancer (TNBC), a PE in my lung and suffered multiple miscarriages. Enough is Enough!

It has been nearly two years since this legislation passed with bipartisan support, yet meaningful progress has been delayed. During this time, hundreds of thousands of Americans have been diagnosed with Parkinson's disease.

Parkinson's is a growing public health crisis that demands urgency, coordination, and adequate funding.

I respectfully ask that you:

- Fully fund and implement the National Parkinson's Plan
- Ensure timely and transparent progress from the Advisory Council
- Support efforts to reduce environmental risk factors, including banning paraquat

We cannot afford further delays. Patients and families are counting on you.

Sincerely,
Joanie Kahn-Rollins
Chino Hills, CA

#004 Ted M. Dawson, MD, PhD | Received: April 13, 2026

To the Advisory Council on Parkinson's Research, Care, and Services:

I appreciate the opportunity to provide public comment as you launch the work of the National Plan to End Parkinson's Act. As a clinician-scientist and Parkinson's disease researcher at Johns Hopkins, I strongly support the formation of this Council and its mandate to coordinate research, care, and services across federal agencies and stakeholder communities.

As you develop your initial strategic framework, I urge you to consider the following priorities:

Trans agency research roadmap

- Develop a coordinated research roadmap that spans basic, translational, and clinical science and is shared across NIH, FDA, VA, CDC, NSF, DoD, CMS, and other relevant agencies.
- Define short, medium, and long term milestones for disease prevention, early detection, and disease modifying therapies, and align federal programs and funding mechanisms with these milestones.

National data and biomarker infrastructure

- Build on existing initiatives (for example, public-private consortia and longitudinal cohorts) to accelerate the development and validation of biomarkers for diagnosis, progression, and treatment response in Parkinson's disease and related neurodegenerative parkinsonisms.
- Promote data interoperability and open but responsible data sharing so that federally supported cohorts, biobanks, and clinical trials can be leveraged across studies and agencies.

Acceleration of disease modifying therapies

- Prioritize support for mechanistically informed, biomarker driven clinical trials that target key pathways implicated in PD and related disorders, including protein aggregation, mitochondrial dysfunction, and neuroinflammation.
- Strengthen federal mechanisms that facilitate academic-industry collaboration and enable efficient regulatory pathways for innovative therapies, including advanced biologics and gene or cell based approaches.

Inclusion of related parkinsonian disorders

- Ensure that progressive supranuclear palsy, corticobasal degeneration, multiple system atrophy, and Parkinson's disease dementia are fully integrated into the National Plan, as specified in the statute.
- Support natural history studies, trial ready cohorts, and targeted therapeutic development for these conditions, which currently have limited treatment options but overlapping biology with Parkinson's disease.

Optimizing care delivery and equity

- Encourage implementation and evaluation of multidisciplinary, team based models of care that address motor and non motor symptoms, neuropsychiatric complications, cognitive decline, and caregiver burden.
- Promote strategies to reduce disparities in diagnosis, access to specialty care, research participation, and supportive services among rural, and socioeconomically and other disadvantaged communities.

Sustained federal commitment and accountability

- While the authorizing legislation does not currently include dedicated research funding, the long term success of the National Plan will require predictable, sustained resources, similar to the approach used in the National Alzheimer's Project.
- Establish clear timelines and transparent reporting on progress toward plan goals, including regular public updates on research, care, and services metrics.

The National Plan to End Parkinson's Act presents a rare opportunity to align scientific discovery, clinical care, and public health toward the shared goals of preventing Parkinson's disease, improving outcomes and quality of life, and ultimately curing these disorders. I commend the Council members and federal partners for taking on this charge and would welcome future opportunities to contribute expertise as your work progresses.

Respectfully submitted,

Ted M. Dawson, M.D., Ph.D.

Leonard and Madlyn Abramson Professor in Neurodegenerative Diseases

Director, Institute for Cell Engineering

Professor, Departments of Neurology, Neuroscience and Physiology, Pharmacology & Therapeutics

Johns Hopkins University School of Medicine

#005 Kelly Grill-Cooper | Received: April 15, 2026

To Whom It May Concern,

Signed into law on July 2, 2024, the Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act (Public Law No: 118-66) created the first-ever federal initiative to combat Parkinson's disease.

The legislation established an advisory council to create a national plan focusing on preventing, diagnosing, treating, and curing Parkinson's and related neurodegenerative disorders.

Every single day my mother suffers the effects of Parkinson's. Despite bipartisan support over the course of years-this initiative has grown stagnant. I implore and urge you to move in a more expeditious fashion towards what Americans living with Parkinson's are entitled too: a life free from debilitating tremors, reliance on expensive medications and all their associated side effects and more over - a diminished quality of life. Imagine this was your child? Your family member? What could you do to keep momentum for a cure and why aren't you doing it?

Citizen,
Kelly Grill-Cooper
Montgomery, IL

#006 Maria Bethune | Received: April 22, 2026

Parkinson's disease deserves the same urgency, attention, respect and care that is given to other similarly devastating neurodegenerative diseases. Please make this a priority with swifter action moving forward.

Thank you.

Maria Bethune
Director of Client Services

#007 Timothy D. Meakem, MD | Received: May 07, 2026

Dear sir or Madam,

Please accept this public comment on the National Plan to End Parkinson's and share this input with the Advisory Council on Parkinson's Research, Care, and Services (ACPRCS).

The National Plan to End Parkinson's must include the use of focused ultrasound (FUS) as a treatment approved by the US Food and Drug Administration (FDA). FUS is FDA-approved to treat the movement disorders associated with Parkinson's disease (PD). This technology is also in clinical trials to help in the treatment of the underlying cause of PD.

Movement Disorders

One of the most challenging symptoms of PD is the variety of movement disorders that limit activities of daily living. These symptoms can lead to "hermit-like" living situations due to the challenges (and likely embarrassment) that arise in social interactions.

Brain lesioning is a proven treatment for movement disorders. There are currently three FDA-approved treatment targets for FUS-induced thermal ablation in the brain: the ventral intermediate nucleus (VIM), the internal portion of the globus pallidus (GPI), and the pallido-thalamic tract (PTT). These targeting options give treating physicians different choices, which enables them to match the target with the patient's symptoms for optimal treatment. In addition, incisionless FUS treatment is done on awake patients, so it does not include the risks from open surgery (e.g., bleeding, burr holes, blood clots, infection, electrodes, battery packs, etc.).

Because many patients with PD face a variety of movement disorders, further research into additional FUS targets could aid in the development of more treatment options. In addition, Medicare reimbursement for all of the established targets is still needed to enable patients to access a precision medicine approach to treating their symptoms. Currently some patients must

wait several years to obtain the optimal treatment that is most appropriate for them because Medicare does not yet cover all FUS treatment targets.

Treating the Underlying Cause of PD

Looking to the future, there is another FUS mechanism of action that may have the capacity to treat the underlying cause of PD. FUS is being investigated as a delivery vehicle for gene and cell therapy. Compared with the thermal ablation mechanism used for brain lesioning, low-intensity FUS is being combined with contrast microbubbles to transiently disrupt the blood brain barrier (BBB). The FUS-BBB disruption process is temporary, and it allows the penetration of intravascular therapeutic agents into the brain. Numerous clinical trials have used the combination of FUS plus microbubbles to repeatedly and safely disrupt the BBB in patients with Alzheimer's disease, ALS, glioblastoma, and PD with a favorable safety profile. Other techniques to gain access to the central nervous system (e.g., intravenous systemic infusion, intracerebral injection, BBB-crossing capsids), have notable limitations. As FUS-BBB disruption is developed, it can become complementary to advances in these other techniques, potentially shortening the time needed to eliminate PD. In the clinical studies on PD, FUS-BBB disruption has been repeatedly done in human patients, and AAV9 capsids have been delivered in large animal studies.

Ongoing clinical trials have generally been funded by nonprofit entities. However, the high costs of large-animal research and clinical trials have prevented more rapid advancement, so government funding of this work is essential to advancing progress and reaching the goal to eliminate PD.

Thank you,
Tim Meakem, MD

Timothy D. Meakem, MD
Managing Director, Co-director of the Research and Education Team
Focused Ultrasound Foundation

#008 Paul Tuite, MD | Received: May 22, 2026

The data demonstrating the benefits of exercise for people with Parkinson's disease is compelling. Ongoing funded studies like SPARX3 are attempting to address if there are greater benefits from high versus medium intensity exercise. Meanwhile other studies are looking at "forced exercise" with cycling. In addition there are numerous other studies showing the benefit of other movement strategies in PD including our published work on the benefits of Yoga. So for patients, they are primarily paying out of pocket for any sort of exercise program that enhances and maintains their health. Insurance does cover BIG physical therapy and its variations as well as LOUD speech therapy and these are helpful but insurance coverage limits how much one can receive. In summary we need to do more for people with Parkinson's and ensure there are funds for something so clearly helpful as exercise. Taking the 10,000 feet view of this mishmash of treatments there are a few outstanding issues that this panel can address.

1. Costs of therapy are a disincentive: this include copayments as well as transportation and travel time - thus some people are reluctant to start physical therapy due to a copay of 30 to 50 dollars per visit, and with 10-12 visits the costs add up and are a disincentive to improving their health; this in addition to the cost and time required to travel to and from visits. To level the playing field copayments should cease to exist for parkinson specific therapy and there needs to be improved accessibility and coverage for virtual programs if not already in place.
2. Continuity of exercise is lacking - if a patient gets formal physical therapy, after a number of sessions that reach the predetermined insurance allotment, the person is left to "exercise" on their own. This means patients are having to make out of pocket payments to find an exercise group like rock steady boxing to keep themselves healthy. Thus it would be helpful to facilitate ongoing therapy to provide assistance to patients which help maintain their function or at least slow their decline. We think there needs to be support for exercise groups such as boxing groups or insurance covered maintenance physical therapy. To date maintenance therapy has neither been studied nor covered by traditional insurance. This is unfortunate as it is clear that medications are needed to maintain a patient's function and exercise is just another form of treatment but does not get its due respect. At a minimum data is needed to either validate or refute the notion that maintenance therapy is going to be useful. We hope the PD advocacy committee will help make this happen.

Paul Tuite MD
Professor Neurology

#009 Jeff Rothman | Received: May 31, 2026

Good afternoon. The following message is a public comment that I'd like to submit for the first meeting regarding the National Parkinson's Project:

Parkinson's Disease is the fastest growing neurological disease in the world. It's long past time for Congress to address this issue and significantly increase funding for Parkinson's research & treatment.

I would also like to request a significant increase in improved treatment & research to better help women with Parkinson's disease. My dear friend Erin Lefler, who is the sweetest, kindest soul I've ever met, has been dealing with Young Onset Parkinson's Disease for 3 years now. It took at least a full year or so for Erin to get a proper diagnosis as well. As thankful as I am that Erin has access to top notch Parkinson's specialists/doctors in New York, I know that there are so many women with Parkinson's disease who may not have the ability to have access to that same level of care. That must change soon.

It's time to stop talking in platitudes and start taking serious action towards finding better treatments & ultimately, a cure for Parkinson's disease. Thank you.

Sincerely,
Jeff Rothman

#010 Ilene Grossman-Bailey, PhD | Received: June 1, 2026

Dear Advisory Council:

I am a Parkinson's Disease patient diagnosed in 2023. I am offering public comment. Initially I had to wait 5 months to see a specialist and for a diagnosis. My symptoms include shakiness, freezing, difficulty standing, stiffness, and make it hard for me to work and do daily activities such as self-care, household maintenance, shopping, and driving. However, I still work part time; I am an archaeologist and still able to research and write. I work for a private firm on compliance and permitting. I rely on carbidopa/levodopa medication to function, which is not always reliable. I also exercise daily and take boxing and dance classes to help with my mobility.

Please do all you can to ease the path for doctors to specialize in neurology/movement disorders -more specialists are needed- and promote promising scientific research such as genetic and stem cell research currently underway and clinical trials for new therapies. Thank you!

Ilene Grossman-Bailey, Ph.D.
Morrisville, PA

#011 Judy A. Grancich | Received: June 01, 2026

Dear Elected Officials,

It has been two years since the passing of the National Parkinson's Project. I am beyond disappointed in the lack of urgency and progress across two different administrations.

I am submitting my public comment to take action and create a plan for the National Parkinson's Project.

Thank you,
Judy A. Grancich

#012 Tom Walter | Received: June 01, 2026

Public Comment — we need the National Parkinson's Project

#013 John and Sandra Bruton | Received: June 03, 2026

Please NPP Advisory Council we ask you for more of your attention and the swiftest action in your plans for the coming year when it comes to YOUNG ONSET PARKINSON'S DISEASE.

Our 47 yo daughter was diagnosed with this disease 4 years ago. She and her family would be most appreciative of your care and action.

Respectfully submitted,
John and Sandra Bruton
[address redacted]

#014 Limda Steve | Received: June 03, 2026

It is time to devote more resources to research and cures for Parkinson's Disease!

-Limda Steve

#015 Marlene Wright | Received: June 03, 2026

This is a Public Comment regarding Parkinson's. When a loved one is inflicted with Parkinson's their immediate family is inflicted along with extended family and friends. Please do all that can be done to acquire the funding for continued research quickly along with support for those people dealing with Parkinson's. Thank you.

Marlene Wright

#016 Loki Bailey | Received: June 04, 2026

Please help. My young cousin is plagued by this crippling disease. No one seems to care how devastating Parkinson's is. Please help and please hurry.

[Expletive redacted] PARKINSON'S!!

-Loki Bailey

#017 Sarah Scott | Received: June 04, 2026

Please support all Parkinson's research!

Sarah Scott

#018 Tim C. | Received: June 04, 2026

Please expedite swifter action on Parkinson's Disease. This devastating disease deserves utmost attention.

-Tim C.

#019 Alicia Delano | Received: June 08, 2026

To the Advisory Council on Parkinson's Research, Care, and Services:

Thank you for the opportunity to provide public comment as you begin the critical work of developing the National Plan to End Parkinson's. As the spouse of a person living with Parkinson's disease, I am grateful that this long-awaited effort will be informed by the experiences of patients, care partners, families, researchers, and healthcare professionals.

My husband, Patrick Delano, was diagnosed with Parkinson's disease in September 2025, just three months before his 52nd birthday. Despite living in an area with the resources needed to recognize, diagnose, and treat Parkinson's disease, his path to diagnosis took approximately 18 months, beginning with his primary care physician, followed by neurology referral, and ultimately evaluation by a movement disorders specialist. In retrospect, his motor symptoms were present approximately 6–9 months before he first sought medical evaluation.

This experience reflects a broader and well-documented challenge in Parkinson's care: delays in recognition, referral, and specialist diagnosis. These delays matter. Time lost to diagnostic uncertainty is time lost to education, care planning, symptom management, and appropriate clinical intervention. Earlier recognition and more timely access to specialists could meaningfully improve outcomes for countless individuals and families.

As the Council develops recommendations for the National Plan to End Parkinson's, I encourage you to prioritize:

- Increased education and awareness among primary care providers and the public regarding early signs and symptoms of Parkinson's disease to support earlier recognition and diagnosis.
- Improved access to movement disorders specialists, particularly in underserved and rural communities, to ensure timely diagnosis and expert care.
- A national priority to identify the causes and modifiable risk factors of Parkinson's disease, including environmental, genetic, and occupational contributors, supported by sustained federal research investment. Parkinson's disease incidence is rising, and understanding its drivers is essential not only for treatment advances, but for prevention. The long-term objective must be a measurable reduction in new cases.
- Continued investment in research focused on earlier detection, slowing disease progression, developing disease-modifying therapies, and ultimately finding a cure.
- Expanded support services and educational resources for individuals and families following a Parkinson's diagnosis, helping them navigate the medical, emotional, and practical challenges that accompany the disease.
- Recognition and support of care partners and family caregivers, whose contributions are essential to the well-being, safety, and quality of life of individuals living with Parkinson's disease.

Parkinson's disease is increasing at an alarming rate, affecting more individuals and families each year. The National Plan to End Parkinson's represents a historic opportunity to address both ends of the disease spectrum: improving care and outcomes for those currently living with Parkinson's, while also advancing the research needed to understand and reduce future incidence. Success should ultimately be measured not only in improved quality of life, but in a meaningful reduction in new diagnoses over time.

My husband's diagnosis at such a young age was unexpected and life-changing. While we cannot change our journey, we hope that the National Plan to End Parkinson's will help create a future where individuals receive earlier diagnoses, have greater access to specialized care, benefit from advances in research and treatment, and, ultimately, where fewer families hear the words, "You have Parkinson's disease."

Thank you for your service and for considering the experiences of families like ours as you develop this important national strategy.

Respectfully,
Alicia Delano
Care Partner and Advocate
Haslet, TX

I would like to be considered for an oral public comment opportunity: No

#020 Allison (Allie) Signorelli | Received: 06/08/2026

Date: June 8, 2026
To: National Parkinson's Project ACPRCS
From: Allison (Allie) Signorelli, Young Onset Parkinson's Patient & Advocate
Subject: Public Comment for June 29th Meeting
Via Email: nationalPDplan@nih.gov

Please accept this submission of my public comments for the June 29th meeting of the ACPRCS. I respectfully request the opportunity to submit my comment orally and in person.

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

Congratulations on your appointment to this important Advisory Council. Your time and energy spent on behalf of the more than one million Americans living with Parkinson's and our families, is deeply appreciated.

My journey with Parkinson's began eight years ago as a forty-three year old working mom in the prime of my life. Never in my wildest imagination would I have thought that the tremor I first noticed in my ankle while watching my daughter's high school soccer practice, would lead me to a Parkinson's diagnosis four years later. With no genetic link or obvious toxic exposure, my diagnosis came as a shock.

I was told by several doctors that the condition at my age was "exceptionally rare". In hopes of meeting other young women living with it, I turned to social media. To my surprise, I quickly found dozens of other people my age living with Parkinson's or serving as care partners. And then it was hundreds. And then thousands.

Today, more than 100,000 people follow my work across social media platforms, and millions engage with my Parkinson's-related content each month. I share this not as a point of pride, but as a warning sign. What I've learned since my diagnosis is that I am not rare, nor alone.

I don't have to tell this accomplished, informed, and connected body that people living with Parkinson's need more support, or that the National Parkinson's Project has the power to deliver those urgently needed resources to the community. Prior to my diagnosis, I was an Alzheimer's fundraiser and advocate. I witnessed firsthand the impact of increased federal investment on accelerating research and improving care. As you know, the annual federal funding level for Alzheimer's research now approaches \$4 billion. Parkinson's disease, despite its growing prevalence and devastating impact on patients and families, has not received the same level of urgency or investment.

For too long, Parkinson's has been characterized as a manageable disease that does not significantly shorten life expectancy. This framing fails to capture the reality of living with Parkinson's. Over the past four years, I have traveled across the country and met thousands of patients and families. Along with my own often debilitating symptoms, I have witnessed the struggles of far too many others. Beyond the physical struggles lies a litany of challenges that are often overlooked: job loss, financial strain, mental health challenges, caregiver burden, social isolation, and barriers to accessing specialized care. These realities are not fully reflected in prevalence statistics or longevity projections, yet they profoundly affect the quality of our lives, and of our families.

We must treat Parkinson's with the same attention and investment that we bring to other neurodegenerative diseases. I ask you, respectfully, to think boldly and prioritize substantial increases in federal research, along with improved investments in earlier diagnosis, expanded access to Parkinson's specialists, and vitally needed support for patients and care partners and families.

Most importantly, I implore you to act with urgency. Every day that passes, more Americans join the Parkinson's community. We cannot afford to wait any longer.

Sincerely,
Allison (Allie) Signorelli
Living with Young Onset Parkinson's Disease & Patient Advocate
Arlington, VA

#021 Margaret Preston, President | Received: June 08, 2026

Good Morning,

Thank you for the opportunity to provide public comment regarding the critical need for a coordinated federal response to Parkinson's disease. As the fastest-growing neurological disorder in the world, Parkinson's demands a comprehensive, unified national strategy to accelerate research, improve care infrastructure, and address the massive gaps in services facing millions of Americans.

I urge the NIH, in collaboration with other federal agencies, to prioritize the development and execution of a National Parkinson's Plan, focusing on the following critical pillars:

1. Highlight Gaps in Research, Care, and Services

- Translational Research Funding: While basic science has advanced our understanding of the disease, there remains a critical funding gap in translating these discoveries into disease-modifying therapies and preventative treatments.

- Equity in Care Access: Significant disparities exist in accessing specialized neurological care, particularly in rural and underserved communities. Comprehensive multidisciplinary care models — integrating neurology, physical therapy, mental health, and social services — are rarely covered adequately by current reimbursement structures.
- Environmental and Preventative Research: There is an urgent need for deeper federal research into the environmental triggers of Parkinson's, including the definitive links between agricultural pesticides, industrial chemicals, and the onset of the disease.

2. Underscore the Urgency of a Coordinated Federal Response

Parkinson's disease is not just a health crisis; it is an economic and societal one. The current siloed approach across federal agencies delays progress. Just as the National Alzheimer's Project Act (NAPA) revolutionized the federal approach to Alzheimer's, a mirrored, synchronized effort is required for Parkinson's. We need a framework that seamlessly connects the research power of the NIH, the regulatory pathways of the FDA, the environmental oversight of the EPA, and the healthcare delivery systems of CMS and the VA. Only a mandate for a coordinated federal strategy can match the compounding velocity of this disease.

3. Priorities, Desired Outcomes, and Recommendations

To achieve a meaningful national plan, the following outcomes should be prioritized:

- Recommendation 1: Form a Federal Interagency Coordinating Committee. Establish a dedicated task force including federal officials, clinical researchers, advocacy organizations, and individuals living with Parkinson's to oversee the implementation of the national strategy.
- Recommendation 2: Expand Biomarker and Early-Detection Initiatives. Direct targeted funding toward the validation of early biomarkers to identify Parkinson's before significant neurological damage occurs, drastically improving the success rate of clinical trials.
- Recommendation 3: Build a Robust Caregiver Support Infrastructure. Formulate federal recommendations to provide financial, educational, and mental health resources for family caregivers, who currently bear the invisible brunt of the care crisis.

The Parkinson's community cannot afford incremental progress. We need an immediate, fully funded, and strategically aligned national directive to end this disease. Thank you for your leadership and your commitment to turning this strategy into a reality that will positively impact those living with the disease and the future of this disease.

Sincerely,
Margaret Preston
Margaret Preston, President

#022 Alice Mullamphy, Advocate | Received: June 10, 2026

Public Comment: National Parkinson's Plan

My name is Alice Mullamphy and I have resided in Florida for the past 20 years after retiring from a corporate position. I have become an advocate for neurodegenerative brain diseases, in particular Progressive Supranuclear Palsy.

My late husband, Kenneth, was diagnosed with Progressive Supranuclear Palsy in 2021 after an MRI of his brain was conducted. His symptoms, however, started years before but were looked at as 'the aging process'. It was more than that. The MRI results listed 'Probable Progressive Supranuclear Palsy' with brain characteristics consistent with PSP. Currently, the only way to officially diagnose PSP is by performing an autopsy. PSP is a terrible disease that robs those affected of their quality of life as the disease progresses -- they can no longer function like they used to. When we received this fatal diagnosis, we learned there was no available medication to slow down the progression, much less a cure - nothing. Mainly, treat the symptoms. Not enough research was available due to the rarity of this disease and lack of funding and clinical trials.

My husband's condition continued to deteriorate – at the time of his death (10/29/2024) he had lost half of his body weight, could no longer walk or talk, and just withered away. I was his main caregiver, and hired aides to help with his care. Two weeks before his death, we celebrated our 55th wedding anniversary.

My husband served in the Marine Corps and was assigned to Camp Lejeune during the time when dumping toxic chemicals contaminated the drinking water sources at Camp Lejeune. Even though Parkinson's Disease is eligible as a presumptive

disease by the Veterans Administration, PSP is not, and my husband was denied disability and compensation benefits available to those with Parkinson's Disease even though they were all exposed to the same toxic chemicals.

This brings me to highlight the HEALTHY BRAINS ACT, HR 9233, a push to fund research on environmental risk factors for those exposed to chemicals and toxins introduced by Senator Jennifer Wexton (who is diagnosed with PSP) along with Representative Gus Bilirakis of Florida. Further Representatives are needed to support, endorse and cosponsor this bipartisan Act.

My husband's journey as he traveled through PSP was a long and difficult one for the PSP patient, caregivers, and family. It robs the patient of all quality-of-life attributes with no hope of ever getting better - it is a death sentence. Caring for a PSP patient takes a heavy toll on the caregiver's health, and because it is usually a late-onset disease, it is necessary to get aides to help with care. This is also a financial drain and is emotionally exhausting for all affected by PSP.

Due to advanced age and the shortness of time from diagnosis to death, my husband did not qualify for the few clinical trials taking place. Traveling to doctors appointments or clinical trial sites is very difficult (near to impossible) for these patients, and more Centers of Care, Neurologists specializing in brain diseases, and access to them is so needed. Teleconferencing is not used widely enough, which negates the PSP patient's chance of seeing a doctor. Without more research, clinical trials, access to care, development of early-detection 'tools', establishment of registries to track the number of people with PSP (and other neurodegenerative brain diseases), there will not be a cure on the horizon, or a way to slow down the progression of this dreaded disease before end-of-life befalls these patients.

It is critical to have more focus, funding, research, develop early diagnostic tools, emerging treatments, and therapies for PSP and other neurodegenerative diseases through government sponsorship on the national and state levels to highlight these diseases in the clinical and public awareness environments.

Alice Mullamphy, Advocate

#023 Allen Nixon, CurePSP Volunteer | Received: June 10, 2026

To whom it may concern;

My wife died 9 years ago from PSP. It took over a year for her to be diagnosed with PSP, because symptoms of the disease are used for the diagnosis and many neurological diseases have similar symptoms. Clearly there is a need for a more clinical means of diagnosis (blood work, spinal fluid, etc.). More importantly there is no cure for PSP/CBD/MSA, and I hope the Advisory Council will coordinate and guide government and private resources to develop a cure for these diseases. In addition, the financial burden caused by the medical needs, therapies (Physical, Occupational, and Speech), and healthcare aid one needs can be overwhelming. In the case of my wife, 10 years ago we spent over \$200,000 during the course of her PSP journey. Fortunately, we had the help of long term care insurance, but few people are fortunate to have this insurance.

I am the CurePSP Support Group facilitator for the State of Connecticut, and also a CurePSP peer supporter. As such I am familiar with the needs of caregivers, those diagnosed with these diseases, and their families; finding a cure, proper diagnosis, and ways to obtain financial support, are the top three needs of these persons.

Thank you for all you do and will be doing to help those persons diagnosed with these neurological diseases.

Allen Nixon, CurePSP Volunteer

#024 Amy Budish | Received: June 10, 2026

Development of a wholistic plan for research and treatment is essential.

This plan must include a review of the environmental impacts that might be contributing to the causes of Parkinson's and atypical Parkinson's, as well as the cumulative effects of low levels of toxins that we are exposed to. Currently, it is far too easy for companies to avoid responsibility because it is virtually impossible to prove that a single toxin is directly linked to these disorders. Indeed, it is likely the cumulative impact, over many years that lowers our immune system's ability to respond to the challenges, so we must address this reality.

Thank you,
Amy Budish

#025 Cheri Rolison | Received: June 10, 2026

PSP and CBD are adult-onset neurodegenerative diseases with significant care burdens, no accurate diagnostic biomarkers, no disease-modifying treatments or cures, and an average life expectancy of 7 years from symptom onset. They are often referred to as atypical parkinsonian conditions, yet progress about three times as fast as Parkinson's disease. They commonly cause frequent falls, difficulty with walking, vision impairment, muscle cramping, urinary dysfunction, poor sleep, swallowing problems, changes to voice and speech and many other debilitating symptoms.

I'd like to tell you a bit more about how I have been personally affected by this issue. James Michael "Mike" Hockersmith, was diagnosed with PSP three years ago. He was a father of 3, husband, grandfather, brother, uncle, great grandfather, Army Veteran and my Daddy. He was the most independent man I have ever known, even at 80. He started having trouble remembering things, he was lethargic and falling a lot. His gait changed, he was unable to stand straight up, his balance was horrible, and he lost interest in his favorite past times. It took months to find a neurologist who could diagnosis him correctly. The worst part about this disease is Lack of Awareness. The medical community is not aware of this diagnosis nor how to treat individuals. The lack of awareness is not limited to PCP's. Dentists, Chiropractors, Podiatrists, Specialists, Physical Therapists, Psychologist, Counselors, Psychiatrist, etc... need to know the signs and how to treat individuals with this disease. Our up and coming medical professionals, and teaching hospitals need to be putting focus on PSP/CBD and studying the signs, symptoms, and how to treat. I watched my sweet, loving, and bubbly Daddy deteriorate in front of my eyes. I watched a man who had pride, lose his will to live. He fought hard until the fight took him. He did not want to burden me, my mom, or my brother anymore. He was hospitalized for a UTI and a seizure in October 2025 and continued to decline until he was discharged by ambulance back to his house with hospice. He passed away on November 2, 2025. He would want me to advocate for him and others. His neurologist is at UAB hospital in Birmingham, Alabama. We need awareness in every state at every government level. I now take pamphlets to medical appointments to share information regarding PSP. Although there is no cure, we have our voices and awareness is so important for this fight. My Daddy is my Hero, and I miss him every single day!!!!!!!!!!

Cheri Rolison
Middlesex, North Carolina

#026 Craig Wiullardson | Received: June 10, 2026

My wife has endured a steady and notable regression with CBD since she was diagnosed 8 years ago at age 61. From an active, energetic 61-year old to a near invalid with little ability to speak today. According to the limited literature available on CBD, she is at a very advanced stage of CBD longevity.

Fortunately for her, her general neurologist diagnosed her correctly very early--using a nuclear DAT scan and in-office cognitive testing. Her diagnosis was confirmed multiple times by other specialists. In a Cure PSP support group I belong to, others aren't so lucky with diagnosis and confusing attempts to properly identify the disease among the 3 atypical Parkinsonisms.

Also difficult was the attempts to address her symptoms with traditional PD medication, which had no benefit but difficult side effects. We hope the field has more support and focus in the future. Including any clinical trials.

Craig Wiullardson

#027 Derik Hillman | Received: June 10, 2026

Hello,

PSP and MSA need equal attention to Parkinson's. We need funding for research, awareness and resources for families dealing with these diseases:

Progressive supranuclear palsy (PSP)
Multi Systems Atrophy (MSA)

My father was visibly fine until he rapidly declined in 2 weeks (drooling and hunched over a walker), then died 2 years later at age 80. It was an agonizing journey for our family and especially my step-mother, who was his primary caregiver.

Dementia-related conditions are so broad, and not enough attention is placed on PSP and MSA as distinct problems. While there is some overlap, we need to better understand, treat and seek a cure to prevent PSP and MSA.

Considering the rapid increase in "dementia" diagnoses in recent years, we need to dig deeper and identify that many of these cases could be PSP and/or MSA.

Thanks,
Derik Hillman

#028 Frank Gruber | Received: June 10, 2026

Public Comment

by Frank Gruber
Sioux City, Iowa

My wife, Diane, died from PSP 6 Feb 2025. I was her caretaker. We had so much trouble going from doctor to doctor trying to find out what was wrong with her as her condition worsened. Without a diagnosis, care advice, equipment, and help was not readily available. We had to go to the Mayo Clinic to get the correct diagnosis--almost instantaneously! She was diagnosed with PSP AND CBD as she had pronounced symptoms of both conditions. With a diagnosis we were able to get some medical advice but since these conditions are incurable and untreatable, there was not much help that could be obtained. Hospice did provide much needed comfort for Diane and for me, as the caretaker. With much faith in helping others, Diane enrolled in a trial program at Mayo but the trip there was eventually too rigorous and long for her to keep within the program. She did donate her brain for research at the Mayo Clinic. At her death it was so difficult to find a surgeon that could properly extract her brain. One was found 75 miles away. Upon completion of the brain dissection, it was revealed that Diane did have signs of PSP but no characteristic signs of CBD. Yet, she had symptoms of both? A campaign akin to that of Alzheimer's for brain donation would help research tremendously.

Thank you to the NIH and the National PD Plan for your help and encouragement to rid humans of these Parkinsonian conditions.

Sincerely,
Frank Gruber

#029 Jim Osborne | Received: June 10, 2026

PSP is one of the variants of FTD along with ALS, PPA, CBD, et al.

I urge you to include PSP and the other FTD disorders in your efforts to develop better methods for diagnosis and treatments.

My wife died from PSP three (3) years ago after a six (6) year ordeal. She basically starved to death. Loss of essentially all motor skills is the norm for PSP; she required full time care for almost six (6) years during which time she could not walk, talk, or eat, and ultimately she even lost the ability to swallow. She had two brothers with Parkinson and another brother with PSP. Obviously, all were genetically related in some way so development and approval of gene modification through use of CRISPR or other similar technology would be ideal. Otherwise, treatment of symptoms through drug therapy is urgently needed.

My major concern is for my children and grandchildren and all succeeding generations. It is a horrible disorder, and at present there is no known treatment.

Other considerations for caregivers under Medicare and/or tax allowances would be welcome.

Thanks in advance for your help advancing the technology and improving the knowledge necessary for treatment of these horrible, debilitating disorders.

Jim Osborne

#030 Laurie Barr | Received: June 10, 2026

Public Comment Submission - Advisory Council on Parkinson's Research, Care, and Services (ACPRCS).

Hello,

My mother's health issues began in 2018 but quickly led to what I call the "whack-a-mole" game of symptoms that by 2019 I had quit my job as an executive of a large hospital system to care for her because I could no longer juggle everything. In the early days of COVID, we moved her in with us and it was then that we realized how bad things were getting. Falls, pneumonia, cognitive decline, and a vascular dementia diagnosis ultimately led to the heart wrenching decision that she could no longer live independently. In the summer of 2020, she moved into assisted living. In 2020, I took her to 81 medical appointments, and that didn't count the appointments my brother, sister-in-law, husband, or a private care giver took her to.

2021 through 2022 brought more falls, more bouts with pneumonia, so many issues with her bladder, urinary tract infections, muscle cramps, double vision, trouble swallowing and suddenly the start of tremors. Just when one symptom arose and we were being referred to another specialist to treat it, another issue involving a different part of her body would arise. Even me, someone who had spent my entire career, in leadership roles in hospitals and medical groups, felt overwhelmed by managing it all. It was heartbreaking to watch my once independent, vibrant, and positive mother have challenges with her judgement, executive functioning, and noticeable cognitive decline, not to mention have to use a walker, a wheelchair and then a scooter to get around. In early 2023, she was diagnosed with Progressive Supranuclear Palsy...something we'd NEVER heard of before. When I first read the description, I could literally check off every single one of her symptoms. Suddenly everything that hadn't made sense, started to make some sense. By late 2023, Mom was wheelchair bound, had a catheter and was oxygen dependent. She passed away during spring break in March of 2024 after the progressive decline of her various diseases.

When I was a care partner for my mom during this period of my life, I felt alone and isolated, and so ill informed. There is so little information about this disease as well as CBD and MSA, which are similar diseases. There is very little known about them and there is a desperate need for increased research funding and targeted disease awareness. My mom encouraged me to write a book about our journey...about her disease journey of having PSP and about my journey of caregiving for her with this disease. There was so little information out there about the disease when we first learned about it that we had trouble finding out information about it. I did that last year, and my book is now available for others who are travelling this painful journey. I now also give back by volunteering my time supporting other care partners through CurePSP and the Parkinson's Resources of Oregon group as a Support Group Facilitator and Peer Advisor. It's the least that I can do.

I attended the World Parkinson's Congress last month in Phoenix, AZ. I spent three days there as a volunteer in the Family and Care Partner classroom. It was a privilege to spend my time supporting others who are care partners to those who are dealing with Parkinson's disease. There were close to 4000 attendees – a mix of clinical providers, researchers, care partners, and people with Parkinson's diagnoses (PD). As I walked through the halls of the convention center, I wondered how many in attendance had been diagnosed with PD, but who instead have PSP, CBD, or MSA. As I understand it, as much as 10-20% of people with one of these diseases are initially diagnosed with PD. We need education for neurologists about these rare diseases and for patients and the public, so they know what to look for. We need funding for research so that we can find better treatments so that we can slow down the disease progression. Please help by supporting this work.

Thank you for your time.

I am interested in providing oral/virtual comment during the ACPRCS meeting if that would be helpful to these efforts.

Laurie Barr
Wilsonville, OR
Author of The Long Fade to Morning

#031 Melissa Ackerly | Received: June 10, 2026

Mom is fighting PSP-31 years as an educator
Dad's mom died with Parkinson's-30 years school cook

We must start mixing Levadopa with brain foods and find a cure. Make a smoothie powder.

Jasmine matcha - highest levels of EEG

Turmeric - anti inflammatory

Beets

Nuts

Salmon

Berries

Kale

Spinach

Please for education, for health, for family. I beg you NIH on behalf of Wexton, my family, and our future.

Patient Advocate,
Melissa Ackerly

#032 Molly Kelly, PhD | Received: June 10, 2026

To Whom It May Concern,

I would like to express my deepest conviction that additional funds and resources must be allocated for research on Parkinsonism diseases. Specifically, rare and low incidence conditions like Corticobasal Syndrome desperately need more attention focused on them with dedicated efforts towards understanding the etiology and designing interventions. Corticobasal Syndrome is a devastating diagnosis leading to neurological degeneration and death. Studying this disease will no doubt have links to other Parkinsonism conditions. My dearest friend was diagnosed with this condition at the age of 65 and she has become an active advocate for finding the etiology and a cure. She has generously donated her time and tissue to the few research efforts focused on her condition.

Please focus attention on Corticobasal Syndrome as a part of this important Advisory Council on Parkinson's Research Care and Services. I am grateful for your consideration regarding this life and death matter.

Sincerely,
Molly Kelly

Molly Kelly, Ph.D.

#033 Renee Bryan | Received: June 10, 2026

Oh how I would love to scoop up one of my grand buddies!

I would love to walk with them holding hands or running in the grass!

I require both hands on my rollator and hope that I don't fall...

I pray everyday to maintain my balance.

I had five falls last month. So far only bruising and a hurt pride.

Renee Bryan

#034 Snaoli Basu | Received: June 10, 2026

Public comment

To the Advisory Council on Parkinson's Research, Care and Services

I am writing as the wife and caregiver of a man in his mid-50s living with Progressive Supranuclear Palsy (PSP).

My husband was initially diagnosed with Parkinson's disease in December 2023. As time went on, he developed worsening eye movement problems, dizziness, instability, backward falls, and severe neck pain. Because he had a history of cervical spine issues, we spent months searching for answers. He underwent CT scans, brain MRIs, cervical MRIs, and vestibular testing. Yet none of these tests could explain why his symptoms were getting worse.

In December 2025, his neurologist suspected PSP and ordered another brain MRI. This time, changes in the midbrain were found, and the diagnosis of PSP was confirmed. Two additional PSP specialists later confirmed the diagnosis. Although we finally had an answer, it was devastating to learn that there is currently no treatment that can stop or slow this disease.

Watching someone you love disappear piece by piece is heartbreaking.

My husband has suffered multiple backward falls, including one that caused a concussion. Reading books and working on a computer, things he once enjoyed every day, have become extremely difficult because of his eye movement limitations, even with prism glasses. He struggles with swallowing, jaw stiffness, severe neck stiffness, cervical dystonia, urinary urgency, and nighttime accidents. Every day seems to bring a new symptom, a new limitation, or another loss of independence.

PSP has taken away so much from him. It has affected his career, his social life, his ability to enjoy food, his hobbies, and the simple routines most people take for granted. I see him living with physical pain, emotional pain, and frustration as his condition continues to deteriorate. It is incredibly difficult to watch someone who was once active and independent slowly lose control over so many aspects of daily life.

We are doing everything we can to help him. He attends physical therapy, occupational therapy, speech therapy, and facial rehabilitation therapy. These therapies provide temporary relief and help him cope with some of the challenges, but they do not stop the progression of the disease. Despite all of our efforts, we continue to watch his mobility, communication, swallowing, and quality of life decline.

One of the hardest realities we face is the lack of treatment options and the limited availability of clinical trials. We have contacted multiple centers searching for clinical trial opportunities because clinical trials represent our only real hope for the future. Unfortunately, we have found very few opportunities available to him. The medications and treatments currently offered only provide temporary symptom relief. They do not change the course of the disease.

Families living with PSP cannot wait. Every day matters. Every month matters. While researchers search for answers, patients are losing abilities they will never regain.

I urge the Council to prioritize increased funding for PSP research, development of disease-modifying treatments, expansion of clinical trials, earlier and more accurate diagnosis, and stronger support for patients and caregivers. We desperately need treatments that do more than manage symptoms. We need hope. We need therapies that can slow, stop, or prevent the progression of this devastating disease.

Thank you for listening to the voices of families affected by PSP and for ensuring that this rare but devastating disease remains part of our nation's research and healthcare priorities.

Sincerely,
Snaoli Basu
Caregiver and Wife of a PSP Patient

#035 Tim Brown | Received: June 10, 2026

My name is Tim Brown, and I have been living with Progressive Supranuclear Palsy (PSP) since 2014. My diagnostic journey began with a dementia diagnosis, followed months later by confirmation of PSP along with frontotemporal dementia, behavioral variant (FTD-bv1). This staggered process is common for people with atypical parkinsonism, whose early symptoms are often misunderstood or overlooked. These delays cost families precious time and highlight the urgent need for better awareness and earlier recognition.

Living with PSP means facing progressive loss — mobility, balance, speech, swallowing, and independence. Access to knowledgeable clinicians, coordinated care, and clinical trials remains limited, leaving many patients and caregivers without the support they desperately need.

I urge the ACPRCS to prioritize earlier diagnosis, targeted research funding, biomarker development, and improved access to specialized care. People living with PSP, CBD, and MSA deserve recognition, urgency, and meaningful investment in their future.

Tim Brown

#036 Chris Storey | Received: June 11, 2026

My name is Chris Storey, and I am the son of a man who has been living with advanced Corticobasal Degeneration (CBD), a rare and progressive parkinsonian disorder, for the past 15 years.

Today, my father requires around-the-clock care. He can no longer communicate, has lost more than 95% of his gross and fine motor skills, has severe limitations with vision and hearing, and depends on others for feeding, toileting, mobility, and nearly every aspect of daily living.

Watching someone you love slowly lose their independence, abilities, and dignity over many years is heartbreaking. Seeing him no longer able to find joy in life, including in the presence of his beloved grandchildren, is even more painful.

While the physical and emotional toll of this disease is immense, the financial burden on families is also overwhelming. Long-term caregiving, medical needs, and support services create significant stress for families already struggling to cope with the realities of a devastating neurological condition. The lack of public awareness about CBD makes these challenges even greater, as many families feel isolated, overlooked, and without a clear path forward.

I urge policymakers and decision-makers to increase awareness, research funding, caregiver support, and resources for individuals and families affected by rare neurodegenerative diseases such as CBD, PSP, and MSA. No family should have to face these challenges without adequate support, recognition, and urgency from the federal research and care community.

I would also be willing to provide verbal testimony and share my family's experience to help raise awareness about the realities of living with and caring for someone with advanced CBD.

Thank you for your consideration.

Chris Storey
President and CFO
Silver Creek Midstream Holdings, LLC

#037 Loren D. Porr, Lieutenant Colonel (Retired), U.S. Army | Received: June 11, 2026

Our journey with PSP began in 2011 when my wife, Nancy, periodically presented with slurred speech, loss of handwriting legibility, general stiffness and confusion. Episodes lasted 1-2 weeks with the time between episodes varying from a month to multiple months. We saw multiple doctors in Brunswick, Maine and were referred to Mass General. Both diagnosed this as Functional Neurological Disorder (FND) which ultimately was a misdiagnosis. We found later that this was a "catch all diagnosis" when they could not identify the problem causing the symptoms. During this time and despite these symptoms, Nancy and I volunteered for medical missions in Central America and the Caribbean. As an Army Reserve Nurse and Nurse Practitioner, missions took her to Central America, South America and First Nation Reservations. She retired from the Army Reserve as a Lieutenant Colonel in 2011 with 27 years of service, 4.5 of which were Active Duty. In 2016 she went to Vietnam for 7 weeks to train nurses in American nursing. I joined her for her last two weeks and we celebrated our 40th Wedding Anniversary there together. In 2017-2018 she was diagnosed with Breast Cancer and with surgery and chemo was cured.

In 2018, FND symptoms began to present as Progressive Supra-Nuclear Palsy. Between 2018 and 2024 Nancy presented with falls, imbalance, inability to look downward with her eyes, loss of any handwriting ability and other PSP symptoms. In three of her falls she broke her collarbone, fractured her clavicle and broke a knee cap into four pieces. She was able to recover from all three. We continued to look for a cause and treatment. Ultimately doctors in Mass General settled on a diagnosis of PSP but could do nothing about it. Between 2018, the pandemic and June 2023 we coped and looked for answers. There were none. Nancy entered CHANS Hospice (an organization she once worked for) in July 2023. She died on January 8, 2024, four days longer than the unofficial six month goal for Hospice Care. She was the consummate nurse.

The timing of our journey does not match up with the 5 to 10 year PSP model and is cluttered with FND, cancer, the pandemic and hospice.

You have my thoughts and prayers that increased funding results from this effort.

Loren D. Porr
Lieutenant Colonel (Retired), U.S. Army

#038 Ekaterina Fomicheva, PhD | Received: June 12, 2026

Dear ACPRCS Members,

I am writing today both as a daughter and as a molecular geneticist. My mother was never diagnosed with PSP. She lived for years with a textbook clinical picture that no clinician named, and our family was left to navigate her decline without a label, without a care plan, and without hope.

My mother's posture, her unexplained falls, the way she stared without blinking, and her stiff, backwards-leaning walk were a textbook picture of PSP. I later saw her 80-year-old friend walking with the exact same stance, and I knew it again. Yet no doctor named it for years. Instead, she was treated for other psychiatric diseases given medications that made her worse, and we were told her struggles were hormonal or psychological. PSP has a recognizable clinical signature—we urgently need education and accessible diagnostic tools so no family has to recognize it by accident, watching a friend walk by, before a professional does.

As a molecular geneticist, I now understand that the science behind PSP, MSA, and CBD is at a pivotal moment. Discoveries in tau biology, neuroinflammation, special genetics X chromosome and novel pathways offer real paths to therapy. But these discoveries will not translate into treatments without sustained federal investment in academic research that is specifically targeted at atypical parkinsonisms—not just Parkinson's disease.

I urge the NIH and the ACPRCS to prioritize dedicated, expanded funding for basic and translational research on PSP, MSA, and CBD, and to ensure these diseases are visibly integrated into the National Parkinson's Plan.

If my mother's story can help shape that commitment, I would be willing to share a 2-3 minute oral comment during an upcoming ACPRCS meeting, virtually.

Thank you for the opportunity to speak up.

Sincerely,
Ekaterina Fomicheva, PhD
Ann Arbor, Michigan

#039 Michelle Graham | Received: June 13, 2026

Hello All,

Here is my public comment:

My mother was recently diagnosed with PSP after living with symptoms since 2017. She has vertical gaze palsy, frequent falls, brain fog, slurred speech, trouble swallowing, etc. However, in 2023 after having a normal DAT scan, doctors said she must not have it. We were told she probably has Functional Neurological Disorder instead.

We didn't believe that and continued to search for answers. Every MRI and other tests kept coming back normal. We had a 2nd DAT scan in 2026, and this time it came back abnormal. Finally doctors accept the diagnosis of probable PSP.

I would like the medical community to learn from this and please not dismiss symptoms. Before DAT scans existed I presume my mom would have been diagnosed with PSP. Just because the first test was negative doesn't mean it was correct. Or maybe for some people damage in the brain doesn't show up by the 6-year point. Sometime between year 6 and 9, it finally showed for her.

Thank you,

Michelle Graham
Daughter of Patient of PSP

#040 Todd + Suzanne Jones | Received: June 14, 2026

I would encourage lawmakers to adopt whatever measures necessary to address psp msa and Parkinson's, imagine being fine one moment and after Covid and four Covid vaccines you start having movement issues, pain and stiffness. After visiting half

a dozen doctors you have a neurologist wave their finger in front of your face and tell you that you have Parkinson's and your wife has psp and there is no cure.

I'm not sure saying anymore clarifies the helpless feeling when the best advice you get is to stay active when that's what we'd all like to do.

life in the slow lane, living in denial, dealing with reality, trying to stay optimistic about the future.

Please help shape our future.

Todd + Suzanne Jones

#041 Frank Xavier McGrath | Received: June 15, 2026

Public Comment Parkinson's Disease:

Veterans are affected by Parkinson's at a disproportionate rate! Since they receive care at VA Medical Centers it would be beneficial to have more control studies through VA! Not a lot of positive hope about VA research or any research at all is provided by VA! I have Lab records close to perfect! Prescriptions are either of no value or make me dizzy! Sometimes I just feel like I am being warehoused! No cure of course, but no history of any VA successes! It will require appropriations through Congress for the studies and Care Giving to take place! I believe making extreme efforts (above and beyond our call to duty), to find a cure will give added value to our efforts! Like the former Congresswoman I am suffering from PSP! I don't have a lot of time, and appreciate your efforts! If you need additional information please let me know! Let's make things happen in an AI world!

Frank Xavier McGrath
VAMC Long Beach CA

#042 Mike Hedges | Received: June 15, 2026

Hello, I would like to start off by thanking Congresswoman Barragan for bringing such an important advisory council to my attention. I will make this message short but as we know Parkinson's disease is anything but that.

My father was not who you would expect to have a form of Parkinson's disease called Lewy Body Disease that is the buildup of alpha-synuclein proteins (Lewy bodies) in the brain. It includes two clinical types. Dementia with Lewy Bodies and Parkinson's Disease Dementia.

My father was a Special Forces Green Beret, A Los Angeles County Sheriff and worked for the United Nations upon retiring. The disease from diagnosis to death was a brutal and long nine and a half years with my father passing in 2019 at 74 years old. I was there for the entire journey and hoped to never have to experience such a horrible disease again and now my long time friend of over 20 years was diagnosed with Parkinson's disease three years ago at 55 years old. He is a Husband, a father, a small business owner that has been active his entire life and now knows it is a progressive disease that will slowly take his "quality of life" and ultimately one day take his life. I applaud you for your efforts as there are so many people in the world that have experienced and will experience this horrible disease.

(I would be open to sharing orally or virtually if needed)

Sincerely,
Mike Hedges

#043 Amy Greenman | Received: June 16, 2026

My sister has PD. She may not see the end of this year. We live about 1,000 apart. I don't have a lot of money to travel, but I'll do what it takes to both see her and help her.

The last time I visited was in January. When I went to see her, I had trouble understanding what she said. Two of my other sisters have seen her since and they say she's worse now.

It must be maddening to have brain function at 100%, yet be unable to communicate or even go to the bathroom by yourself. My question is what can I do to help her?

Thank you,
Amy Greenman
Orlando, FL

#044 Ana Pease | Received: June 16, 2026

Hello,

I received an email from our representative, Nanette Barragan, regarding Parkinson's research. I want to comment on my Uncle's journey here in Los Angeles, specifically Boyle Heights.

I want to start by saying that Parkinson's resources in largely hispanic, black and other minority neighborhoods is slim to none. We have gone through so many referrals, misdiagnoses, opinions and so much time has been wasted. We were finally able to get into Cedar's Sinai Neurology department and the team of doctors could at least establish a hypothesis that made sense based on the multiple doctors appointments he has had. Months later we are still waiting for an MRI for a follow up appointment. So they are not exactly fast either.

This has been so incredibly frustrating and unfair. Your care is largely dependent on where you live. But modern medicine is not equipped to deal with the influx of Parkinson's related disease. We are seeing more and more cases - not caught early and when it's finally diagnosed, it's essentially too late.

Something has to change. Medicine has to be more preventative rather than reactive. I truly hope that more research is dedicated to this epidemic of disease.

Best,
Ana Pease

#045 Annette Mathers | Received: June 16, 2026

My husband battled with this disease for 23 years. The last 5 were heartbreaking. He passed away last year. This disease has taken the love of my life away. As a full time caregiver I ask you to find a cure.

Sincerely,
Annette Mathers

#046 Brian Rogers | Received: June 16, 2026

I live with the effects of Parkinson's Disease. I have been a healthcare professional provider for all of my 50 year career. I would still be a provider had I not felt the effects of Parkinson's on my daily life. Up until 2025 I volunteered my services at Upstate Medical Center in Syracuse NY. I am an advocate for treatment and advances in medical research through the work of the MJF Foundation. Research is needed to try new treatments, that will be made available through NIH.

Please support this important research.

- Brian Rogers

#047 Cindy Mitchell | Received: June 16, 2026

June 16, 2026

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

Submitted electronically: nationalPDplan@nih.gov

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman and Members of the Advisory Council,

I am writing to share my comments regarding the National Plan to End Parkinson's. Please accept this email as my official public comment for the upcoming meeting on June 29, 2026. My name is Cindy, I live in Los Angeles County in California. I am writing in memory of my mother, who was diagnosed with Parkinson's in her early 50's and lived with it until age 80. Although my siblings and I had moved out of the family home before her diagnosis, this disease deeply impacted our entire family for decades.

My mother suffered terrible side effects from conventional prescription medications. Unfortunately, insurance covered such limited options for her well-being throughout the disease, in the end stages, and when on hospice. This underscores the urgent need for federal funding to validate and expand insurance coverage for non-pharmacological, holistic care modalities.

Furthermore, I implore the Council to prioritize robust support, financial help and respite care for families acting as caregivers. For years, my mother required intensive, 24/7 supervision and care. The physical, emotional, and financial strain of around-the-clock family caregiving is immense. The National Plan must include infrastructure that provides resources and support for the families sustaining these patients that age in place with this disease. In addition, it must include an alternative to support those living with PD who do not have family available to help them.

Key concerns or priorities: Putting the plan into action is what matters most. A strong national plan needs clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

Recommended actions:

- Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.
- Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.
- Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

Sincerely,
Cindy Mitchell
West Covina, California

#048 Colin Gibney | Received: June 16, 2026

Hello,

I'm writing at the request of Jessica Shurer, CurePSP's Director of Clinical Affairs and Advocacy, who provided my wife and I with invaluable information, advice, and a caring ear during and after our PSP/CBD journey. You have my permission to, and I truly hope you will, share any part of my story during the public comment section of your upcoming meeting on 6/29. In addition, I'm also interested in providing 2-3 minutes of oral/virtual comments if your agenda/time permits.

The work of this committee is of the utmost importance to me. Sadly, my wife passed away from CBD on January 30th, 2026 at 60 years of age. She was diagnosed with PSP less than two years prior in 2024. PSP remained her clinical diagnosis until a brain autopsy showed unequivocally that she had CBD. Delayed and misdiagnoses are not uncommon with these diseases and the toll this takes on families is all too great. Unfortunately, my wife died when she had breathing difficulties during sleep, and breathing problems are more typical of CBD than PSP. If we had a CBD diagnosis while she was alive, I would have been more focused on monitoring her breathing (in addition to the choking and falling hazards associated with PSP) ... and if this were the case she still might be with me today.

She had none of the known biomarkers for PSP or CBD. Her disease came on completely unexpectedly, as she was otherwise healthy and active. She was a force of positive energy who faced every day, even our toughest, with a smile and a zeal for living. Her quick progression and loss is still shocking to all who knew her.

Clinical trials gave us some short-lived hope. We participated in two NIH funded clinical trials (one at U Penn and the other at MGH) in addition to attending a host of daily medical and rehab appointments. Unfortunately, even though we experienced hopeful moments, it quickly became clear that each trial offered no match for the disease's unrelenting progression -- and each trial was a failure for us. Her progression was more rapid than average and her loss of function was measured in weeks and months, not years, as is the typical case. Life expectancy can range from 5-7 years with great case by case variation (again, my wife died just short of 2 years after her original PSP misdiagnosis).

I continue to do advocacy work through CurePSP and AFTD in hopes that other families and their loved ones will not have to face what we've faced. No family anywhere in the world should have to face a situation like this, but especially in the US today

given our formidable resources to solve complex health problems. One of the main motivators for my ongoing advocacy work is the Healthy Brains Act (H.R. 7779, currently a bill in the US House). This act promises to establish centers for data collection, research into genetic markers and potential causal factors in our environment, as well as dissemination of information and resources to families and patients who have been told they are facing a rare and irreversibly fatal disease. The act will also make ongoing and future clinical trials of promising new drugs more widely known, so that more folks can participate.

There are so many facets to my story as these diseases impact all aspects of life and death. My wife had been a successful healthcare professional but had to leave her practice as the disease began to steal away gross and fine motor function, balance, and speech. Falling and choking became daily hazards, and simple activities like dressing, eating, or expressing her thoughts quickly became arduous and then impossible without help. I left work in 2025 to become her full time care partner. Our enjoyment of social and family life were greatly diminished to say the least.

Lastly, it's important for you to know that there are aspects of the government safety net that worked and were there for us -- and for this I am grateful. We were fortunate to be fast tracked for Social Security Disability, and we were able to access excellent care in Portsmouth NH at Wentworth Douglas Rehab and in Boston at Mass General Hospital. From what I've learned from others, this level of care of support is clearly not the case for many/most folks facing PSP/CBD and I don't think that's fair.

It is my sincere hope that sharing all of this with your group will help further your understanding of the lived experience of those facing these diseases firsthand and that this will make clear the critical need for increased research funding and targeted disease awareness.

I am more than willing to provide any additional information that may be helpful as you embark on this very worthwhile journey.

Sincerely,
Colin Gibney
Portsmouth, NH

#049 Craig Swift | Received: June 16, 2026

public comment

I encourage you to make meaningful commitments to ending Parkinson's and finding a cure. I lost both my Grandfather and Father to Parkinson's over a 15 year period. Both were farmers in Iowa and I strongly believe that their exposure to dangerous pesticides and herbicides over the years gave them their condition. We need a commitment to ending this horrible degenerative disease and fighting back against companies that persist that these chemicals are safe. They are not - and plenty of countries in the EU have banned their use for this very reason. I encourage you to do what is right, not what is easy and to make our farmers and food supply safe.

Craig Swift

#050 Cynthia Bournellis, CWAS | Received: June 16, 2026

Parkinson's deserves more attention. My personal connection to the disease began with my mother, who suffered from 2008 to her passing in 2023. She was a smart, viable, capable woman prior to the disease, which slowly took her down. Parkinson's medication is a double-edged sword: while it helps to some degree, it also deteriorates the mind. My mother suffered the side effects from the drugs: anxiety, depression, paranoia and, worst, hallucinations. While access to care was okay, her doctors really couldn't do much except tweak her drugs to address the changing symptoms. Furthermore, her doctors weren't very hopeful about the disease, which would only depress her further.

After doing home care for a while, my mother finally had to go into assisted living, where she kept falling and became confused about her new environment so the facility gave me no choice but to put her in the memory care unit, which was not equipped to deal with Parkinson's.

The disease is brutal and the medications, unfortunately, are not cures (only band-aids). Watching the disease take down my mother was heartbreaking.

Thank you for hearing my story and for fighting to end this disease.

Regards,
Cynthia Bournellis, CWAS
Certified California Wine Appellation Specialist, with Honors

#051 Dave McFarland | Received: June 16, 2026

This correspondence is a public comment on the National Plan to eliminate Parkinson's. My story begins by saying I enjoyed 50 some years of good health. In my late 40's or early 50's I lost my sense of smell which was attributed to numerous sinus infections at that time. Around this same time, I started having anxiety problems in social settings as well as in stressful situations. At 66 years of age, I experienced a tremor in my left arm with no apparent reason for its existence. I saw a neurologist who told me I had Parkinson's and that the loss of smell, anxiety, and tremors were all symptoms of this disease.

Over the last 7 years I have experienced the following physical symptoms: Constant tremors in the left arm that vary in intensity from day to day. Diminishing dexterity in the left hand and fingers. Loss of strength in the left arm and hand. Rigidity in the left arm and fingers which comes and goes. My voice has gotten softer. Loss of smell still exists which makes most food harder to taste as well. My left leg is not lifting up frequently which causes me to drag my left foot. I have nightmares and act out dreams in my sleep.

All of these symptoms effect my life in some fashion: I have trouble getting my left arm in a shirt or jacket. I then have difficulty buttoning that shirt. I drop things all the time. It is difficult to bathe if I need to use my left arm or hand to do so. It is really frustrating to lay down to go to sleep at night only to have your arm tremoring that much that your whole shoulder shakes, making it hard to go to sleep. Anxiety has had a real impact on my life. I tend to avoid social situations since the anxiety in these situations causes my tremors to increase in intensity. I also have eliminated my driving since the anxiety in stressful driving situations causes the tremors to be unmanageable.

I see a neurologist every 6 months who has prescribed two different prescription meds to help cope with the symptoms. The meds do help but the prognosis is the same: the symptoms will get worse over time. It is just a matter of how much worse and how fast. The meds are costly as most prescriptions are. Exercise is suggested as an important tool to use to slow down the progression of this disease. I am currently using a personal trainer 2 times a week for a half hour each session to work on slowing the progression of my symptoms. I walk almost daily as part of my exercise regimen.

That is my story. I encourage the Advisory Council to work toward a cure for the growing number of people who are suffering from the many physical and mental problems associated with Parkinson's.

Sincerely,
Dave McFarland
Manheim, PA

#052 Debbie Geary | Received: June 16, 2026

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

This is a public comment regarding my experiences as a part-time caregiver for my mother who developed Parkinson's in her 70's.

This disease robbed my mother of so much until she died from Parkinson's, I believe, in 2017. Mom had much to live for with her four living children, fifteen grandchildren, and adoring husband.

When she was first officially diagnosed at a hospital in Chicago, she was having trouble with walking and balance. This proceeded to get worse along with her true fear of falling. Since my parents lived in a two story house a lift was put in for most of the stairs but some additional stairs wrapped around. We had to be there to support her due to her fear of falling as we weren't going to let that happen. Unfortunately, one night she needed to use the bathroom and my father was downstairs. She fell and broke her hip. Surgery and recovery was at a hospital in Chicago then when released she spent several days at the Rehab Institute of Chicago. After that, her fear became so bad that before a couple of doctor appointments we had to call the Chicago Fire Department to get her out of the house due to the five outside steps. Most of the doctor appointments were 40 - 60+ minutes away. Unfortunately, there was not much that could be done for my mom.

As the disease progressed and as soon as possible, we moved our parents to a ranch home and hired a full time caregiver, but my sister and I continued to be helpful and supportive. We watched as she spent her days sitting in a chair all day unless we took her to the porch in a wheelchair, for a drive, or to the doctors. When she still had the use of her arms she would call relatives and friends to pass the time, but then she lost the use of her arms and her voice became very weak which ended her calls with the outside world. She had trouble sleeping because of the constant tremors in her arms which made things worse. Mom also lost the ability for any facial expressions. It was just heartbreaking to see this happening to someone you love with all your heart!

No one should be afflicted with this terrible disease! We need more research and services to find a cure for the many people who have this.

Thank you for taking the time to read this public comment.

Respectfully,
Debbie Geary
Woodridge, IL

#053 Deborah Short | Received: June 16, 2026

I am writing to share the story of two important men in my life: my late brother, John, who passed away in 2022 after living with Parkinson's disease for 15 years, and my cousin, Frank, who has been living with the disease for a decade.

Their fathers worked at a laundry & dry cleaner in Chicago for decades. When the boys, who were very close in age, became old enough to work they would spend their summers working with their dads. Unbeknownst to them, they were all being exposed to dangerous chemicals on a daily basis.

Given that Frank was adopted and shares no biological relation to our family, we believe their shared diagnosis is linked to their environment rather than genetics. Specifically, I am concerned that their exposure to dry cleaning chemicals during those years contributed to their condition. My father and uncle passed away relatively young. My dad died at 57 due to lung cancer, and my uncle in his mid 60's due to a heart attack. I often wonder if they would have faced similar neurological challenges had they lived longer.

It is my hope and fervent prayer that we will continue to see progress in finding a cure and that harmful chemicals linked to this devastating disease will eventually be banned. I am deeply encouraged by the work being done by the Michael J. Fox Foundation and will continue to support your efforts. Thank you for your commitment to this fight.

Best regards,
Deborah Short

#054 Deirdre Barbosa | Received: June 16, 2026

I am submitting this public comment as someone whose older sister is living with Parkinson's disease.

My sister is not only my sister. She is an important part of my children's lives. She helps care for them, watches them after school, and transports them when needed. As her Parkinson's progresses, these everyday things are becoming more and more difficult for her. Thankfully, my children are getting older and do not need as much physical assistance as they once did, but they still need her. They love her. She is part of their childhood, their routine, and their sense of family.

One of the most heartbreaking parts of this disease is hearing my sister fear that she may not be alive to see my children graduate and go on to do great things. As their mother, that breaks my heart. It brings tears to my eyes just thinking about it. My children should not have to quietly wonder how much time they have left with someone who has helped care for them and loves them deeply.

I worry about my sister every day. I will do everything I can to help her and make sure she has the best quality of life possible. But I can see the toll this disease takes on her physically and emotionally. I understand why it can lead to depression, fear, and hopelessness. It is very hard to keep trying to be positive for her when I know that, no matter what I say, at the end of the day she is the one suffering.

This is why the National Plan to End Parkinson's matters. Families need more than sympathy. People living with Parkinson's need better treatments, better support, better access to care, and real progress toward slowing, stopping, preventing, and curing this disease. Caregivers and family members also need to be seen, because Parkinson's affects entire families, including children.

Please make this National Plan meaningful, practical, and fully supported. Please listen to the families living with Parkinson's every day. We need urgency. We need action. And we need hope that is backed by real progress.

Deirdre Barbosa

#055 Elida Rodriguez | Received: June 16, 2026

My name is Elida Rodriguez and live at San Antonio, Tx.

I was a caregiver for my Vietnam Veteran, Joe, up until his recent death on 3/1/2026. Joe was diagnosed with Parkinson's due to his Agent Orange exposure in Vietnam. He suffered with the disease well over 10 years. As his wife and caregiver, I was a witness to everything Parkinson's did to his mind and body. He was being followed by the VA however, many appointments that were scheduled with his neurologist, were constantly cancelled. He did not have consistent visits which I feel would have helped in managing his condition a lot better. It was primarily treated with medication. He received some physical therapy upon my insistence. They never suggested physical therapy on a consistent basis to help his body not be stiff and stay flexible and/or assist him with his balance. This should have been part of his treatment plan because Parkinson's does not get better, it only gets worse. Unfortunately, because of his constant back pain and weakness, he always had to cancel some sessions and was unable to complete them due to illness. We did not have a social life. His body was having more and more tremors and/or shaking that he often compared himself to a "bobble head" that is placed on a dashboard and was embarrassed to be among people. I saw a man that use to be a workaholic become weak, tired, depressed, and sad. I don't know how many veterans have been diagnosed with Parkinson's but, the VA does not seem to take this disease seriously. It also caused him memory issues. When he started to get sicker, the disease caused his body to be too weak to withstand the heart infection he got. I witnessed my husband of 42 years die on 3/1/26.

More research is needed specifically dealing with Veterans. These men and families sacrificed so much for our Country and they CANNOT be forgotten or ignored. Hopefully, my written input will help. If any more information is needed, please do not hesitate to reach out.

E, Rodriguez

#056 Ellen Cantor | Received: June 16, 2026

I support the government's effort to bring awareness to Parkinson's Disease and also the work that is being done to improve our knowledge of the disease and how to live with PD.

I am particularly interested in information on the LRRK2 gene and would like to be included in information coming out of this committee.

Thank you
Ellen Cantor

#057 Fire Chaplain Lee R. Longe | Received: June 16, 2026

Good day,

I am a caregiver for my wife, of 37 years married. She worked in the food marketing world, was an Activity Director at a nursing home, then became a school para, down here in Georgia. Glenda was diagnosed with PSP, well over 6 years ago, at Emory in Atlanta.

I was still able to work until over 4 years ago, when I had to retire to become a 24x7 caregiver. I must add after having been in the firefighting field, in the Marine Corps, an EMT, in politics, this has had to have been the one of most challenging activities I have ever had to endure.

I have learned a great deal about PSP, read a good many a written book, by caregivers, or folks suffering with the illness, like Tim Brown of Canada, who wrote several books, during his walk with this illness. In the meantime I have become an advocate for PSP/CBD/MSA, becoming the nucleus for Resolution/Proclamations in the states of Vermont/Maine. As well being an active member with several sub-committees, anchored with CUREPSP.

My mission is to bring AWARENESS to both the medical and general public world. I seek no recognition, but want to partner with others, in getting the word out there. I am proud to be vocal person, for Glenda and others. The downside, is I miss Glenda, my best friend, helpmate, my wife. Thank you.

Fire Chaplain Lee R. Longe
Georgia

#058 Joe Rhodes | Received: June 16, 2026

Public Comment**"Parkinsons"**

Parkinson's, what exactly has this terrible elusive disease done to my life. I was at the peak of being considered for an advancement in the law enforcement agency which I worked, I was prospering and I was very respected. I was proud to do what I was doing and allowed to be a great dad of 4 Children and a husband. I just loved everything about my life until it came to a halt.

In 2013, I was walking up the stairs to my office, but my mind was telling my body to go forward, yet my left leg had another idea. I froze in place and didn't know what to do. I went into almost a panic mode, why aren't I moving? How come my brain is telling me to move but my leg wants to do whatever it wants to. And that was the beginning, and today I sit 13 years of this disease.

It has been a journey. I see others with it far worse, yet, sarcastically, I do enjoy tremendous shaking in my hands, once in a while I enjoy the shaking of the head, so if you ask me a question you may have to wait for a verbal response because you may think I'm saying yes and no at the same time. My walking has certainly gotten a little slower say to me to slow down when I was walking, but today she is far ahead with my daughter. This has taken a toll on me because of being a retired first responder, and my needing to be a protector, especially for my family. I'm feeling as if I am less of a husband, less of a man, and provider. I was forced into early retirement because my agency told me that with Parkinsons, I was a liability. Most would be happy and relieved, but I loved being a public servant. And now I felt reduced as a person.

My doctor is one of South Carolina's #1 Parkinson's Doc, Dr. Wolschkolup. We have tried everything, and it was looking pretty good for a while, limited shaking, my mind was clear, and my walking seemed to be okay, but as of lately the tremors, shaking, slow walk, handwriting is extremely illegible. Yes, Azilect, Requip, Carbidopa-levodopa, and a few more of the common medications were used, but I guess I'm at the point of where this darn disease gave me a vacation or a few years and has decided to sprint too shaking my life up a bit more. Oh sure, exercise might work, but I sleep with a Bi-pap machine, and my sleeping is next to a whopping 3 hours sleep a day. I'm always exhausted, and for me to push myself into the gym, or just exercising by walking a brisk walk...I just lose all energy. My doc continues to encourage me to exercise, and take my pills regularly, which I do, but I'm discouraged and some days I want to give up. And perhaps at times I've had visions of not being here, not being a burden and allowing my family to heal and move on with their lives.

I reflect upon where the Parkinson's may have come from, was it: helping with the 9/11 Ground Zero recovery in 2001, was it from working by the Hoogendorn Nurseries in Middletown, RI where they used pesticides, was it working for Chaves Plumbing and Heating back in 1985 to where we would mix and layer asbestos onto old pancake boilers, or was it gifted to me from my mother, whom had Parkinson's also? Either way I've done some incredible research relating to Parkinsons, and what can attribute to its development, and I'm guessing that from breathing the dust/smoke of 9/11, to other environmental factors...I was a shoe in for the win.

So, at this point what will I do? Well, I am 100% open to entering into Parkinson's trials, and other options that may slow it down, or better yet, stop it completely. Yes, I've completed two testing trials, one which was just a month ago, the smell test, and another saliva test out of Atlanta, GA. No word of a lie, I am not interested in the deep brain stimulation surgery because it just looks so invasive. I am, however, interested in stem-cell trials, if there is such a thing. I've seen stem-cell programs, but they are so expensive that there's no way I could afford it. Ultimately, I will continue to embrace being a P.D. soldier and grow within whatever change my body feels to evolve towards.

In closing I will state that Parkinson's has altered my life on so many levels, yet I reflect upon other people who suffer from greater gifts. Perhaps I am blessed to be given the road before me, and to find ways to help others through my experiences,

with their newly acquired Parkinson's challenges. Like Mike, who has been beyond any imaginary inspiration, he gives me hope. Mike gives me gratitude for his unwavering dedication, and his strength with his journey, family and career. I am inspired, and given an opportunity to meet Mike, do a commercial, or inspire others to keep moving forward...count me in

Joe Rhodes
Taylors, SC

#059 Laurie McAnespie | Received: June 16, 2026

Hi,

I was diagnosed with Young-Onset Parkinson's Disease in 2024 at age 54, but my journey started nearly 10 years earlier.

For years, I knew something was wrong. I struggled with anxiety, depression, apathy, constipation, a frozen shoulder, changes in my handwriting, difficulty typing, and a racing heart. I saw countless doctors and received multiple diagnoses, including lupus, fibromyalgia, and POTS, but none of them fully explained what I was experiencing.

The turning point came when my right arm stopped swinging naturally when I walked and remained bent at my side. After years of searching for answers, I was finally diagnosed with Parkinson's disease.

While the diagnosis was difficult to hear, it was also a relief. I finally understood why my body had been changing for so long.

Today, Parkinson's is part of my life, but it is not my entire life. I am a wife, mother of three, daughter, friend, and advocate. I've learned that Parkinson's affects far more than movement, and that many symptoms are invisible to others. Some days are easier than others, but I continue to focus on what I can do, not what I can't.

Exercise has become one of my most important tools. Boxing, walking, strength training, and staying active help me manage symptoms and maintain my quality of life.

My diagnosis also inspired me to become involved in the Parkinson's community. Through Team Mac Pack, we have raised more than \$100,000 for Parkinson's research and awareness through events benefiting the Michael J. Fox Foundation.

One of the biggest lessons Parkinson's has taught me is that life doesn't end with a diagnosis. It changes, but there is still joy, purpose, laughter, family, friendships, and hope.

If sharing my story helps someone recognize symptoms sooner, seek answers, or feel less alone, then it is worth telling.

Thank you for reading.

Sincerely,
Laurie McAnespie

#060 Linda Ereku | Received: June 16, 2026

The old me wants to push the new me out.

My mind wants my body to move at 78 rpm, but it moves at 33 1/3.

You move slowly, but age quickly.

My bad days now outweigh the good ones.

I don't want to become an invalid.

I lost my independence, can't go out without my husband or my physical therapist.

My poor vision is getting worse, adding to my fear of falling.

My skeleton feels as if it has been rearranged. I'm not comfortable in my own body.

I'm losing my appetite for food and rarely feel hungry. When I do eat, I fill up fast.

I'm exhausted all the time and never feel rested.

When I take my medication I feel like I'm taking poison. The dyskinesia drives me insane.

Why is it so hard to cure Parkinson's disease?

It is incredibly difficult living with an incurable, progressive disease.
I had DBS surgery which didn't work. After multiple adjustments the doctor sent me back to my neurologist. I felt abandoned. The rub is now I'm not eligible for any clinical trials. I see a different neurologist now.
Simple things are now difficult, and I often repeat tasks until they are done right.
Every morning when I wake up, for about 30 seconds I forget that I have Parkinson's disease.
Recently I was sitting at a bar waiting for a food order. A woman nearby was laughing hard, and I realized how much I miss laughing.
I have a lot of pain. If my vision were better, I might not feel so out of sorts. I'm very slow now, and lately I feel the changes more profoundly.
It is getting harder to stay optimistic, and sometimes I feel very sad.
Diagnosis: April 1, 2009 — no kidding.

-Linda Erekuuff

#061 Lori Rice | Received: June 16, 2026

Hello! My name is Lori Rice. I am here to share my experiences with Parkinson's Disease and would be honored to share my story in person before the ACPRCS committee. If that is not possible, I am also happy to appear virtually before the committee.

I would like to share how personal this mission is to me, and why I believe we should make additional funding and research a very high priority.

As we all know, 2020 was an incredibly challenging year for most, and for me, it was profoundly more difficult because of the deaths of both my brother and my father from Parkinson's just 4 months apart. This disease has hit my family with gale force winds, and as I also have tested positive for one of the genetic mutations for Parkinson's, only time will tell how our story truly ends. I am actively participating in the Parkinson's Progression Markers Initiative research study, or as it's more commonly known, PPMI, as my genetic risks will help science researching future potential clinical trials to aid in detection, symptom management and ultimately, a cure. The biomarker discovery is a direct result of this very important research, but there is so much more to do.

My father was diagnosed with Parkinson's in 2015, and he passed away just five years after his diagnosis in March of 2020.

And in 2017, at the age of 57, my brother, a vibrant, healthy internal medicine physician and professor of medicine at Medical University of South Carolina, was diagnosed with an atypical form of Parkinson's, atypical I soon realized was really a euphemism for record-breaking speed of symptom progression and decline. I watched as his body failed him, his balance so affected, he risked falling with every movement. He had to abruptly leave the practice of medicine as his symptoms would not allow for the continuation of care for his beloved patients. Eventually, he required a wheelchair, which, from that point on, was really the beginning of the end. He was moved into a skilled nursing facility where he remained until his death in July of 2020. In-home caregiving became too cost prohibitive, and I struggled with traveling back and forth from Oregon to South Carolina many times, especially during the beginning of the Covid-19 pandemic.

My brother was robbed of at least 25 additional years of life by this disease – years that he would have continued as a practicing physician, researcher, educator and healer, his life's true purpose. The world is a significantly different place without him and without his valuable contributions.

There are currently 1,000,000 people in the United States living with Parkinson's. This number is predicted to rise to 1.6 million by 2037.

My hope is that we can support additional investments in Parkinson's research. We need additional funding not only for research but for caregiving families dealing with this devastating disease – a disease that will only increase in number with our aging population.

We are closer than we ever have been – I beseech you to help us get over the finish line and claim success for a potential Parkinson's cure.

From the bottom of my heart and in honor and memory of my family members, I thank you for giving me the time today to tell my story and to advocate for Parkinson's patients and families across the country.

Sincerely,
Lori Rice
Hillsboro, OR

#062 Marci Thornsberry | Received: June 16, 2026

I am living with Parkinson's Disease. I am 58 years old and was diagnosed in 2021. My father has PD, his brother has PD, my uncles and cousins have PD. I wake up every day fighting to keep my tremors under control and hoping for an advancement in therapies, such as stem cell treatment/replacement, to slow or stop my parkinson's.

Thanks! Marci Thornsberry

#063 Phil Holderness | Received: June 16, 2026

To: Members and supporting staff of the Advisory Council on Parkinson's Research, Care, and Services (ACPRCS)

Re: Public Comment

In December of 2023, I was unofficially diagnosed with Parkinson's Disease (PD). In April of 2024, I was officially diagnosed with PD after a DaT scan. I am fortunate in that I have access to good medical care, and I can afford to pay for the cost of prescription medication although, the cost is significant. (For a 90-day supply of the medicine I take the cost is roughly \$2,000. Fortunately, my medical team has been able to convince the insurance companies to cover most of that cost, but I never know if the insurance company will agree to cover future costs.)

I write to the Council today to express my frustration in three areas: 1) The need for more government funding to find a cure for PD. 2) The need for more government funding to find better therapies for PD. 3) The need to reduce the cost of the medicine.

The "gold standard" treatment for PD is carbidopa-levodopa. This drug is available in various forms and dates back to the mid 1970's. I repeat, the mid 1970's. When I was first diagnosed, I was shocked to learn my treatment would be a 50-year-old drug. The PD community needs additional government funding for new drug discoveries and ultimately a cure to PD. In the meantime, we need the Insurance companies and Medicare to provide better financial benefits for the more "current" iterations of Carbidopa-levodopa. Those current iterations are simply a different delivery method of the drug. Primarily, an extended release of the drug once it is swallowed.

Thank you for recognizing the needs of the PD community and godspeed in finding funds for better drugs and ultimately a cure.

Phil Holderness
Kansas City, MO

#064 Robert Reilly | Received: June 16, 2026

Fear for my family. Terror of the unknown.

Those two emotions describe in large part my 16 year journey with Parkinson's Disease. As my neurological health has continued to decline inexorably year after year I first experienced self consciousness, then uneasiness followed by loss of confidence ending in a hollowing-out of the vessel that once was "me", a complete loss of freedom due to the progressive loss of key executive functions and thus a growing reluctance to try and function "normally" at home, in the workplace, personal relationships...in life.

PD's iron grip is masked by time. If I think of how I'm doing today vs. how I recall doing yesterday, the steady loss of motor control doesn't seem so bad. But if I look at the last year, I realize I've lost the ability to retain basic information even for short periods of time, I have lost half my bladder control, I have begun dreaming vividly, lashing in my sleep, I have lost the ability to move fluidly and, due to a non-PD related spinal column staph infection exacerbated by degenerative disc disease leading to three separate back surgeries, I have incapacitating pain, certainly not helped by PD, in my back and legs nearly all of the time and have attended the Mayo Clinic's pain clinic in an effort to keep all of "it" in perspective. In the past 10 years, symptoms of PD forced me to elect to retire early from a career I planned to continue into my 70's or 80's. Despite actively volunteering widely in my community, the mental stimulation of a full-time job is simply not there.

PD hasn't taken my joy in living or my propensity to always look forward to each new day. What it has done can, I am convinced, be changed, slowed or even reversed for my children, grandchildren and generations to come if only we prioritize

our efforts to eliminate PD within my lifetime. I'm Robert Reilly. I'm 73 years old and I have PD. I'll continue living as long as the ACPRCS and MJFF continue to give hope to me and the more than 1MM Americans like me for a better life without the dreadful and insidious effects of Parkinson's.

We can tame PD in my lifetime. I'm convinced of it. I'm betting my life on it.

#065 Ron Sable | Received: June 16, 2026

As a disabled Air Force veteran who was diagnosed with Parkinson's disease (PD) more than 10 years ago (My brother also has Parkinson's), due in part to the effects of Agent Orange in Vietnam, I welcome the opportunity to share not only my PD story, but my strong support of ACPRCS.

In any endeavor, to be effective over the long term requires continual attention to the situation. PD, with recent congressional action creating necessary legislation, and the establishment of the National Advisory Council on Parkinson's, suggest we are well on the way to getting the attention required to finding a cure.

In my case, diagnosis by Dr Shannon Jameson (then at the Mohammed Ali Center in Phoenix) in 2016-17 suggested I had early stage PD.

Follow on treatment and later, a cognitive assessment by Dr Sudeshna Bose at Banner University Medical Center Tucson confirmed that assessment and I was scheduled for DBS surgery in July of 2020 (in the middle of the Pandemic). At that point, the most obvious symptom was tremors in my extremities. Once the surgery was complete and the Abbott lab Neurosphere device was activated a few days later, the tremors stopped immediately, and for the most part, have not returned. My wife Patsy and I call that "our little miracle." The other obvious indicator of the DBS effectiveness, was the reduction in the need for carbidopa/levodopa medicine -from the 400mg a day prescription to addressing the symptom with a reduction to 100mg daily. I now use my PD experiences in counseling folks considering DBS.

As time has passed, new symptoms have appeared, most recently the uncontrolled closing of my eyes (left eye prominent) which is being treated with some success with Botox (an interesting aside-Dr Bose has had great difficulty getting the OK from Medicare to do the procedure -before agreeing, they called it "cosmetic"). Fortunately, she persists.

Additional recent symptoms include a shuffle, some difficulty swallowing, and a change in my voice, which goes away and returns of its own volition.

In summary, the road is slowly becoming more challenging with the new symptoms, but my attitude is as positive and strong as ever. I deal with PD on a daily basis, and I'm a strong believer in speaking up for the efforts leading to a PD cure.

Finally, thank you for the opportunity to share my story.

Ron Sable
Immediate Past Chair, Board of Directors
Paragon Space Development Corporation
Tucson, AZ

#066 Susan Everitt | Received: June 16, 2026

My husband died from the ravages of Parkinson's Disease in December 2024 after living a demeaning existence for nearly three years in an old rundown, understaffed nursing home. I was there almost every day, helping him along with other residents, as I felt they all needed an advocate, someone who cared more than the burned-out aides.

Leading up to that nightmare, I could not physically care for him by myself anymore. The impending monthly \$11,000 nursing home expense forced me to hire an attorney, sell my car, sell his 401K investments & pay the taxes, & fill out endless piles of paperwork to qualify him for Medicaid, then wait several months for a room to open up. He wasn't in pain so much as he was suffering, and so was I. But the nightmare only got worse as he declined.

My cousin was diagnosed with Parkinson's a few years ago. Last year I found out that my sister has been diagnosed with PD. I know full well that they will also continue to suffer from this insidious disease, & so will their families. Now I & my siblings must remain cognizant of the fact that our genes make us all more vulnerable to PD.

I myself cannot part with my limited income of Social Security to donate more consistently in finding a cure for PD, but I pray the necessary funding will be provided somehow so more families won't need to endure such heartaches.

Sincerely,
Susan Everitt

#067 William DiMartini | Received: June 16, 2026

Public Comment Submission to the National Parkinson's Project Advisory Council on Parkinson's Research, Care, and Services (ACPRCS)

Submitted by: William DiMartini

Person Living with Parkinson's Disease

Dear Members of the Advisory Council,

Thank you for the opportunity to provide public comment as you work to improve Parkinson's disease research, care, and services throughout the United States.

I was diagnosed with Parkinson's disease in October 2022 at the age of 63 while living in Myrtle Beach, South Carolina. Like many patients, my diagnostic journey revealed some of the systemic challenges that individuals with Parkinson's face. The testing required to confirm my diagnosis was performed by a specialized laboratory in Arizona, which at the time was the only laboratory conducting the specific test. Despite this, my insurance provider initially denied coverage because the laboratory was considered "out of network." It took nearly a year of appeals and discussions before the issue was resolved. While this challenge may seem administrative, it added unnecessary stress during a period already filled with uncertainty and fear.

Following my diagnosis, I encountered another common challenge: access to specialized Parkinson's care. In the Myrtle Beach area, movement disorder specialists were scarce. My initial care was provided by a physician assistant with limited Parkinson's specialization. When that provider left the practice, I was fortunate to find a movement disorder specialist at the Medical University of South Carolina in Charleston. However, the distance and limited availability of specialized care highlighted significant gaps in access that many Parkinson's patients face, particularly in smaller communities and rural regions.

Eventually, concerns about my long-term care, coupled with the fact that I also live with Type 2 diabetes, led my wife and me to relocate to the Philadelphia area, where I now receive care from a movement disorder specialist whom I trust. Not every Parkinson's patient has the ability or resources to relocate in pursuit of better medical care. Access to qualified specialists should not depend on geography.

As someone living with Parkinson's disease, I would like to share several observations and recommendations that I hope the Council will consider as it develops priorities for research, care delivery, and patient support.

The Psychological Burden of Parkinson's Disease

The greatest challenge I face is not necessarily the physical symptoms of Parkinson's disease. It is fear. I fear what the future may hold. I fear falls and injuries. I fear increasing dependence on others. I fear the impact the disease may have on my wife and family. While clinical care often focuses on managing symptoms, the emotional and psychological burden of Parkinson's can be equally significant.

Mental health support should be considered a core component of Parkinson's care. Patients and care partners need access to counselors and therapists who understand the unique realities of living with a progressive neurological disease. Unfortunately, I have worked with multiple therapists who were unable to effectively connect with or address Parkinson's-related concerns. Specialized training and resources for mental health professionals would greatly benefit the Parkinson's community.

Improved Understanding of Coexisting Conditions

In addition to Parkinson's disease, I manage Type 2 diabetes. One of my ongoing challenges is determining whether a symptom, physical issue, or change in health status is related to Parkinson's, diabetes, medication interactions, aging, or another condition altogether.

Many Parkinson's patients live with multiple chronic diseases, yet research and educational resources often address Parkinson's in isolation. I encourage greater emphasis on understanding and communicating how Parkinson's interacts with other common chronic conditions, particularly diabetes, cardiovascular disease, and mental health disorders.

Better Education on Nutrition and Medication Management

Nutrition remains an area where many patients struggle to find clear and consistent information. Questions about healthy eating, dietary strategies, medication timing, and the interaction between protein consumption and Parkinson's medications are common. Yet many patients receive limited guidance beyond general recommendations.

I encourage expanded research and patient education efforts focused on nutrition and Parkinson's disease, including practical guidance that can be easily understood and implemented by patients and caregivers.

Expanded Access to Reliable Information and Patient Navigation

One of the challenges following diagnosis is determining where to turn for trustworthy information and support. I encourage greater collaboration and alignment among Parkinson's organizations, healthcare providers, and government agencies.

Protecting Patients from Misinformation

As Parkinson's patients search for hope, they are frequently exposed to products, treatments, and services that make unsupported or misleading claims regarding disease reversal, symptom elimination, or cures. The Parkinson's community would benefit from stronger public education efforts that help patients identify evidence-based treatments and recognize misleading claims.

Strengthening Research and Community Engagement

Finally, I encourage continued investment in Parkinson's research aimed at understanding disease progression, developing improved therapies, and ultimately finding a cure.

Respectfully submitted,

William DiMartini

Person Living with Parkinson's Disease

#068 William P. Miller | Received: June 16, 2026

To: ACPRCS Public Comment

From: William P Miller

Coordinator, Charlestown Parkinsons Support Group

Catonsville, MD

I was first diagnosed with Parkinsons Disease 11 years ago at the age of 75. While the progression of my disease has been slow, most of the people with PD that I have met in various groups have not been so fortunate. Over 50% of the people I have met with PD have either died or been moved to assisted living or to nursing care. The risks of falling with serious injury, and the failure of existing treatment options seem to be the big problem for people who currently have the disease.

- A major effort is needed to advance early detection and prevention of Parkinsons. This will require the expenditure of public funds for research because the risk/reward ratio for the private sector is too high.
- New medicines and procedures being developed and utilized in other countries need to be fast tracked for use in the United States.
- The cost of new medicines and procedures, some of which may be lifesaving, need to be financially available to those who need them. Many of the currently available advanced treatments are simply beyond the reach of those who need them.
- The availability of movement disorder specialists needs to be greatly expanded. I encounter people who are waiting six months, or more, for an initial appointment. In many areas of the United States there is simply no specialist available. Every State should develop a plan to make movement specialists available in some way to their entire population as a requirement of Medicare and Medicaid funding. It should also be a requirement for all Advantage plans.
- The importance of PT and OT and in-home services for people with movement disorders needs to be more clearly recognized in public policy.

#069 William Steinberger | Received: June 16, 2026

Thank all of you for serving on this important panel. My son, just turned 55, was diagnosed with early-onset Parkinson's 8 years ago. So far, he has been managing his symptoms with a combination of drug therapy and Botox injections. These treatments are becoming less effective over time, so his pain, discomfort, and overall health have not stabilized. He is

dedicated to a very intense exercise routine, which has also been helpful, but obviously, as he ages, this will become increasingly difficult. Your work can contribute to better treatments and hopefully a future cure for this devastating disease.
-William Steinberger

#070 Allison Feldman, Chief Executive Officer | Received: June 17, 2026

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

The Lewy Body Dementia Association (LBDA) appreciates the opportunity to provide this public comment. Our work is grounded in supporting individuals and families living with Lewy body dementia and in working alongside the broader neurodegenerative disease community, including Parkinson's disease.

LBDA appreciates the Council's leadership and commitment to advancing research, care, and services. We encourage continued efforts to build systems that reflect the lived experiences of patients and families across the spectrum of Parkinson's disease and Lewy body dementia. As these efforts move forward, it is important to recognize the full range of symptoms that affect individuals living with Parkinson's disease, including cognitive and psychiatric symptoms that can have a profound impact on quality of life, daily functioning, and caregiver burden. When research, clinical care, and support services are aligned with the realities faced by those affected, outcomes improve for individuals, families, and the broader community.

We also encourage continued collaboration across agencies and stakeholder organizations to promote earlier diagnosis, person-centered care, and meaningful engagement of patients and care partners in research and policy development. Together, these efforts can help ensure that advances in research translate into meaningful improvements in the lives of those affected by Parkinson's disease and related disorders.

Thank you for your consideration of this comment.

Submitted on behalf of:
Allison Feldman
Chief Executive Officer
Lewy Body Dementia Association

#071 Brian McGuire | Received: June 17, 2026

As with many journey's there is some uncertainty at the beginning. You may have multiple routes to get there, questions on who will accompany you and how long it will take. When I walked out of the neurologist's office 13 years ago, I did not have an answer for any of these questions, but I certainly do now.

What I have learned is how important relationships are whenever you prepare to do battle with whatever foe you identify, and I learned this in spades. It turns out the vast majority of friends, acquaintances and even some strangers truly wish to help you if you're willing to ask for it.

Perhaps the greatest example is our local SoCal Ride in which we attracted 800 people and raised nearly \$500,000 on behalf of the MJFF. It is this form of empowerment, my immense gratitude and knowing we all can make a difference that helps sustain me in my personal goals.

My wish is to see every community react the way ours has with equal shares of our success directed to we as patients, caregivers, clinicians and researchers.

Brian McGuire
Writer

#072 Cliff Brundage | Received: June 17, 2026

A Public Comment,

Parkinson's a Debilitating Disease,

My personal connection to this disease, is through the experience of my mother who recently passed due to the complications of the disease.

She was diagnosed six years ago and at first it was mainly tremors that got in the way of her daily existence. Then she progressively worsened to the point that she could no longer keep her balance and fell many times. Therefore, for her safety the hard decision to place her in a nursing home was made where she remained until her death this past May. The worst complication I observed was her inability to move without assistance and she required around the clock care.

This disease and its debilitating effects must be addressed in a way that provides significant government funding to conduct the research and development of meaningful treatments that will someday eradicate it from existence.

I implore you to take up the cause and work with the members of congress who hold the purse strings on this type of funding and bring the point home that this disease must be eliminated for future generations.

I thank you for your time and efforts.

Best Regards,
Cliff Brundage

#073 Diane MacInnes | Received: June 17, 2026

I am submitting a public comment regarding my family's experience with Parkinson's for the first meeting of the National Parkinson's (ACPRCS), which will take place on June 29, 2026.

Both my mother and brother were diagnosed with Parkinson's. My mother needed full time care. Most families have to shut their loved ones away in third rate nursing homes that are permeated with the acrid smell of urine and are not even covered by Medicare. Either that or someone needs to quit work and become a full time caregiver. My brief experience with that was devastating.

I remember trying to lift my mom whose immobility caused her to become overweight. Getting her from a wheelchair to the toilet was nearly impossible. She had improper medication which caused paranoia so that she was biting and scratching me. It took a long time and finding a specialist in another state before her symptoms were well managed. We tried to find a nursing facility for mom at one point, but when we placed her there she deteriorated so quickly that we took her home and provided live in home care for around a decade where she could be with my dad. Fortunately it was less expensive then than it is now and our family could do that. Most families cannot. That's the reality.

My brother is still living independently, but the disease will progress. In home care has increased ten fold since my mother's time. There is no financial help for this. The costs devastate families and the emotional roller coaster is exhausting.

I found an unhoused man on the street in front of a grocery store who exhibited symptoms I recognized. I asked him if he had a place to sleep. He didn't. He volunteered that he had Parkinson's, but could not get medication because Medicaid won't provide unless a person has an address. He was in the process of getting a bed in a shelter with a waiting list.

I live in the state of New Mexico where there is not one Parkinson's specialist and no research facilities. Every office I've called says they have neurologists who "deal with" Parkinson's patients. That means one stop shop for Levodopa, and no meaningful analysis of each patient's symptoms. This is not acceptable.

I am a participant in the remote Michael J. Fox Parkinson's Research study (PPMI), since I have a family history of Parkinson's and have not been diagnosed. I am hoping by completing their questionnaires every three months, the information will help scientists understand more about the disease. I live in fear that if I do get it, there will be no specialized help for me in New Mexico, the land I love, and be able to stay in my home with my husband. I researched the cost of in-home care a few years ago and was told it was then about \$25,000 a month! Who has that kind of money? Prices have gone up since then. I looked at Continuing Care Retirement Communities. There were waiting lists as long as 7-8 years and they were enormously expensive. The only choice at that point for many would be assisted dying. Two of my friends have chosen that route.

I receive information on new Parkinson's research and treatments from PPMI. There has been a significant increase in young people diagnosed with Parkinson's. As a nation, we are going to have to face this.

We need more money for research in underserved areas, as well as help with in-home care. We need to recruit Parkinson's specialists, caregivers, physical therapists, and set up practices and centers. The need is only going to increase.

Please take the reality of the situation families and individuals are facing. We cannot do this alone. It's heartbreaking. What will you do to help?

Thank you,
Diane MacInnes
New Mexico

#074 Douglas Minson | Received: June 17, 2026

It has been said that foundational truth may often be found in the great myths of a people. Those stories convey purposes far beyond the stark facts of our daily lives and call us toward meaning so deep and true words cannot do them justice. One such myth is thousands of years old and comes from the very origin of our civilization. It is the myth of Orpheus and Eurydice.

It was said Orpheus was one of the world's greatest poets and musicians. With his lyre he could charm trees, animals, even rocks and rivers. The beautiful Eurydice fell in love with Orpheus and him with her so completely the entire creation was deeply moved. However, one day Eurydice was bitten by a deadly serpent. Upon her death she entered the underworld of Hades where she was destined to stay. Overcome with his great love for Eurydice, Orpheus descended into the underworld, confronted Hades, its god, and sang such beautiful music it charmed the entire underworld. Hades granted Orpheus a special dispensation to take Eurydice and leave on condition he not look back at her until he reached the light of day. Orpheus could not resist, and looked back just before surfacing, thereby destining Eurydice to the underworld and him to a life of loneliness.

My Eurydice's name was Susan. She was a medical doctor and my wife of over forty years. While I was not blessed with the talents of Orpheus I can say with certainty we made music together. Our love was enough to take us to over fifty countries, every continent, and through deep valleys of forgiveness and mountains of success. Then one day the serpent bit Susan. We were told that the changes we were seeing would take her life; that there were no tests to diagnose the condition and no known treatment. In all likelihood her illness was Fronto Temporal Degeneration. However it could not be diagnosed except through brain autopsy upon her death. I became her caregiver for years, slowly watching the amazing talent and spirit of her magical life fade into memory until it was gone about three years ago. After death her autopsy confirmed a diagnosis of Progressive Supranuclear Palsy.

I am writing this true story in hopes it will provide some help in the effort to find federal funding for research into one of the remaining frontiers of medicine, neuromuscular disease. Like Orpheus I cannot help but look back at Susan's beautiful face. I am compelled to do anything I possibly can to help those confronting these diseases and their families. I have encountered United States Senators, spouses of professional athletic coaches, Olympic runners and so many more citizens like me who are desperate for help in their journeys with these terrible diseases. Because of the magnitude of the problem, governmental action is desperately needed. Our beloved country has done so much for so many. I pray it will rise to this call.

-Douglas Minson

#075 Elaine Ptacek | Received: June 17, 2026

I have Parkinson's. In 2004, I noticed a right side tremor, not really interfering with my work as a children's mental health therapist. LCPC. I thought it might be anxiety as it can cause tremors. In 2006, I saw a neurologist for 8 years and my diagnosis was anxiety and lack of sleep. She continued to increase the meds. In August of 2015, a Neurosurgeon from Colorado did a presentation on how to improve your quality of life with Parkinson's. I was sure I had Parkinson's, but in a very rural area, where do you go for a second opinion when you are already seeing a neurologist. I was seeing children 50-60 hours a week and had a difficult time saying no. After the Neurosurgeon's presentation, I visited with him about my concerns. He had me walk, flipped my arm and gave me his scheduler's name and number. I was seen by him on September 18, 2015. The actual shock of hearing and finally getting a diagnosis was relief but overwhelming. I only knew 2 males in my rural town with it and one was completely dependent on his wife. My dreams of volunteering in my community after retirement were shattered. I didn't know what tomorrow would bring, knowing little about Parkinson's. I did water aerobics for exercise and I walked past a weed patch on the way to the Colby Community College pool. The weeds in the flower garden were as high as my waist. That was my therapy and where I shed my quiet tears to clean up the rose and peonies garden after getting permission from the President of the College. I love flowers and gardening. In August of 2018, the same neurosurgeon came back to do the same presentation. He took a look at me and made the comment "Doesn't look like any of your meds are working." I was seeing a Movement Specialist and on numerous meds for PD. The PD was progressing. I couldn't get on the floor with my clients in Play Therapy and everything was a struggle. I was choking on food, my husband was cutting my foods into smaller bites and making the beds as I wasn't strong enough to pull the fitted sheets over the mattress. I was in Physical

Therapy 2 days a week, OT 1 day a week and Speech Therapy 2 days a week. Every day I drove in the parking lot of the hospital I had tears of defeat. In August when the Neurosurgeon was in Colby, he said, it's time to talk Deep Brain Stimulation. I was approved for DBS the end of December. Those 3 years were lonely and difficult. I thank God for my work with children as it kept my mind off the disease and what I could no longer do. I laid in bed at night thinking about how I and others with PD feel and how we could provide knowledge and support.

In the summer of 2020, a group of individuals with PD and caregivers met to find a way to support the newly diagnosed and the growing members in our community. We brainstormed and decided we would need a 501(c)(3) in order to write grants for funding. We also wanted to include the 9 Northwest counties in Kansas. We received a grant for a pilot program in the fall of 2021. We meet from September to May every Wednesday from 10:00-11:45. We zoom to the counties. We are growing in numbers every year and serve 80-100 individuals weekly in the 9 counties. We finished our 5th year and have learned much every year. At 10:00 we do Parkinson's Wellness Recovery exercises, at 10:35, we have coffee and conversation and a 5 minutes about Parkinson's educational topics. The first Wednesday of the month at 11:00 is PT, OT or Speech, 2nd Wednesday of month is Art for hand, finger and cognitive, the 3rd Wednesday of the month we have speakers on Nutrition, Mental Health, Syn One Testing, the best and worst fruits and vegetables for pesticides, stem cells and therapy for PD, newer drugs and medical devices to improve our lives and the 4th Wednesday is music for voice and cognitive and the 5th Wednesday is presentations by Caregivers. All classes are free. We have raised money through a walk-a-thon every April and have a Parkinson's Conference in September. We encompass 6,000 square miles but reach many.

Elaine Ptacek
Executive Director of Parkinson's Families of Northwest Kansas

#076 Jennifer Crowder | Received: June 17, 2026

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am a 50 year old woman, and have been living with Parkinson's disease for 30 years.

When I was finally diagnosed 10 years ago, I had the attitude that Parkinson's wouldn't be my life. I was full of optimism and defiance. My motor symptoms were well controlled, I was sure that I could take my life off pause and continue just as I had before things got really bad. My career, my education, my planned life would be taken off pause and I could catch up to my peers.

I was so wrong.

My acts of defiance are lesser than I intended. I answer with the truth when asked how I am doing. I wear impractical shoes and white clothing. I rest without apology, and hold my head high as my body fails.

To be perfectly frank, I have little optimism.

For the NIH to put this plan in its entirety to action feels long sighted, too much to ask for, too far away. But, for the millions of patients like me, it is all we have.

Please pause here, and consider the life of a 50 year old woman with 1 avenue of hope in a lifetime of neurodegeneration. Every day that this plan is stalled, my health worsens.

Putting the plan into action is the only life raft I have. It is all my husband has, as my care partner. My friends, family, coaches as my supporters, cling to the same raft. A strong national plan needs clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

Please.

Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.

Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people, women and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.

Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration.

I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease. I don't have time to waste, and neither do the millions who came before me, or the millions coming after. We are begging for action. Please, give us hope.

Sincerely,
Jennifer Crowder
Windsor, CT

#077 Jim and Doreen Price | Received: June 17, 2026

As you consider your efforts for the newly formed ACPRCS, I share these personal frustrations of my husband's battle with this horrific disease.

1. The inability to diagnose it sooner and, often due to a lack of awareness in the medical field, to dismiss it as Parkinson's or a Parkinsonism. By automatically treating it with traditional Parkinson's medicines (carbidopa levodopa) my husband was always disqualified from participating in research studies. They wanted pure, untreated subjects. The medicine is of no help anyway so it was years of harsh, unnecessary treatment and then limits research subjects significantly.
2. Because falls are backwards, no walkers keep patients safely upright, forcing caregivers to constantly walk beside them or force patients into wheelchairs. Money and research is needed to develop options for keeping them upright and moving as long as possible.
3. It was devastating that this cognitive man had no means to communicate due to his loss of speech and ability to write. While some words do escape them, it's imperative better forms of communication be developed for the mental stability of both the patient and their family.

These are just a few that come to mind. Education and awareness, particularly of those in the medical and caregiving field, are so critical. It was so frustrating to have to explain it to them and to have to keep reminding them that no, they did not have Parkinson's and no they did not have Alzheimer's or dementia.

PSP is like all of those diseases and more rolled into one. Please give this the attention it desperately needs. When I looked back to see Dudley Moore died from this back in the early 2000s and nothing has changed since then, I found it unbelievable and shameful. PSP patients need your help now! Thank you.

- Jim and Doreen Price

#078 Joan McGuire | Received: June 17, 2026

My name is Joan McGuire and my husband has Parkinson's disease. He was diagnosed over 12 years ago by a movement specialist.

He attends physical therapy at a gym especially for Parkinson's patients 3 times a week and stays active in other ways (golfing, hiking and kayaking) the rest of the week.

He was involved in a study through Hoag that determined his Parkinson's was likely caused by the environment.

Overall, at age 70 he has many good days and quality of life.

We would love to see even more support groups in our area and also believe insurance covering the cost of physical therapy would be greatly beneficial. The more exercise he gets the better he feels.

As a wife and caregiver, I don't know what the future holds, but with a great supportive family and group of wonderful friends, we stay positive and active.

Thank you for all you are doing to bring an end to Parkinson's.

Sincerely,
Joan McGuire

#079 Joe Harbison | Received: June 17, 2026

Public Comment for the Advisory Council on Parkinson's Research, Care and Services
Submitted by: Joe Harbison

My Parkinson's story begins in the Mekong Delta, 1969-70, where I served as a door gunner with the 162nd Assault Helicopter Company. I was eighteen. I saw things, and did things, that no eighteen-year-old should have to see or do. I also remember the days our flight crews sprayed Agent Orange from specially modified helicopters to clear the foliage around our base's defensive perimeter. I remember the vapor drifting over our tent city, and I remember thinking, "Hell, this doesn't smell so bad."

Twenty years later, I witnessed something worse. I returned to Vietnam on a USAID mission to assess what Agent Orange had done to the next generation, the children born after the war who inherited the worst of a decade of chemical defoliation. The United States sprayed 19.5 million gallons of Agent Orange during that war, intended to strip the enemy of cover and food. What it left behind didn't end when the spraying stopped. It moved into bodies, into bloodlines, into decades.

I carried that exposure for forty-five years without symptoms. Then, in my late sixties, while leading a humanitarian response to the Ebola outbreak in Liberia, my body began to change. A strange sensation that I was ten feet tall. A shift in my gait. A tremor in my right index finger. Eventually, my voice itself began to fail. Six months of tests back in the U.S., an MRI, a DAT scan, an EEG, confirmed what I already suspected: Parkinson's disease.

At the time, I was serving as a chaplain at a hospital in Newport Beach, California. I remember asking myself, half-seriously, whether this was some kind of payback for things I'd done in Vietnam. I don't believe that anymore, and I want to be direct about why: this wasn't karma. It was chemistry. It was a known toxin, deployed for a stated military purpose, with consequences that the science now overwhelmingly links to Parkinson's in exposed veterans. What I once understood as an abstract policy issue, I now carry in my own hands.

As a chaplain, I had a strange vantage point on this disease before I knew it was mine. I'd read a patient's chart before walking into their room, and so often, the diagnosis was Parkinson's. Some patients faced it with remarkable grace. Others were consumed by it. I entered every room with a kind of awe, half there to offer comfort, half a witness peering into what might be my own future. Nine years after my own diagnosis, I am still vertical, and some days that feels like the whole victory.

I'm telling you this not because my story is unique, but because it isn't. There are tens of thousands of us, Vietnam veterans whose Agent Orange exposure didn't show up as cancer or diabetes but waited decades to surface as Parkinson's. The VA now presumes service connection for Parkinson's tied to herbicide exposure, which means the federal government has already acknowledged the causal link. What hasn't caught up is the research, the care infrastructure, and the long-term planning for a population of aging veterans who are going to need it.

I'd ask this Council to consider three things as you shape your recommendations:

First, fund research that treats Agent Orange-linked Parkinson's as its own distinct cohort, not a footnote within general PD research. We are a population with a known exposure, a known latency period, and a known endpoint. That specificity should make us easier to study, not harder.

Second, prioritize care access for aging veterans in rural and underserved areas, many of whom served alongside me and now face this disease without nearby movement disorder specialists, without caregivers who understand the trajectory, and without anyone who connects their service to their symptoms.

Third, don't let our stories stay anecdotal. Every veteran with Agent Orange-linked Parkinson's is a data point your researchers need. I'd ask the Council to find a formal mechanism, beyond a single round of public comment, for veterans like me to contribute our medical histories to ongoing research.

I flew over Vietnam breathing something I was told didn't smell so bad. Fifty years later, it's in my hands, my voice, my gait. I'm still here, still vertical, and still willing to be useful. I hope this Council will make sure that usefulness counts for something.

Respectfully submitted,

Joe Harbison

U.S. Army, 162nd Assault Helicopter Company, Vietnam, 1969-70

Port Hueneme, CA

#080 Larry Gifford | Received: June 17, 2026

Public comment

On behalf of PD Avengers, thank you for the opportunity to provide public comment to the Advisory Council on Parkinson's Research, Care, and Services.

PD Avengers is a global alliance of people with Parkinson's, care partners, families, friends, clinicians, researchers, and advocates working together to end Parkinson's disease. We add urgency to research, wellness, and advocacy by uniting people and organizations around the world to demand change in how Parkinson's is seen, treated, prevented, and ultimately ended.

The National Parkinson's Project is a historic opportunity. It exists because people affected by Parkinson's raised their voices, shared their stories, and demanded national action. Now the challenge is to ensure the National Plan reflects the full reality of Parkinson's.

Parkinson's is not only a movement disorder. It is not only a disease of tremor. It affects sleep, mood, thinking, speech, balance, digestion, pain, fatigue, employment, relationships, independence, and family life. It affects care partners, children, veterans, rural communities, people exposed to toxic chemicals, and people who struggle to access specialists, medications, therapies, and reliable information.

Better care is essential, but it is not enough.

A serious National Plan must include prevention. The United States cannot treat its way out of Parkinson's while continuing to ignore environmental risk factors linked to the disease. Paraquat, trichloroethylene, air pollution, contaminated water, and other toxic exposures must be part of the national conversation. The plan should include coordinated federal action to reduce exposure, improve environmental monitoring, fund research into toxic links, and protect workers, veterans, farmers, rural families, and communities at elevated risk.

The plan must also improve earlier diagnosis. Too many people spend years searching for answers while symptoms are dismissed, misdiagnosed, or treated in isolation. Earlier diagnosis requires better education for primary care providers, improved access to movement disorder specialists, stronger referral pathways, and investment in biomarkers and screening tools that can help detect Parkinson's before irreversible damage has occurred.

The plan must improve care across the full course of disease. Every person with Parkinson's should have access to multidisciplinary care, including movement disorder specialists, physical therapy, occupational therapy, speech therapy, mental health care, nutrition support, social work, palliative care, and exercise programs. These services should not be luxuries available only to people with the right insurance, income, geography, or ability to advocate for themselves.

The plan must also recognize care partners as essential. Care partners provide unpaid labor, emotional support, medication management, transportation, financial coordination, safety monitoring, and daily problem-solving. They are part of the Parkinson's care system, whether or not the system acknowledges them. The National Plan should include care partner education, respite, mental health support, workplace protections, and financial recognition of the true cost of caregiving.

The plan must build better data systems. We need stronger national data on incidence, prevalence, environmental exposures, disease progression, access to care, treatment outcomes, disparities, and care partner burden. Without better data, the country cannot measure progress or identify who is being left behind.

The plan must make research more inclusive and more meaningful. People with Parkinson's and care partners should be involved from the beginning in setting research priorities, designing studies, choosing outcomes, recruiting participants, interpreting results, and communicating findings. Research must include women, younger-onset patients, older adults, veterans, rural communities, Black, Latino, Indigenous, Asian, and other underrepresented populations. It must also include people living with advanced Parkinson's and related neurodegenerative parkinsonisms.

The plan must speed the path for promising therapies while still demanding strong evidence. People living with Parkinson's do not have decades to wait. We need urgency, coordination, smarter trials, better endpoints, faster recruitment, and clearer pathways for treatments that may slow, stop, or prevent disease progression. At the same time, people with Parkinson's deserve honesty, transparency, and rigorous science.

Finally, the National Plan must include accountability. It should set clear goals, timelines, responsible agencies, funding needs, public reporting requirements, and measurable outcomes. The Parkinson's community needs more than a report. We need a living national strategy that drives action.

PD Avengers urges the Advisory Council to ensure the National Plan includes:

- Prevention and environmental risk reduction.
- Earlier diagnosis and better access to specialists.
- Comprehensive, multidisciplinary care for all people with Parkinson's.
- Meaningful support for care partners.
- Better national data and surveillance.
- More inclusive and patient-centered research.
- Faster development of promising therapies with strong evidence.
- Clear timelines, accountability, and public reporting.

This is a defining moment. The National Parkinson's Project must meet the scale of the disease, the urgency of the science, and the lived reality of the people and families affected every day.

Thank you for your leadership and for listening to the Parkinson's community.

Larry Gifford
President & Cofounder, PD Avengers

#081 Linda Erekuuff (Second Submission) | Received: June 17, 2026

I wish the members of the committee could feel what it's like to have Parkinson's. There are also about 57 other afflictions that arise as the disease progresses:

Dry Eye Syndrome - which leads to double vision
Voice Softening - can be difficult for others to understand
Dyskinesia - often mistaken for tremors, uncontrollable movements in the upper body that are caused by dopamine medication, very painful.
Difficulty walking - can cause falls.
Poor posture - effects balance, can cause injury.
Vivid dreams - acting out dreams REM sleep disorder.
Difficulty swallowing - can cause choking.
Depression, anxiety and apathy - shortness of breath and heart palpitations, tightness in chest.
Lack of appetite - leads to loss of bone density.
Pain - extremely high, feels like nerve endings on fire.
Lack of facial expression

PD effects every thing that moves in your body.

Linda Erekuuff

#082 Robert Sturm, CMC, PhD Hon. | Received: June 17, 2026

Good morning. My name is Robert Sturm. I have had PD for more than 11 years. I was medically retired from my profession. I have not seen much progress in medication since Senimet was approved in the late 1960's. This is ridiculous. We are the most powerful and technologically advanced country on the planet, and we can't solve the equation of curing a brain disorder? Yet we can tag a cow and know where in North America that cow is located. I'm tired of taking 10 meds a day plus supplements. My neurologist says the next step is the pump. I have heard good and bad, I do not wish to use the pump. I have listened to the Stem Cell people promoting their system. There has to be a better way. My wife and I donate several thousands of dollars every year. What do we need to do to help the solution arrive more quickly?

Robert Sturm, CMC, PhD Hon.

#083 Ronald J. Rossi, Sr. | Received: June 17, 2026

Thank you for the opportunity to comment.

"Care Partner" is a term that is freely used, however, not extensively addressed by the Medical Profession. This Function/Responsibility must be given higher coverage in appointments with Medical Professionals. I fully realize that Doctors time can be limited, however, Experienced Volunteers (those Care Partners who have traveled that road and no longer have their PWP to care for).

I am an experienced Care Partner for 5 1/2 years, so I believe I know what I am talking about. This experience remains in my Brain and Heart, Unused.

Thank you for allowing me to communicate with this Highly Important event.

Ronald J. Rossi, Sr.

#084 Scott Erickson | Received: June 17, 2026

To whom it may concern: on the ACPRCS council:

I would like to take this opportunity to share my public comment for your consideration.

My name is Scott Erickson and I am a 65 year old that was diagnosed with Parkinson's in 2018. Thankfully I developed the disease at a time when new treatments and therapies are coming on line, giving me hope that a cure can be developed in time to stop my physical decline.

While I will likely never know how or why I developed Parkinson's, I have a pretty good guess. It has been shown that exposure to chemicals such as pesticides and herbicides can be a trigger for the disease. I grew up in central California and spent a lot of time playing and working in my grandfather's vineyards and orchards in the San Joaquin Valley. I remember watching crop dusters flying overhead spraying the vines and trees. I can only guess at what I was exposed to out there. The sad thought is that little has changed since then in terms of the chemicals that are still being used. How many people today have, and are, being exposed that will turn into the next generation of PD patients. While we look for a cure, we need to also stop the practices that will increase the number of future people with Parkinson's.

Good luck in your work and thank you for the opportunity to share a bit of my story.

Regards,
Scott Erickson

#085 Sharon K. Comstock | Received: June 17, 2026

June 15, 2026
Jordan Gladman, Ph.D.
Deputy Executive Director
National Institute of Neurological Disorders and Stroke
National Institutes of Health

Bethesda, MD 20892

Submitted electronically: nationalPDplan@nih.gov

Subject: Public Comment on the National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to provide public comment on the National Plan to End Parkinson's and to share why this effort is deeply personal to me.

I am a person living with Parkinson's disease and the fourth generation of my family affected by this disease. Parkinson's is not an abstract condition for my family. It is a lived, multi-generational reality that has shaped our health, our caregiving responsibilities, and our ability to live with stability and dignity.

I am both a person with Parkinson's and a caregiver within my family. This dual role has given me direct experience of how this disease can progress and how unprepared our current systems are to support families in crisis.

One of the most difficult realities is the loss of basic communication and function in daily care. I have had to try to help a loved one take medication, only to see them no longer understand what swallowing a pill means. Pills are refused or expelled. Instructions that were once simple become impossible. In these moments, families are forced into urgent care decisions without clear guidance, including questions about nutrition support and how to preserve dignity when cognition and function are declining.

These are not rare or abstract clinical situations. They are daily realities for families living with Parkinson's disease. They create emotional exhaustion, moral distress, and a constant sense of crisis management without adequate support.

Our family has also faced a significant financial burden from long-term care needs and fragmented services. Parkinson's disease affects not only health, but also financial security, caregiver capacity, and long-term planning.

Like many families, we earn too much to qualify for Medicaid assistance, yet not enough to afford the care that Parkinson's disease requires. We are caught in a gap that leaves us facing uncertainty about the future and wondering what will happen when our resources run out. No family should have to choose between financial hardship and quality care for a loved one.

Across four generations of my family, one truth has become clear: the burden of Parkinson's is cumulative, and the system of care has not kept pace with the reality of the disease.

What concerns me most is that Parkinson's continues to grow at an alarming rate, while families face delayed diagnosis, limited access to specialists, insufficient caregiver support, fragmented care coordination, and lack of clear long-term planning resources.

The National Plan offers hope, but only if it is implemented with urgency, accountability, and measurable outcomes.

The most important priority is implementation. A national plan without timelines, funding clarity, and accountability mechanisms will not produce meaningful change for patients and families currently in crisis.

Key Recommendations

1. Establish a clear funding roadmap

Provide a transparent, evidence-based estimate of the resources required to prevent, diagnose, treat, and ultimately cure Parkinson's disease. This should include phased planning to guide Congress and ensure adequate investment aligned with national goals.

2. Improve quality of life across all stages of disease

Ensure access to specialized care, rehabilitation, mental health support, respite services, and caregiver assistance at every stage of Parkinson's disease, including advanced stages.

3. Accelerate research into causes and risk factors

Expand urgent investment into genetic, environmental, and occupational contributors to Parkinson's disease, including patterns that appear across generations and remain poorly understood.

4. Establish measurable goals and public accountability

Set clear benchmarks, deadlines, and transparent reporting so progress can be tracked by patients, families, researchers, and policymakers.

The National Plan to End Parkinson's represents a historic opportunity. For families like mine, time is not theoretical. Every day brings new diagnoses, new caregiving burdens, and new losses of function and independence.

I urge NIH to ensure that this plan reflects the lived reality of people affected by Parkinson's disease and moves from planning into urgent, measurable action.

My family has lived with Parkinson's across four generations. I hope no other family will be asked to carry this burden into the future.

Thank you for your time, leadership, and consideration.

Sincerely,
Sharon K. Comstock
Person Living with Parkinson's Disease
Fourth Generation Parkinson's Family Advocate
St. Joseph, Michigan

#086 Stephanie G. Johnson, MSSW | Received: June 17, 2026

Dear NPP Advisory Council Members,

In 2023, I lost my husband of 34 years, Rick Johnson to Parkinson's disease (PD). I was his care partner for 13 years and shortly after Rick's death, I was diagnosed with PD. I founded the Parkinson's Disease Alliance of WI as a policy advocacy organization and to establish a Parkinson's disease registry in Wisconsin. Ideally, the United States should consider a national PD registry to track the incidence and prevalence of this epidemic in our country. PD is the fastest growing neurodegenerative disease in the world. The National Parkinson's Plan has the opportunity to prioritize needed investments so researchers can prevent PD, better diagnose and treat PD, and ultimately cure PD for those of us living with this chronic disease.

Please keep the following priorities top of mind in your work plan:

- Keep NPP on track and produce the first report within 1 year.
- Prioritize production of an estimate of needed investments to prevent, diagnose, treat, and cure Parkinson's disease as an early work product. Congress needs an evidence-based roadmap to right-size federal funding and build a long-term funding strategy. Parkinson's disease and atypical parkinsonisms impose a significant economic burden on patients, families, health care systems and the nation's economy, totaling an estimated \$82.2 billion in economic costs in 2024 alone. Federal investment in Parkinson's research totals less than 1% of this. Early investment is critical for results: in the early years of the National Alzheimer's Project, NIH spending on research increased 4.5 fold in 5 years. For PD that means a reasonable target for federal research funding by 2032 would be \$1.5 billion in federal research funding. Parkinson's organizations have called for an initial investment of \$600 million of annual PD research at NIH to start to narrow the funding gap. Long-term, the Council should consult with individuals with expertise in health economics to identify the necessary level of investment to address the unmet needs in Parkinson's disease.
- Include actionable recommendations to improve access to integrated, high-quality care and to reduce financial burdens. These recommendations should take into account needs across the lifespan, including specific consideration for people with young-onset PD, as well as unique needs for Atypical Parkinsonian disorders. Fewer than 10% of people with PD receive care from a movement disorders specialist and the majority of people have limited access to needed rehabilitation and mental health services.

Respectfully,
Stephanie G. Johnson, MSSW
Director, PD Alliance of WI
Madison, WI

#087 Dee Wieringa | Received: June 18, 2026

For the past 12 years I have facilitated our weekly Parkinson's Support Group for those diagnosed with Parkinson's and their care partners and families. I have witnessed how Parkinson's destroys lives. The loss of mobility, independence and life for those diagnosed and the toll this disease takes on our caregivers and families and ultimately the loss of our loved ones. I spent two decades in the senior living industry and fully understand the extreme cost of care for Parkinson's patients. Often families are required to employ a private caregiver at additional cost, for one-on-one care in senior living communities. Costs are further elevated due to the numerous medication assistance for Parkinson's patients and there is no guarantee that fatal falls will not occur in a senior community setting. With approximately 90,000 diagnoses each year we need hope to find a cure and to raise awareness about the challenges facing those living with Parkinson's. For the past five years I have presented an Annual Parkinson's Awareness Expo in our local community. Healthy people rarely understand all the symptoms of Parkinson's Disease, it is so much more than tremors. Parkinson's damages relationships more than people realize.

Thank you for your advocacy.

Dee Wieringa
ACV Parkinson's Support Group

#088 Jim Gayhart | Received: June 18, 2026

Public Comment to the Advisory Council on Parkinson's Research, Care and Services (ACPRCS) on the Need for Greater Awareness, Research Funding, and Support for Progressive Supranuclear Palsy (PSP) and Rare Neurodegenerative Diseases

My name is Jim Gayhart, and I am writing to share my family's experience with Progressive Supranuclear Palsy (PSP) and to emphasize the critical need for greater awareness, research funding, and support for individuals and families affected by rare neurodegenerative diseases.

My wife, Patty, was diagnosed with PSP in October 2023 at the Mayo Clinic in Rochester, Minnesota. Looking back, however, we believe her journey with this disease began years earlier. Prior to her diagnosis, Patty experienced multiple falls, including one that resulted in a broken jaw and another that required surgery to repair a broken clavicle. She also exhibited symptoms that, in hindsight, were consistent with PSP, including a slowed gait, cognitive slowing, restricted eye movements, and persistent fatigue. One of the most noticeable changes to me was that the sparkle had gone out of her eyes.

Like many families facing a rare disease, we knew something was wrong but did not know what it was or where to turn for answers. Over the course of a year, Patty saw numerous specialists, including an endocrinologist, ENT specialist, cardiologist, and eventually a neurologist. After months of testing, she was diagnosed with Multiple System Atrophy (MSA) in September 2023. Seeking additional clarity, I arranged for a second opinion at Mayo Clinic, where her diagnosis was changed to PSP.

While no one wants to receive a diagnosis of a terminal neurological disease, there was some comfort in finally understanding what we were facing and being able to develop a plan. Unfortunately, for PSP patients today, that plan is focused largely on managing decline rather than treating or curing the disease. We were told that one of the few interventions shown to potentially slow progression is aerobic exercise. Patty had always been an avid walker, often walking more than five miles a day. Tragically, PSP itself makes walking increasingly difficult and dangerous. The very activity that may help slow the disease becomes one of the first abilities the disease takes away.

PSP is a terminal condition, and currently a diagnosis comes with no cure and only limited treatment options. Behind every diagnosis is a person and a family struggling to navigate profound and unrelenting loss: the loss of independence, mobility, abilities, identity, and often financial security.

Watching Patty go from someone who was fiercely independent, physically active, and mentally sharp to someone who can no longer walk without support, who needs help with even the most basic daily activities such as getting out of bed or getting dressed, who struggles to speak clearly, and who faces slowed thinking, apathy, and a loss of motivation has been heartbreaking. Hours of physical, occupational, and speech therapy offer only the possibility of slowing decline—not restoring lost function—and that reality is devastating.

For me, the transition from spouse to caregiver has permanently changed our relationship. The life we imagined together—our hopes, plans, and dreams for the future—has been profoundly altered by this disease.

Rare diseases such as PSP carry a unique psychological burden because so few people understand them. The isolation can be overwhelming. The hardest part is not only the progression of symptoms but also the profound sense of hopelessness that can accompany them. Yet even in the face of this reality, we continue to hold on to hope—hope created through awareness,

compassion, scientific research, and a collective determination to support those living with PSP and the people who love and care for them.

Organizations such as CurePSP play a vital role in addressing these challenges. They support research, provide educational resources, connect patients and families, and advocate for better care and treatment options. When Patty received her diagnosis at Mayo Clinic, CurePSP was the first organization her physician recommended. Over the past almost 3 years, we have witnessed firsthand the invaluable support, guidance, and leadership they provide to families like ours.

PSP desperately needs greater public awareness. Diseases such as Parkinson's disease and ALS have benefited from highly visible public advocates who have helped educate the public and generate support for research. PSP lacks that level of recognition. Increased awareness can lead to earlier diagnosis, improved patient care, greater support for families, and increased investment in research.

Funding for rare disease research is critically important. More than 7,000 rare diseases affect over 25 million Americans. While each disease may impact a relatively small population, together they represent a significant public health challenge. At some point in our lives, nearly all of us will be touched by serious illness or caregiving responsibilities. Investing in rare disease research is an investment in hope, dignity, and better outcomes for millions of families.

I respectfully urge policymakers, researchers, healthcare leaders, and the public to support increased funding for rare disease research, improved access to specialized care, expanded caregiver support, and greater awareness of conditions such as PSP. Families facing these devastating diseases deserve more than symptom management. They deserve hope for effective treatments and, ultimately, a cure.

Thank you for considering my comments and for your commitment to improving the lives of individuals and families affected by rare diseases.

I would welcome the opportunity of sharing oral comments during the ACPRCS meeting if the Advisory Council would deem it helpful.

Jim Gayhart
Maineville, OH

#089 Lucretia Pintacuda | Received: June 18, 2026

To the ACPRCS full committee:

I am submitting the following message as a public comment. I would appreciate the opportunity to speak in person to the committee if it could be arranged. If I cannot address the ACPRCS full committee in person perhaps I could comment virtually. I represent the many, many individuals who have been diagnosed with Parkinson's Disease. Since each person with Parkinson's Disease has their own, unique experience, I believe hearing the stories from many different individuals is important. I respectfully ask that you read and consider my written message. Thank you for allowing me to express my concerns and comments.

My name is Lucretia Pintacuda. Ten years ago, at the age of 60, I became aware of a health issue. I experienced tremors in my right hand, weakness in my right arm, twitching in my right fingers, and slowness of movement. I self-diagnosed Parkinson's disease and received an official diagnosis from a Movement Disorder Specialist nine years ago. As an anesthesia provider, my job required a high level of skill and acuity, so I kept my diagnosis private until I retired at the age of 65. I became public about my diagnosis at the age of 67 by signing up with the Michael J. Fox Foundation to climb Mount Kilimanjaro as part of a fundraising effort. I have been actively raising awareness about Parkinson's Disease through various fundraising efforts, including running two 10K events and climbing three volcanoes in Guatemala last November. I have also written a blog about my journey, titled "trekkingupward.com." I am now turning my efforts to political advocacy to raise awareness about the causes of Parkinson's Disease and the potential for further research to combat this debilitating disease. Parkinson's Disease extends beyond a movement disorder, affecting mood, sleep, smell, and other aspects of life.

The primary treatment for Parkinson's Disease (PD) remains the replacement of lost dopamine due to the degeneration of dopamine-producing cells in the brain. As a patient with PD, I take a form of dopamine orally. There are also alternative options for dopamine administration, including skin or intestinal infusions and nasal sprays for immediate supplementation. Various medications can augment the treatment of PD based on individual needs.

PD affects each person with the condition in its own unique manner. Unfortunately, there is currently no cure or treatment to halt or slow its progression. The only proven method to slow its progression is consistent and vigorous exercise. I engage in heart-pounding activities every week, primarily through hiking. Living with PD requires constant effort to manage the symptoms and challenges associated with low dopamine levels. While I can perform most tasks, I experience delays and clumsiness in nearly everything I need to do for daily life. Activities such as tying my shoes, applying makeup, cooking, folding laundry, brushing my teeth, and typing this message are cumbersome.

The three primary causes of PD are believed to be head trauma, genetics, and exposure to toxins, with the latter being the leading cause. Toxins such as paraquat, TCEs, and glyphosate-based herbicides like Roundup and Dursban are among the main culprits. In my case, I have all three causes. As a young child, I experienced a severe head trauma in a sledding accident. Additionally, I resided near an apple orchard that was treated with insecticides and potentially herbicides. Our well water was undoubtedly contaminated with these toxins. My maternal grandfather, uncle, and two cousins have/had PD. My symptoms are progressing, and I share the hope of the 6 million individuals globally and over 1 million nationally who have PD for a treatment or procedure that can halt or prevent the disease. Currently, 15% of newly diagnosed individuals are diagnosed before the age of 50, known as young-onset PD. The financial burden associated with caring for individuals with PD is increasing, which should be a concern for our government. Addressing this condition requires a comprehensive approach. I am eager to share my story and raise awareness to bring about positive change.

Lucretia Pintacuda
Asheville, NC

#090 Marco Masoni | Received: June 18, 2026

public comment

I would simply like to point out that Bayer is, at once, the manufacturer of Roundup, whose active ingredient glyphosate has been linked to an elevated Parkinson's risk, and the owner of BlueRock Therapeutics, a company at the forefront of Parkinson's neuronal stem cell therapy research. There is hardly any scrutiny of this disconnect, whereby a company stands to profit from both ends of the Parkinson's Disease pipeline, disease cause and disease modification. Why are we not talking about this? It's also worth asking why there is so little attention to the broader fallout from a senior NIH official, who oversaw a \$2.6 billion neuroscience budget, being found to have falsified data behind decades of Alzheimer's and Parkinson's research. His theoretical findings underpin ongoing clinical trials and continue to shape Parkinson's research priorities today. That silence should give us real pause about the systemic consequences of this institutional failure, and about how much of Parkinson's research funding and public trust have been built on findings that were never properly verified.

-marco masoni

#091 Marilyn Ereshefsky | Received: June 18, 2026

As a person with Parkinson's, I have found that medications often affect men and women differently. Dosages may be incorrect and efficacy and side effects may be quite different. Including more women in PD research should not be seen as a request for diversity, but as something essential to accurate scientific research and to our understanding of the disease.

Marilyn Ereshefsky
Timnath, Colorado

#092 Michele (Mickey) Cunliffe | Received: June 18, 2026

Public Comment

Submitted by Michele (Mickey Cunliffe)

Waking up in the morning I think, "What will my day be like TODAY? What new physical challenges will I face today and how best to deal with them without Parkinson's controlling my life?" That's what it's like living with Parkinson's. This neurological, progressive, non curable illness robs me and others diagnosed with Parkinson's from a life of normalcy. The uncertainty of not knowing how your body reacts DAILY living with Parkinson's does take a toll on me, my family and friends. Each day is a challenge when it comes to living with this progressive, neurological disease. It's a two step forward, one step back existence.

One thing I do know is I'm now different after my Parkinson's diagnosis. I look different, I talk different and I walk different. My face is now in a mask like state, my voice is now almost at a whisper level, I walk slowly, hunched over and I must wear 2 leg braces to counteract the inversion, dropped foot and dystonia caused by Parkinson's.

I was diagnosed in 2016 with the disease. My astute PCP noticed a tremor of my thumb. After days of testing by several neurologists at Yale University hospital, I got the diagnosis of Parkinson's. Was I surprised? Not really. My Dad lived for over 25 years with Parkinson's. He worked at a country club-golf course for over 30 years. He was exposed to Paraquat - the weed killer used in the 50's and 60's on golf courses. I was a regular at this country club and played on the course during my childhood years. There is now a direct link between the chemical Paraquat and Parkinson's.

My daily routine is now taking 16 pills of Carbidopa Levodopa (12 pills) and Pramipexole (4 pills). These drugs have managed to slow the progression of this disease along with my strict regiment of daily intense exercise.

Bottom line: Parkinson's impacts patients differently with symptoms ranging from tremors, stiffness, slowness and or instability (balance issues) with the intensity of these symptoms varying by patient. While there is no known cure for the progressing physical symptoms of Parkinson's, the psychological toll it takes on both the patient and their caregivers of the unknown is equally devastating.

Please feel free to contact me with questions or comments. Thank you!

Mickey

#093 Mike DeBartolo | Received: June 18, 2026

Public Comment: Ban Paraquat - My Journey Living with Early Onset Parkinson's Disease

Parkinson's debilitating symptoms entered my life fifteen years ago while training to run the 2011 NYC Marathon on my fiftieth birthday. Six years later I was diagnosed with Parkinson's Disease.

Living with early onset Parkinson's has been an amazing life journey of lost and found. For me, undiagnosed Parkinson's brought with it confusion, compromised coordination, less energy, sleepless nights, uncontrollable shaking, susceptibility to stress, and career transition. Upon diagnosis, Parkinson's motivated my resolve to live with Parkinson's in ways that inspire.

Seeing Parkinson's as an Opportunity

Facing compromised physical, mental and neurological health and an uncertain future, I was bewildered searching for answers to what I later came to understand was Parkinson's gone undiagnosed for over five years. Before diagnosis, I learned I couldn't handle my condition alone. I leaned into my faith in God and loving family. Upon diagnosis, I also came to better appreciate the vital importance of caring friends, playtime, attitude, community and expert medical care. I learned to lose stoicism, avoid playing victim and rather find opportunity, find grace.

My Parkinson's diagnosis lifted a veil of uncertainty. It identified a condition I have, not who I am. It provided certainty even while Parkinson's impact in my life ahead is uncertain. I was relieved. I understood Parkinson's is a condition I can live with. I am learning Parkinson's is a life story not a death sentence. And by sharing my condition with family and friends and reaching out to our Parkinson's community, I knew I wasn't alone.

Career Transition

Parkinson's meant I needed to transform my work life. Professionally, I enjoyed a thirty year media and magazine publishing career in leadership roles with several of America's largest magazines during their peak years including TV Guide, Condé Nast and Parade Magazine, America's most circulated and read magazine at the time. When my undiagnosed Parkinson's showed up and disrupted my life, it handicapped my ability to meet the pace of dynamic leadership roles I had held. Lost in career uncertainty and transition, I motivated to find a second career where I could make a difference for communities in need at a pace I could handle. I discovered joy in fundraising for causes important to me. It was a pace more manageable, mission inspired and the friendships made a blessing.

Yet my advancing Parkinson's Disease eventually disabled me from doing important and specific duties of being a professional fundraiser. My daily fatigue limits ability to travel and drive later in the day. Rest and slow time during the day becomes a necessity. Worsening incontinence results in daily urination accidents. Poor typing slow down correspondence and data entry substantially. Illegible handwriting prevents taking discernible meeting notes. Worsening ability to multi-task makes an attempt to juggle a vast number of relationships implausible. The adverse symptoms of Parkinson's Disease make performing a stressful job more stressful which is particularly troublesome since Parkinson's symptoms become more pronounced when under stress.

I am very fortunate to be covered by two long term disability income policies providing my wife and me with income security. Most of my friends with Parkinson's don't have one let alone two income disability policies to rely upon. I see the stress and hardship faced by friends with Parkinson's who are not well covered.

The Bright Side

On the bright side, I am learning that living with Parkinson's inspires my faith and invites gratitude for loving, caring people in life; sharpens my empathy towards others who face challenges in life too; and encourages patience to savor life's joys.

While my Parkinson's inhibits me from running marathons, I learned I can walk marathons. What a joy it was to walk the 2021 NYC Marathon one day after my sixtieth birthday with my daughter Anna by my side the entire way cheering me on stride for stride. And, similarly, the 2022 Chicago Marathon with Anna and the 2023 Chicago Marathon with my two sons, Peter and Joe.

The Human Costs – Ban Paraquat

We know that exposure to paraquat has high correlation with having Parkinson's Disease. I was exposed to paraquat on golf courses where I caddied and played nearly every day in the Chicago area during the spring, summer and fall of my childhood and young adult years. The human costs are too high not to ban paraquat's use in our society. Please do the right thing and insist that the EPA ban paraquat from any and all use in the United States.

Mike DeBartolo

#094 Susan Leick | Received: June 18, 2026

My name is Susan Leick from the North Bay town of Calistoga, CA.

Through Michael J Fox Foundation I have spoken on several occasions about my husband's journey with Parkinson's and Lewy Body dementia - the 2nd most common form of dementia. This combination made him lose his executive function, his ability to speak, and his memory. In addition he was plagued by hallucinations. Before he was bedridden he alternated between freezes (sometimes as long as 45 minutes in one position) and racing around the house which led to falls and compression fractures in his back. My husband Joe McCrary's journey ended April 3, 2024 - over 2 years ago and just a bit over 5 years after his diagnosis.

In reading over my past notes I recall saying "I cannot bear the thought of losing my darling husband and I cannot bear the thought of caregiving for much longer." These illnesses affect everyone around the stricken patient to a debilitating extent. Between a ton of needed supplies and 2 daily shifts of caregivers we spent over \$80,000. I am lucky that we could afford his care but many others cannot. I needed a caregiver's help to freshen Joe several times a day as the fractures in his back from his many falls took 2 of us to move and sustain him in a position to facilitate changing him. He suffered such indignity.

Not only did I worry about the everyday matters of his illness, living in a high fire danger area was terrifying with a husband confined to a hospital bed and dependent on a mattress that moved constantly to keep him from getting bedsores. Yes I received a tiny discount from PG&E to offset the 24 hour need to supply the mattress with electricity but I had NO guarantee from PG&E that we would not lose power. There needs to be help at times of emergency for the disabled.

Maybe you know this, but everyone's Parkinson's is different but I will relate Joe's to 2 people in the media. My Joe had the same combination of "mixed pathologies", Parkinson's and Lewy Body dementia, that Robin Williams suffered from. When you understand that these conditions rob you of executive function, ability to think or move properly, loss of speech and wit you understand the devastation to Robin's life and career and to Joe McCrary's who made me laugh every day of our almost 37 year marriage. It was so depressing to Joe that he couldn't be funny and "punny" any more that he just stopped interacting with his friends and family.

Another name you know is that of former FBI Director Robert Mueller who died March 20th (Joe's birthday) of this year just 5 year's after being diagnosed. This was the same for Joe. Diagnosed in June of 2019 and gone by April of 2024. This in sharp contrast to Michael J Fox, and other friends of ours that also have Parkinson's - one who is still managing after 16 years.

The Fox Foundation often says that there is a genetic component to Parkinson's but it is the environment that pulls the trigger. The only so called bad habit my husband had was his use of weed killer to try to tame the bumper crop of poison oak on our property. Did he protect himself by wearing a mask or a hazmat suit? NO! he exposed himself to the weed killer without knowledge of all of its potentially harmful effects.

Was that habit at the root of his illness? We will never know...but perhaps it triggered something that morphed into his brain dysfunction.

The product he used did not contain Paraquat - the most dangerous of the products. Paraquat is used on farm crops, vineyards at times, on golf courses. Our first home in CA was very near a golf course. Our country must work to totally ban Paraquat which is already illegal in 70 countries including China who manufactures and sells it to the US.

There is much more to our story but I am just sharing an overview and would be happy to expound upon it whenever needed. I am totally in sync with a motto of Michael J. Fox, "Here until Parkinson's isn't".

#095 Diane LaVeille | Received: June 19, 2026

Good afternoon,

I find it ironic that the very people you need to gather information from have Parkinson's disease. We have different symptoms, such as apathy and procrastination on top of not wanting to submit this public comment because we don't feel well. It's like having a really bad flu a lot of days.

My only comment/question is how come the government/FDA could push through a COVID-19 vaccine in a matter of months and we still don't have a cure for Parkinson's? The "gold standard" carbidopa/levodopa was approved 50+ years ago! Are we less important or is our suffering not recognized because we are a smaller group? This should not only be worked within the United States, but it should be a worldwide medical emergency as cases increase year to year. Beyond the physical ailments, it is astronomically expensive on every level.

Your help to find a cure for Parkinson's is crucial and we will all be watching to see when relief may be in our scopes!

Thank you,

Diane LaVeille

Diagnosed 2-13-2018 and I am waiting....

#096 Donald Brill | Received: June 19, 2026

I was diagnosed unexpectedly in March 2025 with Progressive Supranuclear Palsy (PSP). I am stage 1 which is early to be determined with this disease. A disease with no cure nor any treatment options. Unfortunately, with the rarity of this disease and related neurodegenerative condition diseases it has little attention, and lack of research in the medical research field.

I am writing to have my voice heard and ask for priorities to be focused on these diseases that are associated with neurodegenerative conditions.

I have associated issues with body rigidity (neck and back especially), restless legs, memory and mental health challenges and sleep deprivation and insomnia issues that I have suffered with for years.

Please can we have some direction and assistance with funding for research to help move forward with addressing these neurodegenerative diseases. Thank you.

Sincerely,
Donald Brill
Herndon, Virginia

#097 Jennifer Taylor | Received: June 19, 2026

Hello,

Below please find my public comment for the June 29th advisory council meeting.

Almost 40 years ago, my beloved grandmother, Margaret, died of a little known, rare neurological disease called progressive supranuclear palsy. My mother, Sheila, was her only child and the responsibility of caring for both of her parents fell to her. After my grandmother's death, my mother was diligent about taking herself to see a Neurologist on an annual basis. Armed with the little research she could find, she would share with every doctor she saw her greatest fear....that she would inherit this debilitating disease from her mother. Each doctor had the same response, they knew little about the disease but assured her it was not hereditary.

There were minor falls beginning in my mother's early 60s, all attributed to coordination and dismissed by doctors. Her cognitive decline was subtle, beginning in her early 70s. Subsequent falls were followed with hospital/rehab stays to help her get her strength back. Diagnoses of Parkinson's Disease and parkinsonisms and repeated dismissal of PSP anxieties followed. By the fall of 2017, I could no longer stand by as no one listened to our concerns. We travelled to the Cleveland Clinic in Weston, Florida to see yet another neurologist who confirmed our fears. My mother did in fact have PSP.

Armed with our new diagnosis, we returned to my mother's local neurologist, the third one we had seen as we searched for answers in our small community. After a few additional visits, we were told there was no reason for us to continue as there was nothing the doctor could do for my mother. There were no discussions of clinical trials or resources. Her primary care doctor said essentially the same. "Please get in touch when you feel your mother is ready for hospice care."

And so, we navigated as best we could, alone. We hired a wonderful caregiver to help her shower and dress during the week, I took the weekends. We increased the caregiver's hours as my mother declined, helping her in the morning and again at night. As time passed, it became clear that more help was needed, so I quit my job and arrived for "my shift" as the caregiver was leaving in the late morning and often staying until she returned at dinnertime. My father would tell me almost daily that they would be fine alone for a bit so I could pick up my children on time from practice or not miss one of their games. Her illness was causing him much stress and he was clearly aging by the day. I was neglecting my home and family as I watched my vibrant mother fade away a bit more each day.

In February of 2019, my mother began hospice. But she was not their usual hospice patient and quite honestly, they didn't know what to do with her. She was not dying, she was very slowly losing her ability to live. It took almost six months, numerous conversations with her hospice social worker and many tears on my part to finally get a hospice plan in place. As a family we didn't need a nurse to come in weekly to review the end of life meds that had been placed in the fridge and take her blood pressure. We didn't need help discussing her funeral plans. We had more immediate needs. We needed a home health aide as it was becoming difficult for me to lift her on to the toilet when I was there by myself. We needed a volunteer to sit with her as she slept in a chair so I could focus on my aging father. He needed to see his own doctor. He needed an hour a week where he wasn't sitting next to my mom watching her slowly slip away. Although she could no longer communicate, we were desperately trying to keep my mother engaged. I had to ask repeatedly if she could participate in music therapy.

My mother died at 82 in October of 2021, four years after her diagnosis, many years after her symptoms began. I believe our journey with PSP is a common one. I thank you for giving it more attention.

Thank you,
Jennifer Taylor
Vero Beach, FL

#098 JoAnne H. Duke | Received: June 19, 2026

My husband, Winston Carl Duke, was diagnosed with Parkinson's Disease in 1988, at the age of 46. As he left the neurologist's office that day, he abruptly stopped in the parking lot and looked at me..."I will live with this!" And that is exactly what he did, without complaint.

In the early stages, his neurologist in Richmond suggested that we might want to talk with the doctors at UVA who were doing research on Parkinson's at that time...we made an appointment and headed for UVA!

After examining my husband and his medical history, the doctors at UVA found no genetic indications to implicate Parkinson's, so they recommended that we look back to possible exposure to environmental chemicals. Immediately, my husband named Trichloroethylene...a chemical he had used while on a remote assignment with the US Air Force at Indian Mountain, Alaska. He described skin rash on his hands and continuing headaches while on that remote site for an entire year.

With years of online research, we found that Parkinson's does indicate a connection to Trichloroethylene. After years of appeals to the Veterans Administration, the VA did officially determine that my husband's Parkinson's Disease was 'more likely than not' caused by his exposure to Trichloroethylene.

There are military communities across this Country that have been involved with chemical contamination of dangerous chemicals.

My husband is now deceased...I watched his life be completely destroyed physically and cognitively during a time span of 34 years following diagnosis of this horrendous disease.

I urge the United States to clean this contamination up...our communities do not need to be exposed to these dangerous chemicals that are having horrendous effects on our lives.

Our Country can do better than this...our Citizens deserve better!!!

Respectfully,
JoAnne H. Duke
Moseley, Virginia

#099 Jonathan Holman | Received: June 19, 2026

"You have Parkinson's Disease." This revelation hit me like a ton of bricks. I instantly flashed back to the early 60's and a neighboring farmer who shuffled ever so slowly and talked to my father in a slow whisper, his face void of movement. Was that to be my future?

My initial panic was softened by slowly developing symptoms and communication with a fellow pharmacist whose mother had PD, noting that she got along just fine with drug therapy for around 10 years (forgetting how time flies).

My professional years were spent in critical care units where limited use and consequent knowledge of PD drugs was deficient. Occasionally a PD patient would be admitted to the ICU and presented a challenge with so many home meds and their ever inflexible timing. Since diagnosis I've learned of the importance of timing.

So, what was the genesis of this curse? I grew up in a rural farming community with insecticides and weed killer used in our crops, gardens and flower beds. Don't know 60 years ago which, but suspect some were among those currently associated with PD. Genetics are an unlikely cause based on the absence in an extended family history.

Jumping forward to the final year in practice, my symptoms increased and were a major factor in my decision to retire; a challenging course without PD. Adding to the frustration was the need to alter or abandon plans we looked forward to. I've learned to take it day by day as symptoms fluctuate. Will I be off or on: shop or not, go to dinner or not, maybe later, etc. I am married to an incredible woman who is empathetic, kind and eager to be there despite being deprived of the life we dreamt of and the mate she joined for better or worse 46 years ago. I am very lucky and appreciative.

Things I've noted where more information would have been beneficial are:

- when something changes in the way you feel: is it PD, arthritis, strain from yard work?
- side effects common to the usual PD meds and how to minimize (constipation, dyskinesias, other GI effects)
- hallucinations: I believed what I was seeing was real for weeks before convinced otherwise.

Since diagnosis I have pushed to be physically active and I credit it for the level of mobility I enjoy today, despite early loss of balance: Rock Steady Boxing 3x/week, gym many other days. I am currently participating in my 6th clinical trial. Numbers are critical to discovery and confirmation; participation is encouraged.

Hope for the magic bullet has been given new life from the current increased attention, focus and contribution of interested individuals and organizations such as MJFF. They are deeply appreciated.

Patiently Hoping,
Jonathan Holman

#100 Ken Chason | Received: June 19, 2026

Subject: Public comment from Ken Chason, person living with Parkinson's disease and member of the Parkinson's Foundation's People with Parkinson's Advisory Council

Date: June 19, 2026

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

Thank you for the opportunity to comment as the ACPRCS begins to develop its work plan under the National Plan to End Parkinson's Act. I am optimistic that the Council's work can strengthen our national response to Parkinson's and meaningfully alter the disease's trajectory.

The Parkinson's crisis is real and urgent. More than 1.1 million Americans have the disease, with approximately 90,000 new diagnoses each year. Parkinson's is relentlessly progressive, devastating patients and families alike, and is on track to further strain our healthcare system.

To fully understand the challenge and chart a way forward, it is essential to hear from people who live with Parkinson's every day. I would therefore like to share my own experience.

I was diagnosed in 2023 at age 56, after experiencing a series of symptoms over four years. In retrospect, some of the earliest signs—appearing in 2019—were severe, generalized anxiety without any obvious cause and subtle changes in my handwriting, which grew noticeably smaller and messier. As the anxiety worsened, meetings and social interactions became difficult. It eventually improved with treatment, and I moved on.

Over time, however, other changes appeared. My left arm stopped swinging naturally, my left hand began to curl slightly inward, and there were subtle changes in my gait. I dismissed these developments as they occurred. A foot tremor finally got my attention. At a routine physical, I asked whether the tremor could be Parkinson's; my primary care physician thought this was unlikely. When the tremor persisted, I was referred to a Movement Disorder Specialist who performed a comprehensive motor examination and asked about a broad range of symptoms. The pieces now fit together: it was Parkinson's.

Following diagnosis, I began medication for motor symptoms and completed specialized/intensive physical and occupational therapy. I was also referred to a neuropsychiatrist and soon added a cognitive behavioral therapist experienced in neurodegenerative conditions to my care team.

I am one of the fortunate ones. I live in an area where comprehensive, specialized, and coordinated Parkinson's care is available: care that remains out of reach for many people living with the disease. Yet even with this level of care, I have still experienced difficulties and setbacks. Gait issues, for example, led to a serious fall last year. Less visible symptoms—mood fluctuations, deep fatigue, and occasional periods of "brain fog" that can make it difficult to process multiple streams of information (particularly as medication wears off)—contributed to my decision to retire from a senior career leadership position in the federal government sooner than planned.

As the Council begins its work, I urge it to keep the experiences of those living with Parkinson's in mind and focus on three priorities.

First, establish firm timelines and maintain accountability for implementation.

The National Plan was created because Parkinson's demands a coordinated national response. The deadline for the first mandatory biennial report has already passed. I encourage the Council to adhere to its timelines and sustain momentum. People living with Parkinson's do not have the luxury of delay. The disease progresses every day; progress on the National Plan must do the same. To make up for lost time, I respectfully ask that the overdue report be issued within one year.

Second, estimate the resources required to prevent, diagnose, treat, and ultimately cure Parkinson's disease.

I support the call for an initial annual NIH investment of \$600 million in Parkinson's research as a critical first step toward narrowing the current funding gap. Looking ahead, a reasonable goal would be to increase federal Parkinson's research funding to \$1.5 billion annually by 2032, consistent with the growth in research investment achieved under the National Alzheimer's Project. The scope of research should include disease-modifying therapies, improved diagnostics, environmental and toxic exposures (including those affecting service members—a concern that is particularly important to me as an Army veteran and the son of a career Air Force service member exposed to Agent Orange during the Vietnam War).

Third, prioritize quality care and equitable access to specialized treatment.

My experience illustrates the value of coordinated multidisciplinary care. Working closely with a dedicated team, my symptoms are generally well managed. Unfortunately, this level of care remains unavailable to many people living with Parkinson's.

Access to Movement Disorder Specialists is limited outside major metropolitan areas, and multidisciplinary care is too often out of reach. Telehealth barriers, workforce shortages, and insurance limitations leave many patients without timely access to treatment. The result is unnecessary suffering for patients and caregivers and strain on the healthcare system.

The Council should develop recommendations that expand access to comprehensive care across all stages of Parkinson's—addressing not only motor symptoms but also non-motor symptoms such as fatigue, apathy, depression, anxiety, cognitive changes, and sleep disorders. I especially urge the Council to recognize the central importance of mental health, as mental health challenges are common in Parkinson's—for example, anxiety and depression affect an estimated 40–50% of people living with the disease. Yet access to clinicians with specialized experience in Parkinson's-related mental health care remains limited, leaving many people without adequate support. Comprehensive care must include timely access to specialized mental and behavioral health services when needed.

I applaud the Council members for taking on this important work; it means a great deal to Americans living with Parkinson's and the families who support them.

I request the opportunity to deliver these comments orally at the first meeting of the Advisory Council on June 29, 2026.

Thank you for your consideration and for your service on this Advisory Council.

Ken Chason
Alexandria, VA

#101 Linda Ereku (Third Submission) | Received: June 19, 2026

My best friend had a stroke in 2012. Her neighbor was a physician, who diagnosed her medical emergency. She was treated and released from the hospital and is fully recovered, leading a normal life.

My husband was diagnosed with an aggressive form of bladder cancer 2010. He had three biopsies, the cancer kept moving to different areas of the bladder, even after treatment. Luckily he was treated at MSKCC, is fully recovered and living a normal life.

I was diagnosed with Parkinson's in 2009. At my initial visit with the neurologist, she told me that I will have ten good years plus she can't fix me. I had DBS surgery in 2020, which was unsuccessful.

I told my friend and husband that they were fortunate they got better, I never will.

Linda Ereku

#102 Lyn Olson | Received: June 19, 2026

I am writing this on behalf of my husband Ronald Olson, who currently is in a memory care home with Parkinson's dementia. It has been a long difficult journey for him and our family. Though he was diagnosed in 2016, his symptoms began much earlier, in fact, not long after his service in Vietnam. Subsequently under the PACT Act guidelines, he was rendered 100% disabled due to toxins experienced on his tour in Guam during the Vietnam war.

So many symptoms experienced by Parkinson's patients are not always seen. Confusion, apathy, anxiety, digestive struggles, and sexual dysfunction, have all accompanied his journey. Needless to say this has impacted the marriage relationship and family dynamics. As his wife, I have been his principal caregiver, with love and devotion, however, caring for someone with Parkinson's and dementia involves 24/7 mental, emotional, physical, and spiritual stamina. And there is a limit, especially as this disease progresses. There is isolation and loneliness, and a great deal of grief.

However, we thank God every day for the benefits he is receiving under the PACT Act which is covering about 50% of the \$10,000 per month we pay to the memory care facility. Prior to his moving to the facility I was also receiving a stipend as his Care partner. It included some respite care which was desperately needed for me.

I definitely think more programs should be funded for others with Parkinson's such as farmers, miners and others, vulnerable due to toxin exposure. In fact, the state of Kansas where I live has the largest number of people with Parkinson's and it is a very rural state.

There's more I could say, but I am praying that there will be a cure and that awareness of this disease, which is now outpacing Alzheimer's, will receive national attention and funding. We are grateful for this commission and are hopeful that there will be positive outcomes for the thousands of people and their families suffering with Parkinson's disease and related neurological illnesses.

Respectfully,
Lyn Olson
Kansas

#103 Megan Mindel | Received: June 19, 2026

Public Comment

To whom this may concern,

My name is Megan Mindel and I would like to share my connection to Parkinson's Disease. My dad was diagnosed with young-onset PD at the age of 56 in 2018. While as a family we have been fortunate in our ability to access care and therapies for my dad in order to slow the progression of this disease we have not gone through this process unchallenged.

Even on good days, there are daily reminders - tremors, freezes, medicine...

In the last year my dad received a pump that has been a game changer. As great as the pump has been, there have been continued hurdles to jump to ensure he can continue to use and keep it; endless phone calls, fights and people claiming they understand but not actually able to help.

I urge this committee to start here - making treatments more easily accessible to those who need them. Parkinson's treatments are a constant experiment for patients and their families - trying to find and keep anything that brings a sense of normalcy.

With this committee's help, hopefully we can continue to make PD more manageable for everyone.

Thanks,
Megan Mindel

#104 Patricia Walter | Received: June 19, 2026

To the members of the ACPRCS Committee,

I am a 76-year-old woman living in Wyoming. I was diagnosed in 2019 with Parkinson's Disease. I would like to make a public comment. At the time I thought the diagnosis meant I would probably have tremors in my hands and maybe other parts of my body. Little did I know that there would be no part of my body that would not be affected not only by the disease, but also by the effects of medications that helped control the motor and non-motor symptoms. I had no idea how my diagnosis would affect other people, including my husband, family, friends and members of my community.

I did not have debilitating effects from the disease until 2023 when I noticed that I was unable to stand in one place for any period of time. In the summer of 2024, my husband and I moved to Cheyenne to be closer to our son. We had realized that the progression of Parkinson's would mean that we would need help with my care in the years ahead. I was able to take an active role in the moving process. We had built a new home, with an eye to the future with zero grade entry, safety measures in the bathroom and living space on one floor.

A major disadvantage that Cheyenne presented was the shortage of medical providers. Neurologists could not see me for 3-4 months. Because of support from the Parkinson's Association of the Rockies, I was able to be connected to a Movement Disorder Specialist in Loveland, which is only an hour away.

My disease progressed quickly during 2025, the worst year of my life. I went from being able to walk 1-2 miles a day to needing a rollator to go across the room. I suffered from anxiety, apathy and depression. Two or three nights a week I was unable to sleep at all. When I did sleep, I acted out bad dreams by screaming and hitting my sleep partner. It was with great difficulty that I visited anyone who had steps into their home.

Our social life is nearly non-existent. I am no longer able to attend Mass or participate in bible study. Volunteer opportunities for people who are immobile are rare. I do have friends who, occasionally, take me to lunch. They have learned how to load me and my rollator in the car. They know that I need help opening doors, that steps are very difficult and that using a public restroom is a nightmare.

My husband and I are fortunate to have good health care insurance. There is no way we could pay for some of the prescriptions I take without it. I have been hospitalized for falling because of the balance issues from Parkinson's effect on my muscles and from the effects of some of my meds on my blood pressure. My latest "gift" from Parkinson's is hallucinations. I don't know if the person I see down the road is real or a mailbox until I get close. I have stopped warning my husband about people on the side of the road that only I see. My fear is that one day the person I see will be real and I have not warned him of the danger.

My husband and I are fortunate to have found and become active with a Parkinson's caregiver support group here in Cheyenne. It is reassuring that there are other people who are experiencing the same frustrations as you are, though no two of us are affected the same way and we all agree that no day is the same as the one before. We get up in the morning hoping it will be a "good day". Some are and some are not. Some days I want to sit in my recliner all day and try not to think of the future.

For me, the worst part of Parkinson's is the effect on my family, my husband in particular. This is not how we planned to spend our retirement years. We feel isolated and trapped. Most of our extended family live in central NY. At this point, I can't even imagine navigating travel back home. It makes me very sad to think that I might never see some of my siblings again. That it will be impossible to attend their funeral.

My husband is a remarkable caregiver. He has assumed most of the domestic needs of our home. We have adapted. We order our groceries now and pick them up. Soon we will have them delivered. I am not able to tolerate a grocery store, because of too many choices, too many people, the difficulty of trying to get my rollator through the aisles. My husband feels the weight of responsibility to keep me safe and sane. It took a lot of work to make him trust me to make wise decisions on my actions if he left me alone for any length of time.

We have investigated services that are available as my needs increase. We have been responsible in preparing legal documents and long-term care insurance. I have a medic alert bracelet and a personal emergency response watch. We think we are prepared for whatever the future holds for us.

Unfortunately, my future does not hold much hope for a significant means of stopping the progression of Parkinson's symptoms in time to help me. You on the ACPRCS Committee, however, have the ability to move current research forward. Please consider how many people with Parkinson's would not need to fear the painful and debilitating progression of the disease if there is a breakthrough as a result of your resolve to support research to cure and prevent Parkinson's Disease.

Respectfully,
Patricia Walter
Cheyenne, WY

#105 Sandy | Received: June 19, 2026

Public Comment

I was diagnosed with PD in 2000. My mom was dying with stage 4 lung cancer. Then my husband had prostate cancer. They say things come in threes. I was working in a grocery store, when my left forearm started to move uncontrollably. My Doctor put me on Carbidopa-Levodopa. I started with two x three times per day. Now I am up to 4 x per day. Yes, I believe that our environment has a play in it. I had learned that our neighbor, who was a school teacher, had it when he died. My best friend's husband has it. They live seven miles from us. Another friend's husband has it and they lived only four miles away. The neighbor that lives next to us had city water. We had well water. I believe that the water was bad. Even had it tested several times. I have joined Rock Steady Boxing three times each week. We even have Ladies and men's support groups. It is my home away from home. It gives me so much. Just like my Church family does. I just wish that our insurance would help cover the cost.

Sandy from Cedar Hill, MO

#106 Susan Goodwin | Received: June 19, 2026

My husband was diagnosed with PD over 10 years ago. There are many frustrating experiences, but the amount of medication needed and the frequency of dosage is especially taxing. We are hopeful that as with other diseases (HIV, diabetes etc) that a more effective method of medication could be developed.

Thank you.

Susan Goodwin
Henrico, VA

#107 Suzanne Masso | Received: June 19, 2026

Dear Members of the NPP Advisory Council,

My name is Suzanne Masso. I live in New Jersey. I am a retired early childhood educator of 32 years, author of a children's book entitled "My Grammy Shakes. Does Yours?" which deals with children's understanding of Parkinson's Disease, a wife of 52 years, a mother of two wonderful grown sons, grandma of 2 wonderful grandchildren and a Parkinson's patient since 2017.

I am involved in various Parkinson's organizations both locally and nationally. I take classes designed for people with Parkinson's ranging from exercise and boxing to poetry writing, art and Improv.

I was active in spreading the word about the importance of the passage of the NPP.

I am writing today to petition and encourage you, the members of the advisory council to push for an inclusion of exercise classes in Medicare benefits. It has been shown time and time again that exercise is a NECESSARY component in maintaining an active life when living with Parkinson's disease. Since a majority of Parkinson's patients are senior citizens on Medicare and fixed incomes, it would seem only fair and reasonable that these types of classes should be covered.

I thank you in advance for any help you can be in addressing this lapse of coverage. I look forward to hearing from the Advisory Council as the year progresses.

Good Luck with your endeavors on behalf of myself and the entire Parkinson community.

Suzanne Masso
Cherry Hill, NJ

#108 Atrik Patel, MPH | Received: June 20, 2026

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

Please accept the following public comment for the inaugural ACPRCS meeting on June 29, 2026. I am also interested in providing an oral/virtual comment during the meeting.

Name - Atrik Patel

Professional/Organizational Affiliation - Medical Student, Northwestern University Feinberg School of Medicine; Family Member of PSP Patient

Comment:

One of the greatest gifts of my life has been the opportunity to grow up alongside my grandfather, whom we lovingly call "Dada." Dada has always embodied the virtue of selflessness. As the son of farmers, he became the first in his family to pursue higher education, training as a civil engineer in India. He used that education to improve his community, helping to build infrastructure in his village that would create greater opportunities for future generations. His commitment to service ultimately led him to the United States, where he encouraged his children to similarly strive to build a new life of promise and purpose.

Through Dada's example, I learned from an early age the importance of dedicating oneself to the betterment of others. It is this principle that has defined my personal and professional ambitions and continues to guide me now as a medical student. The

irony is therefore not lost on me that it was only shortly after my acceptance to medical school that he was diagnosed with progressive supranuclear palsy (PSP).

In the years since, I have come to know PSP as relentless in nature. It has become rare for Dada to finish a meal without uncontrollable coughing as the disease impairs his ability to swallow. Every unexpected noise in the home causes concern for Dada's family, as we have subconsciously come to associate it with a potentially serious fall caused by his gaze palsy and retropulsion. Equally heartbreaking are the cognitive and behavioral changes that have accompanied his illness, including slower processing, increased impulsivity, and growing apathy.

As his family, we struggle to understand why someone who spent his entire life uplifting others is now confronting a neurodegenerative condition that steadily erodes his independence and connection to the world around him. Yet our experience is not unique. Families across the country are grappling with this very same reality, often navigating a disease that remains poorly understood, with limited access to support and few therapeutic options, and virtually no prospect of a cure.

Accordingly, while PSP is considered a rare disease, its impact on patients and families is unmistakable. Therefore, as both a grandson and a future physician, I respectfully urge this advisory council to advance efforts to raise awareness of PSP, expand support for affected patients and caregivers, and increase investment in research aimed at developing effective treatments and, ultimately, a cure. Dada spent his life building a better future for others; I hope this council will help to build one for him and for the many others facing PSP across the country.

Thank you for your consideration.

Sincerely,
Atrik Patel, MPH

#109 Catherine Lynn, RN, MSN | Received: June 20, 2026

Public comment

I writing about my struggles with Parkinson's disease is a challenge in itself. In 2020, I was diagnosed with Parkinson's. I had my hip replaced in 2019. A surgery that was done incorrectly. I did not know this until 2020. In 2014, I had breast cancer with a mastectomy. Six weeks later, I was diagnosed with endometrial cancer. Following this diagnosis, I had 7 months of chemotherapy. I was diagnosed with Parkinson's in 2022? I can't walk without a walker. Need a power wheelchair. I had planned to work till 70. All of this changed my plans. I don't have money for self pay care. I am working with the Council on Aging, to get a Medicaid waiver.

I have had many hurdles to overcome. The best support is my family. My sister and I lost our husbands during this time.

I definitely want to see a cure. Another area of concern is when I am asked for a donation when I don't have any extra money to give. Please remember to practice kindness and love to our fellow Parkinson's patients.

I also am a retired RN.

Catherine Lynn, RN, MSN

#110 Elizabeth Kissel | Received: June 20, 2026

My name is Elizabeth Kissel and I would like to make a public comment as a previous caregiver of my husband who suffered with Parkinson's. I believe that a coordinated effort is needed between researchers and neurologists. Getting a diagnosis and getting in for an appointment by a neurologist was difficult. My husband fell and broke his back from orthostatic hypertension before it was confirmed. Then I worked full time and was his caregiver for 8 years. One of the major issues is that everyone with PD has different symptoms and reacts differently to treatment. This was a major burden to our family and very difficult for my husband. Organizations like Rock Steady Boxing was wonderful for him and me. Money is needed to push forward research and entice more doctors into neurology. Waiting over a year to be seen is unacceptable. Coordination of research is vital.

Elizabeth Kissel
St. Louis, MO

#111 Greg Ippolito | Received: June 20, 2026

Ideas for ACPRCS consideration. I have four Parkinson's topics I would like to bring to your attention:

1) Cure: As someone diagnosed with Parkinson's and an outspoken advocate and funder, I am focused on a cure. In order for a treatment to be a cure for Parkinson's, it must be able to break down misfolded alpha-synuclein proteins inside neurons (intracellular). The ability to break down aggregated alpha-synuclein and Lewy bodies is a bonus but the ability to break down misfolded alpha-synuclein is essential. This means that it must be able to operate within neurons which lie within the blood-brain-barrier. I only know of two treatments capable of this:

A) PFFNB2 is a nanobody based treatment developed by Johns Hopkins University in collaboration with the University of Michigan. One last mouse study testing for long term side effects is currently underway and should be completed by the close of 2026. If all goes well, they will then hope to find a pharmaceutical company to license the treatment and proceed with human trials. Project lead: Xiobo Mao.

B) SK-129 is a small molecule based treatment developed by the University of Denver. Project lead: Sunil Kumar.

PFFNB2 and SK-129 are examples of potential cures which were developed to degrade intracellular misfolded alpha-synuclein proteins with the goal of restoring neurological function. Hopefully this panel will be able to help move potential cures towards human deployment and identify other potential cure candidates.

2) There is no hand-off process from University treatment development to pharmaceutical corporations. Hopefully the panel will be able to make some suggestions. I have personally been a part of this process and found it to be a lot of effort and very time consuming.

3) Federal research grants: The system is slow and cumbersome. Research grant applications are submitted and are awarded a year later. This wastes valuable time. This is slow. Can we speed up the process?

4) Parkinsonism: Please consider studies regarding Parkinsonism, not just Parkinson's. Neurotoxins such as mercury mimic Parkinson's and eventually cause traditional Parkinson's. Research into mercury chelation to detoxify the human body of mercury does not exist. Current mercury chelators stir up mercury making patients much worse off. This is an area of research which is being ignored and dismissed. I assure you, the problem is real and growing as the burning of coal, use of compact fluorescent bulbs, use of thimerosal, use in dental amalgam fillings (50% silver and 50% mercury and banned in the EU), consumption of fish and industrial pollution are increasing the body burden of mercury which is bioaccumulative with no treatment available. I am hoping that the panel will be able to identify and raise awareness of the various forms of Parkinsonism including mercury toxicity and the need to encourage the development of a mercury chelator which works. I also hope that some of the Parkinson's foundations and federal grants can provide funding.

Greg Ippolito

Daly City, CA

Affiliation: none. I have been diagnosed with Parkinson's

#112 Jill Ann Thomas | Received: June 20, 2026

I am writing this public comment as a person with Parkinson's Disease (PD). I was diagnosed nine years ago. I have learned that exercise is the most important treatment for PD. Studies have shown that it can improve both motor and non-motor symptoms of the disease and may actually delay the disease. But proper and effective exercise, which should include aerobic, resistance, flexibility, and neuromotor exercise, costs money. I pay \$125.00/month for a PD boxing program and \$61.00/month for neuropong, a ping pong program for PD. I supplement these programs with walking and cycling on my own. But boxing and ping pong allow me to get out and socialize, which is also beneficial. I'm fortunate to be able to afford these programs. Many retirees cannot and are hesitant to ask for help. Since exercise is so vital for PD patients, I propose that the cost be covered by Medicare. I believe such programs can prevent falls and delay the progression of PD and in the long run would save Medicare money. Also, it would encourage people with PD to seek out and try different forms of exercise, freed from worries about paying for it.

I know that funding PD research is key to ending PD, but I believe it's equally important to use what you've learned from the research. We've learned that means exercise, exercise, exercise!

Thank you for allowing me to make this public comment.

Jill Ann Thomas
Salt Lake City, UT

#113 John D. Nicholson | Received: June 20, 2026

PUBLIC COMMENT

I am writing to urge the ACPRCS to treat Parkinson's disease with the immediacy, coordination, and sustained investment this devastating disease requires.

On Saturday, December 16, 2023, my life changed forever – the day I received my Parkinson's diagnosis. Prior to then, I did not think I had anything worse than an essential tremor in my right hand, after all my parents both lived to 95 and were in good health. Like them, I assumed I too would live a longer and healthier than normal life. That all changed when I learned that I would suffer the effects of Parkinson's for the rest of my life.

For too long, Parkinson's has been described mainly as a movement disorder. But for me and the millions of others living with it every day, Parkinson's is far more than the noticeable tremors in our hands. It is relentless, life-altering, and deeply personal. It affects the body, mind, family, home, workplace, and every ordinary routine most people take for granted. I have difficulty buttoning buttons. I have difficulty swallowing food. My handwriting has become illegible. I have lost my sense of smell. I battle constipation. In spite of that list of problems, my Parkinson's is still considered relatively mild. Parkinson's is a progressive disease and what I have to look forward to is the increasing burden of Parkinson's and its additional life-altering symptoms.

For families, Parkinson's is not something that happens only to the patient. It can change marriages, retirement plans and finances. As the disease progresses the burden on care partners becomes heavy as they have to be medication managers, fall-prevention specialists, advocates, transportation coordinators, medical interpreters, financial backstops, and emotional supports—often while also working and caring for others. The burden is physical, emotional, and practical. It is the exhaustion of navigating a fragmented system that too often leaves families to coordinate care alone.

That is why increased funding is absolutely necessary. We need sustained investment in research that can identify causes, slow progression, improve quality of life, develop better treatments, and most importantly find a cure. Current treatments are not enough. They do not reverse or stop the disease. They do not prevent the long-term complications that can become disabling. Too many families are told to adjust medications, manage symptoms, wait, and hope. Hope matters, but hope alone is not a strategy. A cure requires a national commitment.

Funding must support the full continuum of Parkinson's research: basic science, biomarkers, genetic studies, environmental risk research, clinical trials, disease-modifying therapies, neuroprotective approaches, improved drug delivery, rehabilitation, assistive technologies, caregiver support, and better models of care. It must also address symptoms that are often among the most disabling but least understood, including cognitive decline, mood disorders, sleep problems, autonomic dysfunction, pain, speech and swallowing difficulties, and advanced-stage care needs. Parkinson's is not one symptom and one pathway. Our research strategy must reflect the full complexity of the disease.

But funding alone will not solve the problem if efforts remain fragmented. Better coordination is essential among federal agencies, state governments, international research organizations, universities, clinicians, patient advocacy groups, pharmaceutical companies, and community-based care providers. Parkinson's does not respect agency boundaries, state lines, or national borders. Yet patients and researchers too often face silos: duplicative research in one place, care delivery in another, disability support somewhere else, caregiver resources elsewhere, and public health tracking still somewhere else.

The federal government has a critical role in building a coordinated national strategy. Agencies such as the National Institutes of Health, the Food and Drug Administration, and other federal partners should align their work so research findings move more quickly into clinical practice, data is shared freely, trial recruitment improves, care standards advance, and patients can access services regardless of where they live.

States must also be part of this effort. Parkinson's care looks very different depending on geography, insurance coverage, transportation, provider availability, and local resources. Some patients have access to movement disorder specialists, physical therapy, speech therapy, occupational therapy, mental health care, and caregiver support. Others do not. Rural patients, underserved communities, and people with limited financial resources face especially high barriers. Organizations like the Michael J. Fox Foundation and the Parkinson's Foundation are excellent resources, but a national strategy must include state-level public health planning, provider education, resource mapping, caregiver support, and access initiatives so care is not determined by ZIP code.

International coordination also is key. Around the world, scientists, clinicians, agencies, foundations, and patient groups are studying genetics, environmental exposures, biomarkers, new therapeutics, and models of care. Those efforts should be connected, not duplicated unnecessarily. We need shared data, international trial collaboration, and stronger partnerships with global Parkinson's organizations. The fastest path to a cure will require cooperation across borders.

The urgency could not be greater. Every year without a cure means more people diagnosed, more families adversely and materially impacted, and more individuals losing pieces of their independence which serves as a strain on us all. Parkinson's may progress over years, but the national response cannot be slow. People living with this disease need better treatments now. We need coordinated care now. We need support now. And we need a cure.

This Council has an extraordinary opportunity to help shape a response that matches the seriousness of the disease. I respectfully ask you to recommend bold funding priorities, meaningful interagency coordination, state-level engagement, international collaboration, and policies that put patients and families at the center of every decision.

I am truly thrilled with the formation of the ACPRCS and excited by the potential advancements that such a group can facilitate and accelerate. Thank you for your service and for your commitment to the Parkinson's community.

John D. Nicholson
Lake Forest, IL

#114 Nathaniel Moyer, PTA | Received: June 20, 2026

Good morning,

The National Plan to End Parkinson's disease is an important step to improving the lives of those currently diagnosed with Parkinson's disease, and influencing the future for those yet to be diagnosed.

From a policy perspective an effective plan must ensure funding for research into treatment approaches; medical procedure, medication, and rehabilitative therapies. The plan must also address environmental factors due to the overwhelming amount of evidence, that continues to build, regarding the exposure to environmental toxins/pollutants and the development of Parkinson's disease.

The 2nd point is of the utmost importance due to the limited ability of the general population to directly control their personal risk of exposure, and the greater ability of policy makers/government officials to apply regulatory measures for the use, release, and production of these materials.

These two points are the most pressing as they offer the most direct impact for both, people living with Parkinson's disease and people who will be diagnosed in the future.

These points also provide evidence to the importance of having a plan at the national level with federal government involvement. Government is to be "of the people for the people", and people with Parkinson's disease are quickly becoming a large subset "of the people".

Thank you,
Nathaniel Moyer, PTA
LSVT-BIG, Cert-DN, T/NDT

#115 Alex Schmitz | Received: June 21, 2026

Hello my name is Alex Schmitz,

I am the grandson of Robert Schmitz, a WWII veteran. My grandpa developed parkinson's disease in the 90s and when he drove there became a noticeable tic in his hand from shaking. He had clearly been through trauma. The tremor shaking occurred at various times but it was mostly while he was operating a motor vehicle or whenever things felt tense, like finding difficulty being able to walk up the steps or not using a lift installed by the VA. He went from vulnerable to deteriorating in less than a decade. His ashes were cremated and spread in the winner circle at Turfway Park in 2004.

I was wondering about your initiative and the acronym national plan to end Parkinson's. Are you trying to eradicate a disease operating on the RNA or DNA viral level and if so would there need to be a global plan? Is this post-traumatic stress from a

specific type of cruelty or do we see it playing out in other countries as trauma that begets more trauma? I have more questions because I have carefully crafted anecdotes about Grandpa Bob who I loved. I'm willing to offer what I can to help.

Love,
Alex Schmitz

#116 Bruce Hendricks | Received: Jun 21, 2026

Diagnosed with DaTscan initial symptoms at age 71 were orientation with parking my car always crooked, then my left leg/foot was dragging then the doctor recommended the DATSCAN which showed the low dopamine level. Then started PT and CL that was recommended by my doctor. I had increasing loss of balance along with feeling apathy along with ongoing tiredness. I'm hoping that I can give some usable information on my journey through this disease. I pretty much feel like I'm moving through the stages of Parkinson's and my movement specialist has recently proposed vascular Parkinson's or parkinsonism primarily because I have no response to my CL regimen. What seems to be most troubling is that I don't have a response to the medication. That's what put us on the road for vascular Parkinson's so we are going to decrease my dosage gradually to see if I can clearly define an off time to see if the medication I am on is doing anything at all. As you know this disease is dynamic and varies a lot from person to person but has a lot of predictable traits. I think we all hope that you can collect all these different symptoms and find out the cause, the origin of them and also a solution or treatment. I fully realize the daunting task but we do have hope for optimism though. A consistent recommendation for exercise seems to be an issue with regards to the common symptom of being tired and apathetic! Finally, I did have an MRI that reflected possible NPH. I had a spinal drain for that testing but no meaningful results so we're back on track with Parkinson's. That MRI did reflect some small strokes, which has also led us into the Vascular Parkinson's possibility. Still in wonder!

#117 Charmaine Kessinger | Received: June 21, 2026

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

Subject: Public comment

Dear Council Members,

It took four years, two unnecessary operations (carpal tunnel and cubital tunnel decompressions), multiple physical and occupational therapy sessions and numerous doctor appointments to finally be diagnosed with Corticobasal Syndrome (CBS). Since that time, I have been busy juggling getting my affairs in order, educating myself about my disease, donating my brain to science, making arrangements for quality care as my disease progresses, chipping away at my 'bucket list' and continuing to live my life to the fullest.

With this disease, the clock is ticking away as my condition deteriorates right in front of my eyes. The discouraging part is that no matter how meticulous I am in taking care of myself, planning for my future and living my life to the fullest, there is no treatment or cure. My life's longevity is short and limited.

Besides now having to orchestrate a complicated disease and shortened life, I have the added responsibility, no, obligation, to advocate and push forward, to whoever will listen, the critical agenda of increasing research dollars and raising awareness.

Currently, there are no federally funded clinical trials studying CBS. I have routinely checked every month since my diagnosis, but to no avail, no studies. In addition, attention and awareness of CBS is minimal. CBS is a rare neurodegenerative brain disease with only 2000-3000 people diagnosed in the United States. It is frustrating to have a rare disease; it does not get exclusive attention. Typically, it is lumped in with other neurodegenerative diseases and receives mention but not in-depth, thorough analysis, study and reporting. At times, it feels like an afterthought. I'm hoping your committee can change this.

As the ACPRCS committee, please consider 1.) advocating for the urgent need for research funding and 2.) increasing attention and awareness of CBS as well as other neurodegenerative diseases.

Thank you for your consideration. In addition, I would appreciate the opportunity to make a statement/comment during your ACPRCS meeting on June 29, 2026.

Sincerely,
Charmaine Kessinger

#118 David Souerwine (spouse, caregiver, POA) / Susan Souerwine (PSP patient) | Received:

June 21, 2026

Public Comment for ACPRCS Meeting 06/29/26

Dear Dr. Jordan Gladman and others on the Parkinson's Advisory Council:

I'm sure you will receive many many sad, and horrific, stories about Parkinson's and all the related neurodegenerative diseases.

My message is simple. There is totally inadequate diagnostic knowledge, limited treatment options, minimal understanding what causes these diseases, no options for curing them, and insufficient funding to advance these topics.

My wife, Sue, had symptoms starting in 2020. She progressed slowly and in 2022 was diagnosed with Parkinson's Disease. Her symptoms didn't match Parkinson's well and response to dopamine was minimal. Her neurologist, who specializes in strokes, was "100% convinced" it was Parkinson's. He panicked when her symptoms accelerated during 2025 and increased her medicine rapidly from 800mg to 1800mg a day. We sought, and found, a motion disorder specialist. That took time, and in the interim, I read a lot and cut her dopamine from 1800mg to 1200mg because of the additional symptoms that Sue started to exhibit. When we got to the motion specialist, she wasn't pleased that I had done this on my own but agreed with the conclusion and cut her further to 1000mg. She was further reduced the dosage to 800mg and now 600mg. A few of her symptoms have improved. During this process her diagnosis was changed to PSP which fits her overall symptom pattern better than Parkinson's Disease.

There are a lot of important messages in the above paragraph. Hard for the family to recognize what is happening, hard to get into a neurologist, a well trained experienced neurologist who is adamant about the diagnosis but is wrong, prescribing too much dopamine, very very hard to find a specialist (the first call to Emory in December 2025 offered an appointment in June 2027), and now a better diagnosis but with limited options for stabilization and no chance for real improvement.

Sue is in a wheel chair for safety, cannot walk, has no balance, falls easily to the right or straight back, has leg freezing, is urinary incontinent all of the time, cannot sign her name, cannot write, cannot use a keyboard, has some reasoning challenges, has significant double vision, shows beginning signs of vertical gaze palsy, and some other symptoms that go with this condition. On the thankful side, she has no tremor, is not in pain, no rigidity, and her long term memory is totally intact.

At our last meeting with the specialist, I said to her: "so no one knows what causes this, there is no cure, there are limited treatment options, it is progressive and will get worse over time, so we need to recognize symptoms and treat them individually in hopes of some improvement, is that right?" Answer (with some other words around it): yes. That is not acceptable and needs some large scale intervention to make it better.

Thanks for the chance to comment,
David Souerwine, spouse, caregiver, POA
Susan Souerwine, PSP patient

#119 Edward Spauster, Ph.D. | Received: June 21, 2026

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

Submitted electronically: nationalPDplan@nih.gov

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am a person recently diagnosed with Parkinsonism and I appreciate the opportunity to provide input.

In the last year, I lost the fluid mobility I had for 71 years, causing me to limit activities that I enjoyed in the past. I support the American Parkinsons Disease Association's call for a strong national plan with clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

The APDA Recommended actions are:

- Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.
- Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.
- Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

Sincerely,
Edward Spauster, Ph.D.
Pompano Beach, FL

#120 Gary Allen Wassel | Received: June 21, 2026

My name is Gary Allen Wassel. I am 60 years old and have been living with young-onset Parkinson's disease since my diagnosis at age 25.

I initially attributed my early symptoms, such as subtle cogwheel rigidity and left-foot dragging, to a demanding schedule while balancing full-time college courses, an internship, and a career as a paramedic. Over the years, I have managed standard symptoms alongside significant complications, including Deep Brain Stimulation (DBS) surgery and a subsequent MRSA infection. I currently experience bradykinesia, dystonia, difficulty swallowing, extreme stiffness, chronic constipation, soft speech, and sleep disturbances. Frequent falls have resulted in a broken back, a fractured clavicle, and numerous other injuries. These physical challenges have also had a profound impact on my mental well-being, leading to constant anxiety, a fear of falling, and a festinating gait.

I am a veteran of the U.S. Army, having served for seven years, and I am also a responder to the September 11 attacks on New York City.

Best regards,
Gary Allen Wassel

#121 Jennifer Adams | Received: June 21, 2026

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. My husband has early onset Parkinson's, and I appreciate your work to support the Parkinsons community!

Why this issue matters to me: My husband had to retire early because of his Parkinson's. It has impacted his memory and he often gets light headed. I believe we can bend the curve of time and improve health and quality of life outcomes through this Plan to End Parkinson's.

Key concerns or priorities: Putting the plan into action is what matters most. A strong national plan needs clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

Recommended actions:

- Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.
- Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.
- Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

I really appreciate all you do to support the Parkinson's community!

Thank you,
Jennifer Adams
Hayden, ID

#122 Jennifer Johnson | Received: June 21, 2026

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

Submitted electronically: nationalPDplan@nih.gov

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am a 51 year old woman (wife, mother and daughter) living with early onset Parkinsons and I appreciate the opportunity to provide input.

My Parkinson's diagnosis in my late 40s was a gut punch. I was healthy, successful in my career, and managing roles of wife, mother, and daughter to ageing parents. I thought some of my pesky early symptoms were attributable to menopause. Parkinsons was the last thing I expected and it sent my world spinning. I am managing my symptoms well with exercise, medication, therapy, and a positive attitude, but I have underlying fear and anxiety for the future. I recently retired (early) from a rewarding career to focus on my health and our family has had to reevaluate our finances and our dreams for the future. I am a person who likes to PLAN, and the uncertainty with Parkinson's symptoms and progression has made planning difficult. I worry for the burden this disease will place on my husband and children.

I am grateful to this administration for recognizing the urgency and importance of this National Plan to End Parkinson's! The number of cases is accelerating and so is the economic cost of medical care and lost productivity. This plan has the potential to change lives, including mine. I urge this group to develop a strong national plan with clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results, and brings us closer to a cure!

I urge this group to estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate so Congress can provide the right level of funding over time so we can build a serious long-term plan.

This group should also focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.

The NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency. Set firm but realistic deadlines to make up for lost time and keep the important work moving.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

Sincerely,
Jennifer Johnson
West Palm Beach, FL

#123 Jim Stewart | Received: June 21, 2026

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

Submitted electronically: nationalPDplan@nih.gov

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am a person living with Parkinson's and I appreciate the opportunity to provide input.

Why this issue matters to me: As someone diagnosed with PD within the last four years I have been very surprised at the lack of progress toward stopping and reversing the effects of PD. I sincerely welcome your efforts toward finding a cure for PD and ultimately preventing it.

Key concerns or priorities: Putting the plan into action is what matters most. A strong national plan needs clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

Recommended actions:

- Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.
- Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.
- Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

Sincerely,
Jim Stewart
Portland, OR

#124 John C. G'Sell | Received: June 21, 2026

My father who passed away had Parkinson's, my recollection of his final years was being bedridden, with a naso gastric tube for feeding and being unable to talk. I was in dental school and worked at night to help with the nursing home bills! I now have Parkinson's, luckily I have resources few have available. We need more resources for research, and a safety net to help the people who are disabled and can't afford proper treatment.

-John C. G'Sell

#125 Maria De Leon, MD | Received: June 21, 2026

First, congratulations on this inaugural date of first board meeting to help eradicate Parkinson's disease. I know the board has been filled with experts on the subject which gives me comfort knowing that the salient issues will be tackled with the utmost diligence. As a member of the Michael J Fox patient council and public policy forum with a 30 year trajectory of being an MDS diagnosing and treating patients, as well as caring for both my grandmother who had PD and mother who is now recently diagnosed with disease along with my own lived experience with early onset PD - the urgency to halt the rise in PD here and around the globe has never been more urgent. Equally important is the need and urgency to provide relief and hope for those currently suffering.

As you begin this enormous challenge, I urge to consider the lives of those being impacted by the disease here and now. This means that one of the first actions should be to improve resources and access to the many medications currently available to help patients and families live better lives with this disease. Nothing is more devastating to me as a clinician, researcher, and patient advocate than to see the majority of patients still subjugated to living a life not much different than those who had PD 50 years ago despite the advances in the field; because insurances and current health care make it almost impossible to attain the proper care vanishing as disease advances being confined to their homes and worse become bed bound due to falls or severe rigidity and balance issues. This is simply unacceptable since we live in one of the richest countries of the world where medical accomplishments excel. Furthermore, not only is there lack of access to medications for the great majority of families but even worse is the access to specialists. Most people like me have to drive minimum of 3 hours to see our specialist and the availability is worse since the pandemic sometimes taking over a year to be seen for the first appointment. So if we are

really to combat this disease and find a way to cure or halt new cases and progression first must grow the number of neurologists available, that means finding ways to improve incentives for doctors and medical students to choose this field - it would behoove all of us as we are increasingly a country of aging population. That also means finding ways to retain young neurologists practicing by compensating them properly for their mental capabilities and finally invest in making medications available that will maintain people as active members of society reducing disability rates, need for nursing care and frequent hospitalizations saving money in the long run. Finally, we must ensure that water is clean and safe to drink, that the air is not contaminated and that our produce is not equally contaminated with pesticides (which I know some of this is already taking place). In the same context we need more affordable produce to make having a healthy diet much more feasible.

I realize these are not easy tasks but if we are to make a dent in the battle against PD and truly make lives better these things MUST be corrected and overcome - because every life matters. Also keep in mind that one levodopa formulation does NOT equal another levodopa formulation! I am a prime example - I have tried every levodopa formulation available and the only one that works for me is Rytary bringing me close to who I was before PD took over my life. So when making medications available it won't be enough to say we have levodopa available for everyone.

Thank you for your time and best wishes and success in this great endeavor!

Sincerely,
Maria De Leon, MD

#126 Michael Sierchio | Received: June 21, 2026

Personal Perspective and Recommendation for a National Parkinson's Disease Registry
Submitted by Michael Sierchio

To the Members of the National Parkinson's Plan Committee:

Thank you for your service and for your commitment to improving the lives of people living with Parkinson's disease. I am honored to share my perspective as both a Parkinson's patient and an advocate working within the Parkinson's community.

I was diagnosed with Parkinson's disease on January 5, 2023, after my wife first noticed symptoms in December 2022. Before receiving my diagnosis, I consulted multiple physicians before ultimately finding a movement-disorder specialist at the Cleveland Clinic in Las Vegas. My neurologist characterized my condition as a relatively slow-progressing form of Parkinson's disease.

Since diagnosis, I have taken an active role in managing my health. Exercise is a cornerstone of my treatment plan, and I currently walk nearly one hour per day, six days per week. Before treatment, my walking pace averaged approximately 27–28 minutes per mile. After beginning carbidopa/levodopa therapy, my pace improved to approximately 24 minutes per mile.

One of the most meaningful experiences in my Parkinson's journey has been participation in a Phase 3 clinical trial of tavapadon. During the study, I received the medication for approximately one year. The results were significant for me personally. My walking pace improved to roughly 21 minutes per mile, I experienced meaningful improvements in both motor and non-motor symptoms, and I gained confidence in my mobility. I worried less about falling, experienced improvement in constipation, and generally enjoyed a better quality of life.

Today, I continue treatment with rasagiline and carbidopa/levodopa. My quality of life remains very good, and I remain actively engaged in advocacy. I serve as a volunteer and board member of the Parkinson's Foundation Southwest Chapter, where I help educate patients and families about Parkinson's disease, genetic testing opportunities, and participation in research.

My perspective on Parkinson's disease is shaped by several distinct experiences. I live with the disease every day as a patient, I have participated in a Phase 3 clinical trial evaluating an investigational Parkinson's therapy, and I serve as a volunteer and board member with the Parkinson's Foundation Southwest Chapter. I have also participated in Parkinson's advocacy efforts with federal policymakers, including discussions about research, patient access, and public health priorities. These experiences have allowed me to see Parkinson's disease from multiple viewpoints: as someone managing symptoms, as a research participant helping advance new therapies, as an advocate supporting other patients and families, and as a stakeholder engaged in national policy discussions. Together, these perspectives have strengthened my conviction that better data collection, patient engagement, and long-term outcome tracking are essential to improving care and accelerating progress against Parkinson's disease.

Why a National Parkinson's Disease Registry Matters

Among all the opportunities available to advance the goals of the National Parkinson's Plan, I believe a robust national Parkinson's disease registry would be one of the most valuable and enduring investments. While approximately ten states have established Parkinson's disease registries or surveillance programs, the United States currently lacks a comprehensive national registry capable of providing a complete picture of the disease across the country. As a result, researchers, clinicians, policymakers, and patient organizations are often forced to rely on fragmented datasets that make it difficult to measure trends, evaluate outcomes, and assess the effectiveness of interventions on a national scale.

A national registry would help track disease prevalence and progression, identify geographic and demographic trends, improve recruitment for clinical trials, measure long-term outcomes associated with existing and emerging therapies, support health policy decisions, and accelerate scientific discovery through high-quality longitudinal data. As promising new treatments emerge, including therapies designed to improve symptoms and potentially slow disease progression, the need for comprehensive national data becomes even more important.

Importantly, Parkinson's disease affects far more than the individual who receives the diagnosis. For nearly every person living with Parkinson's, there is also a spouse, partner, family member, or friend serving as a caregiver. These caregivers often experience significant emotional, physical, and financial burdens as the disease progresses. A national registry should therefore seek to capture not only patient outcomes, but also the impact of Parkinson's disease on caregivers and families. Understanding the full burden of the disease is essential to developing policies and programs that adequately support the entire Parkinson's community.

Recommendation to the Committee

I respectfully encourage the National Parkinson's Plan Committee to make development and expansion of a national Parkinson's disease registry a priority recommendation. I further encourage the Committee to establish measurable goals for registry participation, support annual public reporting of key findings, and promote broad collaboration among federal agencies, researchers, clinicians, patient organizations, and people living with Parkinson's disease.

As a patient, clinical trial participant, advocate, and Parkinson's Foundation volunteer leader, I believe a national registry can become one of the most powerful tools available to accelerate research, improve patient outcomes, and measure the nation's progress against Parkinson's disease.

The true impact of Parkinson's disease cannot be measured solely by the number of patients diagnosed; it must also account for the millions of caregivers and family members whose lives are profoundly affected by the disease.

Thank you for your consideration and for your leadership on behalf of the Parkinson's community.

Respectfully submitted,
Michael Sierchio

#127 Michael Vitaly Sazonov Jr. | Received: June 21, 2026

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

My name is Michael Sazonov, and I am writing to you because I am interested in providing virtual comment for the inaugural ACPRCS meeting.

I write to you on behalf of my late father, who lived with Parkinson's disease (PD) for over 20 years. I write to you as a dedicated Teaching Artist and Faculty member of Dance for PD® through the Mark Morris Dance Group, with whom I've worked for 12 years, and I also write to you as Policy & Advocacy Chair for Team Fox Young Professionals of NYC, a group that raises funds and awareness for the Michael J. Fox Foundation for Parkinson's Research. In both arenas, as when my father Michael was alive, I strive to enjoy every moment we can and improve the moments we can't, finding joy between the ups and downs that so many in this community face. After all, life is often richest in its smallest and simplest of moments.

Please accept the following as my written public comment for the ACPRCS:

Establishing Federal Standards and Benchmarks for Time-Critical Medication Standards

My name is Michael Sazonov, and I am writing as a former care partner for my father, who lived with Parkinson's Disease for over 20 years. In his last few years, he lived in an assisted living community in Ashburn, Virginia, which inspired me to advocate on his behalf like I never had before. I am submitting this comment to urge the Council to include standardized, time-critical medication administration protocols as a primary goal within the National Plan to End Parkinson's. The problem I intend to fix is "The 'Two-Hour Window' Risk." In many states, assisted living regulations (such as Virginia's 22VAC40-73-680) permit a grace period of one hour before and one hour after a scheduled dose. While this "two-hour window" is standard for general medication, it is medically inappropriate and often dangerous for those living with Parkinson's disease. For my father, who eventually required carbidopa/levodopa doses every four hours, this flexibility meant his window of efficacy could be slashed in half. If one dose is given an hour late and the next an hour early, a scheduled four-hour gap becomes just two hours. This inconsistency triggers severe bouts of dyskinesia (involuntary, erratic movements) followed by a very low energy "off" period, which in turn increases fall risks and unnecessary physical suffering.

My proposed recommendations for the National Plan include the following:

- 1) Federal "Time-Critical" Designation: Establish guidelines requiring long-term care facilities to classify all levodopa-containing medications as "Time-Critical."
- 2) Narrower Administration Windows: Mandate administration within 15 to 30 minutes of the prescribed time, aligning with Parkinson's Foundation Care Standards.
- 3) Specialized Training (Federal/State): Integrate Parkinson's-specific "On/Off" cycle training into federal CMS (Centers for Medicare & Medicaid Services) training requirements for nursing and medication aides. Include Parkinson's-specific education in state-approved curricula for Medication Aides.

I appreciate your time and efforts here today, and I thank you for your consideration as you embark on this task before you. I am happy to contribute to the National Plan in any way, please consider me a resource and ally to your charge. My dad was a kind, fun-loving, and generous man, and it is for him that I still fight --- so that others might not feel the unnecessary pain inflicted from a medically shortsighted and downright incompatible standard for those living with Parkinson's disease.

Thank you.

Sincerely,
Michael Vitaly Sazonov Jr.

Policy & Advocacy Chair, Team Fox NYC
Teaching Artist, Dance for PD®

#128 Stacey Foxwell | Received: June 21, 2026

Public Comment for National Parkinson's Project Advisory Council
June 2026 Meeting

Dear National Parkinson's Project Advisory Council,

I am writing to submit a public comment as someone living with Parkinson's disease.

My name is Stacey Foxwell. After more than a decade of medical tests and scans ordered by multiple doctors and specialists for symptoms that appeared unrelated, I received my Parkinson's disease diagnosis in 2023 at the age of 49. Two years later, I was diagnosed with Lewy body dementia as I am in the advanced stages of the disease. I am currently 52 years old and will need a full-time caregiver within the next year.

My Parkinson's is aggressive and has progressed to the point where my doctor has advised me that I can no longer work due to mobility issues requiring a cane and walker, extreme fatigue, dystonia, anxiety/mood swings, and inability to focus. Despite this, I continue working as a Shared Living Provider/Caregiver for my 28-year-old intellectually disabled daughter, who requires round-the-clock care, to help support my family financially. Although my husband works full time, we cannot afford the costs of my medical care and household expenses without my financial contributions.

My daily challenges include increasing rigidity and bradykinesia that make dressing, bathing, and meal preparation difficult; I often need assistance. On-off fluctuations throughout the day interfere with household chores, social activities, and time-sensitive work documentation. Non-motor symptoms such as difficulty swallowing, night terrors, visual hallucinations, blood pressure fluctuations, bouts of confusion, and incontinence further complicate my daily life.

These physical and mental challenges are compounded by significant financial strain. Even with health insurance, prescription discount cards, and pharmaceutical assistance programs, my monthly healthcare costs exceed \$1,200 and continue to rise. I take Sinemet every four hours for movement symptoms and additional medications for non-motor symptoms including hallucinations, fatigue, and anxiety/mood swings. I also participate in Speak Out! (Parkinson's Voice Project) for speech changes and Rock Steady Boxing for mobility. I have taken part in research studies on speech, swallowing, and loss of smell.

In December 2025, I began using the Parkinson's subcutaneous infusion medication Vyalev. It was life-changing and gave me relief from off time, crippling dystonia, and the constraints of timing oral medications like Sinemet. Unfortunately, I had to discontinue it after developing cellulitis at the infusion site that abscessed. I was taken to the ER for drainage, placed on doxycycline for 14 days, and required eight weeks of wound care. The culprit was not Vyalev itself but the delivery system, which is associated with high rates of adverse site reactions and infections, including cellulitis and staph, in a substantial percentage of patients. I chose to return to oral medication because the risk of recurrent cellulitis and infection was not worth the benefits.

I have been denied SSDI, in part due to the timing between when I stopped working, received my diagnosis, and was advised by my doctor not to work. The COVID-19 pandemic further delayed my diagnosis by about two years, during which I could have filed. Additionally, Social Security does not consider my role as a shared-living provider a qualifying job for SSDI purposes because it is non-taxable income paid through the Medicaid waiver.

I have been approved for Nevada's Medicaid waiver to receive services. However, the wait for daily personal care supports is currently 2–3 years. I must rely on friends for this help, and they receive no financial compensation. Parkinson's-specific resources are often geared toward those 65 and older. I have 13 years until I would qualify under typical age-based criteria, yet I need these resources now.

Due to lack of resources, we face the real probability that I will not be able to remain cared for at home. We do not have the financial means to purchase a home given current prices, and as renters we cannot make the permanent modifications needed to accommodate my increasing physical and cognitive decline. I need ramps, a roll-in shower, wider door frames and hallways for wheelchair access, smooth-surface flooring, window/door alarms, improved lighting and signage for navigation during sundowning episodes, and cameras to detect wandering associated with Parkinson's dementia.

Based on my lived experiences, I urge the Council to prioritize the following in research, care, and federal policy:

- Greater focus on research and affordable access to advanced therapies and targeted drugs that carry minimal risk of major complications such as cellulitis, staph infections, or worsening of non-motor symptoms.
- Policies that streamline disability benefits for Parkinson's, with eligibility determinations based solely on relevant criteria (diagnosis, medical need, and financial need). Benefits should be available promptly to all who meet the standards, regardless of age or filing deadlines, with no more than a 30-day wait.
- Facilitation of ADA-accessible single-family or rental housing designed to accommodate the progressive symptoms of Parkinson's disease, including wheelchair access, safety modifications, space for medical equipment, and support for in-home care and family-directed care models.
- Prioritization of caregiving services that pay family caregivers a living wage based on average state income, provide access to a minimum of 20 hours of respite per month, and include education and training specific to caring for individuals with Parkinson's and related dementias.

Sincerely,
Stacey Foxwell
Reno, Nevada

#129 Susan J. Ullman, LISW | Received: June 21, 2026

Public Comment to National Parkinson's Disease Plan

In 2017, my dentist referred me to a sleep disorder's lab to see if I had sleep apnea. I was not diagnosed with sleep apnea but instead was given a diagnosis of RBD. The doctor correctly diagnosed me and recommended that I start taking melatonin, but failed to inform me that I would almost definitely develop Parkinson's Disease. I learned that RBD was a prodromal symptom of PD when I went home and typed "RBD" into google. The doctor also recommended that I go off my antidepressant (Cymbalta) because it can increase the severity of RBD symptoms. So at the same time I was coping with the probability of a devastating diagnosis I no longer had the symptomatic relief of my antidepressant. The sleep disorder's doctor also did not refer me to a neurologist or a therapist. I went through a year of experiencing feelings of isolation and severe symptoms of depression. When I finally found a movement disorder's specialist, I was taken aback because he told me that I did not have Parkinson's Disease. I found out later that RBD and other non motor symptoms do not meet the diagnostic criteria for

Parkinson's Disease. It took about another year before I came to an understanding with my MDS that I would see him for a check up once a year, he would answer my questions, and he would document the progression of the disease.

My story points out several problems with the fragmentation of care in our medical system as well as the way Parkinson's Disease is diagnosed and treated in our country. Nobody should have to look up their symptoms on google in order to learn that they are at a high risk for developing Parkinson's Disease. It would have been helpful if my sleep disorder's doctor had a relationship with a MDS and could have made an immediate referral. A referral to a therapist who was knowledgeable about PD would have also been helpful. Expanding relationships between sleep disorder's centers and movement disorder's specialists would get patients needed services more quickly as well as providing a rich source of research subjects of patients who are in a very early stage of the disease.

Another problem is the narrow criteria we use to diagnose Parkinson's Disease. I have been experiencing non motor symptoms for over 10 years and my symptoms are progressing, but since I do not experience motor symptoms I do not meet the criteria for Parkinson's Disease. The lack of a Parkinson's Disease diagnosis makes me ineligible for most research studies and deprives researchers of the opportunity to include patients who are in an early stage of the disease in their studies. It fails to address the many non motor symptoms I experience such as anosmia, constipation, overactive bladder, severe constipation, double vision, bradycardia, orthostatic hypotension, difficulty judging distances, inability to recognize faces, and many others.

Thank you for giving me the opportunity to share my story with you. I am willing to share it orally as well.

Susan J. Ullman, LISW
Cincinnati, Ohio

#130 Thomas Sheaffer | Received: June 21, 2026

Thank you for reviewing these public comments directed to the Advisory Council on Parkinson's Research, Care and Services (ACPRCS). They are submitted by a retired civil servant/analyst and a care partner to my wife who was diagnosed five years ago at the age of 70. Fortunately, the progression of her Parkinson's has been relatively slow which has allowed me to assume an advocacy role...for now...as I fully recognize -- with great trepidation -- what might lie ahead for each of us.

Our initial journey was not unlike thousands of others, however I would like to emphasize several aspects worthy of the Council's consideration. The amount of information and the complexity of the disease can be overwhelming for the newly diagnosed. In my urban setting, the number of entities involved is perplexing and as a result, one navigates the best one can; in contrast, I have learned those in rural areas who face a dearth of services. Regardless of residence, we all face a shortage of motor disorder specialists.

I respectfully ask throughout your deliberations, which will undoubtedly concentrate on prevention, slowing progression, treatments, and care, that you make repeated reference to a priority of finding a cure. Please do so in both the actions you undertake and your reporting. Hearing that a cure is the ultimate goal, keeps the hope alive for my wife and thousands of others.

Reflective of my analytical professional career, I humbly recommend the Council pursue the following:

- Institute a National Parkinson's Registry and incorporate its data in the computer model described below.
- Direct (contracted) staff to compile a comprehensive assessment of the financial resources being devoted annually to Parkinson's. Begin with the recent Michael J Fox report. However, in addition to federal and state government expenditures, include best estimates of dollars expended by foundations, non-profit organizations, and individuals. Align said dollars by categories such as research, Medicare and Medicaid outlays, pharmaceuticals, therapies, prevention efforts, exercise programming, marketing and fundraising, medical staff development and training, individual outlays such as co-pays, boxing and dance class registrations. The more granular, the better.
- With data from the aforementioned fiscal analysis, the data registry, population projections and estimated incidence rates by age cohorts, construct a sophisticated computer model which can be used to simulate future financial outlays, given various mixtures of contemplated actions. Use it to imagine the future, 10, 20+ years out, as Australia envisions in its National Plan. Hopefully, the results will offer the economic argument for the Administration and Congress to make necessary investments in the short and longer terms. In an extreme example, the results may suggest that greater investments in more equitable exercise programming would offer phenomenal returns, thus providing informed guidance to individual donors who are attempting to interpret the many requests.

Since my wife and I have met with our US Senators and Representative several times in the past few years advocating for the creation of this Council, we are so pleased to see it get underway. We wish you all the best!

Thomas Sheaffer
Philadelphia, PA

#131 Amy Lavallee | Received: June 22, 2026

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am a person with young-onset Parkinson's, and I appreciate the opportunity to provide input.

Why this issue matters to me: I was 34 years old when I was diagnosed with Parkinson's, this was just after having my third child. This diagnosis completely altered my life and our family's plans. At the time I was a stay at home mom with every intention of returning to work as an engineer after my youngest went to school, but Parkinson's has prevented me from returning to full time work. The disruption to my executive function, the fatigue, and the motor symptoms make it very difficult to work. As a result I am completely dependent on my husband for income and health insurance. I am ineligible for SSDI because I have been unemployed for so long. I am unable to contribute to our family costs and that is a financial and emotional burden for both me and my husband. We are raising three amazing children, but there are many of their life events I have missed because of Parkinson's. It's hard to look your child in the face and explain that I can't attend their basketball game because my body is too rigid to walk to the car. My medication only suppresses my symptoms, and I take that pill every 3 hours. I have to plan my daily activities in 3 hour increments around my medication schedule. I'd also like to mention the lack of research on women with Parkinson's and young women with Parkinson's. Anecdotal evidence shows that we experience different symptom patterns and medication doesn't work the same, but because of the lack of research we find ourselves desperate for any solution. There are times I have experimented on myself with other medications because I was so desperate for relief. I have been living with this progressive degenerative disease with no cure for 10 years. I am exhausted, it is a fight every day to stay healthy and active, and it is hard knowing that no matter what I do, I will never be well again. I have potentially 40 more years of this, and I need hope for the future. I need us to invest in research, patient care, and care partner help to ensure that things will be better for the future and that we can alleviate the financial and emotional burdens of this disease.

Key concerns or priorities: Putting the plan into action is what matters most. A strong national plan needs clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

Recommended actions:

- Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.
- Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.
- Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease. This is a problem that is growing faster than anyone ever expected. And it's no longer an "if" you are affected but a "when".

Sincerely,
Amy Lavallee
Ridgefield, WA

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

Received: 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. 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 FY2026 for Parkinson's research is almost 20% below FY2021 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:

- 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. 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 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 use 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
Executive Vice President, Chief Strategy and Policy Officer
Parkinson's Foundation

#133 Andrea Merriam, Chief Executive Officer | Received: June 22, 2026

On behalf of PMD Alliance, thank you for the opportunity to provide public comment to the Advisory Council on Parkinson's Research, Care, and Services.

PMD Alliance serves people living with Parkinson's disease, atypical parkinsonisms, and other movement disorders, as well as care partners, families, clinicians, support group leaders, and community-based professionals. Every day, we see the impact of a progressive disease moving faster than the systems built to respond to it: delayed diagnoses, inconsistent access to care, limited rehabilitation and mental health support, financial strain, and growing pressure on families. The National Parkinson's Project is a historic opportunity to address these gaps through a coordinated national strategy, but it must move with the urgency this disease demands.

PMD Alliance urges the Council to ensure the National Plan includes:

1. A first report within one year, with clear timelines and public accountability.
2. Regular public updates and meaningful opportunities for community input.
3. A federal investment roadmap to prevent, diagnose, treat, and cure Parkinson's disease and related atypical parkinsonisms.
4. A long-term research funding strategy that matches the human and economic burden of these conditions.
5. Faster development, review, and approval of promising treatments and diagnostics, with strong evidence standards and meaningful patient input throughout the process.
6. Prevention-focused research, data collection, and cross-agency action on environmental, occupational, and toxic exposures linked to Parkinson's risk.
7. Expanded access to integrated, multidisciplinary care for all people with Parkinson's and related disorders.
8. Strategies to recruit and retain more movement disorders specialists and train health professionals across the care continuum.

9. Meaningful support for care partners, including education, navigation resources, respite care, mental health support, and financial assistance.

10. Specific attention to populations that face distinct barriers or are underrepresented in care and research, including women, people with young-onset Parkinson's, people living with atypical parkinsonian disorders, rural communities, agricultural workers, veterans, and other underserved communities, while accounting for differences across gender, race, and ethnicity.

We are encouraged by the work underway and urge the Council and HHS to keep the National Parkinson's Project on track. Regular public updates will help the community understand progress, priorities, and opportunities to contribute lived experience.

One of the Council's first priorities should be to define the scale of investment required to make meaningful progress. Congress and federal agencies need more than general goals; they need a clear, evidence-based funding roadmap that reflects what it will truly take to improve prevention, diagnosis, treatment, care delivery, and the pursuit of cures.

The need is significant. Parkinson's disease and atypical parkinsonisms cost patients, families, health care systems, and the national economy an estimated \$82.2 billion in 2024 alone, while federal research investment remains far below the scale of that burden. Other national disease initiatives have shown that early, sustained federal investment can accelerate progress, build research infrastructure, and create accountability. Parkinson's deserves that same level of commitment.

Parkinson's organizations have called for an initial investment of \$600 million annually in NIH Parkinson's research, with a reasonable goal of reaching \$1.5 billion in federal research funding by 2032. The Council should also draw on health economics expertise to determine the sustained level of investment needed across research, prevention, diagnosis, treatment, care delivery, services, and support.

The National Plan must treat prevention as a core priority. A growing body of evidence points to environmental and occupational exposures that may contribute to Parkinson's risk, including pesticides, industrial chemicals, air pollution, heavy metals, contaminated water, and workplace exposures. Families deserve answers about why Parkinson's is rising, who is most at risk, and what can be done to prevent future cases. To get those answers, we need better exposure data across the lifespan, stronger links between environmental, occupational, clinical, and geographic data, long-term cohort studies, and cross-agency coordination among NIH, CDC, EPA, VA, the Department of Labor, and other relevant agencies. We cannot prevent what we do not measure.

The Plan must also address the needs of people living with Parkinson's and related disorders right now. Fewer than 10% of people with Parkinson's receive care from a movement disorders specialist, and too many face delays in diagnosis as well as limited access to rehabilitation, mental health services, care partner support, and other essential services. Improving access to care must include both integrated, multidisciplinary care models and workforce strategies. Most people will also rely on primary care providers, general neurologists, emergency clinicians, nurses, social workers, mental health professionals, and long-term care teams. These professionals need practical training in Parkinson's-specific care, including medication timing and safety, non-motor symptoms, rehabilitation, mental health, referrals, communication, and care partner engagement.

The Plan must recognize care partners as essential members of the care team. Parkinson's changes households, relationships, finances, work, and daily routines. Care partners often become medication managers, appointment coordinators, advocates, transportation providers, symptom trackers, emotional supports, and crisis responders, often with little training or relief. The National Plan should include concrete recommendations for care partner education, navigation resources, respite care, mental health support, and financial assistance.

Finally, the Plan must reflect the full diversity of the Parkinson's community. People with young-onset Parkinson's, atypical parkinsonian disorders, and families in rural or underserved communities face distinct barriers. The Plan should also account for differences in diagnosis, treatment, progression, caregiving experiences, and access to care across gender, race, and ethnicity, including the experiences of Black, Hispanic, Asian, Indigenous, and other underrepresented communities. A national strategy must be specific enough to meet these realities and accountable enough to change them.

The Council has an opportunity to strengthen the national response to Parkinson's disease and related disorders and drive measurable progress: earlier diagnosis, better access to care, stronger research, reduced financial burden, clearer answers about prevention, and meaningful support for care partners.

Every moment counts when someone is living with a neurodegenerative disease. We ask the Council to reflect that urgency in its recommendations, timelines, and measures of accountability.

Thank you for your leadership and for considering this public comment.

Sincerely,
Andrea Merriam
CEO
PMD Alliance

#134 Bill Kotziers | Received: June 22, 2026

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am a person living with Parkinson's and I appreciate the opportunity to provide input.

Why this issue matters to me: I was diagnosed with PD in December 2024 after retiring from my career as a Professional Geologist (Florida) and lastly as a junior high Science Teacher (go figure!). During my last year of teaching I had noticed that tasks were taking me longer to complete and I had also fallen several times while playing tennis. Now at the age of 64 I am now contemplating how my demise will progress and how this will impact my family. After 1.5 years of being on Carbidopa Levadopa and doing a bunch of research and attending seminars, I am just totally perplexed about why this awful disease has not been cured. Seriously, take some pills and stay active is the only way to delay the disease from getting worse?

The reality of it all came crashing down upon me when I met with my Neurologist about 8 months ago. At the time I was still able to walk long distances, I could play pickleball, go camping and I thought I was doing really well and I remember being happy during the visit and completing the neuro tests. Then the doctor turns and says to me when we were almost done with my visit: "just remember, you are not going to beat this." I was at a loss for words when he told me that and didn't offer a reply. After checking out and leaving the office I went out and sat in my car. Then I just started bawling and after the tears stopped then I got angry about his response and the whole industry that seems to offer little hope for a freaking cure to this disease. Research, fund raise, research, fund raise..... I would rather be part of a clinical trial to find a cure than have to succumb to the DBS option.

So with the advent of AI can we please get it together and find a cure for this disease and all others?

Key concerns or priorities: Putting the plan into action is what matters most. A strong national plan needs clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

Recommended actions:

- Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.
- Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.
- Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

Sincerely,
Bill Kotziers
Fleming Island, FL

#135 Brad Tobias, MPA | Received: Juen 22, 2026

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

Thank you for the opportunity to voice my thoughts and be heard concerning Parkinson's Disease and how the government can assist in finding a cure. Please see my public comment below:

My name is Brad, and my wife is my hero. On February 24, 2023, at only 35 years old, she was diagnosed with Parkinson's Disease. She was so young, so full of life. At first, it was just a slight tremor in her right hand and a stumble when she walked down the stairs. But over time, those small signs grew heavier—her tremors worsened on the right and began creeping into her left side. Now, even her memory and hearing are beginning to slip away.

We believe her Parkinson's is the cruel result of chemical exposure during her service as a United States Marine in Afghanistan back in 2011. She gave her strength, her health, and her future in service to this country. And yet today, she is the one fighting a battle no Marine should ever have to face alone.

In fact, since she's a woman veteran with YOPD, she is one of just 400 women veterans who is going through PD. Unless a cure is found, her and the 1.1 million others will be enslaved to medicines, procedures, therapies, and other treatments. The costs for these are insurmountable for the individual, insurance companies, and the burden on taxpayers.

The Council must impose pressures on Congress to provide funding for actors such as research. We need more movement specialists, neuroscientists, and clinical researchers. This will allow for shorter wait times. The red tape for treatment and testing must be reduced, it should not take years for new breakthroughs to be approved by the FDA. Finally, the Council must be cognizant of entities profiting from the medical industrial complex.

Thank you for letting my voice be heard. Thank you for your service to the Parkinson's community.

Respectfully,
Brad Tobias, MPA
Policy Advocate, Michael J Fox Foundation
Ambassador, Parkinson's Foundation

#136 Brenda CarlLee | Received: June 22, 2026

My Parkinson's Disease story 06-22-26

My name is Brenda CarlLee, I am 73 years old, retired from insurance and investments. I live in Little Rock AR. This is my story.

At the age of 76, my mother was diagnosed with Parkinson's Disease. As I educated myself to be her medical advocate I discovered that I had symptoms myself. Four years later, at my age of 60, I was diagnosed by the NIH while participating in a research study. As I was providing support and care for my mother, I got to watch what I felt could be my future. She made it 8 ½ years. I am 13 years into my journey and continually progressing in a worse direction. One of my husband's friends asked him how I am doing. When he answered that I am progressing, the friend said "oh, that's good"! Most people I encounter do not have any idea of what Parkinson's Disease means. We do not get better.

Many of us have had several symptoms for many years and did not know it was Parkinson's. It is hard to diagnose. For years, no medical professional was able to put all of my symptoms together and I believe that if it had not been for my mother I would not have known for a lot longer. I can never forget that I have Parkinson's because every movement and every thought is involved. It is a struggle to get out of bed, physically and mentally. Patients' brains have lost a lot of their ability to produce dopamine, the chemical that affects almost everything in the body.

Every day I wake up to a different body. I face challenges with walking, dressing, personal hygiene, eating, standing, sitting, writing, typing, swallowing, talking, coordination and just moving in general. I deal with many other symptoms such as tremors and cramps in arms, hands, legs, feet, mouth. I have dry eyes, a constant runny nose and urinary and bowel issues. I'm sorry, but it is not pretty. I have mostly given up on dignity and vanity.

Lack of dopamine causes me to have sensitivity to stress, anxiety and depression. Anxiety aggravates my physical symptoms such as tremors both internally and externally. Profound fatigue can happen on an unexpected basis making it hard to make plans. Extreme temperatures make my symptoms worse.

Most Parkinson's patients have to keep up with taking a lot of medication several times a day. This is supposed to be coordinated around eating a couple of hours on either side of the times it is taken. Medications are changing constantly for what patients need, as their symptoms worsen, and can be expensive. As it stands now, medications are what most patients use for treating Parkinson's. Medication has not proven to slow the progression of, or cure Parkinson's. The most agreed upon way to possibly slow it is through exercise and that varies for everyone. It would be helpful if insurance coverage would

provide benefits for exercise and specialized programs. I am fortunate to live close to a Movement Disorder Treatment Center where there are resources for Movement Disorder Specialists (MDS), the most qualified neurologists to treat this disease. Many people do not have good treatment sources.

I try to exercise on a regular basis, eat a healthy diet, do some reading, some driving, some cooking, manage family finances and have as much of a social life as possible. But I am progressively losing these abilities.

I have little hope that in my lifetime a better treatment, cure or prevention will be developed. I hope there will be discoveries that can help my son, his son and future generations for everyone. I have participated in research through the NIH and the MJFF. It is extremely important that these organizations, as well as the DOD, CDC and VA continue to get as much funding and support as possible. We need to find a way to get rid of this terrible disease. We need more researchers and medical professionals working on Parkinson's Disease.

My son was in medical school when I was diagnosed. I asked him to consider becoming a Neurologist. He said "Mom, neurological diseases can't be cured, I want to see the results of my work" so he became an Orthopaedic Surgeon. Let's change that! We need results now!

Thank you for your time.

Brenda CarlLee
Little Rock, AR

#137 Carolyn Wilson | Received: June 22, 2026

Dear Members of the Advisory Council,

Thank you for the opportunity to provide public comment.

I am an advocate on behalf of my husband and his father, who had Parkinson's, and the 1.1+ million Americans living with Parkinson's and the millions more of family members and care partners whose lives are profoundly affected by this progressive disease.

My husband and his father both developed Parkinson's disease after years of exposure to agricultural chemicals on their family farm. While no one can say with certainty what caused their disease, our family's experience underscores the urgent need to better understand and prevent environmental risk factors linked to Parkinson's.

With urgency, here are the priorities I recommend based on The Parkinson's Plan: A New Path to Prevention and Treatment by Dr. Michael S. Okun and Dr. Ray Dorsey.

1. Prevention

The National Plan must prioritize prevention. Growing evidence links Parkinson's disease to environmental exposures, including paraquat, trichloroethylene (TCE), air pollution, and contaminated water. Federal agencies should coordinate efforts to reduce harmful exposures, strengthen environmental monitoring, protect high-risk populations, and significantly increase funding for prevention research.

One tangible step you can take today: Ban paraquat and help communities transition to less toxic options. The next step would be increasing the research funding and percentage devoted to prevention tenfold.

2. Prevalence Tracking

We cannot solve what we do not measure. Accurate, timely data on Parkinson's prevalence and incidence are essential for understanding disease trends, allocating resources, evaluating progress, and informing policymakers and advocates.

One tangible step you can take today: Establish a national Parkinson's registry. Then set measurable national targets to reduce new Parkinson's diagnoses and reverse the growth of Parkinson's disease by 2035.

3. Access to Care

Every person with Parkinson's deserves access to high-quality, multidisciplinary care regardless of geography, income, insurance status, or ability to self-advocate. Access should include movement disorder specialists, rehabilitation therapies, mental health services, nutrition support, palliative care, and evidence-based exercise programs.

One tangible step you can take today: Expand telehealth access nationwide, including across state lines, to ensure equitable access to Parkinson's care for all.

The National Plan presents a historic opportunity to change the trajectory of Parkinson's disease in the United States. I urge the Council to act boldly and with urgency.

Future generations should inherit a world where Parkinson's disease is increasingly preventable, treatable, and ultimately curable.

Thank you for your leadership and commitment to actions that improve the lives of everyone affected by Parkinson's disease.

In gratitude,
Carolyn Wilson
Parkinson's Foundation Ambassador
PD Avengers Volunteer

#138 Chris Westland | Received: June 22, 2026

Public Comment on National Plan to End Parkinson's

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

I am writing to share my comments regarding the National Plan to End Parkinson's. I am a person living with Young Onset Parkinson's for the past 13 years. As an advocate for disease modifying therapy, I appreciate the opportunity to provide input and welcome the opportunity to provide comment in person.

Why this issue matters to me:

The tremor in my right thumb started when our kids were 8 and 12 years old. It became more noticeable over time when I was playing guitar and keyboards with my band or trying to use a mouse or laser pointer during meetings at work. After a year of neurology visits, blood tests, CT, X-Ray and MRI scans, I had my diagnosis of Young Onset Parkinson's. I was 46 years old with no family history of Parkinson's Disease (PD) to prepare me and a long road ahead to fight the disease.

What I've found most challenging is the unpredictable nature of PD. I can't get out of bed knowing what to expect and how to best navigate the day. On bad days, I could hide a tremorous right hand in a pocket or shift in a chair to hide dyskinesia. I'd get anxious anytime my tremor began to show, believing right or wrong that my co-workers would think less of me. As my disease progressed the signs and symptoms were harder to mask. I was able to continue working for another decade through a combination of medications and surgery.

Eating continues to be complicated as oral administration of dopamine is every 3 hours and absorption is affected by protein. I discovered I had to plan very carefully when I would dose if I had a lunch meeting and learned the hard way that it's better to be a vegetarian than to risk an afternoon of "off" time. To better manage this, I underwent deep brain stimulation (DBS) surgery which is similar to a brain pacemaker for my right side in 2022. I took time off from work for the pre-operative visits and was out on medical leave for 6 weeks to recover.

I went from taking up to 15 tablets a day of dopamine to 5 a day. For about 3-6 months I felt pretty good. Then the non-motor events began to follow me around. The absence of sleep and REM sleep behavior disorder means my wife and I sleep in different rooms now. There are swallowing problems – the first drink of water is often coughed out and my voice becomes tremulous at times for no particular reason. At times my speech would grind to a halt. The thoughts were all there still, I just couldn't quite get the words out. I stopped working at the end of 2024.

The motor dysfunction progressively grew worse and in early 2026 I went back in for DBS for my left side. Again, there were multiple pre-operative visits and a long recovery. This time though we paid for it with private insurance which was a different financial burden. Despite medications and 2 DBS surgeries I'm still trying to wrestle the effect of Parkinson's on my gait.

Exercise is the only disease modifying treatment available at this time, so I need to be able to run again. At this point I'd take normal walking for 30 minutes.

Worried about my fall risk, my wife asked me to get a dexascan and I was diagnosed with osteoporosis at age 58. Since taking calcium supplements wouldn't be enough to recover bone density, I underwent my first Reclast infusion in 2025. I can also say that Parkinson's literally hates my guts based on my leaky bladder and the delayed clearance of the stomach, small and large intestine. Daily management of these last two adverse events can consume a lot of mental anguish and lead to a rigid diet.

I worked in the Biotech and Pharma industry for 30 years, the first 10 in laboratory research (3 of which were spent in a lab studying the mechanisms of neurodegenerative disease) and then 20 years in clinical research and drug development. The process of drug discovery, early trials through late phase and hopefully approval is time consuming and expensive with a very low success rate. Despite working on countless development programs, only one resulted in a drug approval. The observation in clinical research circles that some people never work on an approved or approvable drug is sad, true and indicative of the mountain of time and data and people-hours that it takes to identify and test drug candidates.

With this perspective we need to better understand the fundamental biology behind Parkinson's, produce more drug candidates ("shots on goal") and we need our focus to be on a cure. We need to do better.

Key concerns or priorities: Putting the plan into action is what matters most. A strong national plan needs clear deadlines, measurable goals, and ongoing coordination led by NIH across federal agencies, so it leads to real results.

Recommended actions:

- Estimate how much funding is needed to prevent, diagnose, treat, and eventually cure Parkinson's. This should be a clear, evidence-based estimate with stated assumptions and phases, so Congress can provide the right level of funding and the country can build a serious long-term plan instead of relying on small, short-term increases.
- Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families.
- Set firm but realistic deadlines to make up for lost time and keep the work moving. NIH should set clear progress checkpoints, provide regular public updates, and maintain transparency.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

Sincerely,
Chris Westland
San Carlos, CA

#139 Christine Speranzo | Received: June 22, 2026

Hello...I have had Parkinson's Disease for 8 years. I take carbidopa levodopa for my tremors and amantadine for dystonia in my foot. I see my motion disorder Dr. twice a year.

My tremors are under control. I do have some balance issues and hand dexterity issues, however, I go for physical therapy who specialize in PD and have found many benefits.

At this point PD has not affected my way of life.

Have a sparkling day!

Christine Speranzo

#140 Dan Feehan, Chief Government Affairs and Policy Officer | Received: June 22, 2026

Advisory Council on Parkinson's Research, Care, and Services
National Institute of Neurological Disorders and Stroke
Submitted via email to NationalPDplan@nih.gov.

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

On behalf of The Michael J. Fox Foundation for Parkinson's Research (MJFF), thank you for the opportunity to provide public comment as the inaugural Advisory Council on Parkinson's Research, Care, and Services (ACPRCS) begins its work advising

the Secretary of the U.S. Department of Health and Human Services and helping to develop a national plan to end Parkinson's disease.

MJFF was founded with a single, urgent goal: to find a cure for Parkinson's disease. Since 2000, we have funded more than \$3 billion in research worldwide and worked alongside patients, families, researchers, clinicians, industry partners and policymakers to accelerate scientific progress and improve quality of life for people living with Parkinson's, their families and care partners. This experience gives us a unique perspective on advancing research, improving care and ensuring that advances in research reach people living with Parkinson's disease.

MJFF was proud to support the enactment of the Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act, which established the National Parkinson's Project. A sustained, coordinated national strategy is essential to accelerate progress against Parkinson's disease and atypical parkinsonisms, align efforts across sectors and ensure that scientific advances translate into meaningful benefits. We view the establishment and first meeting of ACPRCS as a critical step toward realizing that vision.

Today, the Parkinson's community stands at a moment of extraordinary opportunity. Scientific advances are creating new possibilities to better understand the biological and environmental drivers of Parkinson's disease, identify people at elevated risk or in the prodromal stages of disease, develop biomarkers and diagnostic tools, advance prevention and risk-reduction strategies, and accelerate therapies capable of slowing, stopping or preventing disease progression. These advances have the potential to fundamentally change how Parkinson's is understood, diagnosed and treated.

At the same time, Parkinson's has become the fastest-growing neurological disease in the world, placing an increasing physical, emotional and financial burden on individuals, families, health systems and the public sector. This growing public health challenge demands a national response that matches the urgency and scale of the disease and the unprecedented opportunities emerging in Parkinson's research. To ensure the pace of scientific discovery meets the growing disease burden, federal investment in Parkinson's and related disease research should reach at least \$1.5 billion by 2032. Federal investment, research infrastructure, workforce capacity and implementation efforts must reflect the magnitude of this disease.

With your leadership, the National Parkinson's Project can significantly advance the nation's response to Parkinson's disease. Its success should be measured by whether the Project accelerates progress toward outcomes that matter most to people living with Parkinson's and their families: a deeper understanding of disease biology, new opportunities to prevent disease and reduce risk, earlier and more accurate diagnosis, broader access to high-quality care and innovation, and the development of therapies capable of slowing, stopping and preventing disease progression. To realize that vision, we encourage ACPRCS to focus on the following interconnected priorities:

1. Build a sustained national strategy with accountable cross-agency leadership and increased, long-term investment. Parkinson's disease does not fit neatly within existing federal structures, and an effective response will require coordination across them. The Project should align federal leadership, investment and accountability around shared goals that advance research, prevention, diagnosis, treatment, care and quality of life.
2. Accelerate progress toward understanding disease biology, advancing prevention and risk-reduction strategies, and developing disease-modifying interventions. Continued investment is needed to better understand the biological and environmental drivers of Parkinson's disease, identify opportunities for prevention and risk reduction, and translate new discoveries into therapies that can slow, stop or prevent disease progression. This should include shared neurodegenerative mechanisms and Alzheimer's-related co-pathologies.
3. Make earlier and more accurate diagnosis the standard. Advances in the development, validation, regulatory acceptance, patient access and clinical adoption of biomarkers and diagnostic tools have the potential to advance research and care. These tools can enable earlier diagnosis, improve clinical trial readiness and support more biologically informed approaches to treatment and care. Realizing this potential will also require a workforce, provider education and care delivery infrastructure equipped to integrate new diagnostics and therapies into routine clinical practice.
4. Improve care, quality of life and independence across the full disease course. Progress in research and treatment development must be matched by efforts to ensure people living with Parkinson's disease can access evidence-based, person-centered care including mental health care, rehabilitation, supportive services, and coordinated, multidisciplinary models of care that improve daily function, independence, caregiver well-being and quality of life.
5. Measure progress and ensure accountability. Establish and strengthen national data systems and annual reporting to track disease burden, diagnosis, care delivery, clinical trial participation, adoption of new diagnostics and therapies, affordability, caregiver impact and health outcomes, and the Parkinson's research funding landscape. Clear goals and transparent reporting

should allow policymakers and the public to assess progress, understand where research investments are concentrated, identify critical gaps, align future funding with scientific opportunity and patient need and ensure accountability for results.

Across each of these priorities, the Project should ensure that advances in research, diagnosis, treatment and care reach people living with Parkinson's disease and atypical parkinsonisms across geographies, races and ethnic groups, sexes, socioeconomic circumstances, disability status and care settings. Success should be measured not only nationally, but also across populations and communities that have historically been underrepresented in research or underserved in care to identify gaps requiring additional attention.

As implementation continues, we encourage ACPRCS to maintain momentum and prioritize completion of its first report within the next year. The urgency of Parkinson's disease and the extraordinary scientific opportunities before us warrant sustained focus on moving from planning to action. We also encourage ACPRCS to maintain predictable opportunities for public engagement. Open meetings, public comment opportunities, Requests for Information and outreach to diverse communities will help ensure that the National Parkinson's Project remains responsive to the experiences and needs of people living with Parkinson's disease, their families and those who care for them.

The National Parkinson's Project represents a rare opportunity to align advances in research, care and treatment with a coordinated national response to Parkinson's disease. If successful, it will help accelerate the discovery of better treatments, enable earlier diagnosis and intervention, improve access to high-quality care and change the trajectory of Parkinson's disease through earlier intervention and therapies that slow, stop, or prevent progression.

For more than 25 years, MJFF has worked with partners across the scientific community, clinicians, patients and families, industry partners and state and federal governments to drive progress toward that future. We appreciate the opportunity to provide these comments and look forward to working with ACPRCS, federal agencies, Congress and the broader Parkinson's community to help ensure the National Parkinson's Project delivers measurable progress for all those affected by Parkinson's disease.

Sincerely,
Dan Feehan
Chief Government Affairs and Policy Officer
The Michael J. Fox Foundation for Parkinson's Research

#141 Deb Jobe | Received: June 22, 2026

Good Day:

I apologize for the late response and hope the below may still be used.

As a person living with CBD for 6 years, this task group is vital.

Critical priorities include advanced research, care and support in addition to coordinated therapeutic approaches.

Advanced Research:

Fluid bio-markers such as blood to identify Tau and other markers fostering a less invasive and expedient diagnosis.

Broaden the availability and affordability of PET.

Care and Support:

As a woman of 60 and living with CBD, a carefully curated coordinated approach to therapy services (OT/PT/ST). I struggle with balance issues and loss of strength. Ensuring these therapies are coordinated and complement one other are key to my quality of life. Affordability across all demographics and geographic populations is so important.

Additional support such as Sleep Studies and Sleep Therapist also necessary for a holistic approach. REM behavior disorder is quite prevalent for those with Parkinson's and I also have RBD. RBD may also be a precursor to Parkinson's and other dementias.

Early diagnosis offers the opportunity for persons with CBD and other dementias to employ therapeutic strategies to improve overall quality of life. In addition a Palliative care plan is necessary to ensure a well rounded approach.

Care support should also be considered for Care partners and caregivers. I see the stress and toll it has taken on my partner and I am in the early stages. It is emotionally draining and physically exhausting for him.

AI and Technology

AI is a powerful technology and diagnostic tool that when employed judiciously will further efforts with identifying proteins and other markers that may slow down the progress and potentially result in discoveries of new pharmaceuticals and who knows, one day cures.

A tool box of technology tools is another key element for those of us living with a movement disorder and diseases. It would contain tools in their simplistic forms to more advanced options. Examples include wearables for tracking, smart devices and others such as speech devices.

I thank you for the opportunity to have a voice and wish you much success!

Best,

Deb Jobe

Co-Chair of the persons living with FTD Advisory Council
AFTD Association

#142 Diane M. Morgan | Received: June 22, 2026

Hello Council,

My connection to Parkinson's Disease is wide ranging. First, my father served in the Air Force during Vietnam. He was diagnosed in 1999 with PD and was awarded compensation due to the exposure to Agent Orange. He suffered the debilitating symptoms of Parkinson's disease and Diabetes right during his retirement years. My parents' plans of RV traveling across the USA was cut short because my dad's stress, anxiety and lack of balance causing him to fall.

My mom became his full-time caregiver, which took a heavy toll on her. She was stuck at home, Dad was embarrassed to go out, to dinner, church, to see friends. He felt it was too difficult with the wheelchair and people watching him shake. Dad went blind from glaucoma and Macular Degeneration. During "Covid" he stopped getting his eye shots to protect himself and my mom from being exposed to the virus, which caused him to go blind sooner. I wish that home health care could have provided these shots. My mom only received 14 hours per week of help. She struggled to have enough time to get to her doctor/dental appointments, get groceries, visit friends or family. Mentally, my mom suffered by being confined to the house even though she was not sick. My parents loved each other so much, my mom promised my dad to not put him into a nursing home. If spouses are the caregiver they need to be compensated. Families need support for getting patients to specialized movement physical therapy, and for dealing with depression and anxiety for both PD patients and caregivers.

My second connection with PD includes watching my mom become a full time caregiver. Draining her strength and joy as she struggled to meet dad's needs and keep herself healthy and happy.

Finally, and the most personal experience I have with Parkinson's Disease is my own diagnosis in 2021. I participated in a genetic research study in 2021 through Indiana University. The DNA showed that my PD and the LRRK2 gene comes from one parent. I don't claim to understand what all this means. I believe that my Parkinson's disease came through my father. I have spoken to a few doctors and people who agreed. I doubt the US government will acknowledge this and that the Agent Orange effects have been passed down to offspring.

The US provided money and compensation to the Vietnamese women who lost babies and had deformed children because of the chemical spray. Studies were conducted for a short period of time on a small number of soldiers exposed to Agent Orange. There was never any long term studies. I believe the increase in Parkinson's Disease today is traceable back to those exposed in Vietnam and other chemical exposures.

We need support for getting better access to movement physical therapy. Movement therapy is a specialized method of physical therapy for those with PD. Compensation for family caregivers along with more hours to give family time to get out of the house. Caregiver support for their mental health.

Please support studies to slow progression and eradicate Parkinson's Disease.

Sincere and thankful consideration to everything that I have shared. I am available for any questions you may have.

Diane M. Morgan

#143 Gary H. Kane | Received: June 22, 2026

Public Comment Submission for the National Parkinsons Plan

Gary H. Kane
Ballwin, MO

The Parkinson's Foundation indicates there are approximately 1.1 million people in the US who have Parkinson's Disease. The annual cost of managing Parkinson is approximately \$82 billion. Significantly, the number of patients diagnosed with Parkinsons is growing at a rate of 90,000 new patients each year, substantially faster than current projections. All of these statistics are eclipsed by the impact to patients and families who struggle clinically, emotionally and financially to manage their journey. This "call to action" is being addressed through the work to develop a National Plan. These public comments are being submitted to the committee. They are encouraged to consider exploring a few ideas and concepts that surfaced through my journey.

Concepts for consideration are:

- Develop a Central Navigator functionality for providing a fast start and ongoing support for all newly diagnosed patients much like a Diabetic Educator who optimizes for each individual.
- Expanded Financial Assistance via public and private insurance to help patients with the financial burden of paying for expanded activity-based programs that have proven substantial benefits.
- Improve Patient Access and Outcomes. Develop and optimize motivation programs to incent patients to seek improved outcomes.
- Develop a National Compendium of Parkinsons Research that informs and provides hope to all impacted by Parkinson's and related diseases.
- Leverage other Disease States for Inclusion of key elements such as public and private funding.

These comments are submitted with a focus on treatment of Parkinsons and related diseases from the perspective of a newly diagnosed patient.

Here is my story:

I was diagnosed with Parkinson's Disease in March, 2024. Instantly, the entire world had changed for our family, as months earlier I had been diagnosed with Diabetes.

The severity of this diagnosis and news that I had Parkinson's was akin to being hit in the chest with a sledge hammer and carried with it an enormous sense of loss. Even worse, the conveyance of this life changing news was handled poorly as I was told that despite what the Neurologist had shared with me 15 months earlier, I now had Parkinsons. The Neurologist delivered the diagnosis, wrote out a script for Carbidopa and Levodopa and was done, without any explanation or discussion as to what to do next. She provided one small brochure with something about Rock Steady Boxing (RSB), yet offered no other insight and frankly seemed disinterested in helping me understand or develop a plan for next steps. At the time, we had no real way of vetting the RSB or other offerings, nor did we understand how RSB could benefit us or where we could go "plug in" to the process of learning about Parkinson's resources.

From this rough start, I realized that a relationship with another Neurologist would provide better guidance and a change was made. Although we had secured a new physician, we had no path forward and no plan to follow to develop treatment options as precious time had slipped away. Again, we felt lost. I became frustrated and angry that I could not seem to gain solid traction for treating my Parkinson's. From the onset of this diagnosis frustration set in as we simply did not know where to go to get reliable information on sorting out treatment options for Parkinson's that did not feel like a social media scam. Simply put

even with intense research the family ran into way too much disparate information and that created frustration from the substantial quantity of data overload.

Our family had much of our life's work in healthcare, the task of trying to figure out appropriate access and treatment options was extremely daunting, even though my wife was an RN and I spent over 40 years as an executive in the hospital and healthcare industry. After intense research a study did appear to help involving Parkinson and diabetes.

After 2 to 3 months of learning more about Parkinson's and curbing the anger that came from lots of mis-direction, I finally called Rock Steady Boxing. For the first time since my diagnosis, I began to see there were some significant benefits to the Rock Steady Boxing (RSB). I joined RSB-Fenton and have been an active participant for two years now, the positive impact of RSB cannot be overstated. The meshing of physical and mental activity through a boxing format was exactly what I was looking for. Two years later, I am happy to say my progress has been fantastic with an MDS-UPDRS score of 23, compared to a score of 30 from the same time in the previous year and I have experienced almost no progression of my Parkinson's. Granted, these are only two data points, yet progress is clear and very encouraging.

During this time frame I became aware that four of my family, friends and associates had also been recently diagnosed and they were reaching out to me to learn how I was dealing with my Parkinson's. Unfortunately, they all had run into the same thing I had experienced, too much or poor-quality information that required a substantial effort to vet and engage in actually beginning to implement their treatment plans.

When asked what comprised their treatment plan, all my friends referenced pharmaceuticals, yet physical activity did not get a mention. I had developed my own multifaceted treatment plan that works for me including a holistic approach based upon the saying that "movement is medicine". For example, we turned our dining room into a boxing gym to augment visits to RSB.

That said, if you have seen one person Parkinson's, you have seen only one person's Parkinson's. The disease is custom to each person it impacts and that makes dealing with Parkinson's so difficult.

Hopefully from my story you can see that there could be significant benefits by developing and implementing some changes to how newly diagnosed Parkinson's patients deal with their sense of loss and subsequent treatment plan.

Thank you for this opportunity.

#144 Greg Baker | Received: June 22, 2026

Hello, my name is Greg Baker. These are my comments ahead of the inaugural meeting of the ACPRCS,

About 3 ½ years ago I was diagnosed with Parkinson's disease. I'm an environmental scientist and at the time of my diagnosis I was working for NOAA, the National Oceanic and Atmospheric Administration. My work at NOAA focused on ecotoxicology and I was active in several professional organizations that study and address the harmful effects of pollution. Chemical exposures have been found to be associated with an increased risk of developing Parkinson's.

Since my 2022 diagnosis my life and that of my family has changed. Once we came to accept our new reality we began to read about the disease and to investigate opportunities to participate in clinical research trials and in advocacy and public awareness efforts. I may not alter the ultimate course of my own condition but I can contribute to scientific efforts aimed at finding disease modifying treatments and early diagnosis and prevention techniques.

How Parkinson's manifests may be different in different people. For me, the stereotypical symptoms such as tremors, worsening posture, slowness, and shuffling while walking, were not as noticeable as certain non-motor symptoms: speech and swallowing difficulties, fatigue, facial masking where I appear expressionless, and increasing memory challenges. I have many more medical appointments now, with a whole team of different specialists. I also attend regular boxing classes for Parkinson's and work with a personal trainer at the gym.

I've turned my attention and daily efforts to supporting and participating in human health research leading to potential treatments. I have gotten involved with the Michael J Fox Foundation and several other organizations that are accelerating our understanding about this awful neurodegenerative disease that directly and indirectly affects so many millions of American lives and people worldwide, at great cost.

In recent years we've made remarkable strides in advancing our understanding of the science of Parkinson's disease. But I believe that we can do more to manage and coordinate efforts across multiple programs: government, academic, and private

sector. The Advisory Council should play a pivotal role by seeking increased federal funding and ensuring that studies and data are communicated and leveraged to the greatest benefit possible.

Knowledge exchange with researchers and institutions in other countries is also vital. Could one of the charges of the ACPRCS be the fostering of shared international research efforts? For instance, in several countries including Canada and the UK, there are active clinical trials, at least one in Phase III evaluating the potential benefits of a repurposed cough medication called Ambroxol for Parkinson's patients. Ambroxol is not approved by the FDA, but it has a good safety record, having been used for decades in other countries to treat coughs. Could the federal government (FDA or NIH) license Ambroxol for clinical trials in the U.S.? Surely safe and promising treatments being examined in other countries deserve consideration here as well.

In recent years science funded by the National Institutes of Health and foundations like MJFF have uncovered cellular and molecular mechanisms that lead to the loss of neurons and the development and progression of Parkinson's disease. Understanding disease mechanisms has pointed us toward potential treatments and clinical trials. I myself have participated in clinical trials aimed at finding potential therapies to slow, stop, and reverse progression, and even prevent the disease. I participated in one such trial for 2 years until recently when it ended because the experimental drug was found to be ineffective. Although this was disappointing, the fact is that it still contributes data and advances our knowledge. And so the search continues.

I recently found out through genetic testing that I have a mutation in one of my genes that is associated with an increased risk of developing the disease and a risk of faster progression of symptoms. But research findings to date give me reasons to be optimistic. We have found good evidence that intense exercise and a healthy diet can slow the progression, and in my personal experience I have found that to be the case. I like to think that my genetic predisposition makes me a useful subject for precision research and testing of new therapies, and I look forward to participating in new clinical trials.

It is crucial that we sustain and quicken our pace toward discoveries, and I respectfully ask the Advisory Council to carefully consider recommendations received through public comments. The sooner we discover disease modifying treatments, the sooner the enormous impacts and costs of this disease across our nation can be ended.

Lastly, I'm on the planning committee for an annual Parkinson's disease symposium organized by the University of Maryland, to be held on Friday September 25th at the Baltimore Washington Airport Hilton. We call the symposium, "Within our Reach" to reflect our sense of optimism that successes are near, and now is the right time to redouble our efforts to end Parkinson's. I'd like to invite members of the Advisory Council to attend this symposium, or others held at other research institutes if possible.

Thank you for considering my comments.

Greg Baker
Catonsville, MD

#145 Gregory Ritscher | Received: June 22, 2026

While living with Parkinson's (PD) for 15 years (I have undergone DBS) I have come to the realization that PD is the most "intentional" disease known to man. With no known cause, and no known cure, and Motor, Non-Motor, and Psychological symptoms that not only vary by person, but vary by the hour; no wonder after 209 years of awareness of the disease, we need to live very intentional lives just to get through the day.

"Houston, we have a problem"! Not only do we not have a progression scale, we are just now learning about the many different types of neurodegenerative diseases and how to properly diagnose them. Many of the therapies associated with PD (Deep Brain Stimulation-DBS) we do not even know how or why they work!

I recently participated in a Parkinson's Advocacy Plan event in Washington D.C. (March 2026) during which I had to turn off my DBS to prove to "staffers" that research dollars are well spent in PD, and that the PD community is worth talking to on a direct basis with our Senators and Representatives.

The cost of PD to the US economy, currently estimated at \$82.2 Billion dollars, is expected to rise to \$112.8 Billion dollars by 2030 (that is almost the GDP of Florida, my home state).

One would think that this Bipartisan issue would get the proper amount of media and political coverage, considering the threat it represents to the American economy, but finding out that two of the four living ex-Presidents have a neurological disease right now, should wake up the American public!

Our Federal government (the EPA) continues to allow the use of Paraquat, a known carcinogen, and manufactured in China. This is a very subtle way to wage war, increase our trade deficit, and kill off millions of US citizens, all while tying up millions of productive people with Care partner responsibilities. Let's hope that the ACPRCS has the initiative and the drive to at least start to pay attention to one of the largest threats currently facing our government!

Gregory Ritscher
Author, "Rising Above Parkinson's"
Executive Producer: "On Firm Ground"
Board of Directors - Parkinson's Pointe
Ambassador - Boston Scientific
Ambassador - Davis Phinney Foundation; 2025 Tom Palizzi Community Champion Award Recipient
Ambassador - PMD Alliance

#146 Heather Root | Received: June 22, 2026

June 22, 2026

Dear Dr. Gladman,

I am writing to you as the daughter/caregiver of a father with Parkinson's. In doing so I have met numerous wonderful people who also have Parkinson's.

My father was diagnosed about 5 years ago. During this time he has had many significant changes/declines with severe permanent injuries due to his gait freezing. I have watched a highly independent person become more dependent than ever just to accomplish the typical activities of daily living. I have seen him on his hardest of days, while wishing I could take away all of this. His speech is declining. My father works hard every single day to combat the progression. He does physical therapy, speech therapy, group exercises, support groups, you name it he goes. It all comes at a cost. The expense that has come with a diagnosis is costly. I am unable to work, so I can keep him home and care for him.

We are pleading for you to make the medication, the therapy more affordable. To come up with a plan for families not on state insurance to be compensated for keeping loved ones home.

My father along with everyone I have met along the way are worth coming up with a new plan to combat this second largest progressive neurological disease.

Feel free to contact me for further details on our journey.

Sincerely, a daughter trying to save her dad and his friends

Heather Root

#147 Irina Goronja and Marko Stanić | Received: June 22, 2026

Dear ACPRCS Council Support Staff,

Thank you for the opportunity to contribute a public comment to the inaugural meeting of the Advisory Council on Parkinson's Research, Care and Services (ACPRCS). Please find below our family's experience and perspective regarding Progressive Supranuclear Palsy (PSP).

We do not request the opportunity to provide oral comments at the ACPRCS Council meeting at this time.

June 22nd, 2026

Public comment submitted to the Advisory Council on Parkinson's Research, Care and Services (ACPRCS)

I am writing on behalf of my partner's father and our family to share our experience with Progressive Supranuclear Palsy (PSP) and to respectfully ask that rare neurodegenerative diseases such as PSP remain a visible priority within research, care and public policy discussions.

My partner's father, born in 1957, lives outside Belgrade, Serbia. He has been experiencing symptoms for more than three years and spent approximately two years visiting physicians and seeking answers before finally receiving a diagnosis in March 2026 of PSP Richardson syndrome (Steele-Richardson-Olszewski syndrome).

Over time, symptoms progressively worsened and included increasing instability, repeated backward falls, changes in speech, swallowing difficulties and loss of independence. Despite repeated medical consultations, it took years before hospitalization and more extensive neurological evaluation ultimately led to diagnosis in March 2026. By that point, the disease had already significantly progressed.

The delay in diagnosis has had a profound impact. During those years, symptoms continued to advance while our family searched for explanations, support and access to appropriate care. Receiving a diagnosis brought clarity, but it also highlighted how limited support can be for people living with PSP and their families. We are grateful for the healthcare professionals and researchers who continue to work in this area despite limited resources and treatment options.

Because he lives outside a major city, access to specialist care requires repeated travel to Belgrade. What might otherwise be a manageable distance becomes increasingly difficult and burdensome as PSP progresses and mobility, safety and independence decline. Furthermore, access to coordinated multidisciplinary care is extremely limited. Services that can meaningfully preserve quality of life - including speech and swallowing support, rehabilitation, mobility and fall-prevention support, protective equipment and caregiver assistance - are largely unavailable or inaccessible through the public healthcare system, leaving families to organize and finance care privately.

The burden of PSP extends beyond the patient. Families often become coordinators of care, transportation providers, advocates, caregivers and financial support systems while simultaneously trying to preserve normal family life and emotional wellbeing. Access to information and support for caregivers should be considered an essential part of care.

His condition has continued to progress. He has experienced significant weight loss and dysphagia (difficulty swallowing), requiring dietary adjustments and thickened food and liquids to reduce risk and support nutrition. He is also managing additional medical complications that further increase the burden of care.

Most recently, over the weekend, he suffered another backward fall - a devastating and common feature of PSP - resulting in a serious head injury that required emergency treatment and stitches. Experiences like this demonstrate how quickly safety, independence and quality of life can change for people living with this disease.

Our family follows developments in PSP research closely and hopes for opportunities to participate in future clinical trials, including those expected to become available in Vienna and elsewhere in Europe.

For rare neurodegenerative diseases, access to research and future clinical trials should not depend solely on geography. Many families are willing to travel and participate but face informational, financial and logistical barriers. Greater international awareness and broader access pathways could help ensure that opportunities reach people before disease progression closes the window for participation.

What we hope for is time - and possibility.

We hope research advances quickly enough that people currently living with PSP still have a meaningful opportunity to benefit from future therapies.

We respectfully encourage the Advisory Council to prioritize:

- Increased funding for PSP and related atypical parkinsonian disorders;
- Faster and earlier diagnosis pathways;
- Greater investment in disease-modifying therapies and clinical trial research;
- Support for multidisciplinary care models including neurology, speech and swallowing therapy, rehabilitation and caregiver support;
- Improved access to care for people living outside major urban centers;
- Greater awareness and education among healthcare professionals.

Behind every statistic is a family trying to preserve dignity, safety and hope while time continues to pass.

Thank you for ensuring that the voices of people living with PSP and their families remain part of this conversation.

This comment was prepared by Irina Goronja and Marko Stanić, son of Dragoljub Stanić, to share their family's experience of supporting Dragoljub Stanić in living with PSP, together with the support and care provided by his wife Nada, daughter Marija and second son Stefan, along with other family members and friends.

Respectfully,
Irina Goronja and Marko Stanić

#148 Janet | Received: June 22, 2026

I am the wife of a person with Parkinson's. My husband was diagnosed 4 years ago at the age of 66. As all of the sad stories go, it was a year after he had retired – looking forward to the glory days of retirement. I was still working at the time. As you can imagine, we were devastated. Years and years of looking forward to the glory days evaporated in an instant. Since I am 8 years younger than my husband, I ended up retiring earlier than I had originally planned. My husband is still doing fairly well (let's say he is in Stage 2). His Parkinson's has affected many of his autonomic systems – constipation, swallowing, movements are extremely slow, sexual dysfunction, etc. While he can still do most things by himself, he needs my help to put some shirts and jackets on, opening containers, etc. He has a very hard time cooking for himself as he cannot use a knife very well and lately, has had issues following recipes. I retired from the workforce to help with household chores, drive him to doctor appts (he can no longer drive to 'unfamiliar places' or at night), but most of all to try to enjoy a bit of retirement life before he was unable to participate and I become more of a full time caregiver. I cannot tell you how many nights I have tossed and turned thinking of what the future holds. The depression and anxiety is very real for both the PWP AND for the caregiver. In the beginning, I spent countless hours trying to learn as much as I could about this chronic disease. I had anxiety (and still do at times) over whether he has atypical Parkinson's or 'normal' Parkinson's since he doesn't have tremors, but has significant rigidity. I met another caregiver thru the parkinsonsbuddynetwork.org website. We live about 30 minutes apart. She is the same age as my husband (69 now) and her husband was 73. We had corresponded since March 2023 and unfortunately, her husband passed just this past May of Parkinson's – at 73!!!. They say people don't die of Parkinson's, they die with it is total BS. Her husband died because he was having hallucinations and developed pneumonia which are both directly attributable to him having parkinsons. It is not an accurate statement to say that he didn't die from having Parkinsons!!

PLEASE HELP US!!

Janet

#149 Jarrod Bailey, PhD, FOCAE, Director of Medical Research | Received: June 22, 2026

June 22, 2026

Sent via email to: nationalPDplan@nih.gov

Interested in providing oral/virtual comment

Re: A phased shift away from primate experiments and toward human-based research will benefit Parkinson's patients and wider society - Inaugural Meeting of the Advisory Council on Parkinson's Research, Care, and Services (ACPRCS)

Dear Secretary Kennedy, Director Adams, and members of the ACPRCS,

On behalf of the Physicians Committee for Responsible Medicine, a 501(c)(3) nonprofit organization supported by nearly one million members and supporters worldwide working for effective, efficient, and ethical medical research and product testing, thank you for the opportunity to comment on this inaugural meeting of the ACPRCS.

The National Institutes of Health (NIH) has been increasingly supporting human-based, nonanimal research approaches, including new approach methodologies (NAMs) across all its Institutes and Centers. Most notably, in late 2022, a Working Group of the Advisory Committee to the Director (ACD) provided comprehensive recommendations to catalyze the development and use of NAMs. These were enthusiastically endorsed by the NIH, which subsequently declared its intent to create the Office of Research Innovation, Validation, and Application (ORIVA) to coordinate this catalysis of NAMs across the agency while reducing the use of animals in research. NIH just announced, on June 15, that this office had been created and that it would lead an agency-wide shift away from animal use and towards the adoption of NAMs.

Other recent NIH initiatives have also been established in support of this shift, including the Complement-ARIE program for funding and validating new and established human-based methods and the Standardized Organoid Modeling Center charged with developing organoids that are reproducible, reliable, and accessible for all medical researchers. With these developments in mind, we encourage ACPRCS to ensure that its priorities align with those of the agency.

Specifically, we urge the Council to support the recommendations at the foot of this letter, as we have encouraged the National Advisory Neurological Disorders and Stroke Council in recent public comments.

The grounds for these recommendations are as follows:

Animal experimentation has not delivered for Parkinson's patients and wider society

Parkinson's disease is now the second most common neurodegenerative disease after Alzheimer's. Its prevalence has doubled over the past 25 years, affecting more than 10 million people worldwide, while also placing major emotional, practical and financial pressures on patients, carers, families and health systems.

Despite extensive research, much of it using animals, progress toward preventing, curing or slowing Parkinson's has been limited. The scientific literature outlines how primate studies fail to recapitulate the human disease, due to intractable genetic differences between primates and humans. A common model of Parkinson's involves injecting the neurotoxin MPTP into primates' brains, but they can show functional recovery unlike human patients, and cannot show many of the nonmotor symptoms seen in humans. Scientists still do not fully understand key parts of the disease, including why certain proteins become harmful, how damage spreads through the brain, and why symptoms worsen over time. Existing treatments, such as levodopa, can help manage symptoms but do not address the underlying disease or stop its progression. More than 23,000 animal-based Parkinson's studies were conducted between 1990 and 2018—an estimated 5-10% of these using primates—but they have not translated into any significant clinical benefit.

Human-based methods are superior models of Parkinson's disease and more likely to translate to clinical benefits

Many researchers now believe that "transformative" human-focused research approaches are needed in place of animal methods. New approach methodologies (NAMs), including human brain organoids, assembloids and organ-on-chip systems, can provide more physiologically relevant ways to study Parkinson's in a human context. In previous submissions of evidence to NINDS, we have outlined notable examples of how these tools are helping researchers to more successfully investigate the disease. For example: organoids and assembloids derived from Parkinson's patients are exhibiting pathologies (hallmarks and manifestations of disease) seen clinically, such as α -synuclein accumulation in Lewy bodies, loss of dopaminergic neurons, and the spread of pathology (synapse dysregulation) between hindbrain and midbrain; they are also revealing more new and more detailed biological mechanisms of Parkinson's, how interactions between the gut and the brain affect these mechanisms, and facilitating the human-specific screening and testing of potential new therapies.

Other recent examples of breakthroughs with human-specific methods fortify the case for a shift away from animal research and to a human emphasis. Using human brain tissue and cultures of patient-derived neurons, researchers have identified an interaction between two proteins that causes damage to mitochondria, in turn leading to neurodegeneration, the loss of brain cells and progression of Parkinson's. They also were able to test a new compound in these human tissue/culture systems that interferes with this damage, restoring mitochondrial function and attenuating neurodegeneration. Further characterization in human tissue and organoids will be the next critical steps to lead to clinical trials of this potential therapy.

Important mechanisms associated with one of the most common genetic variants linked with Parkinson's disease (LRRK2-G2019S) are being elucidated with healthy and patient-derived brain organoids. Using organoid models of the human striatum, researchers have discovered that inflammation and dysregulation of the striatum is intimately involved in dopamine depletion (key to Parkinson's pathology and symptoms), and that modelling of the human striatum and these processes using patient-derived organoids is likely to lead to greater knowledge of associated molecular mechanisms of striatal dopamine loss, which could unveil new therapeutic targets. Similar approaches are also revealing altered functions of microglia (cells in the central nervous system that support neural function) due to this genetic mutation, which leads to inflammation and neurodegeneration associated with Parkinson's, and are also facilitating the testing of new therapeutics to combat the disease.

Human brain-on-a-chip techniques incorporating primary neuron cultures, patient-derived stem cell cultures, and midbrain organoids are being used with small electrodes to study in real time the release of dopamine in a human context, and substantial confidence is being imparted for the wider use and adoption of these human-specific models via the validation of their structure, function, human physiological relevance and replicability.

Summary

Parkinson's disease research is challenging, necessitating only the most appropriate and reliable research tools available. Primate studies have not delivered the clinical advances Parkinson's patients urgently need, while human-focused methods are more human-relevant and ever-improving. By transitioning away from primate research and toward these more successful methods, research will advance from an animal-based "one size fits all" approach, to a wider strategy that incorporates diverse human biology and characteristics. By embracing this, the ACPRCS, NINDS, and HHS can strengthen their scientific leadership, and help advance research that is more directly beneficial to patients.

We therefore respectfully ask the Council to support the following recommendations:

1. Phase out Parkinson's research involving primates, including by reviewing current projects for scientific necessity and prioritizing investment in NAMs instead
2. Support researchers in moving to more human-based models and methods, including through research, training, and infrastructure grants
3. Add stronger expertise in NAMs to the ACPRCS, to NINDS staff and leadership positions, and to Parkinson's related study sections

Sincerely,
Jarrod Bailey, PhD, FOCAE
Director of Medical Research
Physicians Committee for Responsible Medicine

For oral/virtual comment:

jbailey@pcrm.org
Tel: 202-527-7371

#150 Jillian Zivanovic | Received: June 22, 2026

Hello, my name is Jillian Zivanovic, and I live in Newtown, Pennsylvania.

My husband, David, was diagnosed with Young Onset Parkinson's Disease in 2021. He was only 45 years old, and I was 37. We had three daughters in elementary school and were focused on all the things busy families do – work, school activities, sports practices, and planning for the future. Parkinson's Disease was never something we imagined would affect our family.

At first, David went to his doctor because of a tremor in his right hand. He thought it was stress. His doctor agreed and prescribed anxiety medication. After several months, it became clear that something else was going on. The tremor persisted, and new symptoms appeared. His muscles became stiff and rigid, his handwriting became small and illegible. David noticed these changes but said nothing to me because he didn't want me to worry.

The changes happened gradually, but they affected nearly every part of his life. Tasks that once seemed easy became difficult. I found myself helping him button his shirts and put on his jacket in the morning. These small changes were a constant reminder that things would be now different. The diagnosis was clear to the movement disorder specialist. David suspected Parkinson's before the appointment, but I was still in denial. Even today, years later, I still struggle to believe that my husband has a progressive neurological disorder with no cure.

One of the most difficult parts of Parkinson's Disease is that many of its symptoms are invisible. People may notice a tremor, but they don't see the exhaustion. They don't see the effort it takes to get through an entire workday. They don't see the frustration of struggling with tasks that once came naturally. They don't see the fear and uncertainty that go with every new symptom.

David continues to work full time, and I am incredibly proud of him for that. However, balancing work, family responsibilities, medical appointments, and exercise is exhausting. Exercise is considered one of the most important tools for managing Parkinson's Disease, yet finding the time and energy to exercise after a full day of work is nearly impossible. Most days, David is simply exhausted.

Parkinson's Disease affects our entire family. We waited to tell our children until we could not wait any longer. They started asking their dad why his hand was shaking when holding a spoon. They would yell from the front door for him to hurry up when they were ready to leave for a birthday party. When we told the kids about David's diagnosis, they asked lots of questions including: "Are you going to die?" "How did you get it?" "Will I get Parkinson's, too?" But now the disease is like another member of our family, ever present. Every few months, one of the kids will ask me, "do you think Dad will be able to move me into college?" Or, "There's still no cure for Parkinson's, right?" They are observant and wise beyond their years.

Living with Parkinson's means living with unanswered questions every day. For me, the uncertainty can be overwhelming. We don't know what Parkinson's Disease will look like for David in five years, ten years, or twenty years. We don't know how quickly his symptoms will progress. We don't know what challenges our family will face in the future. We continue to worry about the future. How long will the meds continue to work? Will he need a higher dose? What side effects might occur? What treatment options will be available if his symptoms become more severe?

Despite these challenges, we remain hopeful. David and I participate in the Parkinson's Precision Medicine Initiative through the Michael J. Fox Foundation. We willingly take time away from work and family to spend a day at the doctor in Philadelphia every few months because we believe research is the path to better treatments, and ultimately, a cure. David does not have a family history of PD, and he has no known exposure to chemicals associated with the condition. We hope that by participating in research, we can help scientists better understand why people develop Parkinson's and how to stop it.

Families like ours are desperate for more treatment options. We need therapies that do more than temporarily relieve symptoms. We need treatments that slow, stop or prevent disease progression. We need research to better understand the causes of Parkinson's Disease and develop therapies that can change the course of this devastating illness.

Parkinson's Disease affects far more than the person who receives the diagnosis. It affects spouses, children, parents, friends, coworkers, and entire communities. It changes family routines, future plans, and everyday life. Yet people living with Parkinson's continue to show remarkable strength, resilience, and determination.

I am sharing our story because Parkinson's research matters. Every breakthrough brings us closer to a future where families like mine do not have to live with the uncertainty that comes with this disease. I respectfully ask that you support funding and investment in Parkinson's research so that one day we can provide better treatment, better outcomes, and ultimately, a cure for people like my husband, David, and the millions of others living with PD.

Jillian Zivanovic
Newtown, PA

#151 Joyce Morgan | Received: June 22, 2026

My husband had Parkinson's Disease. I think that more information is needed for the caregivers. So many things happen during the course of the disease that caregivers aren't sure what they should do. When Bob was in hospice I found it very comforting to know that I could call a nurse and ask questions concerning something that was happening. I wish I had that during the course of the disease. It isn't always possible to call the doctor to get answers to questions. I also found that everyone has a different idea what to do as things happen. My husband had swallowing issues. The speech therapist wanted to put a feeding tube in him. The doctor said "no" to that. I actually agreed with the doctor, but some people don't understand about feeding tubes. I guess what I am really saying is the caregiver needs an advocate. Someone who can take the time to explain things to them. Doctors are great but they are so busy they don't always have the time. They need someone to lean on besides family and friends.

- Joyce Morgan

#152 Karen Lucas | Received: June 22, 2026

Public Comment:

I would like to bring up the issue with availability of Movement Disorder Specialist (MDS), particularly in non-Metropolitan areas.

I was diagnosed with PD 6 years ago and at the time lived outside of Washington, D.C. Although not plentiful, I did have options for an MDS. I have since moved to the eastern shore of Delaware. Finding an MDS has become more difficult. For a face-to-face visit, I must travel 1-1/2 hours one way. In the winter months, my husband and I live in Arizona. During those months, I cannot have a virtual visit with my doctor as insurance will not cover the visit as I am in Arizona and the doctor is in Delaware. If he did consult with me, the doctor could lose his license. I could drive to an out-of-state doctor for an appointment, but a virtual visit is not an option.

With the limited number of specialized doctors, it would help to have unrestricted access.

Karen Lucas

Diagnosed: June 2020

Treatment - Sinemet, 25-100, every 5 hrs, 3 times a day.

#153 Kimberly Rogers | Received: June 22, 2026

I'm sharing public comments in advance of the first meeting of the National Parkinson's Project Advisory Council on Parkinson's Research, Care and Services. I also welcome the opportunity to deliver comments orally at an ACPRCS Council meeting.

I am writing as a person living with Young-Onset Parkinson's Disease. While research, treatment, and clinical care rightly receive significant attention, one area remains largely absent from the national conversation: financial security.

For those diagnosed during their prime working years, Parkinson's is not only a health challenge; it is a financial one.

Most public programs, workplace benefits, and financial policies are built around the assumption that people will work until their 60s, steadily accumulate wealth, and then retire. Young-Onset Parkinson's disrupts that timeline. Individuals diagnosed in their 30s, 40s, and 50s often face decades of uncertainty regarding future employment, earnings, healthcare costs, caregiving needs, and disability.

People with YOPD are often managing two competing realities. We must prepare financially for a future in which our ability to work may decline, while simultaneously paying for treatments, exercise programs, wellness services, and caregiving needs that help us remain productive and independent today. Yet many financial tools remain restricted by age-based rules that do not reflect the realities of a progressive neurodegenerative disease.

I encourage the Council to recognize financial security as an important component of quality of life and long-term care planning within the National Plan to End Parkinson's.

Several practical policy ideas deserve consideration.

Expand Health Savings Account (HSA) flexibility. Exercise is one of the most effective interventions available for people with Parkinson's. Yet many expenses that support health and function, including gym memberships, personal training, yoga, Pilates, Tai Chi, nutrition counseling, caregiver training, and other wellness interventions, may not qualify for HSA reimbursement. Individuals living with an incurable disease should have greater flexibility to use their own health savings for activities that help preserve mobility, cognition, and independence.

Allow enhanced HSA contributions following diagnosis. Current catch-up contribution rules are largely based on age. A diagnosis of Parkinson's creates future healthcare expenses regardless of age. Individuals diagnosed with a progressive neurodegenerative disease should have the opportunity to make additional HSA contributions immediately following diagnosis to prepare for future medical and caregiving costs.

Allow enhanced retirement savings opportunities following diagnosis. People with YOPD may lose years of earnings during what would otherwise be their peak earning years. Consider allowing enhanced retirement catch-up contributions regardless of age for individuals diagnosed with progressive neurodegenerative diseases, enabling them to build financial security while they are still able to work.

Provide greater flexibility for retirement and education savings accounts. Families facing Parkinson's may need access to resources that were originally intended for retirement or education. We should explore penalty-free access to retirement funds and expanded flexibility for 529 education accounts when a parent is diagnosed with a progressive neurological disease. Families should not be penalized for adapting financial plans in response to a life-changing diagnosis.

Recognize financial resilience as part of disease management. Many individuals with YOPD attempt to build passive income streams, such as rental properties or other investments, to offset potential future loss of earnings. Tax policies that encourage long-term financial planning, asset building, and financial independence could reduce future reliance on public assistance programs while improving quality of life and stability for families.

Incorporate Parkinson's-related financial hardship into federal aid programs. Families often experience reduced earning capacity long before disability benefits begin. Federal student aid, disability programs, and other assistance programs should better account for the unique financial challenges associated with progressive neurological diseases.

People diagnosed with Parkinson's at age 40 face a fundamentally different financial reality than those diagnosed at age 75. Young-Onset Parkinson's interrupts careers, retirement savings, college planning, caregiving responsibilities, and wealth accumulation during the very years when families are typically building financial security. Yet discussions of Parkinson's care rarely include financial resilience as a topic worthy of attention.

Parkinson's affects far more than movement. It affects careers, retirement planning, family finances, caregiving decisions, educational opportunities for children, and the ability to prepare for an uncertain future.

As the Council develops recommendations for improving care and services, I urge you to recognize that financial security is not separate from Parkinson's care. For many families living with Parkinson's and especially Young-Onset Parkinson's, financial security is an essential part of maintaining health, independence, dignity, and quality of life.

Thank you for your consideration and for your work on behalf of the Parkinson's community.

Kimberly Rogers

#154 Kristophe Diaz, PhD, Chief Executive Officer | Received: June 22, 2026

Kristophe Diaz, PhD
Chief Executive Officer
CurePSP

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

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

On behalf of CurePSP, we congratulate the ACPRCS members and thank HHS and NIH for implementing the Dr. Emmanuel Bilirakis and Honorable Jennifer Wexton National Plan to End Parkinson's Act. As the Council begins its work, we urge it to ensure that atypical parkinsonian diseases, specifically progressive supranuclear palsy (PSP), corticobasal degeneration (CBD), and multiple system atrophy (MSA), are intentionally included throughout the National Plan. We are encouraged by the Council's commitment to moving this effort forward and support a timely and transparent process that includes ongoing stakeholder engagement, regular public updates, and the identification of investments needed to improve prevention, diagnosis, treatment, care, and cure for all parkinsonian disorders.

CurePSP is the leading nonprofit organization dedicated to advancing the awareness, care, and cure for three rapidly progressing neurodegenerative diseases: PSP, CBD, and MSA. Through research investments, educational initiatives, support resources, advocacy efforts, and the CurePSP Centers of Care, a growing network of reputable medical institutions, we work to improve diagnosis, treatment, and health outcomes for this complex patient population.

PSP, CBD, and MSA, along with dementia with Lewy bodies and vascular parkinsonism, are often collectively referred to as "atypical parkinsonian disorders." While they share some clinical features with Parkinson's disease, they are distinct with different symptom profiles, disease trajectories, and treatment responses. Yet, patients with PSP, CBD, and MSA frequently receive a misdiagnosis of Parkinson's disease because of overlapping symptoms and limitations in current diagnostic tools. Significant delays to clinical diagnosis can leave patients and families without a clear path forward, such as a lack of appropriate care plans, disease-specific resources, or opportunities to participate in clinical research, all of which can contribute to poorer health outcomes and diminished quality of life. With no FDA-approved treatments currently available for PSP, CBD, or MSA, timely and accurate diagnosis is especially critical.

For these reasons, we encourage the Council to view the inclusion of atypical parkinsonian disorders as an opportunity to strengthen outcomes across the entire Parkinson's community.

CurePSP respectfully requests the Council consider the following priorities in its initial workplan:

1. Ensure that the National Plan implementation explicitly includes atypical parkinsonian disorders - PSP, CBD, and MSA.

Strategies across the federal landscape, such as research initiatives, data collection, and public awareness, should consistently account for PSP, CBD, and MSA alongside Parkinson's disease. At the same time, these conditions must be recognized as distinct neurodegenerative disorders with unique clinical characteristics and care needs. Unfortunately, atypical

parkinsonian disorders are often absent from publicly available data, educational resources, and assessments of disease burden and care needs.

The National Plan should capture the full spectrum of parkinsonian disorders and promote improved identification, reporting, and analysis of data related to PSP, CBD, and MSA to better inform federal planning, resource allocation, research priorities, and patient services. As an early work product, the Council should identify unmet needs and the investments required to improve prevention, diagnosis, treatment, care, and cures across the parkinsonian disease continuum.

2. Advance research that recognizes both shared and distinct scientific opportunities.

There is an urgent need to understand pathological similarities, distinctions, and overlaps across PSP, CBD, and MSA, Parkinson's disease, and other neurodegenerative diseases. Research in this space is essential to unlocking insights into disease mechanisms, identifying shared and distinct biomarkers, tracking disease progression, and accelerating therapeutic development that will benefit patients, families, clinicians, and researchers.

As part of this effort, the Council should identify research gaps, unmet needs, and opportunities that can help guide a long-term federal strategy for advancing scientific discovery, improving patient outcomes, and delivering new treatments and cures.

3. Prioritize methods for earlier and more accurate diagnosis.

For many people affected by PSP, CBD, or MSA, a primary pain point is not just living with disease but obtaining the correct diagnosis and information. Misdiagnosis and diagnostic delays derail access to appropriate care, limit participation in clinical trials, and slow treatment development.

Targeted investments in education and training across the care continuum, diagnostic tools, biomarkers, specialized care, and referral pathways can help close these gaps and improve the accuracy of detecting both Parkinson's disease and atypical parkinsonian disorders. Since diagnosis is a cornerstone of effective clinical care, research participation, and treatment development, sustained investments in improving diagnostic accuracy should be a core objective of the National Plan.

4. Ensure specialized access to care and caregiver support.

Unlike Parkinson's disease, PSP, CBD, and MSA bring debilitating symptoms, including dysphagia, loss of speech, and regular falls, earlier on in the disease course. Patients experience limited benefit from therapies developed for Parkinson's and generally face a more rapid disease progression. Families assume significant caregiving responsibilities while navigating health and long-term care systems that are ill equipped to support their needs.

The Council should ensure that critical resources such as specialized access to care, essential therapies and equipment, caregiver support, palliative care, and community-based services are incorporated in the National Plan. Existing models like CurePSP's Centers of Care network demonstrate that coordinated specialty care can meaningfully improve outcomes for patients and families facing complex neurodegenerative diseases. The Council should look to and build upon such models in shaping the National Plan and identify actionable recommendations with resources and investments needed to improve access to high-quality integrated care while reducing barriers that prevent patients and families from obtaining needed services and support.

As the Council begins this historic effort, CurePSP remains a partner and resource alongside the broader Parkinson's community. We encourage the Council to maintain momentum, engage stakeholders throughout the process, and deliver clear and actionable recommendations that improve research, care, and quality of life for all people affected by parkinsonism. The National Plan should also provide a roadmap for the investments needed to address current gaps and accelerate progress towards better treatments and cures.

By ensuring that PSP, CBD, and MSA are represented from the outset, the Council can build a comprehensive and effective national strategy that will improve the lives of all impacted by parkinsonism. Thank you for your consideration and for your service.

Sincerely,
Kristophe Diaz, PhD
Chief Executive Officer
CurePSP

#155 Larry Wadsack | Received: June 22, 2026

Public Comment

Hello,

Thank you for the opportunity to provide public comment on Parkinson's disease.

I was diagnosed with Parkinson's disease in 2018. Since that time, my life has centered around combating the many symptoms of the disease and fighting to slow down its progression. I have shifted my focus on staying active. If I sit for longer than 15 minutes my legs will have tightened making it difficult to get up from the chair. I am unable to go with my wife to see a movie at a theater without getting up and moving during the movie. The disease has robbed me of the ability to relax.

Living with Parkinson's is challenging because of the myriad of symptoms it presents, both motor and non-motor. I have compared my fight with Parkinson's to the carnival game Whack-a-Mole. While I am dealing with one symptom, another will suddenly appear. I am currently fighting for the ability to move, walk, talk, swallow and sleep. Each day I run the risk of falling, drooling, choking, shaking, involuntarily swaying and moving all while I feel my cognitive ability slowly failing.

Muscles throughout my body ache constantly. While I am exercising trying to loosen muscles, Parkinson's is tightening them. It is a constant battle.

The medical community has no real answers to what causes it or how to stop it. It is rare when I can get in to see my doctor, a movement disorder neurologist. I receive an appointment every 18 months. However, even when I do get to see him, he jots down information but is unable to offer any substantive help. He may prescribe another medication or physical therapy, but no hope of ending the pain and despair.

The medications available for the doctor to prescribe are only effective for about five years. After my diagnosis, I began taking Carbidopa-Levodopa as part of the Parkinson's standard of care. It provided some relief from tremors and stiffness for about five years. Then, the side effects began. The medication caused me to develop dyskinesia. The dyskinesia has worsened with time now causing me to sway back and forth and make involuntary head and arm movements.

Parkinson's is affecting more people each year. It is growing at an alarming rate. Yet, we have little information as to how to prevent it, slow it down or stop it. I live in the greatest Country in the world. If the US really wanted to, it could develop a cure for Parkinson's.

It is difficult to explain the feeling of being in a fight with something that never sleeps, does not slow down and keeps coming at me every minute of every day. I am in a fight that I know I can't win, but I must continue fighting to survive.

I hope you can help.

Thank you.

Larry Wadsack

#156 Laurence P. Bafundo, Esq. | Received: June 22, 2026

To the ACPRCS,

I am writing to share my experience with Parkinson's disease and to offer my opinion as to what action this committee can recommend that would provide the most immediate help to the Parkinson's community. Prior to my diagnosis with Parkinson's, I was a Certified Civil Trial Attorney in NJ for 40 years. In September of 2017, I was diagnosed with Parkinson's disease by a general neurologist. The diagnosis followed an evaluation prompted by my wife's noticing that my right hand did not swing while we walked. Upon providing the diagnosis, the neurologist told me that the condition could be effectively managed with exercise and recommended that I immediately sign up for Rock Steady Boxing.

As a result of being informed that I have Parkinson's disease, I sought two second opinions from Neurologists that are movement specialists. The first was at Thomas Jefferson University Hospital and the second was at the Hospital of the University of Pennsylvania. Both are located in the City of Philadelphia. Both of the experts in Philadelphia confirmed that proper exercise is essential to my successful treatment and recommended that I immediately join a Rock Steady program. I

joined a Rock Steady Boxing program in late 2017 and have regularly participated ever since that date. During the years of the Pandemic, it was necessary for me to continue with the boxing through Zoom classes and there were several changes in my movement specialist neurologists at Penn because of them moving away from Philadelphia to other locations. As a result, I had 3 different movement neurologists during that time period. All three recommended that I continue with the Rock Steady Boxing and other Parkinson's wellness exercise programs.

In 2023, I retired and moved to Virginia. My new Movement Neurologist in Virginia also encouraged me to continue with Rock Steady Boxing and other specialized Parkinson's exercise programs such as Pedaling for Parkinsons or Improvisation. I honestly believe that these Parkinson's exercise programs taught by qualified instructors were as important to my survival with the disease as were the medications prescribed to me by my movement specialists.

I therefore must ask this question, if these exercise programs are so important to successfully fighting the disease and are so widely recommended by Movement Neurologists, why is this essential treatment not paid for by Medicare? I was fortunate that to date, I have had the financial resources to pay for these exercise classes out of my own pocket. However, what about those that can't afford to pay?

Respectfully, I would suggest that there is no other action that this committee could take that would as quickly benefit the Parkinson's community as the requiring of Medicare to provide payment for Boxing and the other essential Parkinson's Wellness Exercise classes. This would allow thousands of people who cannot afford the programs to participate. It would allow countless others who are financially constrained and therefore not able to take all the classes they need, such that because of their limited personal finances, many others can only afford to pay for example their boxing classes but do not have the money to also pay for other classes such as speech classes, which are needed to prevent and minimize swallowing problems from the disease. Therefore, these unfortunate individuals who do not have sufficient money can develop severe choking problems that can result in death or hospitalizations.

I therefore urge the committee to consider among its first actions to correct this inequity that now exists that only those with money can avail themselves of the full benefits of perhaps the most effective weapon available to fight Parkinson's disease which is specialized exercise taught by qualified instructors. This can be quickly done by providing coverage to all for this essential tool of exercise by providing coverage through Medicare.

Respectfully submitted,
Laurence P. Bafundo, Esq.
Leesburg, Virginia

#157 Leslie A. Chambers, President & Chief Executive Officer | Received: 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. 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.

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:

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

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. 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. 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.

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. 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 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 commensurate 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. 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.

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). 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.

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.

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

#158 Linda Ereku (Fourth Submission) | Received: June 22, 2026

HELP

Linda Ereku

#159 Linda Silver | Received: June 22, 2026

My name is Linda Silver and I have been living with Parkinson's disease since I was diagnosed in January 2019.

I would offer the following as my own public comment for the upcoming ACPRCS meeting next week, Monday, June 29.

It is extremely important to have Parkinson's wellness services and exercise, including cognitive, physical exercise and movement classes specifically targeted for people with Parkinson's, covered under health insurance and Medicare. They are not currently covered by Medicare. These therapies represent considerable out of pocket costs and have been proven to help those with Parkinson's disease and slow its progression.

Thank you for your consideration.

Linda Silver
Sewell, NJ

#160 Meredith DeFranco, DPT, PT | Received: June 22, 2026

I would love to be a part of the National Parkinson's Project Advisory Council.

I am a physical therapist that has been working in the movement disorder field for the last 15 years of my career. I was trained and inspired under the great Michael Okun for 10 years at the Fixel Institute.

Upon relocating to the Tampa Bay area, I have been working not only as a PT, but also as a non-profit founder to assist in providing more services for our Parkinson's community.

I have participated in the World Parkinson's Congress Leadership forums in the last two WPC meetings and have an understanding of the needs of PD throughout the world.

I would like to participate in the council to continue to help make change to better the lives of the beloved people impacted by Parkinson's disease I have been fortunate to work with and learn from throughout my career.

Thank you for your consideration,

Meredith DeFranco, DPT, PT
Doctor of Physical Therapy @ Potentia Therapeutics
pdLIFE: parkinsonlife.org

#161 Michael E. Rees | Received: June 22, 2026

6/22/2026

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

Submitted electronically: nationalPDplan@nih.gov

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am Michael Rees, and I appreciate the opportunity to provide input.

I am a person living with Parkinsonism and was diagnosed in September of 2020. Since I was diagnosed, I have seen a decrease in the things I am able to do, both cognitively and physically. It took me a lot longer to compose this letter now than it would have several years ago. Physical activity, particularly if there is a balance component, takes a lot more time and requires more concentration. I have pursued an aggressive exercise program that has not reversed or stopped the progression of the disease, but, I believe, has significantly slowed its progression. Taking all of this into consideration my ability to live independently will continue to decline but, I will always take it one day at a time, being thankful for what I have.

Key concerns and priorities:

1. Find simple, reliable technologies capable of identifying, and tracking the progression of Parkinsons/Parkinsonism.
 - 1.1. This will provide a needed reliable determinant for the disease.
 - 1.2. This would be a significant tool to advance research.
2. Ban the use of paraquat, trichloroethylene and perchloroethylene.
 - 2.1. This will save many lives.
3. Determining what constitutes the differences between Parkinson's and Parkinsonism.
 - 3.1. I believe this may help identify some of the underlying idiosyncrasies and innuendos associated with the disease.

Thank you for your time and consideration. I urge you to ensure that the National Parkinson's Plan reflects the lived experiences and urgent needs of people affected by Parkinson's disease.

Sincerely,
Michael E. Rees
Fairport, NY

#162 Mike Lacinak | Received: June 22, 2026

Hello, My name is Mike Lacinak. Thank you for the opportunity to give public comment to the National Parkinson's Project's Advisory Council.

My wife, Chris, was diagnosed with Progressive Supranuclear Palsy in 2023. She has been exhibiting symptoms of loss of balance, especially falling backwards for some time now. In fact, it was her backwards fall in the neurologist's office that sparked his attention to the possibility of PSP. That day he did a test with striped cloth moving up and down, confirming that Chris had difficulty with tracking the movement. He diagnosed her with PSP. Prior to that day she had a diagnosis of Parkinson's, which she received in 2015.

Her neurologist suspected Parkinson's because her handwriting over several years' time was shrinking. Her beautiful penmanship had become hard to read, very compacted script. At that time she was also having difficulty breathing, as if there were a weight on her chest. Over time her mobility was affected. Her feet started "sticking", which would lead to falls. Then her backwards falls started. It was a scary time for both of us. We couldn't help but think about the future and where this was headed. She was prescribed Carbidopa Levodopa and continued to take it for some time, but it never helped. She began to drool and was prescribed Botox injections. They helped for a while, but then they didn't. And after every treatment she would have difficulty swallowing food for at least a week. A persistent symptom has been dry and painful eyes, since PSP causes a slowing of blinking. Drops help for a little bit. Heated pads can bring temporary relief, but her eyes are uncomfortable for most of the day.

Chris has done a lot of occupational therapy and physical therapy. None of it has stopped mobility issues, but it has been helpful for strategies to start movements forward. She also goes to a chiropractor every 6 weeks which helps with her alignment and tendency to lean.

Chris falls a lot these days. Most of the time her feet stick and she goes down on her knees. They can get banged up. She has taken to wearing knee pads around the house. She also falls a lot on her bottom. Opening the refrigerator door can be tricky as it can start a backward fall, simply pulling the door open. On a "bad" day, Chris uses a U-step walker in our home and I become her "walker" when we go out.

As a care partner, Chris's PSP has changed my life. I am a retired clinical social worker. A lot of my work was with trauma as well as couples. I had planned to work part time well into my 70's. I loved my work and was helping people. I retired completely in 2022 at age 70, because Chris needed my companionship and care as her symptoms worsened and her world was shrinking. It has broken my heart to watch Chris's physical decline, especially the falls, but also the dry eyes, coughing, drooling and now increasingly impaired vision. We care partners are powerless to make it any better. That's hard. I've watched my own and Chris's plans and dreams for an active retirement dissolve. Needless to say, there is a lot of grief with so much loss. For us the path forward has been acceptance, adaptations and kindnesses we offer each other. We still try to do as much as we possibly can, while we can. And as you can tell this has become a "we" thing. We are a team. Support, like we get in groups at CurePSP has been priceless. Friendships have become treasures as has family.

I think one of the most frustrating things is that it took so long to get the accurate diagnosis. It was all by observation with no tests or biomarkers. It is not uncommon for many people to start with a diagnosis of Parkinson's and then later discover it is PSP.

The other big problem is that there is no medication that can slow or stop the disorder. If you have cancer, there are treatments. If you have diabetes, you take insulin and eat the right foods. If you have PSP, there is no comparable treatment.

Finally, caregivers need support. Many caregivers are working full time and caring for their loved one. Many are in need of ways to get assistance into the home without going bankrupt. We are fortunate in that I'm retired and we have long term care insurance. But I bet we are in the minority.

Thank you for accepting this letter and we hope that you are able to be responsive.

Mike Lacinak
Cincinnati, OH

#163 Máiréad Deacy, MPH | Received: June 22, 2026

Public Comment

Dear Advisory Council,

I am reaching out to you today as a public health professional, advocate, and most importantly, as the daughter and caregiver to Michael Deacy, who passed on May 9th 2025 at 64 years old, after a seven-year battle with Progressive Supranuclear Palsy (PSP). The upcoming first National Parkinson's Plan Advisory Council offers newfound hope to the neurodegenerative disease community, and I am hoping that sharing my family's story will help highlight the significance and gravity of acting soon on our priorities, particularly for the Atypical Parkinsonian conditions (Progressive Supranuclear Palsy, Multiple System Atrophy, Corticobasal Degeneration), for which time is of the essence.

While many people diagnosed with Parkinson's disease may live for a few decades before succumbing to their condition, Atypical Parkinsonian conditions progress much quicker and more aggressively, more akin to ALS. These conditions have an average lifespan of only 2-7 years after symptoms start, let alone that many people only receive a diagnosis of an atypical Parkinsonian condition months or years into their disease progression—many may even die without a proper diagnosis. The lack of awareness even among the medical and scientific community leads to most atypical Parkinsonian cases being misdiagnosed as Parkinson's, and then being left to scramble for answers as their disease progresses rapidly.

I would like to tell you more about how this issue has affected me personally, and to tell you about my father.

If there's anything I can say about my dad, it is that he simply was the best. Everyone in our community will echo that he was truly the kindest man and had the utmost patience. Together, we used to love skiing or biking together, traveling, and so much more. He loved soccer, he loved turtles, he loved music, and was even a musician himself until PSP took that away from him.

My father began showing some neurological symptoms soon after I graduated college; barely noticeable things like slowed reaction time, struggling with work, but the kind that made me initially guess if I was even seeing those changes at all, or just imagining them. At this time, my father was in his mid to late 50's, so it seemed unlikely something could really be wrong; however, unlike other neurodegenerative diseases that often occur much later in life, atypical Parkinsonian conditions frequently affect those much younger. After getting in a car accident as a result, we brought him to a neurologist that initially [mis]diagnosed him with Parkinson's. The next few months that followed consisted of dangerous falls and broken bones, difficulty holding down a job, inexplicable coughing fits, and so many more rapidly progressing symptoms that made me say: I have no idea what's happening, but this cannot possibly be "just" Parkinson's. After 8 months of stress, frustration, confusion, and countless doctors' visits, we finally found a movement disorder specialist who gave my father a probable diagnosis of Progressive Supranuclear Palsy; his PSP diagnosis was confirmed upon autopsy. Knowing very little about what PSP could even mean, and not receiving much additional information, I took it upon myself to do research and couldn't find much at all, only that my father would die in 2-7 years after slowly losing the ability to talk, walk, eat... that he had effectively been given a death sentence that would take everything from him in the process.

Over the next 6 years, I chose to stay home while the rest of my friends were beginning their careers and moving out on their own. A lot of life plans shifted to ensure I could be there more for my dad and my family, as he increasingly needed full-time care that we struggled to get help for. I would make those decisions to stay home and help my dad over and over again but I shouldn't have had to. But this is the reality for most families affected by these diseases, because there is currently a huge gap between the level of care and support needed for patients and their families, and what is realistically being made available.

The cost of lack of awareness surrounding PSP, CBD, and MSA is devastating to the families. The biggest concern I should have had when I was told my dad had PSP should have been how do I cope with the fact that my dad has been given a death sentence. Or, how will I grieve as I begin to slowly lose parts of my dad in the most painful way possible? But because so little is known or understood about PSP, even by medical professions, there was never even time to grieve. Quickly my concerns became, how do I become: the PSP expert, the disability benefits advocate, the physical therapist, the occupational therapist, the speech therapist, the nurse, the palliative care specialist, the hospice specialist, and the doctor. Then of course, how do any of these therapies, services, equipment, and eventually skilled care get paid for? We had to sell our family's house in 2020, and I know this is a common story for families with PSP, CBD, and MSA.

When my father passed, after 8 long months on hospice, we were just so relieved he was out of pain, because the final stages of PSP were so horrible. I am still healing from the burnout and trauma from caregiving, from watching my father lose his mobility, watching so many scary falls over the years, spending upwards of an hour trying to understand what he needed after he lost the ability to communicate, or the countless times it took me three hours to feed him while he cried and aspirated in difficulty the entire time. Even now, almost a year after my father has passed, I still have yet to have the privilege of truly getting to grieve the actual loss of my father.

While it may be too late for my father, I sincerely hope sharing my family's story and hearing from the community will encourage this council to do everything in its power to change the outcome for the families affected by Atypical Parkinsonian conditions now and in the future. With so little known about PSP/CBD/MSA, working on any of our priorities would be a gamechanger, as there is currently very little awareness, no current treatments, and very little support for patients and families.

There is currently no treatment available to those with PSP/CBD/MSA; in fact, one of the most common pathways to an Atypical Parkinsonian condition is a failed trial of Carbidopa-Levodopa, which typically offers some improvement for those with Parkinson's. Until we can find a cure, we desperately need medication and healthcare services that can effectively treat those with Atypical Parkinsonian conditions, to improve prognosis, or at the very least offer a relief in quality of life throughout this disease. There are also no biomarkers for PSP/CBD/MSA, which is a major contributor to the delay in diagnosis and appropriate care; patients can only receive a probable clinical diagnosis, often of exclusion, that can be only confirmed upon autopsy. It is also crucial that we re-evaluate the benefits and services offered and covered for those with atypical Parkinsonian conditions. Disability only kicks in two years after approval; while my father was fortunately approved immediately after we applied, he thus only began to receive benefits after he was more than halfway through his disease course in a terminal illness. For another example, by the time my father's text to speech device was approved by insurance, a tool that was entirely unaffordable without coverage, he had progressed too far to be able to use it really at all. Our current healthcare system simply cannot keep up with the rapid progression of these diseases, and there must be workarounds made for individuals to even benefit at all from the few resources that can help them.

It is believed that PSP is likely the result of a combination of lifestyle, genetic and environmental factors, but the nature of these and their interactions are not well understood. Supporting initiatives in line with what the HEALTHY BRAINS bill is trying to accomplish would be a great step in that direction. As a rare disease, there are a few known environmental exposures associated with PSP based on epidemiological studies, but one of those is long-term exposure to well water—something my family relied on for 23 years. I also sadly have encountered a number of people from my area of Connecticut that have a parent with neurodegenerative disease; my father's speech pathologist had said she treated no less than 10 cases of this incredibly rare disease in our county. None of these things tell me why or how my father got PSP, but they do beg that we start asking the right questions about potential contributors through epidemiological methods. We have clear indicators that there are likely environmental contributors that, if researched, would allow us to mitigate the development of or potentially progression of brain disease. I have spoken at length with leading experts on these associations, and also on what the recommended precautions may be for myself to help prevent the development of PSP given my potential exposures; these conversations and information are just one example of the knowledge and resources that should be made accessible and available to all Americans. Additionally, the more we learn about one neurodegenerative disease, whether that be Parkinson's versus PSP, the more we inevitably learn about all.

Caregiver support, or at least resources for finding those, desperately need to be made available. These diseases require full-time care in a few short years, and eventually skilled care. It is simply impossible to work a full-time job and take care of someone with this disease. I spent many years working two per diem jobs in order to help cover care. I myself am struggling to progress in my career after having to put it on the backburner to help my father, my mother as well. My father eventually had to go to a nursing home at 62 years old, where he was the youngest person by at least 20 years, because we were no longer able to take care of him at home. This still required constant visits to ensure he got quality care, and even at an otherwise great facility, we still had incidents of negligence. At one point, my father had been stuck, fallen to the floor out of his chair, for almost two hours until we arrived for a visit, because no one did a good check on him and he had no ability to shout or communicate, and was left without a call button. It is devastating to be unable to help your loved one and to know that even in the best facilities, and with as many visits as possible, my father was inevitably exposed to inhumane conditions. These patients lose the ability to advocate for themselves in any capacity, and it is critical that nursing homes, hospitals, and other healthcare centers be educated on how to care for vulnerable people with Atypical Parkinsonian conditions.

Likewise, efforts to raise awareness about Atypical Parkinsonian conditions may be one of the most important priorities at this time. Awareness would have made all the difference in the world for us. It would have translated into access to healthcare professionals that actually know what PSP is and know how to help, instead of our family having to take on the burden of becoming the experts. Awareness could have helped us connect with more resources in the community to give my father a better quality of life and to support him as best as we could. Awareness would have given us the privilege to be able to trust the experts and focus on enjoying our last years left with my dad. These are all things we need to make available for the families currently and in the future affected by Atypical Parkinsonism. Further, awareness at the federal level is what lays the groundwork for research, quality of life resources, targeted trainings for healthcare professionals, caregiver support, and so much more. Most importantly, raising awareness on a federal level signals hope in a world that currently offers none for this disease community.

Thank you so much for your time and attention, and for all of the meaningful work I trust will be taking place in this council. As a former caregiver, now advocate, I am always more than happy to answer any questions, or discuss any of these matters further. The opportunity to have our story and our priorities heard, alone, has done so much for this community.

Sincerely,
Máiréad Deacy, MPH
PSP Care Partner and Advocate

To the Advisory Council on Parkinson's Research, Care, and Services:

Thank you for the opportunity to provide public comment on the National Plan to End Parkinson's. I write as the caregiver of two loved ones living with Parkinson's disease. Watching them navigate this illness has given me a firsthand understanding of the tremendous physical, emotional, and financial burden Parkinson's places on individuals, families, and caregivers.

While Parkinson's is often discussed as a movement disorder, its impact extends far beyond tremors and mobility challenges. My loved ones have experienced the effects of cognitive changes, sleep disturbances, and the gradual loss of independence that accompanies disease progression. As their symptoms have evolved, I have become their care coordinator, advocate, and transportation provider, all while working a full-time job. The demands of caregiving are overwhelming, yet we receive little support or recognition.

As the Advisory Council develops and implements the National Plan to End Parkinson's, I encourage you to prioritize two key areas:

First, increase investment in research aimed at preventing and curing Parkinson's disease. We need breakthroughs that move beyond symptom management and focus on identifying and addressing the root causes of Parkinson's disease. Research should focus on reducing and eliminating environmental and genetic factors that increase the risk of developing the disease.

Second, strengthen support for caregivers. Caregivers are essential partners in care, yet they often experience burnout, financial strain, and declining health themselves. The National Plan must include resources for affordable long-term services and supports, as well as respite services. For middle-class families like mine, these types of services are severely limited and financially out of reach. The National Plan should also include opportunities for affordable mental health support and programs to help families navigate the complex healthcare system.

For families like mine who live with Parkinson's, this is not just a policy issue, it is a daily reality. The National Plan represents an important opportunity to improve the lives of millions of Americans affected by Parkinson's disease. I urge the Council to pursue ambitious, measurable actions that accelerate research, improve care, and provide meaningful support to families.

Sincerely,
Naomi N.
California

Note: Due to privacy considerations, I have chosen not to provide certain personal contact information requested in the instructions. I appreciate the agency's consideration of this comment.

#165 Richard Vogt | Received: June 22, 2026

Finding a cure would be great, but until then an accurate diagnosis would be the greatest.

In 2020 I was diagnosed with Parkinson's disease. When it kept getting worse, two and a half years later I was diagnosed with PSP, so I am still not sure what I DO HAVE. And that is because there is no testing available for PSP or many other neurological diseases.

-richard vogt

#166 Robbie J Messmer | Received: June 22, 2026

Dear Members of the Advisory Council on the National Plan to End Parkinson's Act:

Please accept this message as a formal "public comment" regarding the strategic direction, implementation, and priorities of the National Plan. As the Council begins its critical work to coordinate a federal response to Parkinson's disease and atypical parkinsonian disorders, I urge you to prioritize aggressive research funding, comprehensive care access, and a rigorous look at environmental risk factors.

My Personal Connection to Parkinson's Disease:

In 2018, I had to retire as my cognitive abilities had declined severely. To get to know me, you would find out that I have always tried to be the best I could. From high school basketball wins to my associate degree in electronic technology and robotics, to working in management, to becoming a fiber optic transport specialist and holding that career for 34 years. I currently hold over 60 certifications in fiber optic transport. I have been a health coach, worked for a company called CrazyMuscle, and am currently an Advocate for the Michael J Fox Foundation. In 2021, I was nominated Top Executive with Marquis Who's Who in America and Strathmore's Who's Who Worldwide.

It all started innocently enough. I remember the day vividly when I decided to lend a helping hand to my son by installing a stereo in his car. Little did I know that this seemingly simple task would reveal the first signs of Parkinson's. As I struggled to align the screwdriver with the screw, my hands trembled uncontrollably. My son couldn't help but chuckle, but deep down, I knew something was not right. In the following months, I noticed that everyday tasks became increasingly difficult. Even at work, as I dealt with intricate circuits and tasks working with fiber optic equipment and cables the symptoms were progressing rapidly, impacting my ability to perform my duties with the same precision and efficiency as before. I used to cut over huge fiber networks, including AT&T, T-Mobile, Verizon, Qwest, SDN, Midco, which included many government agencies and services. We turned up 6700 miles of fiber optic transport while I was there, joining 5 states together in the upper Midwest. I was looking to retire at age 67 with 46 years in my career. To say that this news was a shock would be an understatement. Parkinson's disease is a complex condition that affects the nervous system, causing a range of motor and non-motor symptoms. Determined to find answers and reclaim my life, I embarked on a journey of medical consultations. I visited doctor after doctor, searching for an explanation for the challenges I was facing. I dove deep into any and all information I could find on the disease. The panic attacks and social anxiety disorder were the first major effects that started. Then I started to lose my voice, which for a person in management was not an acceptable issue. Throughout almost 10 years now, every single day or task has been a challenge for me. Just everyday chores are some days impossible to stay up with. I have learned that living with Parkinson's disease requires adaptability and resilience.

Key Recommendations for the National Plan:

To truly change the trajectory of this disease, the National Plan must address several glaring gaps in our current healthcare and research infrastructure. I ask the Council to focus on the following pillars:

Accelerate Disease-Modifying Research: While current treatments manage symptoms, we desperately need therapies that slow, stop, or prevent neurodegeneration. Federal funding must be scaled to support early-detection biomarkers and targeted clinical trials.

Address Environmental Triggers: There is a growing body of evidence linking Parkinson's to environmental toxins. The National Plan should actively coordinate with the EPA and NIEHS to investigate, track, and mitigate public exposure to known neurotoxins, including specific pesticides (like paraquat) and industrial solvents (like trichloroethylene).

Expand Access to Specialized Care: A shocking number of individuals living with Parkinson's do not have regular access to a movement disorder specialist. The Council should recommend expanding telemedicine cross-state licensing, increasing reimbursement for multidisciplinary care teams (including physical, occupational, and speech therapy), and incentivizing neurology professionals to practice in underserved or rural communities.

Support Caregivers and Families: Parkinson's is a family disease. The financial, physical, and emotional toll on caregivers is immense. The final plan must include robust federal support structures, including expanded respite care access and mental health resources for family care partners.

Conclusion:

The passage of the National Plan to End Parkinson's Act brought immense hope to millions of Americans. We are counting on this Council to turn that legislation into a bold, actionable roadmap that breaks down federal silos and treats this crisis with the urgency it demands.

Thank you for your time, your leadership, and for reviewing this "public comment".

Sincerely,
Robbie J Messmer
Rapid City, South Dakota
Parkinson's Warrior
Advocate for MJFF - Here. Until Parkinson's isn't.

#167 Robert Newlin | Received: June 22, 2026

Thank you for this opportunity to provide Public Comment to the Advisory Council on Parkinson's Research, Care, and Services. I am sharing my story and beliefs as a person with Parkinson's now living in Hot Springs Village, Arkansas.

I was diagnosed with Parkinson's by a Movement Disorders Specialist in 2016 at age 64, when I was living in the Philadelphia (PA) area. Being diagnosed with Parkinson's was a relief. I finally had the name of a disease that was affecting me and having this diagnosis freed me up to research and advocate.

Prior to being diagnosed with Parkinson's, I was aware the right side of my body was affecting my overall movement. Working with my Primary Care Physician, I went through a journey trying to find a reason for my right side symptoms. I was imaged, evaluated and tested for many possibilities. During an appointment with a Neurosurgeon, he recommended I see a Movement Disorders Specialist. I remember asking is that a "real thing"? I had never heard of a Movement Disorders Specialist.

I did not choose to have Parkinson's. I have no family history of Parkinson's. I believe compounding exposures to nasty conditions are the cause for having Parkinson's. At the time, I did not think or have awareness that my wellness might be affected by:

Prenatal:

- My mother was a menthol cigarette smoker.

Chicago Childhood:

- My friends and I took great delight riding our bicycles behind slow moving fogger trucks spraying insecticides for mosquito abatement programs.
- Buying new shoes was a great experience because the department store had a fluoroscope to view my wiggling toes to assess fit. Those early generation, wooden clad machines probably bombarded all who were nearby with unintended radiation levels.

College:

- I conducted deforestation experiments without wearing any safety clothing. Have no idea if I was handling Agent Orange, which was used at this time in Viet Nam.
- I participated in student protests that were met with law enforcement discharging irritating chemicals that I inhaled.

Young Adult:

- I started most all of my weekend golf rounds when the grass was wet with dew and the fertilizer and herbicide applications were freshly applied. My socks would be totally soaked long before completing play.

Currently I go to the University of Arkansas for Medical Sciences (UAMS) Movement Disorders Clinic in Little Rock for my Parkinson's care. The symptoms that most affect my quality of life, sleep and speech/swallowing issues, are non-movement symptoms of this disease. The critical medication I was taking ten years ago changed from generic Sinemet to an extended release Levodopa/Carbidopa formulary with a high Medicare Part D monthly cost.

I am very active in a leadership role for the Hot Springs Village Parkinson's Support Group, which according to UAMS is the largest support group in Arkansas. As a retirement destination location, the Hot Springs Village Parkinson's community provides a broad base of personal stories. While everyone has their unique story to share, there are also shared recurring themes.

I encourage the ACPRCS to address these three critical needs of anyone diagnosed with Parkinson's:

1. Access to Movement Disorder Specialists.

- Ten years ago when living in the Philadelphia area, I had choices of movement disorder specialists. Now living in Hot Springs Village with a population of 15,000 the nearest Movement Disorder Specialists are more than a 70 minute drive to Little Rock.
- It is my understanding that other than going to Little Rock, my only alternative to see a Movement Disorders Specialist is driving to Fayetteville, over four hours away.
- Our growing Parkinson's community needs more Movement Disorders Specialists, but there appears to be no incentive for a medical student to become one.

2. Access to Affordable Medication.

- For those living on a fixed income who have original Medicare with a Part D supplement, the cost of prescribed Parkinson's medications is a concern. If available, understanding the process to apply for prescription assistance programs is bewildering. Education is needed.

3. Access to Rock Steady Boxing (RSB).

- It is universally agreed that physical exercise (strength, flexibility and balance) is vital for people living with Parkinson's. For people who have original Medicare with a Part B supplement, gym membership is not covered to attend exercise classes.
- It is my belief that of all the Parkinson's specific exercise programs, RSB is the one to make accessible. This past year I attended RSB at several locations. I attended classes led by three certified RSB coaches. From those experiences, regardless of location or coach, the structure of RSB classes provides remarkable benefits:
- People with Parkinson's can participate in RSB from early through late stage Parkinson's symptoms, including those confined to wheelchairs.
- RSB classes provide opportunities for essential social interactions. The testimonials shared by classmates during the four years I've been attending RSB were transformational for them and me.
- In addition to physical exercises, classes include cognitive activities, hand-eye coordination challenges, and practicing safe-living movements.
- It is my belief a focused effort can resolve known barriers of having access to RSB such as: increasing the number of RSB affiliates and including RSB as an allowable billable Medicare expense.

Respectfully submitted,
Robert Newlin
Hot Springs Village, AR

#168 Robin Mechmet | Received: June 22, 2026

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

Subject: Public Comment on National Plan to End Parkinson's

Dear Dr. Gladman,

I am writing to share my comments regarding the National Plan to End Parkinson's. I am both a spouse and care-giver of a person with Parkinson's Disease, and I appreciate the opportunity to provide input.

My husband is currently 64 years old. He was diagnosed with the disease at 48 years of age. We believe he contracted the illness due to his exposure as a mechanic to TCE [trichloroethylene] commonly known as break cleaning fluid. He is in the advanced stage of the disease.

Here are the issues that matter to us:

Access to a Neurologist with Experience treating DBS [Deep Brain Stimulation] patients

There is only 1 doctor in the Treasure Coast area [Southeast Florida] near our current hometown, that treats DBS patients. She only sees DBS Patients for one afternoon every other month (6 month wait). The level of care provided by this doctor is substandard and the nearest alternate provider is 2 hours away.

Care Giver Health Care

I retired early to take care of my spouse. I qualify for Social Security, but not Medicare (I'm under 65). I've always had employer provided healthcare insurance, but in the interim to Medicare I've had to rely on the Health MarketPlace (government website) to shop for health insurance. Initially I had a PPO plan which was widely accepted in the medical community, however, since we moved to a new location to better accommodate my husband's mobility issues Florida Blue will only provide HMO insurance in our new zip code (how is this even legal?). None of the specialist I've sought treatment from accepts HMO insurance (they compare it to Medicaid). (On a side note, we had to withdraw a large sum of money from savings to move into a more accessible home, which in turn disqualified me from receiving Health Care Credit designed to help those in need. We were forced to pay back several thousand dollars).

One Big Beautiful Bill Act

Our government provides for a \$6,000 tax deduction for Seniors, yet excludes seniors under 65 who are eligible for Social Security. My husband is on Disability and I am on Social Security. Dealing with a life altering disability is difficult enough. Why are we being excluded from a tax break that would provide some much-needed relief?

Recommended actions:

Focus on improving daily life for people with Parkinson's and their families at every stage of life, including younger people and older adults. The report should give clear steps to improve access to high-quality care, improve health outcomes, and reduce the financial strain Parkinson's places on families. Place a higher priority on supporting care givers/spouses of those living with Parkinson's.

Thank you for your time and consideration.

Sincerely,
Robin Mechmet
Port St Lucie, FL

#169 Sarah Easley | Received: June 22, 2026

I am writing to respectfully request, through this public comment letter, that the Council support Parkinson's disease initiatives by increasing funding for research. I was diagnosed with Parkinson's disease (PD) in 2019, and I am currently living with the ongoing challenges and progression of this condition. Looking back, I recognize some of the symptoms from at least 5 years earlier than my diagnosis. PD is essentially the loss of dopamine cells in one's brain. PD is a progressive disease, so, as expected, over time, my symptoms continue to worsen. Below is a list of some of the challenges I currently face.

Movement (Bradykinesia)

The loss of dopamine directly affects control over body movements. I experience mild but visible tremors in my right arm and right leg. I also have micrographia, a condition characterized by abnormally small, cramped handwriting. Over time, I have lost significant muscular control in my dominant right hand, along with fine motor coordination, resulting in extremely small and often illegible handwriting that I can no longer read myself. In addition, reduced control of my right hand makes typing difficult. I rely on a slow hunt-and-peck method and often use my left hand primarily. This significantly delays my ability to respond to clients, as it takes considerably longer to prepare written communication. I also experience hypokinetic dysarthria (see voice below), which affects speech and makes daily communication more difficult and time-consuming. Overall, these symptoms make routine daily activities increasingly challenging.

Communication

Word finding - the inability to say what I am thinking or express my thoughts verbally. I am having difficulty starting to talk, even though I know the words I want to say. I experience "freezing" episodes. Because of this, my ability to communicate effectively in a live environment, whether in person, via Zoom, or by telephone, is diminished. The anxiety about this happening can also get in the way of my ability to communicate fluidly. When I am speaking, my voice may become softer, or it may start strong and then fade away. I have difficulty modulating my voice's volume and tone, resulting in a monotone or a muffled response. This causes me not to communicate effectively all the time. Oftentimes, I reach out to others to return calls that come to my voicemail.

Cognitive Issues

Working memory refers to the ability to temporarily store and manipulate information over a short period of time. I experience difficulties with immediate and short-term memory, which affect my ability to retain recent conversations and details. I often struggle to recall whom I have spoken with over the past few days or the specific topics we discussed. I also find it difficult to recall answers to questions I have addressed previously, which can lead to duplicate research and slow my workflow. At times, this can lead to concerns about providing incomplete or inaccurate guidance. As a result, I may choose to review my proposed responses with others to ensure accuracy. I can also experience periods of distraction or disorganization, which can make it more difficult to plan, prioritize, and complete tasks efficiently.

Attention

Attention is the ability to selectively focus on a particular aspect of my job. I find it difficult to concentrate on longer client questions and on reviewing long documents. I rely heavily on resources such as Bankersonline, ACUs blog posts, InfoSight, PolicyPro, ChatGPT, and other team members when faced with questions. Challenging questions, deciphering regulations, and intense projects require intense focus, which I have trouble maintaining.

Balance

Balance problems in Parkinson's disease (PD), known as postural instability, are caused by impaired postural reflexes, muscle rigidity, muscle atrophy, and reduced dopamine levels. These changes significantly impair the body's ability to maintain balance and recover from shifts in position, leading to unsteadiness and a heightened risk of falls. Postural instability is one of the most disabling symptoms of PD and often requires specialized management to help preserve safety and mobility. In my case, PD has also caused significant muscle atrophy in my back, further affecting my stability and strength. I have since been

diagnosed with osteoporosis, which increases my risk of serious injury from falls. I experience slips or falls nearly every day and have sustained five significant injuries this year (2026), including a fractured rib.

Voice

Voice and speech problems are very common in Parkinson's disease (PD). The most common condition is called hypokinetic dysarthria, which affects the muscles used for speech and voice production. Parkinson's disease (PD) has significantly affected my voice and speech. Due to the progression of the disease, my voice has become softer and weaker, making it difficult for others to hear and understand me, particularly in group settings or noisy environments. I also experience reduced vocal endurance, causing my voice to become increasingly strained and fatigued with prolonged speaking. These communication challenges affect my ability to participate in conversations, interact socially, and communicate effectively in daily activities.

Medication

I take carbidopa/levodopa to manage my Parkinson's disease symptoms; however, I do not experience significant relief from my medications. In addition, the medication often causes nausea, which can lead me to miss doses at times.

My Caregiver

My husband is my primary caregiver and source of support as I live with Parkinson's disease. He assists me in nearly every aspect of daily life that has been affected by the progression of the disease. Because Parkinson's has caused significant balance problems, muscle weakness, and frequent falls, he is constantly vigilant in helping me move safely throughout the day and preventing further injuries. He provides physical assistance with tasks that have become difficult due to tremors, rigidity, fatigue, and decreased mobility. He helps with household responsibilities, transportation, medical appointments, medication management, and many other activities that I can no longer perform independently or safely. In addition to the physical challenges, Parkinson's affects my communication, cognition, and emotional well-being. My husband helps me when my voice is weak, assists with memory and organizational tasks, and encourages me during periods of frustration, anxiety, and discouragement. He also serves as my advocate with healthcare providers and helps coordinate the treatments and care necessary to manage my condition. Most importantly, he provides constant emotional support, companionship, and reassurance as I face the daily challenges of a progressive neurological disease. His dedication allows me to maintain as much independence, safety, and quality of life as possible despite the significant limitations caused by Parkinson's disease. He fulfills all of these caregiving responsibilities while maintaining a full-time job. Balancing the demands of employment with the physical, emotional, and practical support I require places a significant burden on him. Despite these challenges, he remains committed to my care and well-being every day.

I respectfully request your financial support for ongoing research aimed at finding a cure for Parkinson's Disease.

Sincerely,
Sarah Easley

#170 Suhas Subramanyam, Member of Congress | Received: June 22, 2026

I write to the members of the Advisory Council on Parkinson's Research, Care, and Services (ACPRCS) to emphasize the importance of disease surveillance in the mission to find the causes of and prevent diseases like Parkinson's. Building national surveillance infrastructure for neurodegenerative diseases is a complex undertaking, but it is a vital step towards improving research, public health planning, and patient care. I have heard from patients, caregivers, and researchers that progress in building a surveillance system, even with federal investments in the Center for Disease Control's (CDC) National Neurological Conditions Surveillance System (NNCSS), has been slow.

I encourage ACPRCS to examine the feasibility of creating a voluntary national Parkinson's self-reporting surveillance system and pursue it as an option if possible. Many people living with Parkinson's are eager to contribute to research and improve our understanding of neurodegenerative diseases. A nationwide platform could allow individuals to voluntarily report their diagnosis, symptoms, disease progression, treatments, quality of life, and geographic location. Participants could also choose to provide updates over time, creating longitudinal data that reflects patients' experiences with Parkinson's disease.

Data from such a platform could complement efforts at the CDC by providing fast insights into disease trends, regional differences, access to care, unmet needs, and the impact of new therapies. It could also help researchers identify potential study participants, improve understanding of disease progression, and inform healthcare planning as an increasing number of Americans are diagnosed with Parkinson's disease.

I respectfully urge the Advisory Council to look into the creation of a voluntary Parkinson's self-reporting surveillance system as a complement to existing surveillance efforts. Patients are not only the beneficiaries of research—they can be valuable contributors to the data needed to accelerate discoveries and find a cure. I stand ready to build support in Congress for ACPRCS's efforts and I look forward to working with you further as the Council provides recommendations.

Sincerely,
Suhas Subramanyam
Member of Congress

#171 William Palmer | Received: June 22, 2026

Public Comment

William Palmer
Traverse City, MI

My Journey with Parkinson's

In 2017 I retired from teaching English at Alma College. Within six months my body started acting strangely: I felt lightheaded much of the day; when I walked, I often tilted forward or sideways—and my feet sometimes flopped like clown shoes, slapping against the floor.

I had no idea what was happening.

For two years, I could find no doctor in Traverse City able to help me; thus, I took no medication to address my symptoms. The closest diagnosis given was ataxia—which means balance and walking problems. But this didn't cover all I faced each day.

I experienced extreme fatigue. I could not drive into town and shop for groceries without getting so tired I could hardly walk. I could no longer mow the grass. I grew so depressed I no longer wanted to live.

Desperate, I reached out to the Mayo Clinic. But they would not see me.

Then I asked my family doctor to refer me to the University of Michigan. In July of 2020 I met with a neurologist there—within an hour he diagnosed me with Parkinson's. I felt happy—I didn't have some unknown, untreatable disease.

But once I started reading about Parkinson's on Google, I kept finding grim stories. I wondered if I was doomed.

Thankfully, when I joined our local Parkinson's support group, my outlook changed. I learned reliable information about the disease and saw firsthand how variable it is—everyone has Parkinson's in their own way. Not everyone has a tremor or balance problems. I learned about the Michael J. Fox Foundation.

I now have a neurologist who is a movement disorder specialist and an expert in Parkinson's. I also do physical therapy and exercise at home regularly.

My Parkinson's involves some clear patterns. Each morning after I take two carbo/levo pills, I have extreme difficulty walking and talking for two hours. So, with a fresh coffee, I sit at my desk and either work on my writing or read emails or the New York Times. I'm grateful my mind still functions normally.

Although exercise helps slow my Parkinson's progression, I find it does not improve my balance and walking. This is very disheartening. Last week my wife and I went downtown for lunch. The only parking spot was down the block. With my cane I walked to the restaurant okay. But after lunch I went into one of my "off" times when I could barely walk—I felt like an old turtle with two legs missing.

I have received treatment for depression that has helped me accept and deal with my Parkinson's. Because I don't tolerate anti-depressants, I qualified for TMS: Transcranial Magnetic Stimulation. I sat in a chair, and a doctor aimed magnetic pulses at my prefrontal cortex to stimulate neuroplasticity. I did 28 sessions, each for 18 minutes. It worked. I have been less depressed.

Despite this improvement, I feel closer to "the tears of things" (lacrimae rerum.) I lie in bed and cry at times, such as when walking becomes so difficult I have trouble breathing. Yet I also weep when I feel grateful for simple beauty, such as a father and son embracing in a movie or the twilight color of my wife's blue lobelia.

Overall, I am functioning pretty well. I can still drive without a problem. I can pick up pizza at the local market. I can shop for groceries because I can hold onto a cart with both hands. I go to doctors' appointments in the afternoon, to avoid my off time in the morning. And most importantly, I continue to write poems. Making small pieces of art is essential for my spirit to feel alive.

Here is one of my poems, published in One Art: A Journal of Poetry. I imagine myself as a dervish, a spiritual person, who learns he has Parkinson's:

The Dervish

Reaching for a small glass
of apricot juice, I first noticed
the tremble.

It stopped when I danced:
head tilted, right palm up, left palm down,
whirling round.

"Parkinson's," a doctor said.
I listened
and the sky turned lavender.

After a year,
a friend carved a cane for me
etched with phases of the moon.

When I walk with my cane
around the village, the tremble
disappears like a hummingbird.

For this dervish, though he can no longer dance, Parkinson's is not the end of his life.

I hope that stem-cell research or AI will find a cure for Parkinson's. But I'm not counting on this happening soon. If a cure happens within five years and I can use it, I would be almost 80 years old. In the meantime, I hope the Michael J. Fox Foundation will help me and others manage our symptoms better as well as slow the disease. And I hope it will lead the way in Parkinson's prevention.

I am deeply grateful for all the Foundation does.

#172 Yvonne Hylton, Director and Co-founder | Received: June 22, 2026

Following are public comments for consideration by the Advisory Council on Parkinson's Research, Care and Services.

I am a person living with Parkinson's since 2007. Even after deep brain stimulation (DBS) surgery in 2013, my gait sometimes slows to a shuffle, my posture is often stooped. My voice is soft and often my speech is garbled. I live with incontinence, dyskinesia, dystonia, and I fall with varying regularity and seriousness.

However, another facet of my life with Parkinson's is volunteering, giving back - providing support and hope to those more recently diagnosed, leading PD support groups and arranging programming for community education. I also answer a dedicated phone line established in 2024 by the Rochester Parkinson Network, of which I am a co-founder. I have personally responded to over 300 calls - from people that are newly diagnosed who are terrified about their future and from people who've been diagnosed for several years but with symptoms becoming more pronounced who are now concerned about what their future holds. People diagnosed need education immediately upon diagnosis identifying where they can turn for credible, trusted

information and support, whether it be local, regional or national. No person should leave an office or clinic with a new diagnosis of Parkinson's disease empty-handed. It is well-established that an educated PD patient generally has better long-term quality of life than an uneducated one. Providing such information to those newly diagnosed should be a requirement of those in the medical community who deliver such life-altering news.

Many of the calls received on our PD information line come from care partners, people caring for those with Parkinson's. Some of those people with PD refuse to believe they have PD, some have simply given up and refuse to take ownership of their disease, and yet others are so affected that their care partners cannot leave them alone without supervised, hands-on care. The various costs of these situations are dramatic: emotional costs, psychological costs and financial costs.

I have watched both my father and a maternal aunt recoil from the notion of a potential Parkinson's diagnosis yet they display many of what I have learned to recognize as prodromal symptoms. They are leery of a confirmatory diagnosis at this point (both nearly 85 years of age) - who wants a diagnosis for something for which there is no cure? Primary care doctors, general practitioners, physician's assistants and other practitioners (including general neurologists) should be better trained to identify, diagnose and provide counsel for a disease whose prevalence is skyrocketing. People deserve the earliest possible Parkinson intervention in order to absorb, internalize and commit to wellness; to embark on a trajectory that might minimize or slow their Parkinson progression; to live a "life well lived" with PD.

You have been entrusted with developing a national plan to make that happen. Please don't let this and future generations down. Please do everything in your power to end Parkinson disease. We'll do everything we can to help.

Yvonne Hylton
Director and Co-founder, Rochester Parkinson Network