Atypical Parkinsonism Digest

News from the Johns Hopkins Atypical Parkinsonism Center

JOHNS HOPKINS MEDICINE

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Director's Corner

Alexander Pantelyat, MD, FAAN

Reverend Jesse Jackson's PSP Diagnosis and the Challenges of Access *By Alexander Pantelyat, MD, FAAN*

Progressive supranuclear palsy, or PSP, is a rare brain disease that affects balance, walking, eye movements, and thinking. It has recently drawn new attention because civil rights leader Reverend Jesse Jackson had been diagnosed with PSP after living for about 10 years with a diagnosis of Parkinson's disease (PD). Reverend Jackson passed away on February 17, 2026. His story highlights both how hard PSP is to recognize early and how unequal access to expert care can be, especially for African-Americans and other marginalized communities.

PSP and PD can look very similar at the beginning. Both can cause stiffness, slowed movement, and trouble with walking, so many people with PSP are first told they have PD. There is no simple blood test or scan yet that proves someone has PSP, and the "gold standard" for diagnosis is still examination of brain tissue under the microscope after death. Over time, clues such as repeated falls, difficulty looking up or down, slurred speech, and poor response to standard Parkinson's medications can suggest PSP instead. A common type of PSP called PSP-Parkinsonism is a form of disease that mimics PD especially closely, for a number of years after symptoms begin. Studies show that misdiagnosis is very common, which means people can go years without the right explanations, services, or clinical trial opportunities.

Thus, Reverend Jackson's experience of being treated for Parkinson's for years before receiving a PSP diagnosis is, sadly, a common one. PSP is an "atypical parkinsonian" condition, meaning it belongs to a family of disorders that resemble Parkinson's but often progress faster and respond less to dopamine-based drugs. This overlap makes life harder for families, who may sense that something is "different" about their loved one's illness but struggle to get clear answers. Better diagnostic tools, including biological markers, are an active area of research precisely because these delays are so common.

Access to the right kind of specialist is a major challenge for all those struggling with parkinsonian conditions. People with PSP and PD usually do best when they are seen by a movement disorders neurologist, a doctor with extra training in these diseases. Yet Black patients with parkinsonism are less likely to see any neurologist at all, and much less likely to receive advanced treatments or rehabilitation services compared with White patients. One study found that Black people with PD were several times less likely to receive treatment such as medicine, therapy, or surgery, even when they had the same health coverage. These disparities are linked to more severe symptoms, greater disability, and higher risk of death.

For African Americans and other marginalized groups, barriers include fewer nearby specialists, transportation challenges, medical mistrust rooted in history, and underrepresentation in research. Organizations focused on PD and related disorders are beginning to address these gaps through community partnerships, telemedicine, and studies designed to include more diverse participants. Reverend Jackson's recently revealed diagnosis may help shine a light on PSP and on the urgent need to make expert neurological care—and hope—available to every community.

U-Step Neuro Walker Use in Atypical Parkinsonism *by Jeny Rund, PT*

Jeny Rund, PT

Gait impairment, or difficulty walking, is a common finding in patients with Atypical Parkinsonian Disorders. It may be caused by several factors including muscle weakness, postural instability, rigidity, freezing of gait, medication side effects, visual changes, and cognitive deficits to name a few, and can result in loss of balance, falls, and impaired functional mobility. Some patients have mild gait impairment that can be improved with the use of a standard assistive device such as a cane, rolling walker, or rollator. Others need more stability than these devices can provide to enhance safety with walking.

The U-Step Neuro walker is a specialty walker designed for patients with neurological conditions to provide more stability, maneuverability, and control when compared to traditional walkers. Approximately 75% of the walker's weight is in the base, providing a low center of gravity to help reduce falls. The spring-loaded front wheels eliminate the need to lift the walker over small objects, while the rear wheels help to stabilize on uneven surfaces and ramps. The position of the turning wheels allows for a smaller turning radius for ease of mobility. The reverse braking system (walker will not roll until at least one handle is squeezed to release brakes) and rolling resistance control help patients control the walker and their walking speed.

The U-Step walker has 3 models that originate with the same base: standard, platform, and press down. Depending on the model, the walkers can accommodate 4'6"-6'6" for height and 300-375 pounds for weight. The platform walker may be helpful for those with stooped posture or weakness on one side of their body, while the press down walker may benefit those with limited grip range or strength, tremors, or cognitive difficulties. All models can incorporate the laser and sound cueing module to help reduce freezing and optimize gait stride and speed.

U-Step neuro walkers are covered by Medicare (part B) and most insurances for those with neurological conditions (contact In-Step Mobility **https://www.ustep.com** or **1-800-558-7837** to check for eligibility). They offer a refundable 2-week trial period for walkers, and can advise if any local clinics have equipment to be sampled. Our Atypical Parkinsonism Center's JHOC, Greenspring, and Bayview locations each have a standard U-Step walker to try out while in clinic, and Bayview has a platform walker as well.

A Day in the Life of a Clinical Research Coordinator *by Isabella Sterner, BS*

In my work as a research coordinator at the Johns Hopkins Center for Music and Medicine, no two days look quite the same—and that's what I love about it. This variety reflects the interdisciplinary nature of our work and the many moving parts required to carry clinical research forward from idea to impact.

On any given morning, I might start by screening potential participants or coordinating with families interested in enrolling in one of our studies. The next hour, I'm administering neuropsychiatric assessments, preparing physiological recording equipment, or assisting with a music therapy session. Some days I'm deep in data—cleaning datasets, running statistical analyses, or preparing figures for a presentation. On other days, I'm drafting IRB amendments, organizing study logistics, or meeting with students or collaborators across neurology, music therapy, speech pathology, brain imaging, computer science, and more.

It may sound like a collection of disparate roles—recruiter, assessor, therapist aide, analyst, writer, teacher, student—but they all converge toward one goal: to advance rigorous, evidence-based music therapy research.

Over time, I've gained hands-on experience integrating neuroimaging, physiological metrics, and behavioral measures to better understand how music engages neural systems in individuals with neurological disorders. I've contributed to projects examining remote music therapy for autobiographical memory and functional connectivity in mild cognitive impairment due to Alzheimer's disease; auditory cueing for gait regulation in Parkinson's patients with a deep brain stimulation (DBS) device; targeted neurologic music therapy paired with non-invasive brain stimulation for upper-extremity movement in corticobasal syndrome; and recorded music listening for epileptiform activity in childhood/adolescent epilepsy. Alongside these trials, I've supported systematic reviews, participated in community outreach initiatives, and completed graduate training in clinical investigation—continually bridging research, practice, and learning.

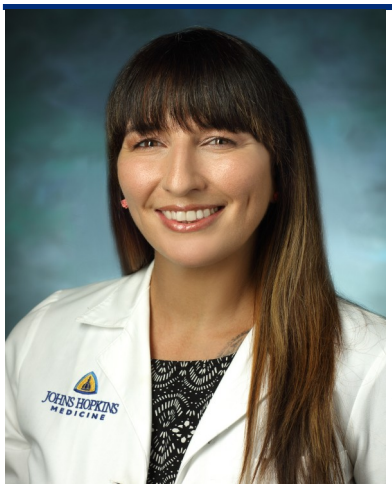
Working within the neurology department has provided me with important perspective. I've seen how neurodegenerative conditions affect not just cognition or motor function, but identity, autonomy, and human relationships. I've learned that these changes can never be fully understood in isolation and that the context of daily life is invaluable. Being a part of research that seeks to preserve communication, mobility, and meaningful connection makes my work here engaging not only on the scientific level, but on a deeply personal one as well.

At its core, my day-to-day role is about assisting in translation: translating patient experience into research questions, practice into observable outcomes, and data into knowledge that can inform care. It's interdisciplinary and incredibly rewarding, and I can't wait to see where future directions lead.

Isabella Sterner, BS

If you're interested in learning more or becoming involved in any of these studies, please don't hesitate to reach out to me at **isterne1@jh.edu.**

Access to Care for Patients with Atypical Parkinsonism *by Maria Schmidt CRNP, DNP*



Maria Schmidt CRNP, DNP

Getting the Right Diagnosis Early

Getting an accurate diagnosis of atypical parkinsonism can be difficult. Even specialists make diagnostic errors 7-35% of the time, often confusing conditions like dementia with Lewy bodies, multiple system atrophy, progressive supranuclear palsy, and corticobasal syndrome with Parkinson's disease in the early stages. These conditions often look very similar at first. Only 58% of Medicare patients with parkinsonism see a neurologist within the first four years of diagnosis, showing major gaps in getting specialist care early. Warning signs that suggest atypical parkinsonism rather than Parkinson's disease include early severe cognitive problems, early drops in blood pressure when standing, poor response to treatment with levodopa, early balance problems leading to falls, and symptoms that get worse quickly.

Where You Live Matters

Access to neurologists varies dramatically depending on where you live. Some U.S. states have only 2.6 neurologists per 100,000 people, while others have as many as 12.1. People living in rural areas face particular challenges reaching movement disorder specialists, who are mostly located in cities. The shortage of neurologists has grown to at least 19% by 2025.[3] Worldwide, most research comes from wealthy countries in Europe and North America, while regions like sub-Saharan Africa, the Middle East, and South Asia have far less information available.

Why Specialized Care Matters

Neurologist care is associated with reduced risks through improved adherence to quality care indicators and more comprehensive disease management. However, only one-third of nursing home residents with parkinsonism receive neurologist care. Multi-disciplinary care models provide a solution by bringing together teams of experts for rare movement disorders and using technology to help patients. Telemedicine offers ways to overcome distance barriers, especially for patients who have trouble traveling due to physical or thinking problems.

Challenges for Underserved Communities and What Can Be Done

Multiple barriers stack up for marginalized populations. Healthcare provider biases and knowledge gaps act as roadblocks, while the combined effects of race, ethnicity, and income create cycles that make access worse. In countries with limited resources, government insurance often covers only part of essential medications or doesn't cover them at all—levodopa was only partially covered in 44% and not covered at all in 16% of African countries surveyed. Patients often must choose between basic needs and specialized care because of out-of-pocket costs.

Fixing these problems requires coordinated action: targeted funding for healthcare infrastructure, systematic education for providers, community-based solutions that work with formal healthcare systems, and advocacy for fair insurance coverage.

My initiatives for addressing critical gaps in access to care include educating advanced practice providers to improve early recognition of these often-misdiagnosed conditions, expanding access through a nurse practitioner-led multidisciplinary clinic that coordinates comprehensive symptom management and palliative care, and reducing barriers through transportation assistance and community outreach. These efforts aim to ensure that patients with atypical parkinsonism receive timely, specialized care that can significantly improve their quality of life despite the absence of disease-modifying therapies.

Your voice is important, and we would love to hear your ideas and suggestions for ways to improve advocacy, community outreach, education, access to care and health equity, and add resources and support for patients with MSA, CBS, PSP, and DLB. Please email me at **mschmi61@jhmi.edu**

A Primer on Genetic Testing in Adult-Onset Neurodegenerative Disease *by Sonja Scholz, MD, PhD*

Sonja Scholz, MD, PhD

Genetic testing can feel overwhelming, especially when managing symptoms of a neurological disease. This guide explains how genetic testing is used for adult-onset neurodegenerative diseases, including atypical parkinsonism syndromes, what common terms mean, and how genetic results may impact you and your family.

Genetic testing is increasingly used in the evaluation of neurological diseases, especially in cases that appear to run in the family or in situations when a disease affects people at a relatively young age. Even when a disease is primarily genetic, the way it is passed down and the likelihood that someone will develop symptoms can vary widely.

Genes are segments of DNA that act as instructions for how the body grows and functions. A change in a gene is called a variant, sometimes referred to as a mutation. Most gene variants are harmless and contribute to normal human differences, while others can increase the risk of disease. When a variant is a known cause of disease, it is called a pathogenic variant. In some cases, testing identifies a variant of unknown significance, meaning that scientists do not yet know whether the change is harmful or benign. Over time, these uncertain findings may be reclassified.

Genetic conditions follow different inheritance patterns. In autosomal conditions, a person needs only one copy of a pathogenic variant to be at risk of developing disease. In autosomal recessive conditions, a person must inherit two altered copies of a gene, one from each parent, to develop the condition. Another important concept is penetrance, which describes the likelihood that a person with a pathogenic variant will actually develop symptoms. Some genes have high penetrance, meaning most people with the variant develop the disease, while others have reduced penetrance, meaning some individuals may never develop the disease.

Genetic testing may be recommended for various reasons. For someone already showing symptoms, diagnostic testing may help confirm or clarify a diagnosis. For instance, finding a pathogenic variant can distinguish between different types of dementia or movement disorders. In families with a known inherited condition, predictive or presymptomatic testing might be offered to relatives without symptoms who want to understand their future risk. This type of testing is a deeply personal choice and usually involves detailed counseling.

Testing approaches can vary. Some tests analyze a single gene when there is a strong suspicion of a specific inherited disorder. More commonly, clinicians use panel testing, which examines multiple genes associated with a particular group of conditions, such as Parkinson's disease and related disorders. In certain cases, broader methods like whole

exome or whole genome sequencing may be used to analyze many genes simultaneously. While broader testing increases the chance of discovering unusual information, it can also reveal unexpected findings.

Genetic testing can offer benefits, including diagnostic clarity, guidance for family members, and potential eligibility for clinical trials. However, it also has limitations. Results may not change available treatments, and uncertain findings can create anxiety. Learning about inherited risk can affect not only you but also your relatives, who may have differing views about whether they wish to know their own risk.

Privacy and insurance concerns are common. In the United States, the Genetic Information Nondiscrimination Act protects against discrimination in health insurance and employment based on genetic information, although it does not cover life, disability, or long-term care insurance. Discussing these issues with a knowledgeable provider before testing can help you make an informed decision.

Ultimately, genetic testing is a tool that can provide valuable information, but it is not mandatory and not right for everyone. Taking time to speak with a genetic counselor can help you understand what testing might mean for you and your family. Making an informed decision, at your own pace and aligned with your values, is the most important outcome.

Updates On Using Emerging Technology to Innovate Research and Improve Access to Care

By Claudia Waddell, BS & Hannah Jackson, AB

During the COVID-19 pandemic, health professionals noticed that clinical care and research were severely reduced due to patients' limited access to clinics and hospitals among strict COVID regulations. As a result, our team aimed to develop and validate a remote assessment platform that would assist health professionals with monitoring disease progression and severity from the comfort of a patient's home. Because falls are an important predictor of progression and survival in Atypical Parkinsons conditions, our remote digital health technology was initially designed to help our study team measure gait imbalance and postural instability without the patient having to physically be in a doctor's office. Our team began this endeavor back in 2021, and we plan to continue investigating how this technology can be used to improve the care and monitoring of Atypical Parkinsonism.

One of the ways we plan to further this technology is by expanding the cohorts we are studying. Our previous studies focused mainly on Progressive Supranuclear Palsy (PSP), but we are excited to share that two of our upcoming research projects will include several different diagnoses. Like our previous research, these studies will utilize our remote assessment platform to monitor symptoms and disease progression at home with the use of a digital tablet and wearable sensors. Our hope is that the data we collect—and the tools we develop as a result—will increase patients' access to efficient and effective care.

The first of our new studies is called **A Wearable Sensor Platform for Remote Monitoring of Individuals on the Frontotemporal Dementia Spectrum (ReMoTe)**. The ReMoTe study will focus on recruiting individuals with FTLD syndromes such as Frontotemporal Dementia or Corticobasal Syndrome/Degeneration. Enrolled participants will be asked to visit our Greenspring Station office 5 times over the course of two years to complete an in-person research visit every 6 months. In between each in-person visit, we will also ask participants to complete monthly virtual activities using the tablet provided as part of the remote monitoring process.

The other study is titled **A Multi-Modal Remote Measurement Platform for Decentralized Clinical Trials (DCT**). DCT will recruit patients with PSP, CBS, and MSA for an entirely virtual study lasting about 5 months. Patients and their caregivers will be provided with a pendant sensor to monitor balance, sway, and falls along with a tablet that has activities to monitor cognitive function.

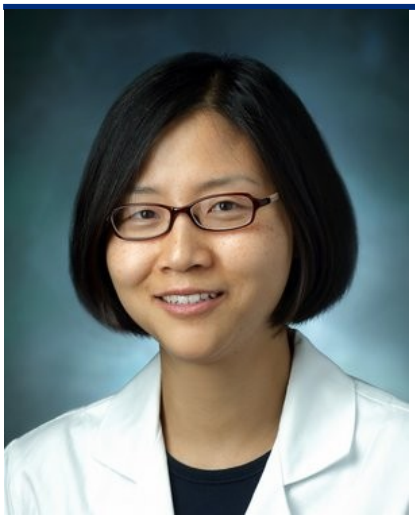
Our team is still in the process of finalizing these studies, but we hope to begin enrolling participants in mid-2026. In the meantime, we would love to hear from any interested patients. Please reach out to Claudia Waddell (**cwaddel4@jh.edu**) and/or Hannah Jackson (**hjacks30@jh.edu**) for additional information or to be placed on the recruitment list. There is no direct cost to you as a research participant if you decide to join either study. Our team looks forward to collaborating with interested participants to further improve and innovate the field!

Claudia Waddell, BS

Hannah Jackson, AB

Updates on Clinical Trials in Atypical Parkinsonian Disorders

by Jee Bang, MD, MPH & Alexander Pantelyat , MD



Jee Bang, MD, MPH

Several clinical trials that aim to slow progression of atypical parkinsonian disorders (APDs) are under way. These studies test drugs that target different parts of the APD disease pathways in volunteers with APDs. Below are some important highlights. Additional information about these trials can be found by searching for the study drug name on **www.clinicaltrials.gov**. As always, we also welcome questions about any trials our patients and families may come across, and are happy to discuss them together.

Progressive supranuclear palsy (PSP) and Corticobasal syndrome (CBS):

AMX0035 was an oral solution that is a combination of two drugs, called phenylbutyrate and taurursodiol. The drug helps improve cellular and mitochondrial function, and has been studied in other neurodegenerative diseases, including ALS (amyotrophic lateral sclerosis, or Lou Gehrig's disease) and Alzheimer disease. Unfortunately, the pharmaceutical company Amylyx announced in August 2025 that the Phase 2b ORION trial (NCT06122662) did not show differences compared to placebo on slowing PSP disease progression. Based on these results, Amylyx discontinued the ORION trial and will not proceed to Phase 3. The decision was not driven by any safety concerns, but rather the lack of efficacy in slowing disease progression as measured by the PSP Rating Scale.

NIO752 is an antisense oligonucleotide (ASO), which reduces the tau protein production. This type of drug is administered into the cerebrospinal fluid (CSF) via a lumbar puncture (also called a spinal tap), every 4 months over a year. This phase 1 study, which focuses primarily on assessing safety, has been completed. The release of the data analysis is pending.

The PSP Clinical Trial Platform (PTP) is an important project being developed to streamline PSP clinical trials. This research project aims to test several potential treatments for PSP at the same time to speed up the process of finding something that works. They will do this by enrolling people with PSP in a study where some receive a new drug and others receive a placebo (an inactive "sugar pill"), with a larger proportion of the people receiving a drug than those receiving a placebo (3:1). They plan to enroll 440 participants at ~50 sites in North America over 24 months. In this scenario, 3 groups each consisting of 110 participants would receive 3 different drugs, respectively, and another 110 participants would receive a placebo.

The first two drugs have been announced: **AADvac1** (an active vaccine against the tau protein that stimulates the immune system to make its own anti-tau antibodies) and **AZP2006** (oral liquid drug designed to reduce tau protein aggregation while also promoting neuronal growth and connections). These trials will be in Phase 2a, which focuses primarily on safety and tolerability. But they will track the participants' symptoms and brain changes over time to see if any of the drugs are helpful. This study will also help researchers learn more about PSP and identify potential markers of the disease in the body. By testing multiple drugs at once, they hope to find effective treatments for PSP faster and more efficiently. In general, the eligibility criteria include the presence of PSP symptoms for <5 years in people who are able to walk independently or with minimal assistance. Enrollment is scheduled to begin in the first quarter of 2026 and Johns Hopkins has been selected as a trial site (NCT07217665).

At Hopkins, the **Scrambler Therapy vs. TENS for CBS trial** is continuing recruitment. Pain can be a common non-motor complication of CBS. Scrambler therapy is a non-invasive electrical approach to neuromodulation that sends "nonpain" information along the existing nerve pathways to modify peripheral and central sensitization. A drug trial for CBS at Hopkins is in the planning stages as well.

Multiple system atrophy (MSA):

Amlenetug, a drug injected through an intravenous route, targets alpha synuclein and reduces its aggregation (clumping). It showed a trend towards clinical benefit and slowing of functional and motor decline, even though it was not statistically significant. But the drug was safe, and a Phase 3 trial is currently recruiting, given its potential to slow down the progression of MSA. The trial is called **MASCOT**, and the general eligibility criteria include the clinical diagnosis of MSA with the presence of symptoms ≤5 years in people between 40-75 years of age. The trial includes a 72-week double-blind period where participants receive either high or low doses of amlenetug or placebo, followed by an open-label extension where all participants are offered treatment with amlenetug.

Updates on Clinical Trials in Atypical Parkinsonian Disorders (continued)

The drug is delivered as an intravenous infusion every four weeks. Enrollment was recently completed and the study is ongoing. Further details can be found on **clinicaltrials.gov** (NCT06706622).

ATH434 is an oral drug designed to redistribute the excess loosely bound iron in the brain tissue, which could in turn reduce the protein alpha synuclein from clumping. Abnormal forms and malfunctioning of alpha synuclein are important contributors to the disease development in MSA. This approach is expected to limit neurodegeneration in patients with MSA. The Phase 2 clinical trials were completed in 2025, with promising results showing the drug was safe, well-tolerated, and associated with slowing disease progression across multiple independent clinical endpoints, including functional measures, mobility metrics, and symptoms of orthostatic hypotension (a particularly debilitating feature of MSA). Treatment with ATH434 reduced or stabilized iron content in key brain regions affected by MSA. There was also some slowing of clinical progression, with UMSARS I scores increasing 3.5 points versus 6.5 historically, and 43% of participants remaining stable. Based on these data, this drug received Fast Track designation by the FDA in June 2025. This is good news, as the data from the study is convincing enough to have the FDA help expedite further development of this drug. The company is actively planning a Phase 3 trial.

AB-1005 (formerly known as AAV2-GDNF) is a gene therapy drug, which is injected directly into the area of the brain called the putamen using a minimally invasive brain surgery technique with MRI-guided convection-enhanced delivery. It is designed to help increase the levels of the protein GDNF (glial cell line-derived neurotrophic factor), which is important in the survival of brain cells, but is significantly reduced in MSA and other parkinsonian diseases. The phase 1 study (called REGENERATE MSA-101) is currently ongoing and completed enrollment as of November 2025. This is a randomized, double-blind, placebo-controlled trial designed to determine the safety and potential clinical effect of AB-1005 in early-stage MSA patients (NCT04680065). Early blinded data indicate detectable GDNF expression and stable motor progression relative to expected natural decline, with full unblinded results expected in 2026-2027.

Besides targeting alpha synuclein, **stem cell therapy** is also being studied in MSA. For example, one's own bone marrow-derived stem cells are injected into their spinal fluid with the aim of stimulating regeneration of nerve cells and protection against the MSA disease process. This study is currently at the Mayo Clinic in Rochester, Minnesota.

Dementia with Lewy bodies (DLB):

Neflamapimod is an oral drug that inhibits an enzyme called p38 mitogen-activated protein kinase alpha, which is designed to reduce neuroinflammation. This drug was studied in a Phase 2b trial (which focuses on fine-tuning the dosage, as well as efficacy and safety) called RewinD-LB (NCT05869669). The trial was a 16-week, double-blind, placebo-controlled study of 159 patients with DLB, followed by a 32-week open-label extension phase. In this phase of the study, all the volunteers received the drug instead of some receiving the placebo.

The data from the **RewinD-LB trial** were promising. An improved capsule formulation that achieved proper drug concentrations showed significant improvement in dementia severity based on a scale called CDR-SB (Clinical Dementia Rating Scale-Sum of Boxes), and clinically meaningful improvement regarding daily lives of the DLB patients who took this drug. There was also a decreased incidence of falls. Patients receiving the improved formulation demonstrated a 67-75% reduced risk of clinically meaningful disease progression compared to placebo, with significant improvements across multiple domains including cognition, behavior, motor function, and daily functioning. The drug also showed marked reductions in a key biomarker of neurodegeneration (glial fibrillary acidic protein, or GFAP). The company CervoMed announced these positive results in October 2025 and plans to seek FDA feedback on the design of a Phase 3 trial later this year, marking an important step forward in developing neflamapimod as a potential first disease-modifying therapy for DLB.

CT1812 (also called zervimesine) is an oral drug called a sigma-2 receptor modulator, which is designed to help protect neurons from the toxic effects of alpha-synuclein. The clinical trial for this drug, called SHIMMER, has shown positive results from the Phase 2 study, which were published in January 2026. The DLB patients who took this drug for 6 months showed improvements in behavioral, functional, cognitive, and movement measures compared to placebo. At the end of the study period, zervimesine-treated patients progressed 86% slower on neuropsychiatric symptoms, 52% slower on activities of daily living, and 62% slower on motor scores compared to placebo. There was also strong reduction in anxiety, hallucinations, and delusions in the patients who took the drug compared to those who took placebo. Notably, there was also a marked reduction in caregiver distress for care partners of those who took the drug. These encouraging results support the potential for zervimesine to slow clinical progression in patients with mild-to-moderate DLB.

(Continued on Page 9)

RESEARCH STUDIES

Condition	Study Name	Objective	Eligibility	PI	Contact
Atypical Parkinsonian Disorders	Complex Neurodegeneration Clinic at NIH	Observational research study for understanding molecular and clinical features from a genetic viewpoint	• Individuals dx with an atypical parkinsonism disorder who have a familial genetic component • Adults (over 18 years) • Study partner required	Sonja Scholz, MD, PhD	Sonja Scholz, MD, PhD Sonja.scholz@nih.gov P#: 240-271-529
PSP	PSP Trial Platform (PTP)	This is a multi-arm randomized Phase 2 clinical trial involving 2 drugs (currently AZP2006 and AADvac1) and pla-cebo, with a 12-month double-blind phase and an optional 12-month open label extension. Additional drugs may be added to this trial in the future.	• Clinical diagnosis of possible or probable PSP Richardson's Syndrome using 2017 Movement Disorder Society (MDS) criteria • Symptoms for ≤5 years at the time of screening • Ability to walk independently or with minimal assistance (for example, a cane or light support), not bedbound or wheelchair-bound • Mini-Mental State Examination (MMSE) ≥25, indicating no more than mild cognitive impairment · • Reliable care partner available to accompany the participant to visits and provide information about daily function	Alex Pantelyat, MD (Site Principal Investigator)	Nichole Marcantoni **nbair2@jhmi.edu**
Parkinson Disease-MCI or MCI with Lewy Bodies Parkinson Disease Dementia (PDD) Dementia with Lewy Bodies (DLB)	Dementia with Lewy Bodies Consortium study	Goal is to study the differences among individuals over time using serial cognitive tests, examinations, and blood and CSF collection over 2 years (annual visits)	• Individuals dx with Parkinson's Disease or Dementia with Lewy Bodies • Willing to have a blood draw and lumbar puncture • Willing to undergo imaging (MRI and DAT scan) • Reliable care partner	Alex Pantelyat, MD	AJ Hall ahall52@jh.edu P#: 410-616-2813

RESEARCH STUDIES (continued)

Condition	Study Name	Objective	Eligibility	PI	Contact
CBS	Scrambler Therapy vs TENS in the Treatment of Pain Associated with CBS	Goal is to compare ST and TENS as pain relief modes Up to 10 in-person visits over 30 days Questionnaires completed at 90 days	• Patients with possible or probable CBS • Chronic pain at a level of at least 4/10 for at least 2 weeks prior to enrollment	Alex Pantelyat, MD	Maria Schmidt, CRNP mschmi61@jhmi.edu P: 410-614-5744
CBS PPA bvFTD	The ReMoTe Study	Goal is to develop remote digital platform to assess FTLD symptoms using a tablet computer at home and wearable sensors. Involves 2 years of monthly at-home tablet assessments and 4 visits to Johns Hopkins (once every 6 mo.)	• Individuals dx w/ an FTLD syndrome (Cortical Basal Syndrome, Primary Progressive Aphasia, or FTD behavioral variant) • Able to walk 10 feet unassisted at baseline • Caregiver or study partner needed to assist with tasks at home.	Alex Pantelyat, MD	Claudia Waddell Cwaddel4@jh.edu P#: 410-616-2825
PSP CBS/CBD MSA	DCT	Goal is to validate digital biomarkers using a wearable neck pendant and tablet computer at home. Involves short virtual screening visit and monthly virtual study visits for 4 months.	• Individuals dx w/ PSP, CBS or MSA • Able to walk 10 feet unassisted at baseline • Caregiver or study partner needed to assist with tasks at home. • Either caregiver or participant able to operate and use a tablet	Alex Pantelyat, MD	Hannah Jackson Hjacks30@jh.edu P#: 410-616-2822

Updates on Clinical Trials in Atypical Parkinsonian Disorders (*continued from page 7*)

Ambroxol is a cough medicine currently used outside of the U.S., to reduce mucous secretions and relieve sore throat pain. It also appears to be neuroprotective by increasing the amount of the enzyme glucocerebrosidase, which leads to a reduction of alpha synuclein's harmful effects. This drug is being studied in a trial in Norway.

In conclusion, there are many current or upcoming clinical trials that test drugs with the goal of slowing down the disease process in APDs, and/or improve symptoms. While some trials like AMX0035 in PSP did not show the hoped-for efficacy, the clinical trial landscape for APDs continues to be active and exciting, with particularly promising developments in DLB (neflamapimod and zervimesine) and MSA (ATH434 and amlenetug), lending hope to patients, families, and those who care for them. The innovative PSP Platform Trial also represents a new approach to accelerate drug development by testing multiple therapies simultaneously. The best way to stay up to date with these studies is by going to **www.clinicaltrials.gov** and further filtering your search by putting in the disease name of interest in the search section.

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A Legacy Tomorrow, an Impact Today — Johns Hopkins Legacy Match

Through the development of diagnostic tools and new treatment options, the Johns Hopkins Atypical Parkinsonism (AP) Center changes lives. As partners in our mission, supporters like you help accelerate the discovery of novel therapies, offering hope to those impacted by AP and aspirations of ultimately finding a cure.

As part of its 150th anniversary celebration, Johns Hopkins has launched its first ever Legacy Match. Through this program, you can be recognized for your generosity and rewarded with a **matching outright gift*** when you support the future of AP research and care in one of the following ways.

Gifts that cost you nothing during your lifetime:

Will or Trust — Retain control and use of your assets and modify your plans if your needs change.

Beneficiary Designation — Make Johns Hopkins the beneficiary of all or any part of your retirement account, investment account, or similar account through a simple form.

Gifts that pay you back:

Charitable Gift Annuity — Receive guaranteed lifetime income and potential tax benefits. Favorable treatment of capital gains when you fund your gift with appreciated stock.

Charitable Remainder Unitrust — Enjoy flexible funding options and variable income payments.

If you have included any area of Johns Hopkins in your plans — or are considering a gift through your will or trust, a gift by beneficiary designation, or a life income gift, such as a charitable gift annuity or charitable remainder trust — please let us know; **your gift could be matched today!**

To ensure your gift qualifies for the Johns Hopkins Legacy Match, please contact the Office of Gift Planning at **410-516-7954** or **giftplanning@jhu.edu** Learn more at **giving.jhu.edu/legacy-match**

Joey Peyton

For more information about how you can make a philanthropic impact that furthers our work, please contact:

Joey Peyton
Development Officer
jpeyton9@jhmi.edu

The Johns Hopkins Atypical Parkinsonism Center

Clinic

Our center has a multidisciplinary team dedicated to comprehensive patient care. Eligible patients are seen by multiple specialists in a monthly multidisciplinary clinic.

Neurologists
Alexander Pantelyat, MD, Center Director
Jee Bang, MD, MPH
Sonja Scholz, MD, PhD

Nurse Practitioner
Maria Schmidt, CRNP, DNP

Clinical Fellows
Sai Sachin Divakaruni, MD, PhD
Ian Cheong, MD, PhD
Rebecca Khamishon, MD
Dylan Del Papa, MD

Center Coordinator
Dominque Coates, BA

Research Program Manager
Anna J. Hall, BA

Research Coordinators
Hannah Jackson, AB
Claudia Waddell, BS

Genetic Counselor
Weiyi Mu, ScM, CGC

Center Health Educator
Sarah Phelan, BS, MS

Physical Therapists
Albert Mears, PT
Ruben Pagkatipunan, PT, OCS
Jeny Rund, PT

Occupational Therapists
Allyson Lancey, MS, OTR/L
Barbara Ruzicka, MA, OTL
Rachael Zangrilli, OTL

Speech Therapists
Theresa Walker, CCC-SLP

Music Therapist
Kerry Devlin, MMT, MT-BC

Postdoctoral Research Fellow/Music Therapist
Kyurim Kang, PhD, MT-BC

Research

Our team is committed to being at the forefront of research in atypical parkinsonian disorders in order to improve diagnosis, develop treatments, and enhance quality of life. Please contact our clinic if you are interested in research opportunities. In addition to the studies below, other opportunities may be available.

ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration (ALLFTD2): a multisite research consortium study
This study investigates both genetic and sporadic forms of FTD-spectrum disorders, including PSP and CBS.
Contact: Chiadi Onyike, 410-502-5816

Genetic Characterization of Movement Disorders
In collaboration with the NIH, this study seeks to discover genetic changes associated with atypical parkinsonian disorders.
Email: Sonja Scholz, sscholz5@jhmi.edu

Eye Movement and Vestibular Research Lab
This lab examines eye movements and vestibular changes in those with parkinsonian and cerebellar disorders.
Email: Dr. Daniel Gold, dgold7@jhmi.edu

Motion Analysis Lab (Kennedy Krieger Institute)
This lab investigates hand/arm movements and walking to develop rehabilitation strategies for patients with parkinsonism and ataxia.
Contact: Anthony Gonzalez, 443-923-2716

*****See our full list of recruiting studies on pages 8-9**

Outreach & Education

Our center has developed a robust outreach and education program to include monthly support groups, seminars, and more. To learn more about these programs or request educational information, please contact Sarah Phelan at 410-955-6684.

Atypical Parkinsonism Community Group (Currently Virtual) Baltimore County
Call Sarah Phelan, 410-955-6684 or Email: sphelan2@jhmi.edu

DC Area Atypical Parkinsonism Group (Currently Virtual)
Call Kristen Weidner, 715-821-3356 or Email: weidner.kristen@gmail.com

Music Therapy Support Group (Currently Virtual) Email: Kerry Devlin, kdevlin5@jh.edu

CurePSP Online Support Groups: https://www.psp.org/ineedsupport/online- support-groups/

Lewy Body Dementia Support Groups (Currently Virtual)
Call Melissa Daily, 248-464-4397 Email: medaily@umich.edu

Online Resources

National Institute of Neurological Disorders and Stroke (NINDS), NIH
https://www.nia.nih.gov/alzheimers/public ation/frontotemporal-disorders-resource- list
800-352-9424

National Organization for Rare Disorders (NORD)
www.rarediseases.org
203-744-0100

CurePSP
www.psp.org 800-457-4777

The Association for Frontotemporal Degeneration
www.theaftd.org 866-507-7222

Lewy Body Dementia Association
www.lbda.org 800-539-9767

Mission MSA
www.missionmsa.org 866-737-5999

ClinicalTrials.gov
ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world.

Atypical Parkinsonism Digest

Johns Hopkins Atypical Parkinsonism Center
600 North Wolfe Street, Meyer 6-181C
Baltimore, MD 21287

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