Atypical Parkinsonism Digest

JOHNS HOPKINS MEDICINE

News from the Johns Hopkins Atypical Parkinsonism Center

Summer/Fall 2025

Director's Corner

Alexander Pantelyat, MD, FAAN

How Can Artificial Intelligence-based technology help patients with atypical parkinsonism?

By Alexander Pantelyat, MD, FAAN

Artificial intelligence (AI)-based technologies, including voice banking with iPhone Personal Voice, Amazon Alexa and large language models (LLMs), have significant potential to assist patients with atypical parkinsonian disorders in their daily lives. These illnesses frequently cause complex motor and non-motor symptoms, including speech (clarity and volume), language (verbal output) and communication difficulties.

Voice banking technologies, such as iPhone Personal Voice (free; go to Settings→Accessibility→scroll to Speech→Personal Voice), enable patients to create a synthetic version of their own voice while their speech is understandable. **This allows for the preservation of personal identity in communication, which is especially important as speech becomes less understandable.** AI-driven voice synthesis can be integrated into augmentative and alternative communication (AAC) devices (usually digital tablets), enabling patients to communicate more naturally and effectively. Machine learning models have demonstrated the ability to analyze and process voice samples for both monitoring disease progression and supporting communication, with smartphone-based tools showing feasibility and high patient satisfaction in Parkinson disease and related disorders.

LLMs can enhance daily functioning by powering conversational agents that assist with medication reminders, scheduling, and providing disease-specific education. These AI-driven assistants can adapt to the user's communication style and cognitive abilities, offering personalized support for activities of daily living. As an example, voice-activated smart speakers like Amazon Alexa can provide medication and appointment reminders, which may improve adherence and disease control, and can help compensate for the executive dysfunction, language memory impairment common in atypical parkinsonism. **Alexa can also facilitate increased independence by enabling hands-free control of home devices, setting reminders for daily tasks, and providing access to information or entertainment, which may help address issues of low mood and social isolation.**

LLMs can also assist with remote symptom monitoring and triage by interpreting patient-reported symptoms (by analyzing the transcript from an audio recording) and generating structured reports for clinicians, thus supporting telemedicine and reducing the burden of in-person visits. Additionally, AI-based analysis of walking and other movements can serve as a digital biomarker for disease monitoring, enabling objective, continuous assessment of motor symptoms outside the clinic. These tools are already being integrated into recent clinical trials. ***In time, I am optimistic that they will support individualized treatment adjustments and both detection and prediction of clinical changes, which is particularly important in atypical parkinsonian syndromes, where disease progression is often highly variable.***

In summary, AI-based voice banking, voice activated smart speakers and LLMs can help improve communication, autonomy, and quality of life for patients with atypical parkinsonian disorders by preserving personal voice, supporting daily tasks, and enabling remote and objective symptom monitoring.

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Managing Festinating Gait and Retropulsion Through Physical Therapy: A Brief Guide for Families *by Ruben Pagkatipunan Jr., PT, DPT, OCS*

Two of the most distressing mobility issues you may encounter when caring for a loved one with an atypical parkinsonian disorder are festinating gait and retropulsion. Festinating gait is a rapid, short-stepped shuffle that makes it look like your loved one is trying to catch up with their upper body. Retropulsion is the tendency to fall backward, often without warning. Both symptoms increase fall risk but can be managed effectively through physical therapy.

A central goal of therapy is postural re-education, which helps correct the forward-leaning posture that contributes to festination. Therapists use wall alignment exercises and core strengthening to train a more upright stance. Another major focus is step-length training. People with festination tend to take quick, small steps, so exercises are designed to encourage bigger, more deliberate strides. Using floor markers, counting steps aloud, or practicing high-knee marching can all help reset walking rhythm.

Therapists also work on balance and weight-shifting drills to reduce retropulsion. Controlled movements, such as gently swaying from side to side or shifting weight from front to back while standing, train the body to stabilize itself more effectively. These exercises should always be supervised, especially early on. A simple but powerful tool is the "stop-reset-start" strategy, which teaches the person to pause, realign posture, and consciously take a large first step to avoid uncontrolled shuffling.

External cueing is another valuable technique. Tools like floor tape, laser pointers, or even rhythmic music can prompt the brain to initiate movement more smoothly.

Lastly, therapists recommend practical fall prevention strategies such as clearing clutter, installing grab bars, and choosing the right assistive devices like rolling walkers or laser canes. Each intervention is tailored to the individual's needs and progression.

Ruben Pagkatipunan Jr., PT, DPT, OCS

Occupational Therapy Summer Tips *by Rachael Zangrilli,* OTR/L

Rachael Zangrilli, OTR/L

Occupational therapy (OT) plays a vital role in helping people with Parkinsonism maintain independence and quality of life. OT focuses on adapting daily activities—like dressing, eating, and writing—to match a person's abilities. Therapists might recommend tools like weighted utensils for tremors, adaptive keyboards, or home modifications to reduce fall risks.

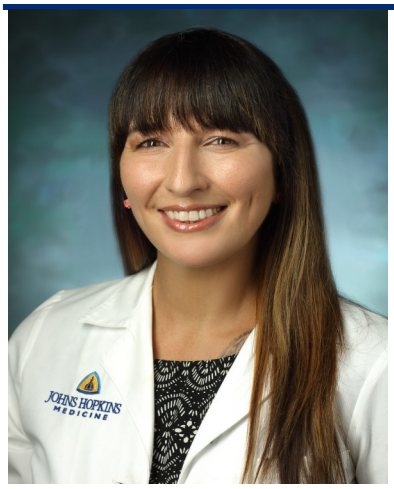
Currently, summer safety becomes especially important for individuals with Parkinsonism. Heat can worsen symptoms like fatigue, dizziness, and low blood pressure.

Here are some key tips:

- Stay hydrated: Aim for 6–8 glasses of water daily, more if you're active or outdoors.
- Avoid peak heat: Plan outings for early morning or evening.
- Dress smart: Light-colored, breathable fabrics help regulate body temperature.
- Protect your skin: Use SPF 30+ sunscreen and wear a wide-brimmed hat.
- Watch for signs of heat stress: Dizziness, confusion, or nausea require immediate cooling and hydration.

Occupational therapists can even help you tailor summer routines—like safe gardening setups or travel planning—to keep things enjoyable and low-risk. Wishing you a safe and enjoyable summer!

Thinking Upstream with Neurodegenerative Illnesses *by Maria Schmidt CRNP, DNP*



Maria Schmidt CRNP, DNP

When neurodegenerative illnesses attempt to rob patients of their autonomy, there is an opportunity to focus on the different ways thinking upstream can help slow progression. Neurodegenerative illnesses like Parkinson's disease (PD), atypical parkinsonian disorders, Alzheimer's disease (AD) and related dementias lead to both motor and cognitive decline. Thinking upstream involves a shift from reactive to proactive approaches in the prevention of these deficits. Since slowing disease progression is a major goal for neurodegenerative illnesses, patients can be given back the power to change their quality of life and health outcomes.

There is a robust body of evidence describing the laundry list of risk factors for neurodegeneration, but the good news is that many are modifiable. A multidomain approach is the most effective way to address risk factors such as high blood pressure, diabetes, obesity, depression, smoking, exercise, hearing loss, social isolation, and low educational attainment. Each of these risk factors can be evaluated and managed in collaboration with a primary care provider.

The adage "you are what you eat" holds true when it comes to preventative health. Researchers have linked dietary interventions—such as the Mediterranean, DASH, and MIND diets—to slower cognitive decline and a reduced risk of dementia. Recent studies have found that taking a daily multivitamin can improve cognition and may potentially delay dementia onset.

Experts consistently highlight regular, moderate to high-intensity aerobic exercise as a key part of managing parkinsonism. It helps improve balance, gait, activities of daily living, and overall quality of life. Physical activity also lowers the risk of Alzheimer's disease and supports better cognitive function, sleep quality, and mood.

Clinicians continue to emphasize managing vascular and metabolic risk factors as the foundation for preventing cognitive and motor decline, as well as reducing dementia risk.

The overall evidence strongly supports a multidomain and proactive approach. Acting early—by managing vascular and metabolic health, encouraging a healthy diet and aerobic activity, and using medications judiciously—offers the most effective strategy for impacting neurodegenerative disease progression.

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**

We look forward to sharing many more exciting opportunities ahead for our patients and caregivers!

A Gift Beyond Life: How Brain Donation Helps *by Sonja Scholz, MD, PhD*

Sonja Scholz, MD, PhD

Have you ever wondered how doctors and scientists learn more about conditions like progressive supranuclear palsy (PSP), multiple system atrophy (MSA), corticobasal syndrome (CBS), or Dementia with Lewy bodies (DLB)? One of the most powerful ways is by studying the brain after someone has passed away. This is called brain donation and is a remarkable gift to the research community that can pave the way for a better understanding of complex neurological diseases. Ultimately, it helps researchers develop new treatments that could change lives in the future.

Brain donation involves gifting your brain to science after death, allowing researchers to gain an up-close look at the changes caused by neurological diseases. Even though we have advanced brain scans and lab tests, as of now the only way to confirm atypical parkinsonian disorders is by directly examining the actual brain tissue. Why is this so important? Right now, there are no cures for neurodegenerative diseases such as atypical parkinsonian syndromes. But scientists are working hard to change that. By studying donated brains, they learn how these diseases develop and test new ideas for treatments. Each donation adds a crucial piece to the puzzle, bringing us closer to treatments that could one day slow, stop, or hopefully prevent these disorders.

Many people worry that brain donation might delay funeral arrangements or interfere with memorial wishes. In reality, programs such as the Johns Hopkins Brain Resource Center work hand-in-hand with funeral homes to coordinate arrangements to avoid such delays. Importantly, there is no cost to the family and an open casket funeral is possible as well. Our clinic can help you learn more, answer any questions, and connect you to a reputable brain bank, such as the NIH NeuroBioBank (**https://neurobiobank.nih.gov**) or the Johns Hopkins Brain Resource Center. By choosing to donate, patients can leave an extraordinary legacy, one that could bring hope to countless families in the years to come.

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 impacted due to patients' limited access to clinics and hospitals among strict COVID regulations. As a result, our team (in partnership with Biosensics, Inc. and colleagues from Massachusetts General Hospital) 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 Parkinsonian 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 technology can be used to improve the care and monitoring of Atypical Parkinsonism.

We are excited to share two new upcoming research studies with you. Both studies utilize our remote assessment platform to help monitor symptoms and disease progression at home through 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 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 visit every 6 months. Between each in-person visit, we will ask that participants also 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.

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A Milestone: Non-Invasive Brain Stimulation and Neurologic Music Therapy for CBS

by Kyurim Kang, PhD., LPMT, MT-BC

Kyurim Kang, PhD, LPMT, MT-BC

We are excited to share that our study combining transcranial direct current stimulation (tDCS) with Neurologic Music Therapy® for Corticobasal syndrome (CBS) has reached an important milestone — 20 participants have now completed their sessions. This achievement allows us to begin our initial data analysis, and we are excited to share our progress with you. CBS is the rarest of the atypical parkinsonian disorders and recruitment for studies in rare diseases can be a challenge. However, our center is currently the only center in the United States actively recruiting CBS participants for treatment trials and this has bolstered enrollment.

Our trial focuses on improving upper limb performance in individuals with CBS by pairing non-invasive brain stimulation with Neurologic Music Therapy® techniques. We use carefully designed musical patterns that naturally support movement — for example, ascending scales to encourage reaching up or outward, and hand drum positioning that helps extend range of motion by adjusting the distance between instruments. We also integrate piano playing exercises to promote finger dexterity and fine motor control. Since functional performance varies across individuals, we designed the sessions to accommodate each participant's unique abilities and movement capabilities.

We are deeply grateful to the 20 participants who have contributed to this research so far. Your time, effort, and enthusiasm are helping us explore innovative ways to support upper motor function through the powerful combination of music and neuroscience.

Recruitment is still ongoing as we work toward our full study enrollment goals. If you or someone you know may be interested in participating, or if you'd like to learn more about the study, please feel free to reach out to **kkang19@jhmi.edu**!

Together, we can advance therapeutic approaches that integrate science and music. Thank you for your continued support!

Using Emerging Technology to Innovate Research and Improve Access to Care

(Continued from page 4)

We will soon be actively recruiting for both studies, so 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 and your clinical care at Johns Hopkins or elsewhere will not be affected in any way. Our team looks forward to hearing from interested patients and families and cannot wait to collaborate with you to further improve and innovate this exciting field!

Claudia Waddell, BS

Hannah Jackson, AB

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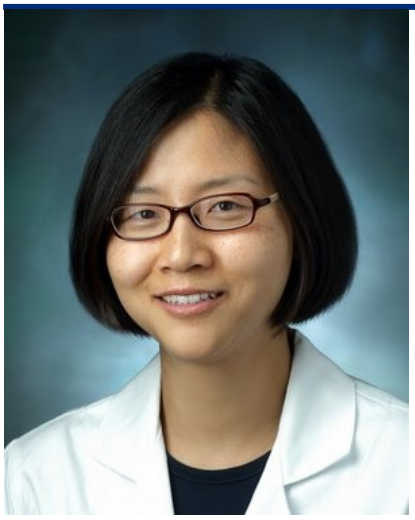
RESEARCH STUDIES

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	FTLD Wearables	Goal is to develop a remote digital platform to assess PSP symptoms using a tablet computer at home and wearables sensors. Involves 1 year of monthly virtual visits on Zoom and 4 visits to Johns Hopkins (once every 3 mo.) . The study involves 12 visits over the course of 12 months and will include 5 in-person visits at Johns Hop-	• Individuals dx w/ PSP • Able to walk 10 feet unassisted at baseline (no wall or device support) *Caregiver or study partner also required for minor participation role	Alex Pantelyat, MD	Hannah Jackson Hjacks30@jh.edu P#: 410-616-2822
Parkinson Disease-MCI Parkinson Disease-Dementia Dementia with Lewy Bodies (DLB)	The B.E.D. Study	Goal is to study the differences in memory, thinking, movement, and body fluids among different individuals using cognitive tests, physical tasks, and blood and CSF collection over 2 years (annual visits).	• Individuals diagnosed with Parkinson's Disease or Dementia with Lewy Bodies • Willing to have a blood draw and lumbar puncture • Willing to undergo imaging • Caregiver or study partner also required for	Alex Pantelyat, MD	AJ Hall ahall52@jh.edu P#: 410-616-2813
CBS	Music Therapy using tDCS in CBS	Randomly assigned study with a goal is to improve upper extremity function in CBS using music therapy + active versus sham tDCS 8 in-person visits over 2 months (baseline + 6 intervention visits over 3	• Individuals with possible or probable CBS • Willing to undergo 8 assessments in East Baltimore (Kennedy Krieger Institute) over approximately 8 weeks	Alex Pantelyat, MD	Kyurim Kang, PhD. Kkang19@jhmi.edu Isabella Sterner Isterne1@jh.edu P: 443-821-2491

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 Question-naires completed at 90	• 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 plat-form to assess FTLD symptoms using a tablet com-puter at home and wearable sensors. Involves 2 years of monthly at-home tablet assessments and 4 visits to Johns Hopkins (once every	• Individuals dx w/ an FTLD syndrome (Cortical Basal Syn-drome, Primary Progres-sive Aphasia, or FTD behavioral variant) • Able to walk 10 feet un-assisted at baseline • Caregiver or study part-ner 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 screen-ing visit and month-ly virtual study visits	• Individuals dx w/ PSP, CBS or MSA • Able to walk 10 feet unas-sisted at baseline • Caregiver or study partner needed to assist with tasks at home. • Either caregiver or partici-pant able to operate and	Alex Pantelyat, MD	Hannah Jackson Hjacks30@jh.edu P#: 410-616-2822
MSA	MASCOT	Double-masked, place-bo- controlled trial to evaluate the efficacy and safety of Lu AF82422 for the treat-ment of participants with MSA. Consists of a 3-6-week screening period, a 72-week pla-cebo-controlled period (PCP). Will include a 72-week optional dose-blinded open-label treatment exten-sion (OLE) period. Participants in the PCP will be random-ized to Lu AF82422 high dose, Lu AF82422 low dose or placebo (1:1:1). All participants entering OLE will receive Lu AF82422 during OLE. Participants will re-ceive IV infusions	• Diagnosis: clinically estab-lished multiple system atro-phy parkinsonian type (MSA-P) or multiple sys-tem atrophy cerebellar type (MSA-C), or clinically probable MSA-P or MSA-C, according to the 2022 MDS criteria for the diag-nosis of MSA at the Screening Visit. • Onset of motor MSA symptoms (i.e., parkinsoni-an and/or cerebellar) with-in 5 years • Anticipated survival of >3 yearsat the Screening Visit. • Suitable peripheral venous access for investigational medicinal product (IMP) administration and blood sampling. • UMSARS Part I score ≤16 (omitting item 11 on sexual function) at the Screening Visit.	Jee Bang, MD	Nichole Marcantoni Email: nbair2@jhmi.edu

Updates on Clinical Trials in Atypical Parkinsonian Disorders *by Jee Bang, MD, MPH*



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 is 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, this drug was not helpful for patients with ALS in a large trial (even though it appeared to help them in an earlier, smaller trial). But the Phase 2b/3 trial (which focuses on efficacy in addition to safety) of this drug for people living with PSP (called ORION) is currently ongoing in North America, Europe, and Japan (NCT06122662). The phase 2a part of the trial is fully enrolled, with 139 participants. Following the analysis of the data from phase 2b, the decision will be made whether to proceed to phase 3.

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.

There is also an important project being developed to streamline PSP clinical trials, called the PSP Clinical Trial Platform (PTP). 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. Two of the drugs have been announced: AADvac1 (an active vaccine against the tau protein) 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. The plan is to complete the set up by the end of 2025.

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. Another recruiting study uses Neurologic Music Therapy and transcranial direct current stimulation (a form of noninvasive electrical brain stimulation) to rehabilitate hand and arm function in CBS.

Multiple system atrophy (MSA):

Amlenetug, a drug injected through an intravenous route, targets alpha synuclein and reducess 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. Further details can be found on clinicaltrials.gov (NCT06706622).

Updates on Clinical Trials in Atypical Parkinsonian Disorders (continued)

ATH434-201 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. This trial was completed in November of 2024, with 77 volunteers receiving either a low dose, a high dose, or placebo. In January 2025, the company announced that treatment with ATH434 reduced or stabilized iron content in key brain regions affected by MSA. There was also some slowing of clinical progression. Based on these data, this drug has 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.

AB-1005 (formerly known as AAV2-GDNF) is a gene therapy drug, which is injected directly into the area of the brain called putamen using a minimally invasive brain surgery technique. It is designed to help increase the levels of the protein GDNF, which is important in the survival of brain cells, but is significantly reduced in MSA and other parkinsonian diseases. The phase 1 study is currently recruiting (NCT04680065).

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 is being studied in a Phase 2b trial (which focuses on fine-tuning the dosage, as well as efficacy and safety) called RewinD-LB. The first part of the trial was 16 weeks long, which was followed by another 32-week open-label extension phase. In this phase of the study, all the volunteers are receiving the drug instead of some receiving the placebo. The data from the first half of the open-label extension are promising! There was 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. After the open-label phase is completed, the plan is to move on to a Phase 3 trial sometime in 2026.

CT1812 is an oral drug called an alpha-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. The DLB patients who took this drug for 6 months showed behavioral, functional, cognitive and movement measures compared to placebo. There was also strong reduction in anxiety, hallucinations, and delusions in the patients who took the drug. There was also a marked reduction in caregiver distress.

K0706 is an oral drug that is a type of tyrosine kinase inhibitor, which is designed to help nerve cells degrade abnormal clumps of alpha synuclein. The trial has been completed, but the full results are not available yet.

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 (GCase), which leads to a reduction of alpha synuclein's harmful effects. This drug is being studied in Norway and Australia.

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. The clinical trial landscape for APDs continues to be active and exciting, lending hope to patients, families, and those who care for them. 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.

The Importance of Philanthropy *by Kimberly Willis, Executive Director of Development, Neurology & PM&R*

Philanthropy is essential in advancing the mission of the Johns Hopkins Atypical Parkinsonism (AP) Center. It fuels groundbreaking research, fosters innovative clinical care, and provides comprehensive support for individuals and families affected by AP. Thanks to the generous contributions from individuals and foundations, the Center has made significant strides in understanding the diverse forms of AP. This progress has led to the development of diagnostic tools, new treatment options, and the aspiration of ultimately finding a cure. Philanthropic funding accelerates the discovery of novel therapies, offering hope to those impacted by AP.

As a key example, philanthropic contributions have supported Maria Schmidt, CRNP, DNP—the Center's dedicated Nurse Practitioner. Maria plays a crucial role in delivering the highest standard of care and education to our patients. She combines personalized treatment approaches, incorporating holistic and non-medication therapies—such as music-based rehabilitation—with conventional medication treatments. Beyond providing exceptional patient care, Maria is committed to educating patients and their families about AP, empowering them with essential knowledge and resources and expanding access to care for the underserved.

The invaluable support from our donors is what makes our work possible. Philanthropy not only directly funds our Center's faculty and clinical as well as research staff, but also enables us to offer vital services like parking vouchers and transportation assistance for those in need. Additionally, these funds fuel groundbreaking research endeavors in our laboratories and help sustain our Movement Disorders Fellows.

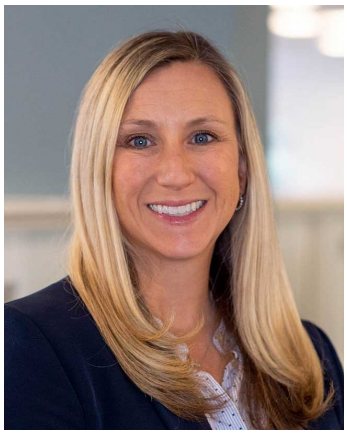
Together, with the continued partnership of our donors, the Johns Hopkins Atypical Parkinsonism Center remains at the forefront of discovery and exemplary clinical care, bringing renewed hope for a brighter future for all affected by AP.

Thank you for your support!

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

Kimberly Willis
Executive Director of Development
Departments of Neurology and PM&R
kwillis@jhmi.edu

Joey Peyton
Associate Director of Development
Departments of Neurology and PM&R
jpeyton9@jhmi.edu



Kimberly Willis

Joey Peyton

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.

A Multi-Modal Remote Monitoring Platform for Frontotemporal Lobar Degeneration Syndromes (The FTLD Wearables Study)

This study aims to determine whether PSP movement and cognitive function can be reliably tracked at home and to develop a fall prediction model in PSP.
Email: AJ Hall, ahall52@jhmi.edu

ARTFL-LEFFTDS Longitudinal Frontotemporal Lobar Degeneration (ALLFTD): a multisite research consortium study

This study investigates both genetic and sporadic forms of FTD-spectrum disorders, including PSP and CBS.
Contact: Ann Fishman, 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

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/publication/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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