Penn Medicine

The Transmitter

Parkinson's Disease and Movement Disorders Center (PDMDC) Newsletter of Penn Medicine

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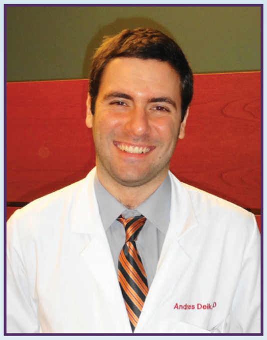
PARKINSON'S RESEARCH —*From Bench to Bedside*

This issue of The Transmitter *highlights the ever-changing and growing world of Parkinson's research. From genetics to biomarkers, to the relationship of clinicians and scientists to their patients, we examine critical developments and new possibilities.*

The Future of PARKINSON'S RESEARCH



Andres Deik, MD, PhD

For more than 200 years, physicians and scientists have been trying to understand Parkinson's disease (PD) and develop better ways to care for the people living with it. While treatments such as levodopa and deep brain stimulation have transformed the way symptoms can be managed, there are still no therapies proven to slow down or stop the progression of the disease. Clinical research is the path forward. Step by step, discoveries made in the laboratory are tested in clinical trials, refined, and—if shown to be safe and effective—brought into clinical practice. This process takes time, but it is the only way to move from promising ideas to real improvements in care.

Research Focused on Genetics

One of the most active areas of research focuses on genetics. Although the majority of Parkinson's cases are not directly inherited, scientists have identified certain genetic changes that increase risk, and about 15% of patients are thought to carry one of these genes.

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The Future of PARKINSON'S RESEARCH

Two of the most studied are in the LRRK2 and GBA1 genes. People who carry these changes may have a higher chance of developing PD, and researchers are trying to see whether targeting these pathways can alter the disease process.

In a trial testing a LRRK2 inhibitor, participants take an oral medication designed to reduce the overactivity of a protein made by the LRRK2 gene. The hope is that this will lessen harmful changes inside nerve cells. In the case of GBA1, clinical trials are testing small molecules, taken as pills, that may help brain cells clear out waste proteins more efficiently. These studies are still in early phases, which means their main purpose is to determine whether the drugs are safe and to get the first signals of whether they might make a difference. If you would like to learn more about these studies, please visit **www.med.upenn.edu/pdmdc/research-at-pd-and-mdc.html**.

Looking for Biomarkers

At the same time, researchers are looking for biomarkers—objective signals of disease that can be tracked over time. Biomarkers could make it possible to diagnose Parkinson's earlier, before symptoms become obvious, and to measure whether new treatments are working. For example, in the international Parkinson's Progression Markers Initiative (PPMI), thousands of volunteers have contributed blood, spinal fluid, brain scans, and digital data. This study has already shown that abnormal forms of the protein alpha-synuclein, detected in spinal fluid, may help identify Parkinson's even in early or "at-risk" stages. Other researchers are studying whether changes in the way the brain uses dopamine on imaging scans, or even subtle shifts in speech patterns recorded on a smartphone, might serve as markers of disease activity. None of these tests are ready for routine use in clinics yet, but they are beginning to be used in trials as tools to monitor whether an experimental drug is having an effect.

How the Trials Access Data

Technology is also beginning to change how Parkinson's research is carried out. In many trials, participants wear wrist devices similar to fitness trackers. These sensors continuously record movement, tremor, or walking patterns, providing a detailed picture of daily symptoms. In other studies, patients use smartphone apps to complete short tasks—like finger tapping, speaking a phrase into the microphone, or walking a few steps—so researchers can monitor performance remotely. This allows data to be collected more often and under more natural conditions than the occasional office visit. The information from wearables and apps is then analyzed, sometimes with the help of artificial intelligence. Computers can look for patterns across thousands of recordings, potentially identifying small but meaningful changes that doctors might not be able to detect in patient visits.

New Designs for Clinical Trials

The design of clinical trials themselves is evolving. Traditional studies often require participants to travel repeatedly to research centers, which can be difficult for people with mobility challenges or those who live far from major hospitals. Newer approaches are testing decentralized or hybrid models, which combine in-person visits with home-based assessments. For example, some exercise studies now allow patients to join supervised sessions via secure video calls, while still coming to the clinic a few times for in-person evaluations. Drug studies may provide electronic diaries so participants can log symptoms from home or arrange for blood samples to be collected at local labs rather than requiring travel to the main research site. These changes are not only more convenient but also may make it possible for a more diverse group of people to take part in research.

It is important to be realistic about what clinical trials can offer. Participation is not the same as receiving an approved treatment. In many early-phase trials, the primary goal is to learn whether an intervention is safe, what dose is best tolerated, and how the body processes the drug.

Later trials focus on whether the intervention improves symptoms or slows progression compared to a placebo (pill, treatment or procedure that is harmless but has no effect). For instance, a trial might randomly assign participants to receive either an investigational drug or an inactive pill, without either the patient or the researchers knowing who is in which group until the study is completed. This "double-blind" design helps ensure that results are unbiased. Some trials test surgical procedures, such as gene therapy delivered by infusion directly into certain brain regions. Others examine lifestyle interventions, like whether a structured program of aerobic exercise improves balance and mobility. Each type of study has specific safeguards in place, including review by independent ethics boards, informed consent discussions, and close monitoring for side

effects. However, even when minimal, there is always a risk involved when participating in a clinical trial.

Do You Want to Participate in a Trial?

For patients and families, deciding whether to participate in research can be complex. Some are motivated by the possibility of gaining access to new treatments before they are widely available. Others participate as a way of contributing to the knowledge that may benefit future generations. It is equally important to understand the potential drawbacks: investigational therapies may not help, and participation can involve time, travel, and sometimes procedures that might carry unforeseeable risks. Patients considering a trial are encouraged to talk with their care team about the purpose of the study, what participation would involve, and what support is available.

Despite the uncertainties, each study provides information that moves the field forward. Even when a drug or intervention does not prove successful, researchers learn what does not work and can redirect efforts accordingly. The cumulative progress from thousands of volunteers is what has made today's treatments possible, and what will lay the foundation for tomorrow's advances.

How To Get to the Finish Line

Looking ahead, the path of Parkinson's research is unlikely to involve a single breakthrough that suddenly changes everything. Instead, progress will probably continue to come in small but meaningful steps: refining genetic therapies, validating biomarkers, improving digital monitoring, and making trials more inclusive and efficient. While it is difficult to predict when new therapies may become available, the scientific community remains steadily focused on the goal of providing more effective and individualized care.

Patients and families who choose to participate in research—whether by joining a trial, contributing data, or simply learning more about opportunities—play a vital role in that process. To learn more about research opportunities at our center, please email us at **movementresearch@uphs.upenn.edu**, or visit any of the following links:

www.ppmi-info.org

www.med.upenn.edu/pdmdc/research-at-pd-and-mdc.html

PPMI and *The Michael J. Fox Foundation*

Ashwini Ramachandran, MS

The Parkinson's Disease and Movement Disorder Center (PDMDC), with approximately 200 participants enrolled in the landmark PPMI (Parkinson's Progression Markers Initiative) study funded by The Michael J. Fox Foundation, is one of the leading sites and contributors to PD research. PPMI is an observational study which follows individuals who have been diagnosed with PD, individuals who are higher risk of developing PD (people who are experiencing loss of sense of smell), those who have been diagnosed with RBD (REM sleep behavior disorder) or those who have a strong family history of PD, and healthy control subjects.

Since its inception in 2010, PPMI has illuminated more about how Parkinson's starts and how it progresses. This helps scientists and doctors develop better treatment, diagnostic tools and even identify preventative therapies.

In 2023, using PPMI data, scientists validated a test for PD with over 93% accuracy. This test is capable of detecting alpha-synuclein protein, a hallmark of PD. Since this scientific breakthrough, the study has started sharing some results directly with participants, demonstrating transparency and cementing participants as true partners in the goal of understanding PD better.

PPMI Team (left to right): Taylor Siegal, Katie Horton, Joana Salievska, Adaeze Njoku, Danielle Potts, Ritikha Vengadesh, and Ashwini Ramachandran, Project Manager.

To learn more about this study and how to get involved, please visit PPMI: The Study that's Changing Everything | Parkinson's Disease.

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Parkinson's Disease and Movement Disorders Center (PDMDC) Newsletter of Penn Medicine

HOW CLINICAL RESEARCH *Could Affect You*

Neda Almassi, MS

Think about where we might be today without treatments like carbidopa-levodopa or deep brain stimulation. Without research studies and the efforts of study participants, we may not have some of these treatments that we currently use! Clinical research is fundamental to advancing our understanding of movement disorders and can help us to identify ways to prevent, detect, and/or treat disease.

The PDMDC at Penn has a robust clinical research program that exists to support our patients. Our research portfolio includes:

- **Observational Studies,** which help us understand patterns of disease, risk factors, and disease trajectories.
- **Interventional Studies,** also known as *clinical trials*, which can help us understand whether an intervention (like a drug, device, surgical procedure, or a behavioral intervention) can impact health outcomes. Study participants play a key role in the scientific process by volunteering their time to undergo certain study procedures, such as health assessments, questionnaires about their disease, biologic samples, neuroimaging, and more.

Many of our patients volunteer to participate in clinical trials for various reasons. Some folks may aspire to help advance scientific understanding or to help others. Others may partake to receive extra care and attention from study staff and doctors or to stay highly in-tune with their health. Some people may even join a study to be on the forefront of the newest potential treatments for their disease or to feel proactive in their healthcare and regain a sense of control.

If you're interested in learning more about our existing research portfolio, or just to get a better understanding of the research process, we encourage you to contact our research team. Our clinical research coordinators work closely with our movement disorders specialists and will be happy to guide you every step of the way.

Contact us at movementresearch@uphs.upenn.edu or visit our website at: **www.med.upenn.edu/pdmdc/research-at-pd-and-mdc.html** to learn more.

REGENERATE-PD *Clinical Trial Now Recruiting*

In partnership with AskBio, Inc., the University of Pennsylvania is participating in a clinical trial to study the safety and effectiveness of an investigational gene therapy called AB-1005 (formerly known as AAV2-GDNF) to improve or stabilize motor symptoms in adults with moderate Parkinson's disease (PD). This trial, REGENERATE-PD, involves a neurosurgical procedure to infuse the investigational gene therapy directly into the brain areas affected by PD.

Individuals meeting study entrance criteria will be randomly assigned to one of two groups. Two of every three participants will be randomly assigned to receive the investigational gene therapy, and one of every three participants will be randomly assigned to undergo the mock surgery. Other than the team performing the surgery, the participants and investigators will not know which group they are assigned to, to help minimize any bias. At the end of the study, participants will learn whether they received the investigational therapy or not; those who did not receive it may be offered the investigational therapy, if they still qualify.

If you or someone you know meet the preliminary criteria below:

- Age 45-75
- Diagnosed with Parkinson's Disease in the past 4-10 years
- On a stable anti-parkinsonian medication regimen
- Not allergic to gadolinium-based contrast agents *(commonly used in MRI scans)*
- No history of prior cell or gene therapy
- On a stable dosing regimen of any diabetes or high blood pressure medicine
- Not pregnant or nursing and willing to follow contraceptive use during participation and for 3 months after dosing
- Willing to attend study visits, approximately twenty visits over four years
- Willing to travel for imaging and surgery *(travel expenses are covered for participants and one caregiver)*

and would like to learn more about participating, please contact Karishma Patel, Karishma.Patel@Pennmedicine.upenn.edu, at (215) 834-8842. We look forward to speaking with you!

Researchers SPEAK OUT

The PDMDC has been a leader in advancing new therapies for PD and other movement disorders. Much of the success of the program is due to leadership from our neurologists but also from dedicated research coordinators. Coordinators are the driving force behind research protocols, maintaining the integrity of the study, supporting their volunteers, and working with sponsors who have tasked us with doing this work. Hear what they have to say about research in their own words:

"Regardless of the outcome of the research study, I find that our research participants become more empowered in their health management as they navigate the research process. They often learn more about their symptoms and are more proactive with their healthcare team and start to make use of all the amazing resources that our center offers. Through this, some have connected with other patients navigating similar challenges and have made life-long friends in the process."

Neda Almassi, MS

PD trials on disease modification, atypical PD

"I love getting to be part of my patient's journey. We get to spend so much time together on these trials that we become almost like family. When you see that a drug is working for a patient, the feeling of being able to make a difference in their life is unmatched. I always knew I wanted to do something to help people, and this really is an amazing way to contribute to a person's life."

Gwen Toti, BS

Huntington's Disease Research Coordinator

"It is very rewarding working in clinical trials. I enjoy being able to bring the hope of better treatment options to patients through the studies we work on."

Alexandria Oliver, BS

Research Manager and lead coordinator on gene therapy trial

"Folks that participate in research get to talk to someone who is knowledgeable about their disease outside of their care team. And all PD patients eventually benefit from clinical trials because research is how medications, devices, interventions, and clinical practices get approved and integrated into clinical care."

Victoria Vaughan

Exercise in PD and REM Sleep Behavior trials

"Being a research coordinator at the PDMDC has been both humbling and formative, as facilitating Parkinson's disease research allows me to better understand the disease, contribute to advancements in early detection and treatment, and ensure that our communities of color are included so our findings reflect diverse experiences and needs. I believe diversifying research and centering on these communities is essential to capturing how cultural, social, and systemic factors shape health outcomes, and I value this work as a way to bring more inclusive and compassionate care to those living with Parkinson's."

Danielle Potts

Coordinator on NIH Diversity in Research trial

"I like forming long-term relationships with research participants and their families. It is heartening to share the wins and be supportive through challenges."

Anne Beckett-Fedarko, OTR/L

Coordinator on Ataxia studies

"Our research team is filled with amazing social workers and a counseling team and has helped increase access to care. Connecting patients to support groups and our social workers through research has helped them feel seen and heard while dealing with difficult diagnoses."

Karishma Patel

Lead Recruitment Specialist

Exercise: PHILLY POWER HOUR —MOVEMENT AND MIND

For 25 years, the therapy team at the Dan Aaron Parkinson's Rehabilitation Center (DAPRC) has been a cornerstone of care and support for Parkinson's patients across the Philadelphia region. Their work goes beyond physical, occupational, and speech therapy—it's about helping patients and their families build lives filled with hope, strength, and resilience. In pursuit of even more comprehensive care, the team saw an opportunity to reintroduce a beloved resource: exercise classes. These classes were available prior to the pandemic and had long been missed by both patients and staff. Reviving them, however, would require funding and coordination.

That's when the DAPRC team partnered with Good Shepherd Penn Partners - GSPP Rehabilitation to explore possibilities. The result? A prestigious grant from the Parkinson's Foundation launching a brand-new initiative: **PHILLY POWER HOUR — MOVEMENT AND MIND**.

This four-week, multidisciplinary program combines physical activity, mindfulness, and cognitive exercises to support both the body and mind. It's tailored specifically for Parkinson's patients, providing an uplifting and empowering environment for continued support. Each month features a different theme to keep the experience fresh and engaging. The program draws on the strengths of physical, occupational, and speech therapy to deliver a truly holistic experience.

This exciting milestone is more than just a win; it's a powerful reflection of our team's passion and ongoing commitment to person-centered care. For more information, contact: gspp.pahpowerhour@pennmedicine.upenn.edu

November is CARE PARTNER MONTH

We honor our caregivers this month by offering their perspectives as well as the insights of those in the profession helping caregivers navigate their new world.

Gloria Williams, MSW, Social Worker, PDMDC

As a social worker in the PDMDC, I provide both the patient and their care partner with the support they need to navigate the challenges that come with PD. For the care partner, my role involves offering guidance on understanding the progression of the disease and how best to adapt to the patient's evolving needs. I also provide emotional support, helping alleviate the stress that caregiving often brings. Whether helping care partners find respite care, local support groups, or counseling services, I aim to ensure that they have the tools and support needed to maintain their own well-being while providing care to their loved one.

Dolly Johnson, MA, Counselor, PDMDC

I continually admire and applaud the strength and courage care partners demonstrate as they share the ups and downs of their journey with me. PD is a "We" disease and the many aspects of giving care and compassion to a spouse and/or loved one is full of challenges: physical limitations, cognitive changes, and differences in life now from the way it was before PD. In my work with care partners, we explore the available resources and opportunities for emotional support, be it in a support group, or with family members and friends. Self-awareness is one of the benefits of this ongoing journey. We need to learn and acknowledge what stressors can be managed and what choices to make that will enable the wellbeing of both the loved one and the care partner.

From our Care Partners:

After talking to Dolly, I realized that she had given me the necessary tools to continue my journey alone. I found her extremely helpful, knowledgeable, and caring, and I greatly appreciate the time she spent counselling me. **– Joan S.**

My caregiving journey has unexpectedly become one of self-discovery. Through the ups and downs I find I have a resilience and strength that I never knew and an understanding that asking for help is necessary and not a sign of weakness. **–Chris R.**

Welcome NEW STAFF

Charles F. Palmer, MD

Dr. Palmer is a dual-trained psychiatrist and neurologist who specializes in the comprehensive care of complex neuropsychiatric conditions. He is an Assistant Professor of Neurology and Psychiatry at the University of Pennsylvania. In the PDMDC, he focuses on managing psychiatric symptoms associated with neurological disease, including depression, anxiety, impulse control disorders, hallucinations, and behavioral changes associated with cognitive decline. Many of his patients have Parkinson's, but he has expertise in conditions including PSP, MSA, ataxias, dementia, and Huntington's Disease, as well as psychiatric conditions including bipolar disorder, schizophrenia, obsessive-compulsive disorder, and others.

Dr. Palmer is a member of the Penn Interventional Psychiatry Network and a Center Scientist in the Penn brainSTIM Center. His research includes developing and improving access to personalized, targeted neuromodulatory therapies such as transcranial magnetic stimulation (TMS), deep brain stimulation (DBS), and focused ultrasound (FUS). He is currently working on approvals for clinical trials utilizing these technologies to treat psychiatric symptoms in Movement Disorders. Through collaborations in psychiatry, neurology, neurosurgery, psychology, neuroscience, and rehabilitation, his goal is to provide a bridge and to break down barriers in the care of brain disorders.

Caroline Kruse, MD

Dr. Kruse is a first-year Movement Disorders fellow at the University of Pennsylvania, where she also completed her Neurology residency in 2025. She received her BA degree in Neurobiology from Harvard College and her MD degree from the Icahn School of Medicine at Mount Sinai. Dr. Kruse is passionate about the holistic care of patients with movement disorders and has special interests in clinical trials, quality improvement, and medical education. Outside of work, she enjoys cooking and baking, crocheting, traveling, and spending time with her husband and yellow Lab, Murphy.

Emily Lubas, MD

Dr. Lubas is a first-year Movement Disorders fellow in the PDMDC. Originally from Linden, NJ, she attended Cooper Medical School of Rowan University and then completed her residency in Neurology at Thomas Jefferson University Hospital. She is particularly interested in quality-of-life metrics for patients with movement disorders, and hopes to get more involved in these efforts throughout her fellowship. Outside of work, she loves trying new workout classes in the city, watching reality TV, and spending time with her 10-month-old niece.

Programs & *Resources*

Living Well at Home

Living Well at Home is the online series to keep PwPs (people with Parkinson's) and care partners connected. This program consists of a support group every Monday as well as movement groups throughout the week.

FOR MORE INFORMATION

Call Sue Reichwein at **215.829.7273** or email **sreichwein@pennmedicine.upenn.edu**.

Date Night & Intimacy

Having PD can strain partner closeness and intimacy. A new online program, sponsored by the Parkinson's Foundation and PDMDC, offers support for those in a relationship with a PwP.

FOR MORE INFORMATION

Visit **www.datenightintimacy.com**
or contact **judith@anyonecanmove.com**.

Close Contact for Couples® with PD

Moving safely and easily with a partner out of chairs, beds, cars, and the shower can be managed with cueing and the right kind of touch. Sign up for this new in-person version of Close Contact for Couples to assist in research about partners living with PD.

FOR MORE INFORMATION

Visit **www.anyonecanmove.com**
or contact **judith@anyonecanmove.com**.

PingPongParkinson®

Fall is a great time for ping pong! Our program in Philadelphia runs every Friday from 2 -3:30 pm at Pingpod, 325 Chestnut Street.

FOR MORE INFORMATION

Contact **santanavelezcarlos@gmail.com**
or visit **www.pingpongparkinson.org/philadelphia**
to sign up.

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The Transmitter *is published biannually to inform the public about Parkinson's disease and other movement disorders. The information contained herein is solely to raise awareness of developments in the field of movement disorders. Nothing written in this newsletter should be used as a guideline for treatment.*

800.789.PENN
PennMedicine.org

The Parkinson's Disease and Movement Disorders Center is a Parkinson Center of Excellence.

The Parkinson Council News

24th Annual Walk to Stamp Out Parkinson's

Saturday, November 1, 2025 @ 11:00 am - 2:00 pm
Philadelphia Navy Yard – Central Green

Join The Parkinson Council's oldest and largest community awareness and fundraising gathering in the Philadelphia region to celebrate **24 years of A Walk to Stamp Out Parkinson's** at the iconic Philadelphia Navy Yard.

The theme for this year, **"Caring in Motion,"** ensures that local families have the momentum and support they need to face a Parkinson's journey. Whether this is your first walk or you are a couple of decades in, each step taken funds programs and services that families depend on to support one another, including care-partners.

Family, friends, colleagues, and healthcare providers are part of our movement against Parkinson's disease. What is even better is that the funds raised at the Walk stay in our region.

For event information and to register, visit **events.theparkinsoncouncil.org/walk2025** or scan the QR code for the event website.