



The Transmitter

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

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THE PPMI (Parkinson's Progression Markers Initiative) UPDATE

PPMI is a landmark initiative to better understand and measure Parkinson's disease (PD). PPMI follows people —with and without Parkinson's— over time to learn more about how the disease starts and changes. This information may lead to insights and tools that can help better diagnose, treat, and even prevent brain disease.

A Landmark Parkinson's Study –

PPMI *By Maggie McGuire Kuhl, Vice President, Research Engagement
The Michael J. Fox Foundation for Parkinson's Research*

In 2010, The Michael J. Fox Foundation and a core group of academic scientists and industry partners launched the Parkinson's Progression Markers Initiative (PPMI) to track critically needed biological markers of Parkinson's onset and progression.

The goal was to identify biological markers of Parkinson's risk, onset, and progression to better inform the development of new and better PD treatments. Since then, the study has changed the way research is done and what scientists know about the brain. It is a cornerstone of our understanding of disease and has informed the design of dozens of therapeutic trials.

Since its inception, this landmark international study has successfully partnered with many other institutions to create a robust open-access data set and biosample library to speed scientific breakthroughs and new treatments. PPMI has engaged scientists, industry experts, philanthropic partners, and — most importantly — study volunteers.

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(continued from cover)

A Landmark Parkinson's Study – PPMI

The University of Pennsylvania Health System and its patients have long been critical to the study and continue to fuel its contributions.

Recent and Ongoing Enrollment

PPMI follows people—with and without PD—over time to learn more about how disease starts and changes. That information may lead to insights and tools that can help better diagnose, treat, and even prevent brain disease.

In 2020, PPMI tripled its enrollment from its original 1,400 and added online data capture for tens of thousands. Currently there are approximately 2,200 participants enrolled (with a goal of 4,000) at about 50 sites worldwide. The study cohorts include people with PD, those who are not yet diagnosed but do report risk factors and/or parkinsonian symptoms, and, for comparative purposes, there are also healthy controls with no symptoms.

A New Biomarker

Just this year, PPMI announced a breakthrough in the hunt for biomarkers, or objective measures of disease. Using spinal fluid, researchers developed a laboratory test that can detect dysfunction in the alpha-synuclein protein, a known culprit in PD pathology. (See Andrew Siderowf's article in this edition of *The Transmitter*).

Biomarkers will transform clinical care, allowing doctors to diagnose patients in the earliest, pre-symptomatic stages of PD and tailor treatment to individual cases and disease subtypes. Biomarker identification will also revolutionize drug development and clinical trials as scientists are able to measure treatment effectiveness more clearly.

Parkinson's Biomarker Breakthrough

A Look at How aSyn-SAA Works

A new spinal fluid test called aSyn-SAA, the most significant breakthrough yet in the search for a Parkinson's biomarker, detects disease in the alpha-synuclein protein with great accuracy — even before symptoms arise. **Here's how it works:**

A Powerful Tool for Detecting Parkinson's



Synthesize normal alpha-synuclein in a lab.



Combine normal protein with a spinal fluid sample from a PPMI participant.



If the normal protein clumps, Parkinson's disease is present.

Making Drug Trials Faster, Smarter and Cheaper



Identify the right people for the right studies.



Making trial outcomes clearer, so we can tell if treatments are working.



Earlier detection sets the stage for testing therapies that could prevent PD.

Our Roadmap Forward



Integrate aSyn-SAA into ongoing drug trials.



Develop the first biological staging of Parkinson's to make all trial outcomes clearer.



Fund research using the test to deepen understanding of Parkinson's biology and disease subtypes.

Graphic provided by The Michael J. Fox Foundation

You Can Get Involved

Anyone can join PPMI. The study's online platform is open to anyone, with or without Parkinson's, aged 18 and older.

PPMI is especially interested in partnering with:

- People with diagnosed with Parkinson's in the past two years and not yet taking PD medication.
- People aged 60 or older without Parkinson's.
- People without PD and without known risk factors who are interested in acting as control volunteers at a clinical site.

If you would like to volunteer for PPMI, please visit www.michaeljfox.org/ppmi to get started.

PPMI and Research *at Penn Medicine*



Andrew Siderow, MD, MSCE

For over a decade, the Parkinson's Progression Markers Initiative (PPMI) study has been collecting samples, like spinal fluid, and clinical data on patients with PD as well as people at risk for Parkinson's and healthy control subjects.

Throughout this time, the Parkinson's Disease and Movement Disorders Center (PDMDC) at Pennsylvania Hospital has been a core recruiting site. The value of these banked samples and long-term clinical follow up is amply demonstrated in a recent research paper in *The Lancet Neurology*, perhaps the most impactful of all neurology specialty journals. The study showed that the build-up of abnormal protein deposits linked to PD in cerebrospinal fluid can accurately detect patients with the disease. In addition, the findings suggest that the test can identify at-risk people and those with early, non-motor symptoms prior to diagnosis, which will set the groundwork for early detection and the prevention of disabling motor symptoms, like tremors.

Penn Medicine Research

Researchers at Penn Medicine are a major part of the PPMI team, which is an international consortium supported by The Michael J. Fox Foundation. The effort at Penn is spearheaded by Professor of Neurology Nabila Dahodwala, MD, and Charles Bae, MD, MHCI, an associate professor of Sleep Medicine and Neurology. Daniel Weintraub, MD, Professor of Psychiatry at Penn, and I both serve on the PPMI steering committee and contributed to the Lancet publication.

What our research confirms is that the technique known as α -synuclein seed amplification assay (α Syn-SAA) is highly accurate at identifying PD patients and classifying them based on genetic and clinical markers. α Syn-SAA works by increasing the amount of abnormal alpha-synuclein in samples from Parkinson's patients to the point that they can be detected using standard laboratory methods. This approach builds on the ground-breaking discovery of synuclein protein deposits as a biological hallmark of PD by researchers including Penn Medicine's Virginia Lee, PhD, the John H. Ware 3rd Professor in Alzheimer's Research in Laboratory Medicine Pathology, and the late John Q. Trojanowski, MD, PhD, former professor of Geriatric Medicine and Gerontology in Pathology and Laboratory Medicine.



The Lancet Neurology paper outlines α Syn-SAA results from more than 1,100 PPMI participants, including individuals with PD, those with genetic or clinical risk factors but not yet diagnosed with Parkinson's, and control volunteers. Samples of cerebrospinal fluid – which surrounds the brain and spinal cord – were analysed using α Syn-SAA. The large-scale analysis confirms previous, smaller reports that α Syn-SAA gives positive results in 88 percent of all participants with PD, both cases that occur in families and carry specific genetic variants (genetic cases) and those that do not include genetic variants (sporadic cases). Over 95 percent of control volunteers had negative test results.

In addition, a portion of participants had conditions that are known precursors to PD, without a diagnosis. These conditions include rapid eye movement (REM) sleep behavior disorder, and unexplained loss of sense of smell. Among those recruited based on their loss of smell, 89 percent had positive α Syn-SAA results. Similarly, in REM sleep behavior disorder, positive α Syn-SAA results were present in 85 percent of cases. Results were also positive in some participants who carried genetic variants associated with PD but had no clinical manifestations of disease.

Future Implications of α Syn-SAA

This research has important implications for finding better treatments for Parkinson's disease. While the research does not directly herald a new therapy, α Syn-SAA will undoubtedly be integral for testing therapeutics in the future. The central role of α -synuclein in the cause and progression of PD is well-established. Until now, the field did not have a reliable way to measure this pathology. α Syn-SAA has given us this crucial missing piece and with it a way to test drugs faster and more accurately.

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PPMI—Recruiting Diverse Groups

*Nabila Dahodwala, MD, MS, and
Ashwini Ramachandran, Research Coordinator*

For over a decade, the PDMDC has partnered with the Michael J. Fox Foundation on the Parkinson's Progression Markers Initiative (PPMI) with the aim of obtaining valuable information from individuals—both with and without Parkinson's Disease—to gain a deeper understanding of PD onset and progression. The participants in this unique observational study have contributed to ground-breaking findings in understanding the risk of PD, new diagnostic tests (including the new alpha-synuclein seeding assay described by Dr. Siderowf in this newsletter) and markers and predictors of disease progression which have revolutionized the ways in which we diagnose PD and design clinical trials to develop new therapies.

Our PPMI research is led by Andrew Siderowf, MD, national co-principal investigator (PI); Nabila Dahodwala, MD, site PI; and Ashwini Ramachandran, project manager. Our amazing team of research coordinators includes Amanda Cruz, Grace Lamoure, Ryan Manzler, Theo Kapogiannis, and Ritikha Vengadesh. Katie Horton is our research administrator.

We are currently broadening our PPMI recruitment to reach more diverse individuals to gain an even better understanding about PD biology and experience and, ultimately, prevention. In addition to those who have been diagnosed with PD, the study is now recruiting individuals who have lost their sense of smell, and individuals who have REM sleep behavior disorder. The study also has an online platform that is open to anyone over the age of 18.

Those who have participated in the study have already contributed to new understanding of PD biology and experiences, with the study's findings informing more robust clinical research.

We currently are following 140 participants at our site: forty-four have PD, there are ten healthy controls, and the rest belong to those who are at higher risk for Parkinson's. This year alone we recruited eight new PD participants, with a total of 25 PD participants over the previous two years.

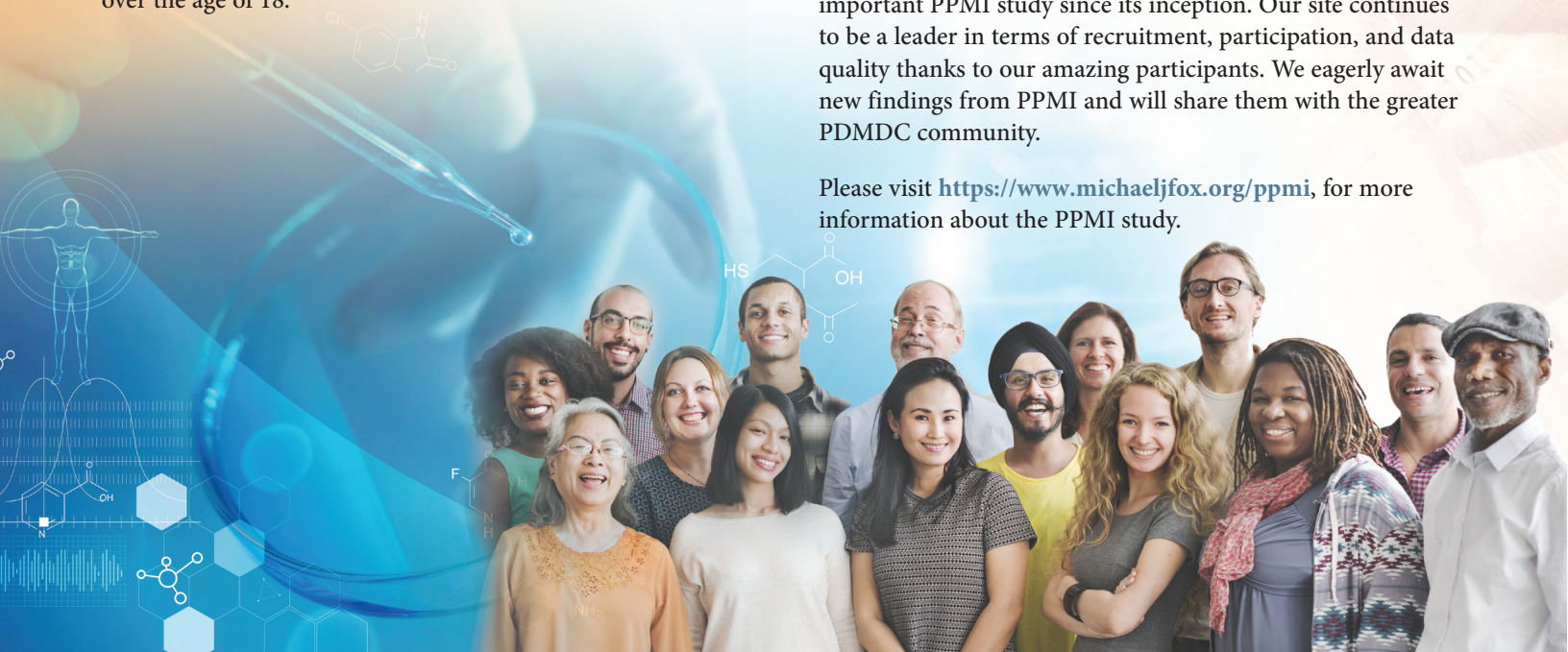
We are open to recruiting as many PD participants as we can through the end of the year. Recruitment has been a challenge for the PD cohort as they need to be newly diagnosed (two years since diagnosis) and not be on any medications that treat Parkinson's.

In addition to those who have been diagnosed with PD, the study is recruiting individuals who have lost their sense of smell and individuals who have REM sleep behavior disorder. These individuals are known as the "prodromal" group.

Although we have met our initial goals for recruitment, we will accept PD participants and healthy controls through the end of the year, and we will continue recruiting for the prodromal cohort through the end of 2024.

Our team at the PDMDC is honored to be a part of this important PPMI study since its inception. Our site continues to be a leader in terms of recruitment, participation, and data quality thanks to our amazing participants. We eagerly await new findings from PPMI and will share them with the greater PDMDC community.

Please visit <https://www.michaeljfox.org/ppmi>, for more information about the PPMI study.



National FAMILY CAREGIVERS Month



Lauren Zelouf, MSW, LCSW

For National Family Caregivers Month this November, we honor our resilient, resourceful, and hard-working care partners who provide a constant source of support to their loved ones with Parkinsonism, which includes PD

and the various atypical parkinsonian syndromes. Having a supportive care partner helps to improve the quality of life and overall wellbeing of the person with Parkinsonism. Our care partners are a pillar of the care team. They carry the vital role of managing their loved one's care day-to-day and advocating for their needs throughout the disease journey.

Please note we use the term "care partner," as it is an inclusive term for all stages of care needs. Care partners for a Parkinsonian patient fill numerous roles and take on so many responsibilities over the course of this disease. The care partner serves as a support person at the time of diagnosis and assists with activities of daily living as needed. Often, the care partner provides care coordination and emotional support while navigating the disease.

We want to empower care partners and give them the tools they need to feel equipped in their loved one's journey. This journey is both long-term and uncertain due to the nature of neurodegenerative disease. Care partners are tasked with supporting a person physically, mentally, and emotionally given the many motor and non-motor symptoms that come with PD. The care partner's role is challenging, as they constantly need to adjust to the changing symptoms over time. Our goal is for care partners to understand the huge range of symptoms caused by the disease, be knowledgeable about available resources, have access to self-care techniques for coping, and feel connected to a supportive community.

We aim to accomplish this through engaging care partners in the Living Well at Home: Care Partner Series, a virtual meeting for care partners specifically on the Zoom video platform. A new schedule is released at the beginning of each month, which includes a speaker event and four support groups that meet at a specific time.

The speaker event is either educational or focused on wellness. Past speakers have included a yoga therapist who provided strategies to de-stress and reduce exhaustion; an elder law attorney who explained Medicaid/asset protection planning for long-term care costs; and our clinical neuropsychologist who spoke on the cognitive changes in PD.

Uniquely, we offer a support group for adult children of people with Parkinsonism. The variety of speakers and support groups we offer cater to the varying needs of the care partners we serve.

Please join us for future speakers and groups. To be added to the Care Partner Series email list, contact lauren.zelouf@pennteam.upenn.edu

CARING FOR THE Carer



Caring for the Carer is a six-session online learning forum dedicated to education, resources, support, and empowerment of Care Partners of people with Parkinson's Disease.

The program meets online via Zoom the second Saturday of the month from 10 am to 12 pm beginning Saturday, October 14th.

2023 MEETINGS DATES:

- October 14, 2023
- November 11, 2023
- December 9, 2023

2024 MEETINGS DATES:

- January 13, 2024
- February 9, 2024
- March 8, 2024

For more information or to register please contact Julia Wood at jmwood525@gmail.com.

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DONOR'S Corner

Caring for the Carer is supported by the George C. Beyer Caregiver Wellness Fund. This fund was established in 2015 by Karen Beyer who cared for her husband George during his 12-year struggle with Parkinson's disease. Karen often remarked that she felt fortunate that she had resources to care for her husband but also knew the emotional toll that caregiving could take on an individual.

"My intention for creating the GCB Caregiver Wellness Fund was threefold: to honor caregivers and respect all aspects of caregiving; give hope and perseverance to care givers; and connect caregivers through education and support. It is so important to not feel alone as a caregiver." Karen pointed out that once she got over the anger she felt after her husband's diagnosis and worked toward gaining acceptance, she was able to separate out PD from the man that she loved. Her gift to the PDMDC for the caregiver fund honors George's memory and brings programs to people who are currently facing the challenge of caregiving.

For more information or to find out how to support the George C. Beyer Caregiver Wellness fund, call **Suzanne Reichwein** at 215.829.7273.

Diversity, Equity, and Inclusion **INITIATIVES**

Amanda Cruz, Clinical Research Coordinator, University of Pennsylvania

With the advancement of research in Parkinson's disease, especially at our center, we are committed to recruiting a diverse pool of participants to ensure that results are representative of all races and ethnicities. In efforts to address racial disparities in PD, the center has been a part of two separate studies aiming to identify and understand the causes of these disparities and find ways to mitigate them.

The Fostering Inclusivity in Research Engagement for Underrepresented Populations in Parkinson's disease (FIRE-UP PD) study focused on understanding the barriers which prevent underrepresented populations from getting involved in research. This study included an intervention phase focused on building trust in the community. It also measured trust in medical research through surveys administered to our patients and their caregivers. The FIRE-UP PD study has helped us understand these barriers and work towards mitigating them.

Our current study is the National Institutes of Health (NIH) Racial Disparities in Parkinson Disease which aims to identify potential differences between Black and White people with PD, including how PD looks, how it is managed, and genetic variability. We are asking both Black and White patients with PD to partner with us to better understand how PD affects the lives of a broader, more diverse group of people with PD than has been traditionally reported.

It is critical that in addition to our goal of recruiting participants, we also build awareness and trust in the community by being a present and consistent resource.

To this end, many of the movement disorder specialists and social workers at the PDMDC have partnered with the Delaware Valley Endeavor for Racial Solidarity in PD (DIVERSITY-PD). This group works collectively with providers within the Philadelphia area to spread awareness about Parkinson's and brain health within the Black and Brown communities, along with sharing resources of where to seek clinical advice. Additionally, the PDMDC has re-established a support group specifically for patients of color with PD.

OUR UPCOMING RECRUITMENT EVENTS INCLUDE:

- **The Parkinson's Council walk** on November 4th at the Philadelphia Navy Yard.
- **DIVERSITY-PD collaborative event** in late April 2024, just in time for Parkinson's Awareness Month.

If you would like to get involved with the support group or the studies, please contact **Amanda Cruz** at 215.829.7128.



The Parkinson Council News

By Wendy Lewis, Director

THE PARKINSON COUNCIL
A WALK TO
STAMP
OUT
PARKINSON'S



NOV 4



AT PHILADELPHIA NAVY YARD

Join The Parkinson Council's oldest and largest community awareness and fundraising gathering in the Philadelphia region.

This year's theme for A Walk to Stamp Out Parkinson's is **"Circles of Support."** It's important to have a team of people around you throughout the Parkinson's journey.

Whether it's family, friends, colleagues, or healthcare providers, a solid circle of support is vital to help you stay active, engaged, and empowered. Let us come together and be circles of support!

For more information and to register, go to:
<https://events.theparkinsoncouncil.org/walk2023>



WELCOME the Newest Members of the PDMDC

FELLOWS

Carly Marshall, MD, received her medical degree in 2019 from Indiana University School of Medicine. She completed her internship and neurology residency at the University of Michigan. As a fellow at the PDMDC, she looks forward to learning all about movement disorders while exploring career and research interests in medical education, physician wellness, and social determinants of health.

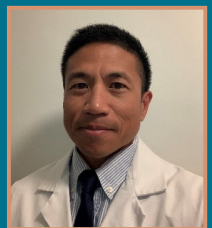


Joaquin Vizcarra, MD, earned his medical degree from Universidad Peruana Cayetano Heredia in Lima, Peru. His professional journey includes a movement disorders research fellowship at the University of Cincinnati, an internal medicine internship, and a neurology residency at Emory University, where he served as chief resident. Joaquin is the co-vice chair for the Parkinson's eDiary Development Working Group, sponsored by the International Parkinson and Movement Disorder Society (MDS). His primary academic interests include clinical research in Parkinson's disease and ataxia.



NURSING

Gavin Villacorta, MSN, CRNP, received his BSN and MSN from Villanova University. He was an inpatient bedside RN for five years and a unit-based RN educator for two years at Penn Presbyterian Medical Center in Philadelphia. In April 2023, he joined PDMDC as a nurse practitioner. He has a long-standing interest in providing care to adult populations with Parkinson's disease. He is an avid runner and enjoys exploring Philadelphia with his wife and young son.



Stephanie Bash received her BSN from Holy Family University in 2020. In March of 2021, she started her nursing career in Pennsylvania Hospital's operating room (OR) as part of the ENT/neurosurgery teams, and became interested in deep brain stimulation (DBS) surgery. As a nurse at the PDMDC, Stephanie looks forward to working with a team of providers to follow the progression of each individual patient.





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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.

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

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Events AND Programs

Living Well at Home

Online series of groups, classes, and educational program. Contact sreichwein@pennmedicine.upenn.edu to get on the mailing list.

Dance for PD at the Willow Grove YMCA

We are dancing in person at the Y every Friday at 1 pm. Join us for an hour of movement and music every week. For more information, please contact Judith Sachs at www.anyonecanmove.com/contact-us.

PingPongParkinson®

Data shows that table tennis hits the trifecta for people with Parkinson's: physical, mental, and social engagement. PingPongParkinson (PPP), a non-profit (501 (c) (3) organization, was founded in 2017, and its mission is to create a global community.

Come join the Philadelphia PingPongParkinson group every Monday from 2 -3:30 pm at Pingpod, 325 Chestnut Street. Contact sreichwein@pennmedicine.upenn.edu for more information.

