

JUNE 2023

Barbara Marquardt, Editor, M.Ed., MCHES, WCP, RYT

JUNE MEETING—Wednesday, June 7, 2023 – 2:15 p.m.

We welcome back **Amy Chan, Physical Therapist** at the **Cleveland Clinic** who is a Board Certified Clinical Specialist in Neurology in their Rehabilitation & Sports Therapy Center. Amy has worked with a number of our members and is well regarded. She will speak on Balance and Vestibular Disorder in Parkinson's Disease

Cleveland Heights Senior Activity Center/One Monticello Blvd., Cleveland Heights, OH 44118

July Meeting—July 5, 2023 We welcome Fatima Perkins from the Western Reserve Area Agency on Aging who will talk on many of their wonderful programs and services for those living in Cuyahoga and surrounding counties. Fatima will focus on their Family Caregiver Support program.

From David Brandt

We've seen many advances in research for PD over the years. In past year, we have had speakers at our PEP meetings talk of these advances, whether it be local such as studies done by Steven Gunzler at University Hospitals or Angela Ridgel and her studies at Kent State University. We had Ignacio Mata speak in April about all of the advances in genetics that he and others have done. Later in the year, we will have someone talk on The large PPMI project going on.

Another research milestone was recently reached when researchers discovered of a new tool that can reveal a key pathology of the disease, abnormal alpha-synuclein in brain and body cells. **This biomarker opens a new chapter for research. See the article in this newsletter for more details.** I am looking forward to more advances in the coming years.

Upcoming Events

Friday June 9, 2023 Living In Motion – Put on by InMotion in partnership with the Ohio Parkinson Foundation Northeast Region. Time is 9:30 a.m.–12:30 p.m., 23905 Mercantile Rd, Beachwood, 44122 Living In Motion is an opportunity for people affected by Parkinson's disease to learn about InMotion™ as well as other resources available to them. The event will feature:

- ♦ Exercise class demos—Experience InMotion's™ evidence-based exercise classes designed to help people with Parkinson's disease.

- ♦ Wellness Education + Support Information—Meet professionals in social work, physical therapy, occupational therapy, nutrition and more.
- ♦ Medical + Pharmaceutical Partners—Learn about the latest breakthroughs in treatments for PD
- ♦ PLUS—Learn how YOU can become an InMotion™ client and take our classes free of charge. We're HERE FOR YOU!

EVENT KEYNOTE SPEAKER: Michael Okun, MD

- ♦ Topic: "Ending Parkinson's Disease and Updates in Research"
- ♦ Dr. Okun is Chair of Neurology, Professor and Executive Director of the Norman Fixel Institute for Neurological Diseases at the University of Florida Health College of Medicine.

Saturday June 10—Moving Day put on by the Parkinson's Foundation. Brookside Reservation, 11 a.m., 3900 John Nagy Blvd., Cleveland, OH 44144.—For more information, contact Alexis Caldwell, 614-918-7307 | acaldwell@parkinson.org

Participants are invited to put on their Moving Day gear and join us at Moving Day Cleveland. The event will put our community's energy on full display as we celebrate movement together. Bring friends and family to exercise, learn about Parkinson's resources, take part in our signature *We Move Ceremony*, and, of course, enjoy the *Moving Day Walk*. Don't miss this inspiring day we have planned for you!

Breaking News: Parkinson's Disease Biomarker Found

(Excerpt from www.michaeljfox.org)

In an enormous leap forward in the understanding of Parkinson's disease (PD), researchers have discovered a new tool that can reveal a key pathology of the disease: abnormal alpha-synuclein — known as the “Parkinson's protein” — in brain and body cells. The breakthrough, announced last night as it was published in the scientific journal *The Lancet Neurology*, opens a new chapter for research, with the promise of a future where every person living with Parkinson's can expect improved care and treatments — and newly diagnosed individuals may never advance to full-blown symptoms.

The tool, called the α -synuclein seeding amplification assay (α Syn-SAA), can detect pathology in spinal fluid not only of people diagnosed with Parkinson's, but also in individuals who have not yet been diagnosed or shown clinical symptoms of the disease, but are at a high risk of developing it.

The assay can confirm the presence of abnormal alpha-synuclein, detected in most people with PD, with astonishing accuracy: 93 percent of people with Parkinson's who participated in the assay were proven to have abnormal alpha-synuclein. “We've never previously been able to see in a living person whether they have this alpha-synuclein biological change happening in their body,” says Todd Sherer, PhD, chief mission officer, The Michael J. Fox Foundation (MJFF).

The biomarker breakthrough was achieved by an international coalition of scientists led by MJFF and its landmark clinical study, Parkinson's Progression Markers Initiative (PPMI). Its significance as a milestone in the pursuit of a cure and better treatments and therapies for Parkinson's is highlighted in an article today on leading health and science news website STAT, which stated “The trophy is science — and specifically research funded by the Michael J. Fox Foundation for Parkinson's Research that has resulted in the clearest evidence yet that the presence of a particular misfolded protein, alpha-

synuclein, can be used to determine if people have Parkinson's. It is an advance that may soon be used to develop better diagnostics, but more importantly could rapidly accelerate the search for treatments for the disease.” [Read the article here.](#)

A protein normally found in the nervous system, alpha-synuclein — like amyloid in Alzheimer's disease — can start to misfold and clump, damaging neurons and causing Parkinson's disease to develop. It has previously been possible to confirm the presence of these clumps only through postmortem analysis.

The new tool cleverly takes advantage of a telling characteristic of alpha-synuclein that is pathologic: it causes nearby, normal alpha-synuclein to also misfold and clump. For the assay, spinal fluid samples are prepared with a fluorescing agent that lights up if alpha-synuclein clumps form. Normal alpha-synuclein is then seeded into the spinal fluid sample. If abnormal alpha-synuclein is present in the sample, clumps form and the dye lights up. If no abnormal alpha-synuclein is present, the dye doesn't fluoresce.

After being tested in small, independent studies, in 2022 the assay was validated in the large, well-characterized cohort of PPMI. The validation was carried out in some 1,123 samples of spinal fluid contributed by PPMI participants over the years. The assay proved amazingly accurate, with 93 percent of participants with Parkinson's having an abnormal test. (Very few tests for neurologic disorders are over 90 percent sensitive for disease.) And, importantly, the test was abnormal in less than 5 percent of people without Parkinson's.

Steady and critical advances in the pursuit of a reliable and accurate biomarker test have been the hallmark of PPMI, which was built for this purpose. The discovery enabled by the new test is the latest, and most significant, finding to date from the study.

(Cont'd on pg. 3)

DISCLAIMER: The material contained in this newsletter is intended to inform. PEP makes no recommendations or endorsements in the care and treatment of Parkinson's disease. Always consult your own physician before making any changes. No one involved with the newsletter receives financial benefit from any programs/products listed.

Parkinson's Disease Question Corner

Email: barbaramarquardt@outlook.com

Question: What are some examples of neurotoxins that damage the brain?

Answer: The following neurotoxins are known to damage the brain, and would be good to avoid:

1. Mercury
2. Lead
3. Aluminum
4. Arsenic
5. Excessive alcohol & illegal prescription drugs
6. Fluoride
7. DDT/DDE
8. Pesticides & herbicides
9. Polychlorinated Biphenyl's (PCB'S)
10. Aspartame
11. Monosodium Glutamate (MSG)
12. Flame retardants (PBDE'S)
13. Polycyclic Aromatic Hydrocarbons

Ref: www.drjockers.com

Breaking News: Parkinson's Disease Biomarker Found *(Cont'd from Page 2)*

Today, with this discovery in hand, Parkinson's is moving from a disease primarily understood, diagnosed and measured through subjective clinical assessments to an objectively biologically defined disease — which makes possible new paradigms for clinical care, including earlier diagnosis and targeted treatments, and faster, smarter and cheaper drug development.

By helping to identify people at the earliest stages of PD, "We could then study what happens at different biological stages of the disease," says Dr. Sherer. Says Ken Marek, MD, PPMI principal investigator, "αSyn-SAA enables us to move to another level in effecting new strategies for prevention of disease."

The expansion of PPMI to increase volunteer recruitment efforts and remote testing for those at-risk for PD, as well as expanding efforts to enable breakthroughs such as αSyn-SAA, is supported by

major funding from Aligning Science Across Parkinson's (ASAP), a coordinated research initiative focused on accelerating the pace of discovery and informing the path to a cure for Parkinson's. In addition to ASAP, PPMI is supported by the Edmond J. Safra Foundation, the Farmer Family Foundation, Connie and Steven Ballmer, and Susan and Riley Bechtel.

MJFF is urgently driving the next stages of development of αSyn-SAA toward widespread and standard use. Since today the tool can elicit a binary response — showing that abnormal synuclein is either present or not — there is tremendous promise in optimizing it, in order to measure the amount of alpha-synuclein present. Optimized assays would also detect abnormal synuclein through blood draw or nasal swab — a simple test that could be done in any doctor's office.

"I'm moved, humbled and blown away by this breakthrough, which is already transforming research and care, with enormous opportunity to grow from here," says Michael J. Fox. "I'm so grateful for the support of patients, families and researchers who are in it with us as we continue to kick down doors on the path to eradicating Parkinson's once and for all."

Read more of Michael J. Fox's thoughts on the historic importance of the biomarker breakthrough and its implications for "biology's century" in his opinion piece published today in STAT. [Go to article.](#)

PTSD Linked to Increased Risk of PD in Meta-Analysis

(Excerpt from parkinsonsnewstoday.com)

People with post-traumatic stress disorder (PTSD) were found to be at a higher risk of PD or related neurodegenerative conditions, a small meta-analysis suggests. "The small number of studies to date provide preliminary evidence of an association between mid- to late-life onset PTSD and subsequent development of PD and related neurodegenerative synucleinopathies," the researchers wrote in "Post-traumatic stress disorder and risk of degenerative synucleinopathies:

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PTSD Linked to Increased Risk of PD in Meta-Analysis *(cont'd from pg. 3)*

More research is needed to understand this potential relationship, they said, noting such studies must include standardized neuropsychiatric assessments, more detailed clinical profiling, and longer-term follow-up.

PD is a neurodegenerative disease marked by the toxic buildup in the brain of the alpha-synuclein protein. Mental health conditions such as anxiety and depression are known to be early symptoms of PD, emerging before its hallmark motor symptoms in many cases. Indeed, both depression and anxiety have been associated with an increased risk of PD.

PTSD is a mental health condition where people who've had a fear-inducing trauma continue to experience

feelings of significant stress even when they're no longer in danger. It's highly prevalent in military veterans, potentially affecting more than 20%, but it also occurs in victims of abuse or those who've undergone physical, sexual, or emotional trauma. Emerging evidence suggests a relationship between PTSD and the later emergence of PD or other neurodegenerative diseases.

We need your donations to continue bringing you the PEP News and for other expenses. A special thanks to those who contribute at the monthly meetings. To send a donation, please make your checks payable to Parkinson Education Program and mail to 2785 Edgehill Rd., Cleveland Heights, OH 44106

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TRIBUTES

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