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Parkinson Press

Parkinson Partners of NW PA, Inc. (814) 899-3030 www.parkinsonpartners.org

“You are not alone.”



Parkinson Partners' Mission Statement: To encourage, educate and support those with Parkinson's disease, their caregivers and loved ones as they cope with the challenges of disease. Exploring better resources, services and outcomes for people with PD.

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Please remember Parkinson Partners in your estate planning. Your gift can ensure that local services and support continue for the Erie PD community.

Parkinson's Disease Biomarker Found

April 13, 2023—from the Michael J. Fox Foundation: 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.”

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. 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. **Continued on Page 4**

News and Notes

The Basics & Beyond

Webinar Recording: Here is the link for the recording of the April 21st webinar. The passcode is required and is listed below. Please note: there is a O (capital O) not a zero in the passcode. If you are getting an error message, please check that first. One solution is to copy and then paste the passcode into the box.

https://us06web.zoom.us/rec/share/befjO1FwArSEg_0X_86lJV6cnnnglYR6Wkqg4tDe9Bi0Z3SQZRQkhYObb_IHWwaQk.FOTTcYnMnVb6bIhM?startTime=1682095266000

Passcode: +75320@8

Social Clubs with Small

Games of Chance: Did you know that clubs that offer small games of chance in PA are required to donate some of the proceeds to charity? If you or someone you know is a member a social club, we would be very grateful if you would suggest Parkinson Partners as a possible recipient of the proceeds. As a small nonprofit, we rely on donations, fundraisers and grants in order to survive, and we continue to look for new ways to secure funds, all while the need for our services continues to grow, due to the increase in PD diagnoses. We'd appreciate your help and welcome ideas you may have for fundraising ideas.

Mark Your Calendars:

Lake Erie Speedway will be hosting Great Lakes Cars and Coffee, a car show in tribute to Elmer "Porky" Chambers on Sunday, July 9th from 8:00 AM-noon. 50% of the gate proceeds will be split between Parkinson Partners and the Alzheimer's Association. For more information go to:

<https://www.lakeeriestracking.com/great-lakes-cars-coffee>

Home PD Exercise Options Including Local Options

Here are some at-home exercise options. The links are LIVE so if you are reading this newsletter online, just right click on the link and you'll be taken directly to the website. Remember to consult your physician before starting any new exercise program.

Local: Our Purposeful Movement and Wellness team including Gannon University Professors Dr. David LeVan, OT and Dr. Courtney Roca, PT and retired Professor Tom Hudson, PT along with graduate OT students Taylor Mandley, Lily Bargabus, Ashley Tomasko and Brianna Murosky, Aurora Brown, Lauren Greenlee, Caitlin McKee, Carrie Pratt, Claire D'Amore, Alexandra Gyory, DPT student Brandi Tirado and Radiological Sciences student Riley Fanaro, have created some home exercise videos that you can access on YouTube:

- **NEW:** <https://youtu.be/DKXrGoaizJ8>
- **NEW:** <https://youtu.be/C7Y8rLMUjzA>
- Winter 2021: <https://youtu.be/HqUZ7CyOcjA>
- Winter 2021: <https://youtu.be/shnsCH9rqC8>
- Fall 2020: <https://youtu.be/mowyEaf7qK0>
- Fall 2020: https://youtu.be/PZ62_U84Hq8
- Fall 2020: <https://youtu.be/fFkGBU-vJ90>
- Summer 2020 Part 1: <https://youtu.be/lcsBTPoX1dU>
- Summer 2020 Part 2: <https://youtu.be/l8pjybERaxA>
- Spring 2020 Part 1: <https://youtu.be/-ud1erTZcmA>
- Spring 2020 Part 2: <https://youtu.be/2XiSyoixBfM>

Seated:

- Power for PD: <https://www.youtube.com/channel/UC9QTeS9SMZKbSzDS-nvhr3g/videos>
- Sit and Be Fit: <https://www.youtube.com/user/SitandBeFitTVSHOW/videos>

Seated and Standing:

- Unique Physique Fitness Center: <https://www.facebook.com/watch/UniquePhysiqueFitnessCenter/>
- APDA: <https://www.apdaparkinson.org/free-online-exercise-and-therapy/?eType=EmailBlastContent&eld=4c51adf3-809e-4c84-b67a-623c6512cf34>

LIVE Classes from Parkinson Foundation of Western PA: remember you must pre-register to attend these live classes. There is a large variety of options, so we encourage you to check them out. Thank you, PFWPA for including our group.

- <https://pfpwa.org/exercise/>

Best Wishes for those with Special Celebrations

Happy Birthday and Happy Anniversary to our members!

To have your birthday or anniversary added to our list call 814-899-3030 or email: info@ParkinsonPartners.org

May

4—Charles Ramsey
9—Charles & Linda Ramsey Anniv.
16--Linda Sensor

June

15—Peggy Trichel
19—Patricia & Michael Hall Anniv.
26—Mike Hall
29—Deborah Hakel
30 – Paul Goodwin

PURPOSEFUL MOVEMENT & WELLNESS PROGRAM FOR THOSE WITH PD



If you have PD, you know you should be exercising. Join us for a class specifically geared towards the challenges of Parkinson's disease. Plus, it's FUN! Activities are designed and supervised by an Occupational and Physical Therapists and Gannon University OT and PT students will be available to assist and to provide added safety. Class size is limited, so sign up today!

The Summer Session runs Tuesdays, May 23rd-June 27th from 10:00-11:30 AM at the Salvation Army Senior Center, 1022 Liberty Street. Cost is \$80. Call 814-899-3030 for more information or an application. Applications can also be downloaded from our website:

www.parkinsonpartners.org



Covid Policy: "It is important that you understand the inherent risk of exposure to COVID-19 exists in any public place where people are present. According to the Centers for Disease Control and Prevention, senior citizens and those with underlying medical conditions are especially vulnerable. All attendees of Parkinson Partners of NW PA's in-person events and classes must agree to adhere to our guidelines and the guidelines of our community partners and voluntarily assume all risks related to exposure to COVID-19. We also encourage you to stay home if you are feeling unwell or if you have been exposed to Covid-19, the flu or any other virus."

Parkinson Partners of NW PA, Inc.

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DONATIONS:
Checks should be made payable to "Parkinson Partners" and mailed to the address above. Donations can also be made via PayPal on our website.

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Continued from Page 1: 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."

If you wish to be removed from the mailing list, please call 814-899-3030.

Like us on Facebook!



We're on the Web!

See us at:
www.ParkinsonPartners.org

DISCLAIMER: The material presented in this issue is solely for the information of the reader. It is not intended for treatment purposes, but rather as a basis for discussion with the patient's physician.

Support Group Meeting Schedules

Remember: all events are also listed on our Events Calendar on our website including live links to Zoom meetings.

ZOOM MEETINGS:

- **Parkinson Partners Support Group Meeting** via Zoom on **Wednesdays, May 3rd, 17th and 31st at 1:00 PM.** Join Zoom Meeting:
<https://zoom.us/j/93010770942?pwd=bzhTYTgxVEIXV0pONnYwbEt5TnZzZz09>
- **Parkinson Caregiver Only Support Group Meeting** via Zoom on **May 25th at 1:30 PM.** Join Zoom Meeting:
<https://zoom.us/j/96391675305?pwd=ZHqxbXhnRS9GTGpKdlpTeURHSiJjdz09>

IN-PERSON MEETINGS:

- **Wegman's PD Support Group** will meet at the Peach Street Wegman's on **May 9th at 5:30 PM for newer members with the rest of the group joining at 6:00 PM** in the dining area. All are welcome.
- **Care Partner Only Lunch:** Join other Care Partners for conversation at **Sara's at Presque Isle (moved for the summer) on Monday, May 22nd at 11:30 AM.**