

PEP NEWS

JANUARY 2020

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

JANUARY MEETING

Please note that we will not be having a January meeting.



From David Brandt

As we near the end of 2019, I thought I would share a few words from the Michael J Fox Foundation regarding this year and next and the optimism that abounds.

As we count down the last days of 2019, The Michael J. Fox Foundation is reflecting on the momentum we've built together with the patients, families, caregivers, researchers, industry partners and donors who are part of our community.

Today, we are amid the most robust Parkinson's disease (PD) drug development pipeline ever. And we are primed for the next breakthrough. Our landmark clinical study, the Parkinson's Progression Markers Initiative (PPMI), has built the most robust data and biospecimen library in Parkinson's research history, influencing the future of PD research and pushing the field closer to better treatments and a cure.

We also look ahead to 2020 with optimism for new opportunities to make Parkinson's history. As Michael J. Fox shared with Bloomberg earlier this year, "I'm absolutely sure we are on a path to answer the questions about what causes Parkinson's and how to cure it."

In fact, we're on the cusp of getting answers into treatments against leading genetic targets — alpha-synuclein, LRRK2 and GBA — that will have implications for the future of therapies that can stop or slow disease progression. Next year, PPMI will expand to lay groundwork for future prevention trials. And technology-

enabled research — from wearables to online studies — is complementing therapeutic development, connecting virtually with tens of thousands of PD patients and families. Because people are at the heart of everything we do.

Happy Holidays and Happy New Year!

Upcoming events in the area.

- April 4, 2020 – 22nd Annual Parkinson Symposium from Ohio Parkinson Foundation Northeast Region / 10 a.m. – 2:30 p.m. Location: Hilton Garden Inn Twinsburg, 8971 Wilcox Dr., Twinsburg, OH 44087. Check in begins at 9 a.m.
 - * Highlights: Join in this Outstanding Annual Community Program of Sharing and Learning There is no charge for this event.
 - * Door Prizes & Free Lunch Provided
 - * Donations Welcome Register by March 30, 2020
 - * Call 1-800-630-3193. Your phone registration will be your confirmation - online registration coming soon.

TRIBUTES

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 17930 Birch Hill Drive; Chagrin Falls, OH 44023

Parkinson's Disease Question Corner

Email barbaramarquardt@outlook.com with questions!

Question: Do you know of an at-home test that could help improve my brain function?

Answer: Yes, it is an at-home test called **BrainSpan**!

To date, it is the only tool validated to improve fatty acid levels and nutritional compliance at an average of 60+% with an associated improvement of brain function of 30%.

The test looks at 7 Metrics: Three cell fatty acid markers to include RBC Omega-3 Index, AA/EPA Cell Ratio, Cell Palmitic Acid and four cognitive functional indices including memory, speed, focus/attention, and flexibility.

Your results will be in a detailed, 10-page report that's highly engaging, easily understood, graphically illustrated. The report includes trend analysis and provides personalized, evidence-based nutritional and lifestyle recommendations.

Visit <https://brainspan.com/how/> for an introduction to **BrainSpan**, and to learn how it works. To order, visit www.brainspan.com or call the Help Desk at 1-800-535-1518, M-F 10:00am-7:00pm.

Musical Therapy Study to Receive \$20 Million in Funding

(Excerpt from www.Parkinson.eu)

The National Institutes of Health (NIH) is donating US \$20 million to a medical trial researching the effects of musical therapy on brain conditions, including Parkinson's.

The trial will be carried out by the Sound Health initiative, a joint partnership between the NIH and The John F Kennedy Center for the Performing Arts. The initiative was created to expand current knowledge of how listening, performing and creating music could be harnessed for health and wellness.

Francis S. Collins, director of the NIH, said: "We know that the beat of a metronome can steady the gait of someone with Parkinson's disease, for example, but we don't fully understand how that happens.

"If we can pinpoint in the brain how music therapy works through the use of imaging and biomarkers, the hope is that we can improve its effectiveness and apply it more broadly to improve the lives of millions of people."

PEP February 5, 2020 Meeting

We welcome Ben Rossi, owner of ATP Evolution Performance Training Center and co-founder and Program Director of InMotion. Ben will give an interactive discussion on exercise and brain change. It will include Boost exercises that are designed to address specific symptoms of PD.

Cruising With Mobility Issues

(© Cruising with Mobility Issues, Ellen J. Richman, 2019)

Following is the last segment of our two-part series from our PEP meeting guest speaker of September 4, 2019, Ellen Richman. We thank you for sharing this information with us.

Arriving at the Airport:

By arranging a ride to the airport, the non-disabled traveler or your driver can check your luggage (curbside if available) while you wait in the car. If your mobility device is going to stay with you as you proceed to the gate, you can request an assistant to take you all the way to your gate. If you are not using your own wheelchair, you can use one provided without charge by the airline. An airline assistant can help you get through the security area quickly. There is no charge for the service or an assistant, but plan to have cash for a gratuity.

Leave plenty of time before your flight to use the bathroom. Bathrooms on planes are very small and awkward to use with a walker.

Where Does My Mobility Device Go?

If you have your own wheelchair you can take it all the way to the door of the airplane. Then it will be gate-checked and waiting for you at the airplane's door when you arrive at your destination. When you arrive at your gate, check with the gate agent to tag your wheelchair for a gate-check. You cannot take your own wheelchair to your seat. (See note about aisle chairs under Pre-Cruise Arrangements above.)

Airlines have certain restrictions regarding what kind of wheelchairs they will accept. Manual wheelchairs that fold are fine. Check with the airline for any other kind of wheelchair. Most airlines will not accommodate scooters.

You can use your walker to get to your seat. Flight attendants may take the walker and store it for you until your arrival.

Carry-on Luggage:

Be smart when it comes to taking items on the plane with you. If possible use only one carry-on to hold everything. That way the non-disabled traveler will have an easier time assisting the disabled traveler. Remember to take all medications in your carry-on.

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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.

From Airport to Ship:

Most cruise lines provide transportation to the ship for a cost. But their mode of transportation may not be suitable for someone who cannot climb steps into a bus or van. A taxi, Uber or Lyft that has room for your mobility device may be more practical.

Additionally you will have more flexibility in timing your transportation and not have to depend on the cruise line's schedule.

Arriving at the Port:

The port staff is usually very helpful in getting disabled travelers through the registration process. If you complete as much pre-registration documents as possible online, it will shorten your time at the port check-in.

On-board Activities:

Cruise ships offer a wide variety of activities from trivia games to art auctions, to casinos, to Broadway-type shows and more. Just about every site on board is handicapped accessible. Some pools may have lift chairs. Check the ship's newsletter which is distributed every evening and lists what activities are available the following day.

The major evening entertainment is held in the ship's theater and handicapped seating is limited. Best to get there early.

Land Tours:

The cruise line offers various tours at each of the stops. There may be some stops do not have ports large enough for cruise ships to dock in which case the ship will anchor at sea and use tenders (usually large life boats) to take passengers ashore.

Unfortunately, wheelchair users cannot board a tender for this purpose. But ocean cruisers continue to have many activities available during the day for those who remain on board.

Unfortunately, there are very few tours available for wheelchair-bound travelers. Check out the available tours online before you depart. But don't assume that a tour is really accessible just because it is listed as "handicapped accessible." Sometimes these tours require a lot of walking over uneven or hilly terrain, or include water activities that are impractical for a disabled person. You may have more success browsing and shopping around the port, or hiring a private taxi or van to take you where you choose to go.

Disembarking:

Most cruise ships have a service agreement with

major airlines in which they will ship your luggage directly to your destination airport. You can avoid sorting through hundreds or even thousands of bags at the port and taking them through customs. In fact, you won't have to handle your luggage at all until it arrives at your home airport. A few days before the end of your cruise, check with Customer Service to see if you can use this service. There is no charge. If this service is not available to you, be sure to use a port assistant to help you. The assistant will retrieve your luggage and help you move swiftly through customs.

And finally, as with any trip, it's inevitable that something will go wrong whether you're disabled or not. So just smile and enjoy all the wonderful times that go right!

12 of the Best Domestic Tools for People with Parkinson's Resources & Tools

(Excerpt from parkinsonslife.eu)

From attachable plate guards to ergonomically designed grabber tools, there are lots of products that make home living that little bit easier. Here's some of the most useful items for people with Parkinson's

Plate guard – Plate guards can be subtly fitted onto ordinary plates to help those who can only eat with one hand or have an unsteady grip. The inward facing slopes helps with food collection and prevents spillages.

Tailor-made cutlery – Electronic stabilizing handles are designed specifically to help people with hand tremors. The utensils are tailor-made to counteract the effect of tremors and have inbuilt sensors and motors to help combat tremors.

Kettle pouring stand – Making your morning 'cuppa' has never been easier with kettle tippers that helps users pour boiling water without lifting the kettle up – reducing the risk of spills. The frames handily wrap around your kettle, and are held in place with a secure Velcro strap.

Foam tubing – Sliding easily over popular household items such as hairbrushes and toothbrushes, foam tubing gives users a firmer grip – making everyday grooming easy and quick.

Electric razor – Parkinson's symptoms like dyskinesia and tremors can make completing everyday tasks like shaving difficult or dangerous. An electric razor is one simple swap that can speed up a morning routine and avoid nips and cuts.

Grabber tools – Ergonomically designed to mimic how a finger and thumb pick things up, hand grip grabber tools help users reach for things high or low, small or large around the house without stretching or bending.

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PEP NEWS

Parkinson Education Program
of Greater Cleveland
17930 Birch Hill Drive
Chagrin Falls, OH 44023

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We try to keep our roster current. If you no longer wish to receive this bulletin or would like to receive it via email instead, notify Katherine.A.Kaminski@gmail.com or call 216-513-8990.

TRIBUTES

Anonymous

Annabelle and Jerry Hughes

Touch lamps – Touch table lamps help to avoid a struggle with tricky light switches. Simply touch the bases lightly to control the light output and reach the desired brightness, making it that bit easier when settling in for bed.

Reading rest – For those who find it hard to keep a book still, consider a reading rest for a more comfortable reading experience. Simply clip the book in and adjust the angle for when in bed or at a desk.

Button and zip hook – You can find many easy-to-use, low-cost hooks that help combat fiddly buttons and zips while dressing and undressing.

Elastic laces – Get out of the door quicker in the mornings by turning lace-up shoes into slip-ons. Elasticated laces eliminate the need to bend down and tie and untie shoes before leaving the house.

RollerMouse – A wireless RollerMouse sits directly in front of the keyboard and the cursor can be moved by touching the rollerbars lightly. Users can switch control between hands when fatigue sets in – improving accuracy and increasing the amount of time spent online in comfort.

Keyguards – Keyguards are placed above the keys on a standard keyboard and stop people with hand tremors hitting unwanted keys whilst typing. While it slows down typing speed, it improves accuracy and comfort.



**TO REACH US
AT PEP**
440-742-0153
dbrandtpep@gmail.com



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