

# PEP NEWS

JUNE 2020

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

## June Meeting—NO MEETING

Due to the COVID-19 outbreak, our June meeting has been cancelled. We will reschedule our speaker at a later meeting this year. See below regarding opportunities for our meetings to go virtual.

### From David Brandt

We are all itching to get together with family, friends, and also for our support groups. Things are very slowly opening up, but unfortunately, the Cleveland Heights Senior Center has announced that the building is closed for the summer and plans after that are still up in the air. Even though we can't meet in person, we hope and encourage you to take advantage of sites I mentioned last month to stay engaged and informed. Sites such as Michael J Fox Foundation, Parkinson's Foundation, Davis Phinney Foundation, InMotion, etc. give access to webinars, podcasts, virtual programs and exercise videos and are well worth your time to explore.

We also have the opportunity to have some online meetings/presentations from local doctors and other speakers in place of our normal meetings. With that in mind, we need to collect your email addresses so that we can send invitations to these events. We only have email addresses for about 25% of PEP members, so please either send a quick note from your email address to Katherine.a.kaminski@gmail.com or if you prefer, call her at 216-513-8990. We hope to get something set up in the next month or two.

We also want to send our deepest sympathies to Ruth Gettinger upon the passing of her husband Jerry. Jerry was a recent PEP Board Member and he will be deeply missed.

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.

### Upcoming Events

**June 1— 1 p.m.**, Live Local Panel: Fighting off Covid-19 in our Homes now that we're venturing out; how can we stay safe now that we've re-opened locally?  
Clinical Panel:

- Geriatrician, Dr. Barbara Messinger Rapport, Montefiore, Louis Stokes VA Hospital, Cleveland Clinic.
- Nurse, Roberta Brofman, Infection control Consultant to 18 local nursing homes and home health companies.
- Moderator, Rabbi/Chaplain Shalom Plotkin, Owner of Right at Home Beachwood; the top rated private duty home care agency on the East Side of Cleveland.

Zoom Meeting ID: **554 815 0790**

Zoom Call in number: 646 558 8656

**September 13** – Pals in Motion Run/Walk/Yoga/Obstacle Course Orange High School

**September 26 \*\*PLEASE NOTE REVISED DATE\*\* – 22<sup>nd</sup> Annual Parkinson Symposium** — 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. and highlights include Attorney John Baumann who was diagnosed with PD at age 41 and is now an internationally recognized speaker. Also "Be Alive" with Drums Alive!. Experience this evidence based participatory journey to brain and body health, fitness and wellbeing with music, movement and rhythm that is designed to renew the spirit and ignite your passion. Door Prizes and Free Lunch Provided.

## How to Prepare for a Telemedicine Appointment

*(Excerpt from [www.parkinson.org](http://www.parkinson.org))*

**T**he coronavirus pandemic quickly changed our day to day lives and has given rise to an increase in healthcare appointments being administered through telemedicine (the distribution of health-related services and information using technology).

Telemedicine appointments can be completed using a laptop, computer, tablet or phone with a camera, often through an app or program using an internet connection. Telemedicine appointment benefits include easy access to healthcare professionals, and no transportation hassle or waiting rooms. Below are nine tips to help you prepare for your next telemedicine appointment:

1. Get ready. Prepare as you would for an in-person visit. Make sure you have your medication list handy and write your list of questions you would like to ask.
2. Medication check. Check to see if you have enough pills at home or if you need refills. Remember, try to have a 90-day supply on-hand during quarantine.
3. Communication program check. Download the technology/application your physician is using for the call ahead of time. You will most likely use a program such as, Epic, Zoom, FaceTime, Skype or others. Your provider will let you know which program to download.
4. Device preparation. Make sure you set up in a location with a good internet connection. Charge your device before the appointment starts or try to keep it plugged in.
5. Be ready to move. Try to position yourself near a space where you can perform typical tasks your doctor or specialist may ask you to complete. For instance, a movement disorders specialist or physical therapist may ask you to walk. It may be helpful to have a family member ready to help during

the appointment.

6. Final touches. Have a paper and pen nearby, along with any items your healthcare specialist may have asked you to bring to your appointment (for instance, a thermometer).

### Video Tips:

- Limit any clutter between you and the camera
- Avoid backlighting (like windows behind you)
- Limit background noise that may come from a TV, radio, pets or affect your device's microphone (a fan overhead, loud AC unit, open window)
- Speak in your normal voice
- Do not place papers or objects near the microphone. If you are not using your cell phone, place it away from your device.
- Ask your questions. Take notes and add them to your medical file.
- Provide updates. Your pharmacy, insurance or contact information may have changed. Let the doctor's office know before your appointment ends.

## TRIBUTES

In memory of Deacon Jim Duffy  
Mary Anne Duffy

Dorothy Ort

## Turmeric Smoothie

- 1 cup hemp or coconut milk
- 1/2 cup frozen pineapple or mango chunks
- 1 fresh banana
- 1 tablespoon coconut oil
- 1/2 teaspoon turmeric
- 1/2 teaspoon cinnamon
- 1/2 teaspoon ginger
- 1 teaspoon chia seeds
- 1 teaspoon maca (optional)



## June 2020: PEP PD Question Corner

**Question:** What is BrainHQ?

**Answer:** BrainHQ is your online headquarters for working out your brain. Think of it as a personal gym, where you exercise your memory, attention, brain speed, people skills, intelligence and navigation instead of your abs, delts, and quads. Just as our bodies require care and exercise over the course of life, so do our brains—especially as we age. BrainHQ provides the exercise your brain needs to be at its sharpest.

The BrainHQ brain-training program represents the culmination of 30 years of research in neurological science and related medicine. It was designed by an international team of neuroscientists, led by Michael Merzenich, a professor emeritus in neurophysiology, member of the National Academy of Sciences, co-inventor of the cochlear implant, and Kavli Prize laureate.

To learn more about BrainHQ, visit [www.brainhq.com](http://www.brainhq.com) or call 1-877-848-2504.

Ref.: [www.brainhq.com](http://www.brainhq.com)

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### News in Context: The PASADENA Study

*(Excerpt from [www.michaeljfox.org](http://www.michaeljfox.org))*

**O**n April 22, 2020, the pharmaceutical company Roche announced results from the first part of the PASADENA study, a Phase II clinical trial (human study) of its potential Parkinson's treatment prasinezumab. This therapy, which researchers call a monoclonal antibody, is one of many targeting the protein alpha-synuclein. Alpha-synuclein is the subject of intense interest by Parkinson's researchers and the patient community, because it forms clumps in the brain that are suspected to be toxic and give rise to Parkinson's disease. Thus, therapies that target these toxic forms of alpha-synuclein might protect brain cells and slow progression of Parkinson's disease.

Though PASADENA did not meet its primary

objective, it did show signs of providing benefit to study participants on multiple tests that were part of the study. Based on those positive signals, Roche is evaluating the data and exploring next steps for prasinezumab.

The PASADENA study was designed for detection of potential signals of efficacy. While the study did not reach the prespecified level of statistical significance for the primary endpoint, it did show signals of efficacy on multiple prespecified secondary and exploratory clinical endpoints — predetermined measures that were also included to evaluate efficacy as part of the study. The study also demonstrated that prasinezumab was generally well-tolerated. At this time, we are continuing to evaluate the data to determine the possible next steps, including further clinical studies. We also plan to present the data at a medical conference.

Based on years of scientific research around alpha-synuclein and the combined evidence from animal studies, genetic clues and early clinical studies in humans, including the PASADENA study, we continue to be optimistic about the potential for therapies that target alpha-synuclein to provide a meaningful difference in the lives of people living with Parkinson's disease and their caregivers.

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### Isradipine Study Results Disappointing

*(Excerpt from [www.parkinson.org](http://www.parkinson.org))*

The prevalence of Parkinson's disease (PD) is expected to double in the next 20 years. To date, there are no proven strategies for slowing the progression of PD. A calcium channel blocker medication used to treat hypertension called, Isradipine, has been shown to be neuroprotective in animal models of PD. Several studies of people also indicated the possibility that taking Isradipine may reduce the risk for PD.

A study published in *Annals of Internal Medicine*, "Isradipine Versus Placebo in Early Parkinson Disease: A Randomized Trial" (Parkinson Study Group, 2020), sought to  
*(cont'd on last page)*

## PEP NEWS

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

### Address Service Requested

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.

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determine if treatment with Isradipine was effective in slowing the progression early-stage PD (within three years of diagnosis).

For 36 months, approximately half of the participants were given 5mg of immediate release Isradipine twice daily, and 166 were given a placebo, also twice daily. Motor function, cognitive function, global measures of disability, functional status and quality of life were measured at baseline, and again at the study conclusion.

#### Results

While the study research was sound, unfortunately the data revealed that Isradipine did not slow PD progression. Unwanted side effects occurred in less than 5% of the participants, with dizziness and edema (water retention) being the most common.

#### What Does This Mean?

Compared to taking a placebo, taking 5mg of

Isradipine twice daily over the course of 36 months confers no protective benefit in slowing the progression of PD. In other words, the Isradipine did not work as hoped.



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

Facebook – Parkinson  
Education Program of  
Greater Cleveland

Partial grant support provided by OPFNE



[ohparkinson.com](http://ohparkinson.com)

**PEP July 1, 2020 Meeting—To Be Determined.**

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