

# PEP NEWS

SEPTEMBER 2021 Barbara Marquardt, Editor, M.Ed., MCHES, WCP, RYT

## SEPTEMBER MEETING

Wednesday, September 1, 2021 – 2:15 p.m.—NOTE NEW START TIME

**W**e welcome **Dr. Brian Appelby, MD Neuropsychiatrist at University Hospitals and Professor Department of Neurology, Case Western Reserve University.** Dr. Appleby will be speaking on Dementia and Parkinson's. This will be our first in-person meeting in a long time.

**Cleveland Heights Recreation Center / One Monticello Blvd., Cleveland Heights, OH 44118**

(Last names N through Z please bring light refreshments)

## From David Brandt

It was wonderful to see all of you that came to our picnic earlier this month. The weather ended up being perfect, the food was great, and it was so darn good to see you in person again. There were a number of new members who came as well, and I hope you enjoyed meeting some of the regulars as much as we enjoyed getting to know you.

A special shout out to Darlene Reid and Marlys Bremer who despite "taking a side trip" before finding the pavilion, brought a good portion of the food and drinks on behalf of PEP. All in all, it was a great get together.

Please note that our new meeting times going forward are at 2:15 p.m. instead of 2 p.m.

I hope you can participate in the **5th Annual Pals In Motion** which will take place on **Sunday, September 19** at Beachwood High School, 25100 Fairmount Blvd., Beachwood, OH 44122. Here are the details.

Race events include:

- Chip-timed 5K Run
- 5K Walk
- 1 Mile Walk
- 100-yard Dash Relay
- Yoga session
- Tai Chi session
- Obstacle Course

Other Information about the race:

- Race registration open now at [www.palsinmotion.org](http://www.palsinmotion.org)
- People can register to run, walk, participate virtually, or just Fundraise for InMotion
- Funds raised by the event benefit InMotion, a holistic wellness center for people with Parkinson's disease.
- Check-in begins 7:30 a.m. and the race begins at 9 a.m.

## Upcoming Events

### **Saturday, October 23, 2021 – Empower U Taking Control of Parkinson's Disease**

Presented by the Cleveland Clinic. This will again be a virtual event

- 8-9 a.m.—Connection test and exhibit hall
- 9 a.m.– 3 p.m.—Empower U live stream program. Special guest speakers include Tim Hague Sr., founder of U-Turn Parkinson's Wellness center, Indu Supramaniam, MD Director VA Southwest Parkinson's Disease Research, and Joseph Rudolph, MD Cleveland Clinic.
- Register at <https://my.clevelandclinic.org/departments/neurological/depts/neurological-restoration/empower-u> or by calling 216-444-0998.

### **Sunday, November 7, 2021 – Big Band Brunch**

Put on by the Ohio Parkinson's Foundation Northeast Region; Noon – 3 p.m., Landerhaven, 6111 Landerhaven Dr., Mayfield Heights, OH 44124

## **Parkinson's Disease Question Corner**

**Email:** barbaramarquardt@outlook.com with questions!

**Question:** Could Neurofeedback help Parkinson's?

**Answer: Neurofeedback (NFB), also called neurotherapy,** is a type of biofeedback that presents real-time feedback from brain activity in order to reinforce healthy brain function through operant conditioning. Typically, electrical activity from the brain is collected via sensors placed on the scalp using electroencephalography (EEG), with feedback presented using video displays or sound.

**Neurofeedback** improves quality of life, sensory integration, motor skills, movement initiation, and balance in Parkinson's disease.

Peer-reviewed research shows the following effects in neurofeedback applications to Parkinson's disease:

- improvement in static and dynamic balance
- improved motor symptoms, on a par with other therapies such as rTMS – while being non-invasive and drug-free
- improvement in life quality
- potential to train up speed of movement initiation by 37%
- increased sensory integration in 10-12 sessions
- reduced symptom severity

**General (non-PD specific)** effects of neurofeedback training include:

- overall increased fine motor skills
- boost behavioral performance and learning

Comorbid mental health issues, such as anxiety, depression, aggression, and mood imbalances can be addressed directly with neurofeedback.

Chronic Pain is another application for **neurofeedback**, where studies have demonstrated its efficacy. Subjectively, people with PD find neurofeedback training calming, reassuring and report an improved sense of feeling being part of their body.

Ref: <https://en.wikipedia.org/wiki/Neurofeedback>  
<https://neurofeedback.io/uses/parkinsons>

## **Five Big “Wins” in Public Policy**

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

**T**he first half of 2021 has been a remarkable time for MJFF's public policy advocacy on behalf of people and families living with Parkinson's, as well as for researchers working on a cure.

Thanks to your efforts, there's a few big “wins” that have happened in this year alone. When you step up to make your voice heard on Capitol Hill, you send a ripple effect of change throughout the federal government. Here are some recent advancements:

U.S. House Appropriators approved the FY 2022 spending bill for the Dept's. of Labor, Health and Human Services, Ed., and related agencies, including research funding increases at the National Institutes of Health. The Appropriations process will continue well into September before the end of the current fiscal year, which ends on September 30. Increased funding at NIH means there will be greater opportunity for researchers to apply for funding. In the House Appropriations Labor-HHS report language, the subcommittee included language referring specifically to Parkinson's and the need to prioritize research funding for the disease.

The CA Gov. approved record-level funding of \$8.4 million for the CA PD Registry in the state's new budget and to expand the registry to other neurological diseases. The registry's goal is to acquire, record and analyze epidemiological data of the incidence and prevalence of disease that can identify PD's “hot spots” throughout the state that will aid scientists in their work toward finding a cure.

The Massachusetts legislature approved and the governor signed PD registry with similar goals as the registry in CA mentioned above. We'll be working with commonwealth officials on funding and next steps.

The EPA reversed a rule that not only restricted science and data access for researchers, it also threatened to violate the privacy of people diagnosed with PD.

The VA announced they will now provide health care and VA benefits for veterans who served in the military in Southwest Asia with Parkinsonism related to Agent Orange exposure.

**TO REACH US AT PEP 440-742-0153**

**[dbrandtpep@gmail.com](mailto:dbrandtpep@gmail.com)—Facebook – Parkinson Education Program of Greater Cleveland**

## Every Victory Counts® Preview: Friendships and Parkinson's

*(Excerpt from davisphinneyfoundation.org)*

Written by Cidney Donahoo, Davis Phinney Foundation Ambassador

**R**ecently, during my Parkinson's Voice Project speech training, I was asked to read (with INTENT, of course) the song/poem with the well-known line of "make new friends, but keep the old, one is silver and the other gold." I remember this song well from my childhood; we even had it written on a plaque in our house while I was growing up. When I was young, I didn't quite understand if it was the new friends or the old friends that were silver or gold. I guess I just knew that friends were important.

There are various obstacles that a person with Parkinson's can face when it comes to friendships, both with making new friends and keeping "the old." Friends from before diagnosis simply may not understand the complexities of Parkinson's (and a newly diagnosed person with Parkinson's also may not understand these complexities). Apathy, fatigue, cognitive changes, and other symptoms may be difficult for both the person living with Parkinson's and their friends to understand. This can be a challenge when you, the person with Parkinson's, are having a hard time just trying to figure out what it is and what to do about it. What do you share with friends and what do you keep to yourself?

Some friends may find a Parkinson's diagnosis too much to process. That's okay. Just be where you can with them. Others may not completely understand but will be by your side, nonetheless. Treasure the friendships wherever they are. Some will fade, and again, that's okay. Give grace to those friendships and let them go where they naturally will. The others, the ones who stick around even though they don't understand — I think they might just be the "gold."

Doom and gloom do not need to follow a Parkinson's diagnosis. Everyone reacts differently, but in getting to know hundreds of people with Parkinson's, I have seen that typically there is a period where denial or shock or disbelief sets in, and most people will keep the diagnosis to themselves and possibly a few close family or friends. This is normal. Don't get stuck there, though. Making new friends who understand what you're experiencing can be the balm that nourishes your soul.

Where do you find these new friends who, like you, are

living with Parkinson's? How can they help? Look to your local resources to find a Parkinson's group nearby who you can begin sharing this journey with. Many local Parkinson's organizations will have support groups; try to find one that reflects who you are. Look around and find one that fits. Exercise groups can also become a great source of community and friendship. Rock Steady Boxing, Pedaling For Parkinson's™, Dance for PD®, and more can become your new friend group.

The value of having friends with Parkinson's is that they "get it." They offer a safe place to just be yourself. You will laugh, and cry, and have deeply serious moments with these new friends. You may come from vastly different backgrounds, and yet one thing, Parkinson's, will bind you. These new friendships very likely will become the silver lining in your Parkinson's diagnosis.

I don't know what I would do without my Parkinson's friends. They have become some of my closest friends, even though many of them live in other parts of the country (and world). It's like that old friend whom you haven't spoken to in a very long time, and then you get together and it's like time never passed; you're laughing and joking like you've never been apart.

So, like the song says, make new friends and keep the old. You will find a lovely journey through life as you embrace new friends who can help support you, and you will be a support to them in return. That sounds like a "gold" medal to me.

## Hand-held Device for Vagus Nerve Stimulation of Benefit in Parkinson's

*(Excerpt from parkinsonsnewstoday.com)*

**O**ne month of non-invasive vagus nerve stimulation (nVNS), administered at home using a hand-held device by electroCore, improved walking and motor abilities, and eased freezing of gait in adults with Parkinson's disease, according to data from a small clinical trial.

Freezing of gait refers to a patient's feeling for an extended period as if their feet are "glued" to the floor, and they are unable to move forward.

*(Cont'd on last page)*



## PEP NEWS

Parkinson Education Program  
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## Hand-held Device for Vagus Nerve Stimulation of Benefit in Parkinson's

(cont'd from page 3)

**N**otably, these motor benefits were accompanied by a reduction in pro-inflammatory molecules and a rise in antioxidant and nerve cell survival molecules, suggesting the therapy has potential anti-inflammatory, antioxidant, and neuroprotective effects.

Larger trials are needed to confirm these early findings in this patient population, the researchers noted.

Increasing evidence also suggests that VNS can reduce pro-inflammatory molecules and oxidative stress, both involved in Parkinson's.

son's. (Oxidative stress is an imbalance between the cell's production of harmful free radicals and antioxidant molecules to detoxify them.)

However, the effects of sustained nVNS treatment in Parkinson's patients remain unclear.

### Meeting—October 6, 2021

To Be Advised

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

Partial grant support provided by OPFNE



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

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