

PEP NEWS

MAY 2022

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

MAY MEETING

Wednesday, May 4, 2022 – 2:15 p.m.

We welcome back **Ellen Walter, Certified Nurse Practitioner at the Cleveland Clinic Neurological Institute**. Ellen is heavily involved with the Northeast Ohio PD community and will talk about the Non-Motor Symptoms of Parkinson's. Please don't miss this informative talk.

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

(Last names A through M please bring ***individually wrapped snacks**)

*Policy of Rec Center prohibits serving food "buffet style"; everything must be individually packaged. Thanks so much!

From David Brandt

The **OPFNE** Annual Parkinson Symposium held on April 9th was a great success as over 200 people came to hear the great speakers and enjoy the company of one another for the first time in over 2 years. It was a chance to learn more and visit vendor tables as well as enjoy some fun warm up physical and mental exercises.

Moving Day Cleveland 2022 is coming up on June 11. This wonderful fundraising event is detailed more in the upcoming events section below. As we have in the past, **PEP** sponsors a team, Team Get **PEP!**, and we will be having our own fundraising event on Wednesday, May 25. Please order lunch or dinner at the **Café Tandoor** in Cleveland Heights and the restaurant will donate 15% of all proceeds to Moving Day Cleveland.

If you haven't been to **Café Tandoor**, it is a great Indian restaurant that specializes in both vegetarian and non-vegetarian dishes that utilize many foods that are highly recommended for living well with Parkinson's. More details are listed below. I hope to see you there!!

Upcoming Events

May 10 - Parkinson's, Sleep and Me – Tri-C Corporate College East (Warrensville Heights) 1:30 – 3 p.m. This presentation put on by the **Parkinson's Foundation**, will feature Shannon Shaffer, CNP, Cleveland Clinic talking on how PD affects sleep and ways you can get a better night's sleep. There is no charge for this event but you must register at Parkinson.org/Cleveland or call 440-568-0093.

May 25 - Café Tandoor 2096 South Taylor Rd., Cleveland Heights 216-371-8500 Please join us for lunch (11:30 a.m.- 1:30 p.m.) and dinner (5 – 9 p.m.). Foods are available for dine-in, take-out and home delivery at this fine Indian restaurant. 15% of the proceeds will benefit Moving Day Cleveland. Reservations for lunch are required but not for dinner.

June 11 - Moving Day Cleveland 2022 – This annual event put on by the Parkinson's Foundation Great Lakes Chapter will be from 11 a.m. – 1 p.m. at Brookside Reservation/Cleveland Metro Parks (right next to the zoo). This is the same place it was last year, in the parking lot, but there is a paved circular track right beside the lot that we will be using for the actual walk this year. The website is now live and people can sign up their teams! www.movingdaycleveland.org. They will also be offering the participants a discounted zoo admittance voucher just like last year.

June 16 - Living In Motion - InMotion 23905 Mercantile Rd Beachwood 1 – 4 p.m. put on by **InMotion** and **OPFNE**, this is a day of education and exploration for those affected by PD. Experience our evidence-based exercise classes designed for those with PD, meet professionals in social work, physical and occupational therapy, nutrition & more. Hear Dr. Cynthia Comella, Professor of Neurological Sciences at Rush University Medical Center in Chicago speak on "New Advances in Parkinson's Treatments & the Importance of Exercise". Registration is required at <https://www.eventbrite.com/e/living-in-motion-tickets-264535020367> or call 216-342-4417.

June Meeting—June 1, 2022

Please join us to hear **Amy Rodgers Smith, Chair of the Center for Music Therapy at The Music Settlement** talk on Music Therapy and Parkinson's. We look forward to this interactive presentation.

Parkinson's Disease Question Corner

Email: barbaramarquardt@outlook.com with questions!

Question: What are some natural sources of Levodopa?

Answer: Pharmaceutical-grade L-dopa (pharmaceutical levodopa) is often the drug of choice in conventional medicine for Parkinson's patients. L-dopa can help many Parkinson's symptoms, though it has its limitations.

Pharmaceutical L-dopa drugs can also cause numerous side effects, including nausea, hair loss, anxiety, hypotension, respiration disruption, disorientation, confusion, insomnia, hallucinations and others. Chronic use of L-dopa drugs also cause drug-induced dyskinesia, a loss of muscle control.

Conventional doctors typically try to curb the effect of L-dopa with the addition of Carbidopa (Lodosyn). This increases the metabolism of L-dopa drugs, allowing them to more easily cross the blood-brain barrier. This means the patient can be prescribed less L-dopa, possibly slowing down the dyskinesia eventually.

There are natural forms of levodopa, the amino acid dihydroxyphenylalanine. Levodopa is also found in many herbs and foods. The seeds or beans of the following plants will contain from anywhere from less than 1% to more than 5% levodopa by weight:

Fava bean	Chaste tree/horseshoe vitex
Velvet bean	Siberian Ginseng
Mat beans	Maloo creeper
Leadwort	Palo verde
Cowpeas	Hairy Senna
Zombi peas	Cocobolo
Chilean mesquite	Birdwoodina beans
Purple orchard tree	Hawaiian orchid tree

Ref: <https://www.realnatural.org/acupuncture-improves-parkinsons-symptoms/>

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.

Medical Marijuana and PD

(Excerpt from Michael J. Fox Foundation)

SECOND OF A 3-PART SERIES

What is cannabis?

Cannabis refers to products from the Cannabis plant, including marijuana.

Cannabis comes in several forms and can be taken different ways: smoking or vaping dried leaves, swallowing pills or eating or drinking foods (edibles) that contain cannabinoids, putting liquid or drops under the tongue, or applying creams or ointments to painful areas. Two U.S. Food and Drug Administration (FDA)-approved prescription cannabis medications also are available for specific conditions, such as epilepsy or cancer- or AIDS-related symptoms. The amount of THC, CBD, other cannabinoids and other (sometimes unknown) substances varies across products. Sometimes, the levels of these contents may not be known. And even if the product does have a label, studies have shown the label may not accurately represent what's actually in the product. This is because there are no federal governing standards of purity or label accuracy. Most states have their own regulations, but these vary. Still, it's important to read labels, ask questions, and have a general idea of the amount of THC or CBD in a product. For those who choose to try cannabis, use caution — start with a low dose and increase slowly, if at all. Using medical marijuana is often a process of trial and error to figure out what might work because solid studies to guide dosing and formulation are lacking.

Is cannabis safe? Effective?

There are many anecdotal reports of benefit. But controlled trials — on motor and non-motor symptoms as well as dyskinesia (involuntary, uncontrolled movement) — have not yet proven the safety or benefit of cannabis in Parkinson's. Clinical trials have generally had mixed or conflicting results (some positive, some negative). On questionnaires, people often report benefit on pain, sleep, mood, or motor symptoms such as tremor or stiffness. But

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Music Therapy May Help Parkinson's Patients Change Their Brain's Abnormal Tempo

(Excerpt from <https://www.braintomorrow.com>)

Most people are aware of music's soothing abilities. According to Johns Hopkins Medicine, music has the potential to lower blood pressure and anxiety, as well as, enhance mood, sleep, and even memory. New research from the University of Colorado School of Medicine suggests that music also has the potential to treat Parkinson's disease by re-wiring certain signal pathways of the brain.

Assistant Professor, Isabelle Buard, Ph.D., teaches Neurology at CU School of Medicine. She and her colleagues set out to investigate the effects of neurologic music therapy on individuals with Parkinson's disease. This particular type of therapy involves rhythmic patterns and motor activities designed to alter the brain's normal signal frequency.

"In Parkinson's, beta frequencies are the most likely to be impaired," said Buard. "The idea of the study is to use external rhythms that specifically target those frequencies by entraining them to a different level, modulating them to restore some kind of homeostasis in brain activity."

Those with Parkinson's meet with music therapists three days a week throughout the span of Buard's research, which is supported by the National Institutes of Health. Each therapy exercise begins with coordination practice and repetitive hand/finger motions, followed by physical training with castanets (a type of drum) and keyboards with heavier keys for cognitive-motor therapy. Patients are instructed to do the activities at their leisure throughout the rest of the week. Tempos become faster and faster with each passing week of therapy.

To conduct her research, Buard divided the participants into four categories based on the type of therapy received. The first group received no form of therapy, the second group received the usual therapy given to Parkinson's patients, the third group received neurologic music therapy wherein the tempo, or beat, was determined by the patient's motions, and, the fourth group received the same cognitive therapy, however, therapists used a metronome to maintain a consistent beat.

Since rhythmic patterns outside of the brain are known to stimulate the brain, Buard hypothesized that those in

the fourth group who were exposed to the metronome's steady beat would benefit the most. "The idea is that if you're doing internally generated movements, you rely on motor neuronal loops that are impaired in Parkinson's, so you have some problems doing movements, or they are slow and not coordinated. When your movement is driven by external rhythms, then the movement seems to be easier to perform," said Buard. She and her team were looking for refined motor skills to justify this theory. "I'm looking at the networks that are mobilized during internally versus externally driven movement and trying to disentangle which different aspect is meaningful in terms of mobilization of brain networks," added Buard.

Additionally, there is an opportunity for patients to engage in freestyle piano playing as part of cognitive music-based therapy. Earlier studies have shown that musical improvising can enhance mood and the feeling of contentment. "It seems to increase the quality of life for some people," said Buard. "A lot of people feel very uncomfortable improvising at the beginning, but by the end, they're very much liking it."

According to Buard, she and the team aim to gather evidence over the course of the trial, testing motor coordination with a "grooved pegboard test," which includes the correct movement of about 25 different pegs in order to be properly inserted into the board. Additionally, they will assess the overall standard of living along with feelings of stress and despair.

For individuals with Parkinson's disease and other neurological conditions, the results could contribute to additional studies regarding therapy and rehabilitation measures. Furthermore, this study helps neurologists better understand the brain mechanisms exploited by music.

Buard believes that the research will ultimately bring about a musical therapeutic approach intervention that will enhance fine motor abilities in people with Parkinson's.

"Right now, if you have fine motor difficulties due to Parkinson's, your medications are not helping with that," said Buard. "The medications help with gait and balance, and some medications help with tremors. But fine motor skills are not really handled well by medication therapy. It's really a symptomatic approach, so if we find that it's effective for Parkinson's, we will do a larger clinical trial so that music therapy can be further approved as one of the clinical therapies for fine motor skills."

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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.

Medical Marijuana and PD

many also report side effects. This leaves patients, doctors and researchers with insufficient evidence to guide use. In low doses, cannabinoids appear to be relatively well tolerated. But, like all treatments, they have potential side effects: new or worsened nausea; dizziness; weakness; hallucinations (seeing things that aren't there); mood, behavior or memory/thinking (cognitive) changes; or imbalance. Regular smoking or vaping also could cause lung damage. The potential risks on cognition, mood and motivation — to exercise, socialize, or participate in other activities, for example — are especially important for people with PD. Cannabis also could interact with other medications you take. While interactions are largely unknown, adding cannabis to a complex regimen of Parkinson's and other prescription medications could present a risk. It's important to tell your Parkinson's any non-prescription medications you use, including medical marijuana, so that they can alert you to possible interactions.

TRIBUTES

Ann and Tom Brokaw

Roberta Tonti

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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