

MAY 2024

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

MAY MEETING—Wednesday, May 1, 2024 – 2:15 p.m.

We welcome **Beverly Keeler, RDN, LD University Hospitals Medical Center** who will speak on Healthy Eating with a Focus on Nutrition Strategies for People and Families with Parkinsons.

Please join us to hear about a popular subject for our members.

Cleveland Heights Senior Activity Center/One Monticello Blvd., Cleveland Heights, OH 44118

JUNE MEETING / Wednesday, June 5, 2024

We welcome **Charles Babbush, DDS, and Founder of Papa's Path**. A long time Oral Surgeon, Charles was diagnosed with Parkinson's in 2017 which led to his retirement. He underwent successful DBS surgery and started a new path. To that end, the family has organized Papa's Path, a multi-pronged effort to create a community for those who have been afflicted by Parkinson's. The Babbush Family Fund has been established for education, research and innovation at University Hospitals.

From David Brandt

I am writing this right after the OPFNE 24th Annual Parkinson's Symposium which around 300 people enjoyed. We were moved by the inspirational talk of Dr. Sara Wittingham and moved even more with David Zid and his Brain and Body Connection. It was an excellent and informative day and thanks go out to Kathy Stull, OPFNE President, for her leadership in bringing the event to fruition.

There is a new opportunity for those with PD to participate in a unique exercise event. Shaker Rocks, a rock climbing facility is starting a class that provides guided rock climbing for people with PD. The classes are on Wednesdays from 11 a.m. – 1 p.m. and free because of a partnership with Up Ending Parkinsons, a non-profit group. Shaker Rocks will provide all of the appropriate gear. Climbing has been shown to be an effective therapy for those living with PD. It is a great cardio workout that strengthens your muscles while being low impact. It can improve your posture and is a perfect therapy for those with PD. Shaker Rocks, 3377 Warrensville Center Rd., Shaker Heights. Phone: 216-848-0460, Email: info@shakerrockscimbing.com.

Upcoming Events

Saturday, June 1 – Moving Day Cleveland sponsored by the Parkinson's Foundation at the Cleveland Metroparks Brookside Reservation, 3900 John Nagy Blvd in Cleveland. Activities begin at 11 a.m. and the walks begin at 12:30 p.m. Register at <https://movingdaywalk.org/event/moving-day-cleveland/> or by calling 614-918-7307.

Friday June 14 – Living In Motion 9:30 a.m. – 12:30 p.m. at In Motion. This is an opportunity for people affected by Parkinson's Disease to learn about InMotion as well as other resources available to them. Keynote speaker will be David Leventhal, Founding teacher and program Director for Dance with PD.

Saturday, August 17 – Empower U Expo: Taking Control of Parkinson's Disease presented by Cleveland Clinic Held at the John S. Knight Center in Akron The expo format returns this year. More information and registration details will follow.

TO REACH US AT PEP 440-742-0153 dbrandtpep@gmail.com
Facebook – Parkinson Education Program of Greater Cleveland

Sniffing Out the Mechanism Behind PD Smell Loss

(Excerpt from neurosciencenews.com)

Summary: Up to 90% of patients report experiencing a diminished sense of smell, even prior to the onset of other symptoms of PD disease (PD). A new study reveals the mechanism behind smell loss associated with PD, reporting mouse models with olfactory impairments had severe pathology in projection neurons of the olfactory pathway. The mice also had reduced neurogenesis in the olfactory bulb.

PD is an illness well known for its motor symptoms—tremor, stiffness, and slowness of movement. In a new paper published in *Journal of Neuroscience*, researchers at Yale School of Medicine have uncovered the biological mechanism behind another common, but less studied symptom – the loss of smell. About 75-90% of PD patients report diminishing sense of smell, even prior to the onset of motor symptoms, and is now recognized a non-motor symptom of PD.

Researchers at the Greer Lab and Chandra Lab at Yale School of Medicine determined the biological mechanisms behind this olfactory impairment by using an alpha-synuclein A30P mouse model used to mimic symptoms of PD in mice. Using buried food tests, the researchers found that the mice with later stage symptoms of PD exhibited olfactory impairment. They found that those mice with olfactory deficits exhibited severe pathology in projection neurons of the olfactory pathway. They also found these mice showed reduced neurogenesis in the olfactory bulb. In contrast, studies have shown that healthy aging brains continue to form new neurons in the olfactory bulb throughout life.

PD patients had been reporting diminishing sense of smell for years, says corresponding author, Charles Greer, PhD, vice chair of research at the department of neurosurgery and professor of neuroscience at the Yale School of Medicine. However, since the motor symptoms of the disease were more debilitating, very little research had been done to understand the underlying biological mechanism of the olfactory dimension.

“We are excited to begin to understand the basis of anosmia in PD patients,” says Sreeganga Chandra,

PhD, associate professor of neurology and neuroscience. “We set out to understand the nature of a symptom that’s associated with PD that’s been largely anecdotal. People that are diagnosed with PD would report loss of smell up to 10 years before their diagnosis. These findings could help in developing a very early diagnostic tool for the disease,” says Dr. Greer.

Common Degenerative Brain Disease may begin to Develop in Middle Age

(Excerpt from sciencedaily.com)

Lewy body disease is the second most common brain degenerative disease after Alzheimer's disease. Lewy bodies, deposits of alpha-synuclein protein, are found in the brainstem, limbic system and cerebral cortex. Similar tissue changes are also seen in patients clinically diagnosed with Parkinson's disease. Lewy body disease can be difficult to recognize at the beginning of the disease, as it progresses slowly.

Symptoms often include movement disturbances, memory problems and psychiatric symptoms. In their recent study, researchers from the Universities of Helsinki and Tampere investigated for the first time, the occurrence of Lewy body disease markers in young and middle-aged subjects who were not known to suffer from Lewy body or Parkinson's diseases.

Previous similar studies have investigated the occurrence of the disease markers in people over 60 years old. The researchers found that Lewy body disease changes may begin to develop in the brain already in middle age, even if there are no actual symptoms yet. "Our findings indicate that Lewy body disease may be more common in people over 50 than previously thought. In the study, we found disease changes in 9% of people over 50 who did not have a clinical diagnosis of Parkinson's disease or Lewy body disease. However, further studies are needed to confirm the results," says Associate Professor Liisa Myllykangas from the University of Helsinki.

Earlier diagnosis means more effective treatment – In their study, the researchers used internationally unique Finnish forensic autopsy data, which consists of approximately 600 people aged 16-95 who died outside hospitals. Myllykangas says that in the future the treatments developed against degenerative brain diseases will be aimed at patients who are in the early stages of the disease, or are at risk of developing the disease. "Finding out the prevalence of disease changes in younger age groups is therefore important as this will be the most effective time to start therapies," she comments.

DISCLAIMER: The material contained in this newsletter is intended to inform. PEP makes no recommendations or endorsements in the care and treatment of PD. Always consult your own physician before making any changes. No one involved with the newsletter receives financial benefit from any programs/products listed.

PD Question Corner

Email: barbaramarquardt@outlook.com

Question: What websites do you like for Parkinson's information and related symptoms?

Answer: There are so many websites I could list, but below are several of my favorites:

American Association of Naturopathic Physicians
www.naturopathic.org

Institute for Functional Medicine
www.ifm.org

American College of Functional Neurology
<https://acfn.org>

Interdisciplinary Association of Functional Neurosciences and Rehabilitation
www.iafnr.org

Functional Neurology Society
<http://functionalneurologysociety.com>

Foundation for Alternative and Integrative Medicine
<https://www.faim.org>

American Academy of Anti-Aging Medicine
www.a4m.com

American College for Advancement in Medicine
www.acam.org

Welcome to Orthomolecular.org
<http://orthomolecular.org>

When Traveling with PD, Pack Less and Laugh More

Navigating the Airport can be Especially Stressful with a Disability

(Excerpt from Parkinson's News Today) / by Jamie Askari

Traveling can be so stressful that it often feels like we need a vacation after the vacation. For my husband, Arman, who has early-onset PD, and me, all of the relaxation we enjoy during much-needed trips melts away as soon as we return to the airport. A cloud of darkness seems to hang over the terminal, and once we're in, we can't get out.

When departing for a trip, we try to use the airport's valet parking service if it's available. Even though it's expensive, we've found it's convenient and accessible. I just wish they offered discounts to people with

disability placards. Maybe I will suggest that next time.

Unfortunately, on several occasions we've arrived at the airport only to find that the valet parking was full and unable to take more cars. We had to circle the airport in hopes of locating an accessible parking spot. Cue the tight jaw and anxious belly. Once we figure out the parking situation, we head to the baggage counter. When we arrive to check our bags, one of them is likely to be overweight. I'm somewhat of a minimalist in my daily life, but not so much when it comes to packing for a trip. I always realize I have overpacked during vacation, but I seem to block that out when packing for the next trip.

The representative at the counter lets me know that all I need to do is move some of my items to one of our lighter suitcases and all will be well. But instead of opening all our suitcases on the terminal floor, I just pay the hefty fee and promise to remember next time. (Will I, though?) My main concern is that Arman will fall or trip over the open suitcases, so the fee feels like a small price to pay for his safety.

Because PD is unpredictable, I always select "wheelchair assistance" when booking Arman's plane ticket. This gives us the option to use the airport's disability services in case Arman has trouble walking on that particular day. The problem is that it takes time for an attendant to arrive to push the chair. We have been close to missing flights because we were waiting. Recently, I have started to push him myself, which is key to getting to our gate on time. I just need to be careful going down ramps so that Arman doesn't go flying ahead of me!

As we approach the security checkpoint line, my stress level increases, and deep breathing becomes essential. Arman had deep brain stimulation surgery in 2017 and, as a result, is unable to go through most metal detectors. He needs help communicating this to the security officers, but it can be tough to do so amid the chaos. All of the passengers are in a rush; children and parents are screaming; people are taking their belts, shoes, and jackets off; phones and computers are being removed from bags — need I say more? We always make it through, but I probably sprout about a dozen gray hairs each time.

(cont'd on last page)

PEP NEWS

Parkinson Education Program
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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.

**When Traveling with PD,
Pack Less and Laugh More**

(Con't. from Pg. 3) / by Jamie Askari

We typically arrive at our gate with plenty of time to spare and breathe a massive sigh of relief. I always grab us some overpriced water to maintain our hydration and sanity. Preboarding is necessary so we don't have to deal with the crowd while getting Arman seated and buckled up safely. Then, it's finally time to recline our seats and enjoy a few hours in the air.

Our return trip involves a similar process, almost like the movie "Groundhog Day." I always look forward to returning home, where Arman will have the comfort and safety of familiar surroundings. For me, there's nothing better. Travel can be complicated and stressful for anyone, but adding PD or another chronic illness to the mix can make the process even more complex. With proper planning and a sense of humor, you may be able to find a laugh amid the stress. And take it from me: Less is more when it comes to packing!

	<p>Partial grant support provided by OPFNE</p>  <p>ohparkinson.com</p>
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**Laughter is Medicine
I was making a joke about
retirement.
It did not work.**

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