

**SEPTEMBER 2023 Barbara Marquardt, Editor, M.Ed., MCHES, WCP, RYT**

**SEPTEMBER MEETING—Wednesday, September 6, 2023 – 2:15 p.m.**

**W**e welcome back **Taylor Rush Ph.D., Director of Behavioral Services and Interdisciplinary Programs | Center for Neurological Restoration /Cleveland Clinic.** She has been with the Clinic since 2015 after her Residency at the University of Florida. has been active in speaking to a number of Parkinson's related events including our group back in 2019. Her topic will cover "How to Effectively Communicate Needs and Get the Support You Deserve"

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

**October Meeting—Wednesday, October 4, 2023 / 2:15 p.m.**

We welcome Lynell Lemon, **Director Medical Science Liaison for the Institute for Neurodegenerative Disorders** who will talk on the Parkinson's Progressive Markers Initiative (PPMI). PPMI is a landmark study collaborating with partners around the world to create a robust open-access data set and bio sample library to speed scientific breakthroughs and new treatments. PPMI aims to identify biological markers of Parkinson's risk, onset and progression — critical tools for the development of new and better treatments — and to provide the broad research community a comprehensive, standardized, longitudinal data set and bio sample library to speed breakthroughs and enable validation toward clinical application of new findings.

## From David Brandt

Our annual picnic/ice cream social last month was a great success with both long time members and newer members joining us on a perfect weather day. A big shout of THANKS goes out to Darlene Reid and Marlys Bremer for providing all of the main dishes as well as Bob Eckardt for providing the ice cream and fixings. After that meal, I am already looking forward to next year's picnic.

By the time you read this, the Empower U program by the Cleveland Clinic will have already occurred. Next up on the important programs list is the 14<sup>th</sup> Annual Parkinson's Boot Camp by University Hospitals which occurs Saturday September 23 at the Holiday Inn S in Independence. You can call 216-983-6683 to register.

Barbara Marquardt, Editor of the *PEP* newsletter, has recently started conducting virtual Parkinson's holistic and lifestyle coaching, and she created a website ([www.pdhipp.com](http://www.pdhipp.com)) that provides the details. The Holistic Health Individual Parkinson Program (HIPP) is a program where she will work alongside you in partnership in developing an individualized plan to

achieve greater wellness with Parkinson's. Please check it out if you have interest.

As a reminder, please note that *PEP* does not make recommendations or endorsements in the care and treatment of Parkinson's Disease.

## Upcoming Events

**Saturday, September 10 – Pals In Motion Walk** put on by InMotion will be held at Beachwood High School, 21500 Fairmount Blvd in Beachwood begins at 9:00 a.m. Events include a 5K run, 5K walk, a 1 mile Family walk, yoga, and an obstacle course. Please register at [beinmotion.org/pals](http://beinmotion.org/pals)

**Saturday, September 23 – Parkinson's Boot Camp** put on by University Hospitals to be held at the Holiday Inn S in Independence. Please call 216-983-6683 for details.

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

# Sleepiness and Fatigue in PD and What To Do about Them

(Excerpt from Parkinson's Foundation)

Two of the most common and disabling symptoms we hear about from people with Parkinson's are fatigue and sleepiness. What we've learned, however, is that some people call it fatigue when they really mean sleepiness. Or, they say they're tired all of the time when what they're really experiencing is fatigue. Do the words people choose really matter? Yes, because treatments for sleepiness are different than ones for fatigue. And the more you understand each situation, the better chance you have of getting the care you need.

**DEFINITIONS** – Before we dive into some of the research, let's first define what we're talking about.

**Fatigue:** "an overwhelming sense of tiredness, weakness, lack of energy, and exhaustion (subjective fatigue); or as a mismatch between expended effort and actual performance; or as a reduction in the capacity to either initiate or sustain voluntary activities (objective fatigue)."

**Parkinson's Fatigue:** "a sense of exhaustion unexplained by drug effects, other medical, or psychiatric disorders, present for a defined period, and associated with other fatigue-related symptoms, such as reduced motivation and nonrestorative rest, or constraints on activities."

Fatigue can affect one's quality of life in many ways.

• Prevent you from being physically active	• Make everything feel like an intense effort
• Get worse over time, as PD progresses	• Get in the way of connecting with others
• Make it much more difficult and exhausting to cope with PD and non PD related challenges	• Make depression worse (it doesn't cause it, but it can add a level of intensity to it)
• Undermine countless daily activities	• Make it difficult to focus and concentrate on important tasks

With that term explained, we can move on to excessive daytime sleepiness.

**Excessive Daytime Sleepiness (EDS):** "an inability to maintain wakefulness and alertness during the major waking episodes of the day resulting in periods of irrepressible need for sleep or unintended lapses into drowsiness or sleep. EDS can be debilitating and even dangerous. Those who experience EDS may:

• Choose to give in to their excessive sleepiness during the day by taking frequent naps, thereby impacting their ability to get a good night's sleep each evening	• Miss out on opportunities to improve their quality of life by exercising or connecting with others because they are too sleepy to leave the house
• Experience it when they are driving, posing a risk to others	• Fall asleep during the day, often multiple times and in random places

## THE CRITICAL DIFFERENCE BETWEEN SLEEPINESS

**AND FATIGUE** – Fatigue is a physical or psychological feeling where people feel weary and exhausted and lacking energy. EDS is about needing and having the urge to sleep. Fatigue is something that people can experience along with EDS; however, people who experience fatigue on its own—the feeling of being tired and out of energy— do not also necessarily fall asleep when sedentary, as people who experience EDS often do.

**NEXT STEPS** – Now that you, hopefully, have a clearer picture about your own situation and whether you typically experience fatigue or EDS or both, here are a few actions you can take to try and manage them.

## POTENTIALS WAYS TO REDUCE FATIGUE

Exercise. It may seem counterintuitive get moving if you're feeling fatigued; however, the right kind and the right amount of exercise can significantly reduce fatigue.

Experiment. Sometimes just getting out the door for a walk in the fresh air can reduce fatigue. Talk to your doctor if you think you may be depressed. It's possible that an anti-depressant could reduce fatigue.

Plan your time. Identify when you tend to have the most energy throughout the day and plan to get your most important jobs done then.

(Cont'd on last page)

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

**Email:** [barbaramarquardt@outlook.com](mailto:barbaramarquardt@outlook.com)

**Question:** What do you think about tap water?

**Answer:** Please try to avoid tap water, and bottled water in plastic. The following are toxins commonly found in tap water:

**Pesticide/fungicides/herbicides; Pharmaceutical drug residues; Radioactive substances; Perfluorooctanoic acid (PFOA); Fluoride; Dioxins; Polychlorinated biphenyls; Chlorine; Heavy metals; and Perchlorate.**

Try to drink filtered water, I like the Berkey Water Filter. If you want to buy bottled water, always try to buy in glass, I like Mountain Valley spring water. If you use a reusable water bottle, please use glass or stainless steel, never aluminum or plastic.

For additional information, please visit:  
<https://www.berkeyfilters.com>  
<https://www.mountainvalleyspring.com>

## **Tips for Traveling with Parkinson's Disease**

*(Excerpt from <https://www.parkinson.org>)*

**P**arkinson's Disease (PD) can make it harder to leave the house on a daily basis, let alone travel to a new time zone. However, as with any trip, planning can help. PD is something you can factor into any itinerary. Check out these tips for traveling with PD.

**Bring all PD medications and assistive equipment –** Wherever you travel, pack all the medications and dosages you will need, plus extras, in your carry-on bag. Remember to include snacks, a water bottle and anything else you need to take with meds.

**Write your list of essentials before packing. –** Pack your go-to outfits that make getting dressed a little easier — wrinkle-free items, shorts and pants with elastic waistbands — and assistive devices you use.

**Before your trip, check in with your PD doctor. –**to ensure that you have all the medications you need.

**Request assistance in airports. –** Consider requesting special assistance at airports, such as a wheelchair or an electric cart service to help with luggage. This can

make traveling smoother and reduce stress. A physician's written certificate of need may be required, so call the airline ahead of time.

**Call hotels to inquire about accessibility and special accommodations. –** call ahead to request a room with accessibility features, such as a near the elevator or with wheelchair access. Ask about transportation services ahead of time.

**Continue to take medication as prescribed when changing time zones. –** It is extremely important to take prescribed medications using your everyday intervals between doses. Set (or keep) your medication alarms the same as when you're home.

**Call our Helpline to find local resources. –** Call the PD Foundation Helpline at 1-800-473-4636 to find out if there are local PD resources (such as exercise classes and support groups) in the area you are visiting.

**Check your medical insurance policy. –**Check with health insurance before travelling to be aware of any coverage or lack thereof.

**Take your time, relax and enjoy. –** Give yourself extra time for everything — enjoy longer meals, breaks between sites, coffee houses. Plan to see fewer sites so you enjoy them more, and when possible, book tickets for sites online ahead of time to minimize lines.

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

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



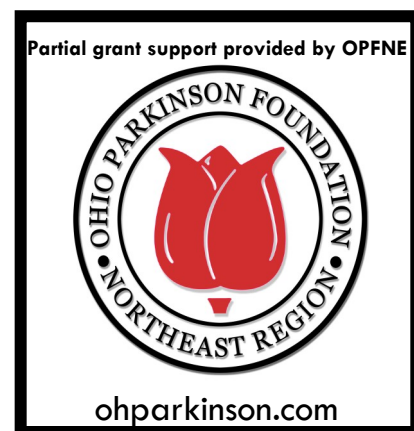
**DISCLAIMER:** The material contained in this newsletter is intended to inform. PEP makes no recommendations or endorsements in the care and treatment of Parkinson's disease. Always consult your own physician before making any changes. No one involved with the newsletter receives financial benefit from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

## **PEP NEWS**

Parkinson Education Program  
of Greater Cleveland  
2785 Edgehill Rd.  
Cleveland Heights, OH 44106

### **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.



## **Sleepiness and Fatigue in PD and What To Do about Them**

*(Cont'd from pg. 2)*

Be realistic, but still do something. If you're feeling extra exhausted on a certain day, don't put pressure on yourself to accomplish everything you planned. Do something—because accomplishing something will give you an energy boost— but be realistic about what you're capable of doing.

Delegate. It's not easy. You may have concerns about being a burden to others. Most people will be thrilled to help. Let them.

Organize and declutter. Opening up space—physically, emotionally, mentally and logistically—can help you reduce stress and as a result reduce feelings of fatigue.

Connect with others. We know that when you feel wiped out that the last thing you want to do is attend a support group meeting or event, but connecting with others in a positive way has the potential to not only make you feel supported and encouraged and loved, but it may very well give you the exact bump in energy that you need.

## **POTENTIAL WAYS TO REDUCE EXCESSIVE DAYTIME SLEEPINESS**

Assess the underlying cause (are sleep disorders such as REM Sleep Behavior Disorder affecting nighttime sleep, which impact daytime sleepiness?) Improve nocturnal sleep through medications, cognitive behavioral therapy, diet, light therapy and more. Evaluate all medicines being taken—some have hypersomnia as a side effect—and adjust as needed. If taking dopaminergic medications, consider dose adjustment. Watch consumption of alcohol or sleep-inducing foods/ingredients (sometimes people are allergic to or intolerant of certain foods that can impact sleepiness). Experiment with caffeine.

## **SHARE THIS WITH YOUR DOCTOR**

Do you experience sleepiness and/or fatigue but find it challenging to communicate with your doctor about it? Consider printing this out, highlighting the sections you relate to and taking it with you to your next appointment. And, don't forget to share it with your care partners as well. It might help them understand your behavior and symptoms in a way they haven't been able to before.