

MARCH 2023

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

MARCH MEETING—Wednesday, March 1, 2023 – 2:15 p.m.

We are pleased to welcome **Richard Huckabee who is a Parkinson's Foundation Aware in Care Ambassador and Research Advocate.** Aware in Care Ambassadors are volunteers who help the Parkinson's Foundation advocate for hospital safety for people with Parkinson's. He will be explaining the Aware in Care Kit along with distributing them.

He will also share a bit of his story and personal anecdotes on how he fights Parkinson's Disease every day!



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

Beginning with our March meeting, *PEP* will provide refreshments going forward during our monthly meetings, so we will ask that you no longer bring any.

Thanks to everyone who has provided snacks in the past.

From David Brandt

As mentioned below, the 23rd Annual Parkinson Symposium is coming up in April sponsored by the Ohio Parkinson Foundation Northeast Region (OPFNE). I thought I would share a little about OPFNE here and for transparency purposes, I am a board member. Started in 1997, OPFNE was created to improve the quality of life for those affected by Parkinson's Disease (PD) The foundation supports the efforts of many charitable organizations involved in the development of education and wellness programming for the Parkinson community, such as exercise and dance classes, and offers funding for local and national PD research. The foundation also maintains contact and general information for the Parkinson Support Groups such as *PEP* in the 16 counties that it serves. OPFNE is in the process of updating their website (ohparkinson.com) to be even more helpful to anyone looking for local support and information on PD.

I want to personally thank the OPFNE Board for providing an annual grant to *PEP* which partially covers the costs of the *PEP* newsletter. We wouldn't be able to continue without your support.

Upcoming Events

April 1—Shaking With Laughter in conjunction with CWRU School of Medicine presents A Funny Fundraiser to benefit PD Research. The show will feature the Bria Skonberg Quartet and comedian, Jake Johanssen and will be at The Maltz Performing Arts Center in Cleveland at 8 p.m. You can purchase tickets at <https://case.universitytickets.com/w/event.aspx?id=1993> or call 216-368-6062.

Saturday April 22, 2023—Ohio Parkinson Foundation Northeast Region, 23rd Annual Symposium: Practical Living with Parkinson's, 10:00 AM – 2:30 PM at the Hilton Garden Inn, Twinsburg—Speakers include Dr. Erin Presant, Board certified Neurologist and additionally certified in Culinary Medicine who will speak on Everyday Nutrition for Parkinson's.—Registration instructions will be in April newsletter.

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

The Unmet Needs of Women with Parkinson's

(Excerpt from Parkinson Foundation)

Second of a 2-part Series

Top 12 Unmet Needs of Women with Parkinson's –

Below are some of the unmet needs of women with Parkinson's the authors highlight:

1. Customizing treatment for women's body weight and unique drug metabolism
2. Developing a tool to communicate with providers and improve symptom tracking (including the tracking of menstrual cycles, pregnancy, peri-and post-menopause)
3. Improving access to subspecialty care and advanced therapies (i.e., DBS) for women with PD
Guiding self-care/stress reduction strategies for women with PD
4. Guiding self-care/stress reduction strategies for women with PD
5. Creating culturally sensitive resources for communities, including LGBTQ+ and women of color, with PD — guide planning for the future, especially for single women
6. Educating male caregivers with carefully chosen and organized resources and support
7. Increasing awareness in the community to improve the recognition of PD in women and the intersection of other representative populations
8. Educating health care professionals on the importance of referral to a movement disorders specialist for women
9. Increasing awareness of hormonal stages in the lives of women with PD
10. Understanding why women are not engaging in research and develop strategies to improve engagement
11. Recruiting more women in clinical drug trials to improve counseling on the effects and side effects of treatments
12. Conducting research on reproductive factors (e.g., natural vs. surgical menopause) on PD risk in women and the protective effects of estrogen and effects of timing of exposure

What does this mean?

In 1993, it became federal law that the National Institutes of Health (NIH) — the world's largest funder

of biomedical research — had to include women as well as men in clinical studies. However, even when women have been included, the influence of sex or gender is neither widely analyzed nor reported. PD is no exception.

PD is erroneously represented as a disease of white, older men. However, Parkinson's cannot be fully understood without increased representation of women and underserved populations in PD research. Without being represented in PD research women will continue to experience disparities in treatment and care.

Women experience a delayed diagnosis of PD compared to men. In short, best practices need to be established for all healthcare professionals who provide care to women with PD. Healthcare professionals (including all training) should work to include the unique symptoms of women and the impact of estrogen level changes during menstruation, pregnancy and menopause and how that may affect medications.

It is essential that empowering patient educational tools be created. For example, the authors propose a symptom diary that includes hormonal cycle tracking and a PD symptom reporting guide to help women communicate their personal motor and non-motor symptoms with their healthcare professionals.

Lastly, to help address unmet research and care needs of women with Parkinson's, the Foundation created the first national agenda specific to women with PD. This agenda identified research and care practices that better capture the needs of women. We need to continue to diversify Parkinson's research that will ultimately help further treatments for everyone living with this disease.

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.

TRIBUTES

Alicia Warren

Maxine Jacqmin

Parkinson's Disease Question Corner

Email: barbaramarquardt@outlook.com

Question: What does glutathione help?

Answer: Glutathione helps many functions in the body.

The top six of the many health benefits of Glutathione:

1. Provides antioxidant support
2. Supports healthy cell function and healthy aging
3. Supports detoxification
4. Supports a healthy immune response
5. Enhances the antioxidant activity of vitamins C/E
6. Protects against neurological damage from toxins

Ref: <https://www.immanencehealth.com/>

Stay Active this Winter: 5 Indoor Sports

(Excerpt from parkinsonslife.eu)

Regular exercise can improve physical and mental health, and it has been shown to have a positive impact on people with Parkinson's. But in the middle of winter, exercise options can be limited. We round up five ways to stay active – and warm! – during the colder months

1. **Swimming** – For people with PD, swimming and aquatic therapy (performing physical movements in water) could be beneficial. The buoyancy of water helps support a person's weight, which may reduce fears of falling and the risk of fatigue. It can also strengthen muscles and decrease stiffness. Pool-based activities are especially popular in the early and middle stages of PD, with many finding it easier to exercise in water than on land. It's recommended that people discuss the sport with their doctor to ensure it's the right activity for them.
2. **Pilates** – Exercise designed to stretch and strengthen the body has grown in popularity in recent years, with in-person and online courses offered around the world. Focused on improving core strength, posture, breathing control, balance and flexibility, the sport is well suited to those with PD. It mainly takes place on the floor, often requires little movement and can be adapted to different physical

limitations and levels of fitness. Routines can be carried out at home or in a group setting. Research has found that the benefits on lower-body function may be superior to other conventional exercises, with the potential to boost body-brain signaling and offer participants more control over the way their body moves. The Brian Grant Foundation describes it as a "low-impact activity with big-impact results".

3. **Weight training**—According to the Parkinson's Foundation, it can improve levels of dopamine and increase muscular strength, endurance, balance – and even cognitive functioning. Given the decrease in strength and postural difficulties associated with PD, weight training is considered by many to be a useful and safe way to increase strength, stability and confidence by gaining "muscle power". While people are encouraged to consult a doctor before embarking on exercise routines, many might benefit from a "sitting workout" that uses dumbbells or resistance bands. This can be achieved at home or in specialist classes hosted by gyms or PD support groups.

4. **Tai chi** – Tai chi and its cousin qigong (martial arts activities both founded on breathing, movement and meditation) could be useful therapies for people with PD with the potential to improve flexibility, balance, walking ability and mindfulness. These Chinese wellness practices involve gentle, fluid movements and can be carried out in classes or household settings, with a plethora of online tutorials available. A scientific study found it had a significant beneficial impact on balance, gait and motor scores among people with PD with fewer reported falls compared to those not on the program. As tai chi and qigong do not rely on strength or speed, the activities can be suitable for a range of ages and abilities.

5. **Wall climbing** – Indoor climbing walls can be found in many towns and cities, offering the physical benefits of the sport without the weather. Climbing requires strength, coordination and balance, with some doctors saying that the systems impacting movement in people with PD are "the same ones we retrain when we have to climb a wall". A 2021 study found that in addition to being a feasible activity for people with mild to moderate Parkinson's, wall climbing may also significantly improve posture – with one study author commenting: "As long as you can walk independently and up a stair, you can go climbing."

PEP NEWS

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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.

Long-Term Exposure to Air Pollution Could Impact PD Mortality Risk

(Excerpt from parkinsonslife.eu)

New research has suggested that long-term exposure to air pollutants could increase the risk of death from Parkinson's. A team of European researchers conducted the study, published in the journal *'Environment International'*, as part of the Effects of Low-Level Air Pollution: A Study in Europe (ELAPSE) project – a Europe-wide initiative looking at the effects of low air pollution levels on people's health.

The researchers used ELAPSE's datasets to analyze figures for over 200,000 adults from six European countries. They also looked at air pollution models, estimating the concentrations of air pollutants in these countries to explore the link between pollution exposure and deaths from Parkinson's. The results suggest that long-term exposure to PM2.5 particles at

high levels was associated with a 25% higher risk of death from the condition, and the authors of the study added that the research "adds strong evidence in support of an association between air pollution and Parkinson's."

Partial grant support provided by OPFNE



ohparkinson.com

April Meeting—April 5, 2023

We welcome **Ignacio ("Nacho") Mata, PhD** Cleveland Clinic Lerner College of Medicine and Assistant Professor of Molecular Medicine at Case Western Reserve University who will talk on "Parkinson's Disease Genetics, Why Should I Care?" **Dr. Mata** was prominently highlighted in the Parkinson's Foundation Spring 2021 Quarterly report regarding him leading their Hispanic Parkinson's Advisory Council. He has worked to diversify genetics research since 2005.

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