

PEP NEWS

FEBRUARY 2023

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

FEBRUARY MEETING—Wednesday, February 1, 2023 – 2:15 p.m.

We are pleased to have back **Angela Ridgel, Ph.D., ACSM-EP**. Dr. Ridgel is a **Professor in Exercise Science/Physiology and the Associate Director of the Brain Health Research Institute at Kent State University**. She received her undergraduate degree in Biology from The College of William and Mary in Virginia, a Master's degree in Biology at Villanova University in Pennsylvania and her Doctoral degree in Biomedical Sciences from Marshall University in West Virginia. Dr. Ridgel completed her Post-Doctoral training at Case Western Reserve University and Cleveland Clinic. Her early work used animal models to examine the neurobiology of movement and the effects of aging on movement. Over the last 15 years, she has been interested in how aging and neurological disorders limits movement and cognition in humans. Dr. Ridgel's current research project examines how exercise and movement therapy can be used for neurorehabilitation in Parkinson's disease. She will be talking on her ongoing research collaborations with colleagues at University Hospital, Case Western Reserve University, and the Cleveland VA Medical Center.

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

Last names A through M, please bring **individually wrapped snacks**. S.A.C. policy prohibits serving food "buffet style"; everything must be individually packaged. Thanks so much!

From David Brandt

Upcoming Events

Saturday April 22, 2023 — Ohio Parkinson Foundation Northeast Region

- 23rd Annual Symposium: Practical Living with Parkinson's
- 10:00 AM – 2:30 PM
- 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.

March Meeting—March 1, 2023

Richard Huckabee 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!

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)

First of a 2-part Series

40% of the people living with Parkinson's disease (PD) worldwide are women. Right now, in the U.S. there are more than 400,000 women living with PD. To this day, women are woefully underrepresented in PD research. With the limited research we do have, compared to men with Parkinson's, women with PD experience:

1. Different motor and non-motor symptoms
2. Different disease risk factors
3. Different treatment side effects
4. More challenges with access to healthcare delivery
5. Less social support

The inherent biological, psychosocial (the influences of social factors on an individual's behavior and mental health), sex and gender differences are seldom considered when research and care priorities are being selected. 400,000 women live with Parkinson's in the U.S.

Six women researchers, of whom five are doctors of medicine and three are living with PD, recently published a review article in the journal, *Movement Disorders*, titled, "Unmet Needs of Women Living with Parkinson's Disease: Gaps and Controversies" (Subramanian et al., 2022). They sought to rigorously evaluate and document the current knowledge, gaps and possible strategies to address the unmet needs of women living with PD, with a focus on the clinical and psychosocial aspects.

Summary – Below we summarize the authors findings, highlighting the distinctive experiences of women with Parkinson's. The authors note that many research findings have not been conclusive yet. In addition, the researchers emphasized the need for additional studies focused on better understanding PD in women. Findings include:

Sex, Gender & Risk Factor Studies

- PD risk is lower in current male smokers, compared to current female smokers.
- Alcohol consumption had more pronounced risk-lowering effect in women than men.

- Very little is known about the experience of women with PD in the Lesbian, Gay, Bisexual, Transgender, Queer or Questioning plus other sexual identities (LGBTQ+) community.
 - ⇒ Discrimination and stigma as barriers to accessing care may hinder knowledge, diagnosis and involvement with multidisciplinary approaches to treatment.
 - ⇒ 33% of older members of the LGBTQ+ community reported experiencing stigma from their doctor, which led to general mistrust of the medical system.

Premenstrual, Pregnancy and Premenopausal

- Women often report worsening of motor symptoms, just prior to getting their menstrual period each month.
- Approximately 5% of women are diagnosed with PD before they turn 40, thus how PD impacts pregnancy warrants further study.
- PD symptoms have been reported to worsen during pregnancy and postpartum.
- Women often report premenopausal worsening of PD symptoms, also possibly due to a decrease in estrogen.

Sex Hormones Studies

- Estrogen may be neuroprotective, possibly accounting for later PD onset in women.
- Longer duration of hormone replacement therapy in women with natural menopause was associated with reduced risk of PD.
- Whether hormone replacement therapy is beneficial in treating fluctuations in PD symptoms during peri-menopause and post-menopause remains unclear.

Care

- The public (and physicians) believe PD is a disease primarily of elderly white men.
- Women experience a delay in getting an accurate diagnosis of PD and getting a referral to a movement disorder specialist.
- Women often downplay symptoms, and/or may not realize the symptoms are PD-related.
- Women are less likely to get advanced treatments, such as deep brain stimulation (DBS), despite the potential for quality-of-life improvements in mobility.

Parkinson's Disease Question Corner

Email: barbaramarquardt@outlook.com

Question: What is new in Parkinson research this year?

Answer: An article was published in January 2023, in ScienceDaily, "New Study Puts Gut Microbiome at the Center of Parkinson's Disease Pathogenesis."

The summary of the article states that new research says the gut microbiome is involved in multiple pathways in the pathogenesis of Parkinson's disease. The findings show a wide imbalance in microbiome composition in persons with Parkinson's disease. The investigators employed metagenomics, the study of genetic material recovered directly from the stool microbiome of persons with PD and neurologically healthy control subjects.

Ref. and to read more on the study, please visit:

<https://www.sciencedaily.com/releases/2023/01/230110191417.htm>

EPA to Reconsider Herbicide Paraquat

(Excerpt from Michael J. Fox Foundation)

This week saw an important breakthrough in ongoing work to ban paraquat, an herbicide thought to increase Parkinson's risk by 100 to 500%, depending on overall exposure. The Michael J. Fox Foundation (MJFF) and the Parkinson's community have long made it a priority to eliminate this troubling environmental trigger of Parkinson's.

Now, due in part to years of effort by Parkinson's advocates nationwide — including amassing more than 100,000 signatures on a petition to the Environmental Protection Agency (EPA) and logging tens of thousands of emails and phone calls to Congress — EPA has agreed to reconsider the evidence that paraquat causes brain damage and other harm. This could lead to the chemical being banned in the United States, as it already has been in more than 50 other countries.

What happens next: EPA will prepare new analyses of paraquat's risks and cost-benefit balancing. The agency will accept public comment on these new analyses, which are expected to be proposed around a year from now. MJFF will continue to keep you informed of future opportunities for patient and family advocacy to keep pushing for the ban. As always, thank you for helping MJFF do whatever it takes to better treat and prevent Parkinson's disease — and ultimately, to eradicate it altogether.

The Unmet Needs of Women with Parkinson's *(Cont'd from pg. 2)*

Mental Health Issues

- Despite decreased abilities, women with PD often continue performing their usual activities, including working and caretaking for family and home. Men with PD do not.
- Women who perceive themselves as caregivers are more likely to be in poor health, have difficulty in accessing needed medical care, and experience greater degrees of depression.
- Women with PD have significantly less social support, more psychological distress, and worse self-reported (but not physician-reported) disability and health-related quality-of-life at initial PD care visits, compared to men.

Relationship Issues

- Married women with PD, with disability, receive fewer hours of informal caregiving compared to married men with the same level of limitations.
- Women living with an illness are more likely to need non-spousal help to fill in the gaps in their needs.
- Women with PD are more likely to live in a nursing home compared to men with PD.

Top 12 Unmet Needs of Women with Parkinson's TO BE CONTINUED IN THE MARCH PEP NEWSLETTER

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

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Is the Rate of PD Diagnosis Higher in the US Than First Thought?

(Excerpt from parkinsonslife.eu)

Previous figures have suggested that between 40,000 and 60,000 people are diagnosed with Parkinson's every year in North America. Now, a new study has indicated that this figure could be higher. Research published in the journal 'NPJ Parkinson's disease' suggests that almost 90,000 people aged 65 and over are diagnosed with the condition in the US each year.

Researchers analyzed five healthcare datasets – one from Canada and four from the US – and found that the number of people diagnosed with Parkinson's in the US could now be around 50% higher than previously thought. Study co-author Dr. James Beck said: "These updated estimates of incidence are necessary for understanding disease risk, planning healthcare

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delivery and addressing care disparities."

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ohparkinson.com

TRIBUTES

In Memory of Judy Weidenthal
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Sally Tatar