PEPNEWS

MARCH 2021

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

March PEP Meeting — March 10, 2021

e welcome Dr. Robert Smith, PHD Psychology and Director at MetroHealth. and Assistant Professor at Case Western Reserve University School of Medicine. Dr. Smith will present "Resilience in 2021: Coping with COVID-19, Political, Economic and Social Unrest and a Partridge in a Pear Tree!". Please join us for this very informative talk. Please note that this date is different from our normal first Wednesday of month. It will be Wednesday, March 10 at 2:00 p.m. The Zoom link is https://us02web.zoom.us/J/88611069824

Meeting ID: 886 1106 9824, +1 312 626 6799

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

From David Brandt

Towards the end of last year, I had the pleasure of being asked to join the Board of the Ohio Parkinson Foundation Northeast Region (OPFNE). It is a wonderful non-profit organization created in 1997 whose mission is to improve the quality of life for those affected by Parkinson's Disease. This is done through offering an annual, free, educational symposium, supporting 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. Their mission is to also provide backing to the many local support groups in the area including PEP. PEP receives an annual grant from OPFNE which helps cover the costs of this newsletter.

The annual symposium put on by OPFNE has been going on for 22 years and is attended by over 200 people. Unfortunately, this year's event was cancelled due to COVID but we are scheduled again for April 9,2022.

Recently, Sharon Andrisin stepped down as President of OPFNE after heading the organization for many of its years, but we are happy to say she will continue to be a Board member. Kathie Stull is the new President and Fred Discenzo is the Vice President, and I know we are in good hands to keep the mission of OPNE alive and well.

I strongly urge you to check out the OPFNE website at http://ohparkinson.com/. It is a great place to find support groups that are near you as well as see what the upcoming Parkinson related events are where you can find local classes related to Parkinson's and educational items. It even keeps past copies of the *PEP* newsletter!

April PEP Meeting—April 7, 2021 – Dr. Shnehal Patel, M.D. Neurologist from Ohio Health Physicians Group will speak on "Moving Forward: Finding Options for Advanced Parkinson's Disease"

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

People with Parkinson's Disease have a "High Interest" in Herbal Drugs, Study Finds

(Excerpt from https://parkinsonslife.eu/)

esearchers in Germany conducted a survey to assess how people with Parkinson's disease perceive and experience medical cannabis. As part of the study, the team analyzed answers from more than 1,300 people with Parkinson's. They found that 65% of participants who did not use medical cannabis were interested in it, but lacked knowledge and feared side effects. Around 8% of participants reported using cannabis; of these, 54% reported beneficial effects – including 40% who reported reduced pain.

Professor Dr. Carsten Buhmann, lead study investigator, said: "Our data confirm that Parkinson's disease patients have a high interest in treatment with medicinal cannabis. The data reported here may help physicians decide which patients could benefit, which symptoms could be addressed, and which type of cannabinoid and route of administration might be suitable.

"It has to be stressed, though, that our findings are based on subjective patient reports and that clinically appropriate studies are urgently needed."

Parkinson's in The News: January

(Excerpt from Parkinsonslife.eu)

wo proteins that could slow the progression of Parkinson's disease – Researchers in Israel discovered that two bone morphogenetic proteins (BMPs), which play a role in the development of dopamine-producing neurons, could be used to slow or prevent the progression of Parkinson's disease.

The study revealed that the two BMPs prevented the loss of dopamine-producing neurons in a mouse model of Parkinson's disease.

Dr. Claude Brodski, head of the laboratory of Molecular Neuroscience at Israel's Ben-Gurion University and senior author of the study, said: "These findings are very promising since they suggest [the BMPs] could slow or stop Parkinson's disease progression. Currently, we are focusing all our efforts on bringing our discovery closer to clinical application."

Dr. Galit Mazooz Perlmuter, senior vice president of business development, biopharma at BGN Technologies, added: "There is a vast need for new therapies to treat Parkinson's disease, especially in advanced stages of the disease. We are now seeking an industry partner for further development of this patent pending invention."

New Study: Can People with Parkinson's Experience Apathy and an Impulse Control Disorder at the Same Time?

istorically described as being on opposite ends of the spectrum, <u>apathy</u> affects about 40% of people with Parkinson's disease (PD), while <u>impulse control disorders (ICDs)</u> affect between 14% and 40% of people with PD. How are they different?

Apathy — which comes from the French, *apathie*, meaning "passionless existence" — is the feeling of being emotionally flat, lacking enthusiasm or interest in doing anything. Apathy can express itself in different ways, often leading people who experience it to stop exercising, keeping up with friends and family or even stop taking medications. Of note, apathy is often confused with depression, but they are not the same: with **depression**, there's a profound sense of feelings of guilt and worthlessness.

Impulse Control Disorders (ICDs) are the inability to stop doing something that is harmful, or could become harmful, to yourself or others to the point that they impair one's ability to function at work, home and navigate day-to-day life. Performing the activity can lead to a feeling of elation. Examples include online gambling, compulsive shopping and hyper sexuality.

Since apathy and ICDs elicit opposite feelings, is it possible for a person with PD to experience both at (cont'd on pg. 3)

Parkinson's Disease Question Corner

Email barbaramarquardt@outlook.com with questions!

Question: I am looking for a new mattress to help me sleep better with Parkinson's, any ideas?

Answer: Since we spend approximately eight hours a day in bed, it is wise to make a good investment and do your research. I believe an **organic** mattress is best, but they can also be expensive. If an organic mattress is out of reach, many companies offer organic mattress toppers, which is something you could put on top of your mattress.

Organic mattress companies to look into:

- Saatva: https://www.saatva.com; 1-877-672-2882
- **Happsy**: https://happsy.com; 1-844-742-7779
- Lifekind: https://lifekind.com; 1-800-284-4983
- Essentia:

https://myessentia.com; 1-888-764-4116

- Avocado Green Mattress:
 - https://www.avocadogreenmattress.com
- Birch: https://birchliving.com

Lastly, one easy tip for sleeping better with Parkinson's...although flannel sheets are warm they make it difficult to turn over in bed, so please try a silk or silky soft sheet that will help you turn over in bed. It always amazes me how little changes can make a big difference, sweet dreams!

Apathy and an Impulse—(cont'd from Pg. 2)

the same time? It seems counterintuitive, but may not be. A study recently published in the journal, *Neurology*, "Co-occurrence of apathy and impulse control disorders in Parkinson's disease" (Scott et al., 2020) sought to explore whether a lack of motivation or interest can co-exist with an irresistible urge to perform activities.

Study participants included those with Parkinson's experiencing:

- An impulse control disorder (ICD): those with clinically significant ICD symptoms only
- Apathy: those with clinically significant apathy symptoms only
- Both: those with both clinically significant apathy and ICD symptoms

Neither: those with neither clinically significant apathy nor ICD symptoms

Results

- 61.6% of study participants had both ICD symptoms and apathy
- 41.3% of study participants with apathy also had ICD symptoms
- The ICD-only group had higher daily dopamine agonist medication use than patients in the apathy group
- There was no significant difference in dopamine agonist use between the Neither group and the apathy group
- Anxiety and depression each positively correlated with both apathy and ICD symptoms, separately

What Does It Mean

A person with PD can indeed experience both apathy and ICDs — suggesting they are not on opposite sides of the spectrum. In fact, a significant majority (62%) of those with PD in this study with ICDs had clinically significant apathy; while 41% of people with PD experiencing apathy also had ICD symptoms. Further, having both apathy and one or more ICDs resulted in having the highest levels of anxiety and depression.

This study suggests that it is imperative that clinicians, researchers, healthcare providers and care partners consider that these two PD symptoms are not mutually exclusive — you can experience both at the same time. Knowing that someone with PD could have apathy and ICDs simultaneously, could profoundly impact clinical study designs, how novel medications are designed and tested, the approach (and mindset) of caregivers, and perhaps how those

TRIBUTES

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In Memory of Ray Brandt Bill and Annette Cappaert

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Margaret Meehan

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Study Finds

(Excerpt from https://parkinsonslife.eu/)

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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.

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