

PEP NEWS

OCTOBER 2022

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

OCTOBER MEETING—Wednesday, October 5, 2022 – 2:15 p.m.

We welcome **Dr. Steven Gunzler, MD, Parkinson's and Movement Disorders Center Neurological Institute at University Hospitals Medical Center Cleveland and Case Western Reserve University School of Medicine.** Dr. Gunzler will provide an update on Research and Treatments in Parkinson's Disease. Dr. Gunzler was unable to make our July meeting so this was rescheduled.

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

Last names N through Z, 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

The Annual Big Band Brunch sponsored by the *Ohio Parkinson's Foundation Northeast Region* and *Come Dance With Me* is coming up soon. The event will be held as usual at Driftwood Catering at Landerhaven in Mayfield Hts. on Sunday, November 6, 2022 from Noon-3 p.m. Music is provided by the Swing City Band. You can enjoy the fabulous buffet brunch while listening or dancing to the all of the popular hits of the Big Band era to today.

This has always been a well attended and fun event and just like in years past, *PEP* is willing to cover the \$20 cost to enter. Just email me (dbrandtpep@gmail.com) or call me (440-742-0153) and I will add you to the list.

The recent Empower U event was sold out and very successful. You have a chance to attend the Parkinson's Boot Camp put on by Univ. Hosp. Please see details below and also directions on how to register.

Finally, InMotion's Pals In Motion run/walk raised a record \$450,000 for Parkinson's research on Sept. 18. It was perfect weather for all of the events.

Upcoming Events

October 29 Parkinson's Boot Camp – This annual event put on by University Hospitals will be held at LaCentre Conference and Banquet facility in Westlake from 9:30 a.m. – 3 p.m. Doors open at 8 a.m. for registration. A light breakfast and lunch will be provided and there is no charge for the event. Scheduled speakers include Camila Kilbane, MD and Director of the Parkinson's & Movements Disorders Center at University Hospitals; Cynthia Comella, MD and Professor Emeritus at Rush University Medical Center (Keynote speaker); and Angela Ridgel, PhD and Professor Exercise Science at Kent State University. To register, please call 216-983-6683.

November 6 Big Band Brunch Sponsored by Ohio Parkinson Region Northeast Region (OPFNE) at Driftwood Caterers at Landerhaven, 6111 Landerhaven Dr., Mayfield Hts., OH – At Noon for a fabulous buffet brunch and 1-3 p.m. will feature the Swing City Band. You can register online at ohparkinson.org. Tickets are \$20 per person.

TO REACH US AT PEP 440-742-0153

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

Introducing The “First-Ever” Legislation Devoted Solely to Ending PD

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

Nearly one million people are currently living with Parkinson’s in the US. Now, members of the US House of Representatives have introduced the National Plan to End Parkinson’s Act – a bill focused on tackling the condition

In a historic step for the Parkinson’s community, members of the US House of Representatives have introduced a new bill focused on the condition: the National Plan to End Parkinson’s Act.

Hailed the “first-ever” legislation devoted solely to addressing Parkinson’s by the Michael J Fox Foundation, the bill was introduced by representatives Paul Tonko and Gus Bilirakis.

“I’m proud to introduce this common-sense, compassionate bill that will establish a robust response to Parkinson’s,” commented Congressman Tonko. “Receiving a Parkinson’s diagnosis is truly devastating for individuals and their loved ones – it is incumbent on Congress to ensure Americans know that they will be supported during this life-altering time.”

Embarking on a “mission to cure and prevent Parkinson’s” – According to a press release from Congressman Tonko, the aim of the National Plan to End Parkinson’s Act is to “unite the federal government in a mission to cure and prevent Parkinson’s, alleviate financial and health burdens on American families and reduce government spending over time”. American taxpayers currently pay over US\$52 billion annually to provide treatment to those living with the condition, with the cost estimated to increase to more than US\$80 billion annually by 2037.

The Act will also see the creation of an advisory council, involving people in the Parkinson’s community as well as members of every federal agency that supports care, services and research for the condition. The council will be tasked with evaluating current federal programs related to Parkinson’s, creating a national plan to prevent and cure Parkinson’s and reporting annually to Congress on the plan’s progress.

The value of cooperation – Commenting on the introduction of the bill, Congressman Bilirakis – who has shared his personal connection to the condition – said: “We must change our approach to get better results [...]. This critical legislation will provide hope to those who are suffering and hopefully lead to better patient outcomes and less expensive disease management.”

The bill is now undergoing the usual congressional process before it is voted on by the House of Representatives. The Michael J Fox Foundation, which is working with two senators to introduce the Senate’s “companion bill”, has called for members of the US community to show their support by emailing their representative.

“Together,” said Congressman Bilirakis, “we can work to end this debilitating [condition].”

Parkinson’s Disease Question Corner

Email: barbaramarquardt@outlook.com

Question: What is Lewy Body Dementia?

Answer: Dementia with Lewy Body happens when abnormal structures, called Lewy bodies, build up in certain areas of the brain. There are important distinctions to note in the difference between Alzheimer’s and Lewy Body Dementia (LBD). Alzheimer’s affects the brain’s ability to store new information in the form of memories, while Lewy body dementia targets a different set of cognitive functions, specifically, problem solving and reasoning.

It can include both Parkinson’s disease dementia (PDD) in which Parkinson’s disease is first diagnosed and symptoms of LBD appear later), and Dementia with Lewy bodies (DLB) which starts with dementia and is often misdiagnosed as Alzheimer’s disease, but may include Parkinson-like symptoms at the time of diagnosis or later. Over time, people with dementia with Lewy bodies or Parkinson’s disease dementia may develop similar symptoms.

(cont’d. on Page 3)

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.

Parkinson's Disease Question Corner

Cont'd from Page 2

Symptoms: LBD includes visual hallucinations, delusions, paranoia, tremors or shaking, apathy, quick changes in mood, and frequent variations in cognitive ability, attention or alertness. There are also changes in walking or movement, as well as a sleep disorder called REM sleep behavior disorder, in which people physically act out their dreams. *LBD patients may also have a severe sensitivity to medications prescribed for hallucinations.

For more information on Lewy Body Dementia, contact the Lewy Body Dementia Association at:
Lewy Line: 1.800.539.9767; National Office (Atlanta, GA): 1.404.935.6444

Ref: <https://holisticaging.com/lewy-body-dementia-pittsburgh/>
<https://www.lbda.org>

PD Symptoms Linked to Protein Deficiency in Fruit Flies

(Excerpt from parkinsonslife.eu)

Researchers in Germany have linked a specific protein to motor disorders and learned more about the cell processes associated with Parkinson's – by studying fruit flies. In a recent study, researchers at the University of Bonn, Germany, investigated fruit flies to learn more about a protein known as Creld – and found it may play an important role in Parkinson's. A previous study at the university indicated that the protein is involved in the development of the heart in mammals, but now, said University of Bonn lecturer Dr. Margret Helene Bülow: "We wanted to find out exactly what the protein does."

A layered investigation – To learn more about Creld's properties, the team genetically modified fruit flies so that they were unable to produce the protein. The study revealed that this led to signs of slowed heart rate and severe motor disorders in the flies, signaling energy deficiency.

In a press release, Dr. Nicole Kucharowski, one of the key contributors to the study, said: "Creld may play an important part not only in impaired heart function but also in Parkinson's." The researchers made a link

between this deficiency and the cell's energy source: the mitochondria, which transforms food into the energy needed for the cell to carry out its function of sending signals between cells and clearing away old cells.

Impaired mitochondria can lead to the death of nerve cells still needed for motor function, which can, in turn, lead to symptoms of Parkinson's. This, however, posed another question: what is the link between Creld and the mitochondria?

The pesticide effect – To investigate this question, the researchers turned to pesticides – using prior knowledge that rotenone, an ingredient used in pesticides that has been linked to Parkinson's onset, may cause similar problems with mitochondrial function. They administered small amounts of rotenone to healthy fruit flies and found that these flies displayed motor symptoms similar to those that did not produce Creld.

Rotenone is thought to cause cell damage by inhibiting the mitochondria's energy production. The researchers noted similarities between the impact of rotenone and a lack of Creld, revealing that the protein may play an essential role in increasing energy function in cells.

The researchers concluded that Parkinson's might therefore be linked to a chronic undersupply of energy due to a lack of Creld. "The findings of a recent analysis are consistent with this," said Dr. Nicole Kucharowski. "It suggests that Creld production is often reduced in [people with] Parkinson's."

November Meeting—November 2, 2022

We are pleased to have Anne Reed, Board Certified Music Therapist and Interim Chair from The Music Settlement join us to talk about Music Therapy and Parkinson's. Music therapy is an established health profession that uses clinical and evidence-based music interventions to address physical, emotional, cognitive, and social needs of individuals.

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

PEP NEWS

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

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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.

Early Symptoms of PD Evident Years Before Diagnosis, Study Shows

PD is marked by a number of symptoms that may make driving difficult and/or unsafe, including motor symptoms such as tremor as well as non-motor disturbances such as unusual sleepiness or hallucinations. But getting care typically requires patients to travel long distances in order to see specialists; the average in-person specialist visit would involve traveling about 100 miles, requiring a patient to spend more than three hours driving, according to Miller.

The idea for a project about autonomous vehicles arose during the development of an app for Parkinson's patients, as the scientists were working to understand the practical needs of people with the disease.

Autonomous vehicles, sometimes called "self-driving" cars, are designed so that certain actions — particularly functions critical for safety, like steering, acceler-

ation, or braking — don't require active input from the driver.

"A recurring theme that has come up is that people with Parkinson's disease have different lifestyles but they share the desire to carry out tasks independently," Miller said. The aim of this project is to create an autonomous vehicle specifically designed to accommodate the needs of Parkinson's patients. This summer, the researchers will be working to design the study, which will involve simulated driving scenarios conducted at labs across the three UM campuses.



TRIBUTES

In memory of George Smearsoll
and Ron Wiant
Dianne Knepper