

APRIL 2024

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

APRIL MEETING—Wednesday, April 3, 2024 – 2:15 p.m.

We are pleased to welcome **Adam Margolius, MD, Center for Neuro-Restoration at The Cleveland Clinic**. He will talk on Palliative Care and Parkinson's Disease. Dr. Margolius has been with the Clinic since 2020.

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

From David Brandt

I am writing this in mid-March as spring is approaching. We've had a mild winter so flowers are already blooming and we have what seems like much more sunny days in Northeast Ohio than normal. Spring also announces the arrival of Parkinson's Awareness month in April. Each April is marked as Parkinson's Awareness Month, shining a light on the struggles and advancements in dealing with this disease. There are several ways to participate in Parkinson's Awareness Month:

- **Learn and Share Information:** Educate yourself about Parkinson's disease and share this knowledge with others.
- **Support Research:** Donate to organizations conducting research on Parkinson's disease.
- **Participate in Events:** Join walks, runs, or other events organized to raise awareness and funds.
- **Advocate:** Advocate for policies and programs that benefit the Parkinson's community.
- **Volunteer:** Offer your time and skills to local Parkinson's support groups or events.

We try and do our little part at PEP and trust you will to.

There is still time to register for the free Ohio Parkinson Foundation Northeast Region 24th Annual Symposium which will be Saturday, April 13 at Embassy Suites in Independence. Register by April 5 440-345-6401. More details below.

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

Upcoming Events

Saturday, April 13 – 24th Annual Parkinson Symposium - Embassy Suites, 5800 Rockside Woods Blvd. N, Independence, OH; 10 a.m. – 2:30 p.m.; **Phone registration required:** Call 440-345-6401 to register.

Saturday, June 1 – Moving Day Cleveland sponsored by the Parkinson's Foundation at the Cleveland Metroparks Brooklyn Reservation. More details to follow.

Friday June 14 – Living In Motion, 9:30 a.m.—12:30 p.m. at In Motion. This is an opportunity for people affected by PD to learn about InMotion and other resources. Keynote speaker David Leventhal, Founding teacher and program Director for Dance with PD. Free Registration: <https://www.ticketsignup.io/TicketEvent/LivingInMotion>

Treating Mitochondrial Dysfunction with Natural Supplements

(Excerpt from www.townsendletter.com)

Mitochondrial dysfunction, resulting in impaired cellular energy production, produces excess fatigue, making the simplest tasks feel onerous. It occurs in aging and in all kinds of chronic diseases: neurodegenerative, cardiovascular, metabolic, autoimmune, gastrointestinal, chronic infections, neurobehavioral, and cancers. Non-genetic, acquired mitochondrial dysfunction responds to treatment with natural supplements, writes Garth L. Nicolson, PhD, in a 2014 article.⁵ Dr. Nicolson is founder, president, and research professor at the Institute for Molecular Medicine's department of molecular pathology (Huntington Beach, California).

(cont'd on Pg. 2)

PD Question Corner

Email: barbaramarquardt@outlook.com

Question: What is Young-Onset Parkinson's Disease, (YOPD)?

Answer: Young-onset PD can develop between the ages of 21-55 and brings a unique set of challenges. These patients often display different initial symptoms than older patients and may take longer to get diagnosed. Research published in the *Journal of Neurological Sciences* in 2012 shows that patients with young-onset Parkinson's diseases take longer to get an accurate diagnosis, with one study finding the discrepancy in time to diagnosis was on average 15 months longer for younger patients.

This may be due to a different presentation of symptoms and the disease being overlooked simply due to the patient's age. In addition, the course the disease takes is also different in younger patients than older ones. In young-onset patients, the first symptoms tend to be rigidity, pain, cramps, and dystonic posturing, which is often misdiagnosed as tendonitis.

Young-onset patients are also at increased risk for non-motor symptoms of PD, including sleep disorders, depression, anxiety, constipation, low energy, urinary issues, and apathy. However, these patients also have a lower rate of PD related dementia.

Looking for additional help with Young-onset PD, visit Young Onset Parkinson's Network at yopnetwork.org

April is Parkinson's Awareness Month

Please help us spread awareness of all Parkinson's!

Ref.: <https://www.verywellhealth.com/young-onset-vs-late-onset-parkinsons-disease-2612166>

Treating Mitochondrial Dysfunction with Natural Supplements

(Con't. from Pg. 1)

During the process of creating energy, mitochondria also produce damaging free radicals that cause oxidative damage to cellular and mitochondrial membranes. As a result, function is impaired and inflammation ensues. Nicolson explains that people with chronic fatigue typically show signs of excess oxidative stress in blood tests, including elevated peroxynitrite levels. He considers alpha-lipoic acid, L-carnitine,

coenzyme Q10, and phospholipid therapy to be among the "most promising supplements" for improving mitochondrial function and reducing fatigue.

Alpha-lipoic acid is a necessary co-factor for important mitochondrial enzymes. In addition, it helps reduce oxidative stress by stimulating the production of glutathione. Alpha-lipoic acid has the added benefit of being able to remove excess metals associated with hemochromatosis, Parkinson's, and other chronic diseases. Although α -lipoic acid's effect on chronic fatigue had not yet been studied in controlled clinical trials (as of 2014), Nicolson said, "...its widespread use as a safe supplement (usually 200-600 mg/d) to support mitochondrial function and reduce oxidative stress has justified its incorporation into various supplement mixtures."

L-carnitine transports fatty acids into the mitochondria for oxidation and removes excess acyl groups. It also increases the rate of mitochondrial oxidative phosphorylation, which tends to decline with age. Reduced phosphorylation impairs energy production and increases damaging reactive oxygen species and reactive nitrogen species. Nicolson cites a study in which 70 centenarians who took L-carnitine for six months experienced significant improvement in physical and mental fatigue. They also showed improved cognitive function, increased muscle mass, and better endurance (Malaguarnera M, et al. *Am J Clin Nutr.* 2007;86(6):1738-1744). Studies involving L-carnitine, most of which have focused on insulin resistance and cardiovascular disease, indicate doses up to 2 grams per day are safe.

Coenzyme Q10 is vital for electron transport along the mitochondrial electron transport chain. It also affects the expression of genes associated with cell signaling and metabolism. Coenzyme Q10 has the added benefit of being a strong antioxidant in its reduced form. Nicolson says, "Clinically, it has been used in doses up to 1200 mg per day, but most studies used lower doses."

Lipid replacement therapy provides the molecules needed to replace damaged phospholipids in mitochondrial membranes, thereby improving mitochondrial function. Oral phospholipid supplementation, in doses ranging from 500 to 2000 mg per day, have decreased fatigue in people with Gulf War illness,

(cont'd on last page)

7 Things People Newly Diagnosed with Parkinson's Should Know

(Excerpt from Parkinson's Foundation)

If you or your loved one has recently been diagnosed with Parkinson's disease (PD), it is normal to feel overwhelmed. Our Newly Diagnosed guide is designed to help people with Parkinson's and their loved ones who are beginning their PD journey. Below we highlight seven things every newly diagnosed person should know, featuring information from our Newly Diagnosed guide.

You are not alone – There are one million people living with PD in the U.S. and nearly 90,000 are newly diagnosed every year. Even if you have a relative or friend with Parkinson's, a diagnosis may feel shocking. Know that there is a passionate PD community ready to support you, in-person and online. When you're ready, the Parkinson's Foundation is here with the information and resources you need. Call our Helpline at 800-473-4636 and follow us on social media

Adjusting to a diagnosis takes time – It's common to experience a wide range of emotions after receiving a diagnosis — relief, sadness, confusion and determination, to name a few. Take the time you need to understand what you're feeling and reflect on what brings you joy.

Begin to educate yourself on Parkinson's and the steps that you can take to live well. Taking control of the things you can, like staying informed, will help to minimize stress.

Parkinson's symptoms affect more than movement

– Though PD is often thought of as a disease that only impacts movement, most people develop other symptoms as well. Early signs of Parkinson's include tremor, small handwriting, loss of smell, trouble moving and trouble sleeping. Many people with PD experience non-movement symptoms related to mental health like depression, anxiety and apathy. If you are affected by these symptoms, know that you are not alone. Prioritizing mental health is critical to overall well-being. Consider reaching out to a loved one, a counselor or a spiritual advisor and start building your support team.

Every person's experience with PD is unique – As you start to learn more about this disease, remember that everyone's journey is different. No two people with Parkinson's will have the exact same symptoms or rate of progression. Begin tracking your symptoms to develop a stronger awareness of how PD impacts you and try to focus on what is most affecting you right now. You are the expert on your experience. Physical, occupational and speech therapists can help at any stage. Talk to your doctor about building your care team, and asking for referrals for specialists who can help address symptoms that impact your daily life.

Make the most of your PD care appointments – Preparing in advance of your PD care appointments will help your care team tailor treatment to your needs and goals. Come prepared with a list of current medications, notes about current symptoms including which ones have the greatest impact on your daily life and at what time of day, and a list of questions for your doctor. Try to bring someone with you to appointments who can help take notes and ask questions. At the end of appointments, ask for clarification if something is unclear and ask for a printed copy of notes or instructions.

Exercise is essential to managing PD – There are many things you can do between appointments to help manage PD. Parkinson's Foundation research shows that people with PD who start exercising earlier in their disease course for a minimum of 2.5 hours per week experience a slowed decline in quality of life compared to those who start later. Establishing early exercise habits is vital to managing your PD symptoms. Exercise can help you maintain balance, mobility, and flexibility, as well as reduce the impact of non-motor PD symptoms like depression and constipation.

You can live well with PD – By educating yourself about PD, building health habits that include taking care of your mental health, and working with your care team to tailor treatment to your needs, you can lay the foundation to live well with PD.

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.
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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.

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ohparkinson.com

Treating Mitochondrial Dysfunction with Natural Supplements

(Con't. from Pg. 2)

chronic fatigue syndrome, fibromyalgia as well as fatigue associated with aging.

In addition to the supplements discussed by Nicolson, the pineal hormone melatonin is useful for mitochondrial dysfunction, according to Reza Sharafati-Chaleshtori and colleagues. Melatonin helps regulate mitochondrial function. It also stimulates antioxidant enzymes, including superoxide dismutase, glutathione peroxidase, glutathione reductase, and catalase; and it inhibits lipoxygenase, an enzyme that takes part in oxidation of unsaturated fatty acids. The authors say melatonin is an inexpensive, safe medication with mild adverse effects. Drug interactions, however, have occurred with anticoagulants, immunosuppressants, anti-diabetes, and birth control pills.

TRIBUTES
Ida Howze



Laughter is Medicine

What do you call an illegally parked frog?
Toad.

MAY MEETING / Wednesday, May 1, 2024

We welcome Beverly Keeler, Registered Dietician Nutritionist (RDN), LD with University Hospitals. She will talk on the popular subject of Nutrition and Parkinson's Disease. Please join us for this informative talk.

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