

JULY 2026

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

July MEETING / Wednesday, July 1, 2026 2:15 p.m.

We welcome back **Ben Rossi, Co-Founder and Chief Program Officer, of InMotion**. We have been fortunate to have Ben present and lead us in exercises specific to helping those with PD many times over the years. All in a fun and helpful way!

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

AUGUST MEETING / Wednesday, August 5, 2026 at NOON

PEP Picnic at Forest Hills Park in Cleveland Heights. More details to follow next month.

From David Brandt

The Ohio Parkinson Foundation Northeast Region (OPFNE) is a 501(c)(3) non-profit organization that maintains a Grant Program providing financial support for Parkinson's programs in Northeast Ohio. Through the Grant Program, OPFNE provides funding for PD related research and the efforts of many organizations involved in education and wellness in the 16-county area it serves.

A request for Grant funds or questions about the Grant Program can be submitted anytime via email to: grants@ohparkinson.org. A grant request template is available on the OPFNE website at <https://www.ohparkinson.com/grant-application/>. Grant requests are reviewed by the Grant Review Committee and their grant recommendations are submitted to the OPFNE Board of Directors for final review and release of grant funds if approved. Since the OPFNE Grant Program started in 2017, over \$60,000 in grant funds have supported programs including remote and in person exercise, dance, boxing, speech therapy, tennis and mindful movement.

Upcoming Events

Saturday, August 1-2, 2026 – Papa's Path presents its 24 hour walk at the Beachwood High School Track. All day events will be planned ending in the Sunday morning walk to Ahuja Medical Center.

Sunday, August 30, 2026 – Pals in Motion is the biggest event and fundraiser for InMotion and includes a run, a walk, and many family friendly activities.

Saturday, October 31, 2026 – 17th Annual University Hospitals Parkinson's Boot Camp at the Cleveland Marriott East in Warrensville Hts. Headline speaker will be Dr. Sarah Wittingham, a participant in the 2023 IRONMAN World Championship. details to follow.

TRIBUTES

Tim Beegle

**In Memory of Ray Brandt
Dr. William and Annette Cappaert**

Franklin and Jean Barry

Carole Smith

PD Question Corner

Email: barbaramarquardt@outlook.com

Question: Is there a gene that causes Parkinson's disease? How direct is the link?

Answer: About 15% of people with PD have a family history of the condition, and family-linked cases can result from genetic mutations in a group of genes — LRRK2, PARK2, PARK7, PINK1 or the SNCA gene (see below). However, the interaction between genetic changes, or mutations, and an individual's risk of developing the disease is not fully understood, says Ted Dawson, M.D., Ph.D., director of the Institute for Cell Engineering at Johns Hopkins.

There's a long list of genes known to contribute to PD, and there may be many more yet to be discovered. Here are some of the main players:

SNCA: SNCA makes the protein alpha-synuclein. In brain cells of individuals with PD, this protein gathers in clumps called Lewy bodies. Mutations in the SNCA gene occur in early-onset PD.

PARK2: The PARK2 gene makes the protein parkin, which normally helps cells break down and recycle proteins.

PARK7: Mutations in this gene cause a rare form of early-onset PD. The PARK7 gene makes the protein DJ-1, which protects against mitochondrial stress.

PINK1: The protein made by PINK1 is a protein kinase that protects mitochondria (structures inside cells) from stress. PINK1 mutations occur in early-onset PD.

LRRK2: The protein made by LRRK2 is also a protein kinase. Mutations in the LRRK2 gene have been linked to late-onset PD.

Among inherited cases of PD, the inheritance patterns differ depending on the genes involved. If the LRRK2 or SNCA genes are involved, PD is likely inherited from just one parent. That's called an autosomal dominant pattern, which is when you only need one copy of a gene to be altered for the disorder to happen.

If the PARK2, PARK7 or PINK1 gene is involved, it's typically in an autosomal recessive pattern, which is when you need two copies of the gene altered for the disorder to happen. That means that two copies of the gene in each cell have been altered. Both parents passed on the altered gene but may not have had any signs of PD themselves.

Ref.: <https://www.hopkinsmedicine.org/health/conditions-and-diseases/parkinsons-disease/the-genetic-link-to-parkinsons-disease>

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.

How Self-Efficacy Helps One Man Navigate Life with Parkinson's Disease

(Excerpt from parkinsonsnewstoday.com)

Connecticut resident Steve Yellen was a weekend athlete before being diagnosed with Parkinson's disease seven years ago. After noticing a tremor in his left hand, he consulted a neurologist and received the diagnosis. Rather than succumbing to apathy, Yellen decided to do everything he could to fight back.

With an engineering background and a love of problem-solving, Yellen began learning about Parkinson's disease and the benefits of exercise. He soon started setting short-term goals that gave him a sense of control and purpose. To stay motivated, he signed up for athletic events. Over the last three years, he has completed 11 Spartan races, six triathlons, and climbed the Empire State Building three times.

Those accomplishments helped Yellen discover the power of self-efficacy—the belief that a person can take charge of their situation. He explains that achieving short-term goals builds confidence and momentum, making it easier to tackle the next challenge.

As his confidence grew, Yellen became involved in Parkinson's advocacy and research. Encouraged by a friend, he eventually decided to write a book about his experiences. On January 1, 2025, he committed to the project, and by year's end he held the first paperback copy in his hands. His book, *Living Parkinson's*, is now available on Amazon.

The book outlines seven strategies that have helped him navigate life with Parkinson's: attitude, education, support from family, friends and healthcare providers, exercise, wellness, participation in research, and advocacy. Yellen describes the book as a guide that helps people build their own roadmap rather than prescribing specific actions.

Although he recognizes that every Parkinson's journey is different, Yellen believes self-empowerment can provide a sense of autonomy in an otherwise unpredictable situation. The book includes 35 practical actions readers can begin today. "I'd rather not have Parkinson's," he says, "but the fact that I have it gives me a purpose—to help as many people as possible improve their journey."

How Walking Poles can Benefit Those of Us with Parkinson's Disease

(Excerpt from parkinsonsnewstoday.com)

I may have found the perfect exercise. For me, having goals is very important. For instance, in the 5K race that I ran last weekend, my goal was to smile for the last 100 meters or so, because that is when they snap a photo of you. Does it matter that I came in 1,153rd? No, it does not, because I had a smile on my face and the photo to prove it!

About four months ago, someone sent me a social media post about a Parkinson's walking group. This group looked like a happening place; they used walking poles, had a walking coach, and were enjoying all the benefits of walking, getting outside, and camaraderie. I instantly wanted to be a part of it, but it was somewhere in the U.S., so this Canadian gal needed a local solution. The more I read about pole walking, the more I wanted to be part of a similar group. The benefits are innumerable for people with Parkinson's. According to the Parkinson's Foundation, using poles can promote larger, more symmetrical movements, improve balance, correct posture, and increase stride length, ultimately helping to reduce the shuffling gait common in those with the condition.

Not only are the physical benefits of pole walking astounding, but the psychological benefits are fantastic as well. Increased confidence, improved mood, and social connection are all on the table. It seems like the perfect exercise routine.

The only solution that seemed obvious to me was to start my own group. After some discussion and a heaping helping of patience on my part, I finally met with the powers that be at our local Parkinson Society. I had a proposal ready. One of our boxing coaches agreed to coach the walking group, and the society generously covered the associated costs, secured a few sets of poles, promoted it, and essentially took it over. I don't have to do anything but show up! We plan to meet for a walk once a week on Thursday mornings until September, when we have our big Walk for Parkinson's fundraiser. This clear schedule helps keep everyone committed and aware of upcoming opportunities to participate.

We plan to build our skills and resilience every week, with our ultimate goal being to walk 5 km (3.1 miles). Seeing this program come to life has given me a deep sense of fulfillment. I look forward to each session, feeling proud to contribute to my community and support others.

New Molecule Designed to Block the Protein Buildup Behind Parkinson's

In Parkinson's disease (PD), a protein called alpha-synuclein misfolds and clumps together inside brain cells. These clumps are thought to damage neurons over time and can spread from cell to cell, driving the disease forward. Currently, treatments for PD only manage symptoms — none can slow or stop this underlying process.

Scientists are working hard to find disease-modifying therapies for Parkinson's. A new study published in *Science Translational Medicine* may offer a path forward. Researchers at the University of Denver and NYU Abu Dhabi — co-led by Sunil Kumar, PhD, a Parkinson's Foundation Stanley Fahn Junior Faculty Awardee — have developed a special molecule called SK-129 that shows promise in blocking alpha-synuclein from clumping and spreading in the brain. The Parkinson's Foundation directly funded this work.

Think of alpha-synuclein clumping like a chain reaction: one misfolded protein causes the next one to misfold, and so on, eventually building up harmful deposits. SK-129 is designed to interrupt that chain reaction before it gets started.

Study Highlights:

- Researchers developed a molecule, called SK-129, that enters the brain and attaches to toxic forms of the protein associated with Parkinson's called alpha-synuclein.
- SK-129 latches onto the protein and prevents it from launching a clumping chain reaction. It targets the toxic, clumped forms of the protein rather than the healthy form.
- In multiple models of PD (including cells, worms, mice and human-derived tissue), treatment with SK-129 prevented alpha-synuclein clumping and rescued signs of neurodegeneration.

(Cont'd on Page 4)

PEP NEWS

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of Greater Cleveland
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Cleveland Heights, OH 44106

Address Service Requested

New Molecule Designed to Block the Protein Buildup Behind Parkinson's

(cont'd from Page 3)

SK-129 shows promising therapeutic properties, including binding to toxic forms of alpha-synuclein and remaining in brain tissue for a prolonged period of time.

What do these findings mean to people with PD?

SK-129 is not yet a treatment available to people. It is still in the preclinical stage, meaning it is being tested in labs and animal models but not in human clinical trials. More research is needed to confirm safety, determine dosing and long-term effects before testing in people can begin.

For people with PD, continue current care — medications, exercise, therapy — and consider joining **clinical trials** if interested. While SK-129 is likely years away from human testing, the development of molecules like this represents meaningful progress and demonstrates the importance of supporting preclinical PD research.

Laughter is Medicine

What kind of sandals do frogs wear?

Open-toad

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