



**AMERICAN
PARKINSON DISEASE
ASSOCIATION**

GREATER ST. LOUIS CHAPTER

Strength in optimism. Hope in progress.

SEPTEMBER/OCTOBER 2020



**AMERICAN
PARKINSON DISEASE
ASSOCIATION**

Join Us October 17th for the 2020 Greater St. Louis VIRTUAL Optimism Walk!

We are only a couple weeks away from the 2020 APDA Virtual Optimism Walk and we thought it was time to answer the big question on everyone's mind:

WHAT EXACTLY IS A VIRTUAL WALK?

Different Walk, Same Reason. The world may look a little different right now, but one thing hasn't changed: our commitment to helping everyone impacted by Parkinson's disease live life to the fullest. This year, the APDA Optimism Walk is everywhere — on every sidewalk, track, treadmill, and trail. We won't have a large in-person gathering — instead, we invite you to walk with your family or friends while others in our community do the same. Because we are all still walking and fundraising for the same thing: a world without Parkinson's disease.

NEW THIS YEAR!

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REGISTER TODAY

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Each year, the Greater St. Louis Chapter serves more than 12,000 people impacted by Parkinson's disease through support groups, exercise classes, wellness programming, educational events, and more. Your support of the Optimism Walk helps ensure these programs and services are there for people when they need them the most.



Meet Mark Kodner - 2020 Optimism Walk Honorary Chair

Mark Kodner was only 40 years old when he received life changing news - he had Parkinson's disease (PD). Most people associate PD with an older generation, but Mark had Young Onset Parkinson's disease.

Twenty years later, Mark is still going strong. He credits a lot of his success to his Deep Brain Stimulation surgery. "The impact of research on my life is unreal, because the medicines and the procedures and the possibilities are endless if research can continue to go on." Mark is grateful to the research that led to this life-changing surgery and is passionate about the need to continue funding research.

He wants what we all want — a cure.

This year, Mark continues to fight for the future as the Honorary Chair of the 2020 APDA Greater St. Louis Optimism Walk. As Honorary Chair, Mark hopes to continue to raise awareness about PD, and to offer hope to the Parkinson's community. You aren't in this alone! Join Mark and the APDA Greater St. Louis Chapter for the Virtual Optimism Walk on October 17th and be a hero for people with Parkinson's!



WHEN PARKINSON'S SYMPTOMS RETURN

Most people have the same routine every morning: they wake up, open their eyes, and get out of bed. Now imagine waking up and opening your eyes, but not being able to get out of bed. Your arms and legs won't move.

This was the morning routine for Mike, who has Parkinson's. When he woke up, he couldn't move his arms and legs. It felt like they were tied or wrapped up. Without assistance from his wife Gail, Mike couldn't get out of bed or perform the basic tasks of putting on his pants and buttoning his shirt. Gail also had to help Mike into the living room, where he would sit and take his Parkinson's medication. Mike sat there, sometimes for up to an hour, waiting for the pill to take effect.

Mike was diagnosed with Parkinson's in 2007 and began taking oral Parkinson's medication 2 – 3 times a day to manage his symptoms. After a while, he began experiencing symptoms more frequently, and his dosage was increased to every 3 hours. But sometimes he still experienced symptoms before his next pill was due.

About 40% of the nearly 1 million people in the United States living with Parkinson's report that within 5 years of starting oral Parkinson's medication, it starts wearing off before the next scheduled dose. This means the time when the medication controls their symptoms gets shorter, causing their symptoms to recur sooner than expected.

This is known as "return of symptoms," and approximately 350,000 people with Parkinson's experience return of symptoms (sometimes referred to as "off" periods). This can take the form of motor (movement-related) symptoms, such as tremor, rigid muscles, and slowness of movement (bradykinesia), as well as non-motor symptoms, such as anxiety, fatigue, and irritability.

In an on-line survey of more than 3,000 people with Parkinson's conducted by the Michael J. Fox Foundation, nearly 70% said they experienced return of symptoms at least two times each day.

When people first start taking Parkinson's medication, they may still have some of their own dopamine from dopamine-producing cells. Because of this, their response to medication is much more predictable. However, they still may experience some return of symptoms, and they might simply adjust their plans around them. But as the disease progresses, more dopamine-producing cells die off. After five or more years on PD medication, return of symptoms becomes harder to predict, and people may cancel activities for fear of being in a public place or unfamiliar setting during these periods.

Mike was still working when he was diagnosed with PD, and initially just tweaked his schedule to coincide with periods of symptom return. He made sure he had time to get to his next appointment, take his next dose, and have it take effect before he met with customers. But as the periods became less predictable, Mike developed anxiety, as he spent more and more time planning for return of symptoms.

Gail describes how Mike's anxiety became a real problem, as he grew more concerned about the medication wearing off too early. He lost interest in visiting friends or attending events, and felt less comfortable going out and more comfortable staying at home. Mike's world started to shrink.

As Mike grew more dependent on Gail and she spent more time at home, her world also started to shrink. As people with Parkinson's become more reliant on their care partners, it's not uncommon for the care partners to experience feelings of depression, frustration, and being overwhelmed, similar to those experienced by people with Parkinson's.

If you think you may be experiencing return of symptoms, talk to your doctor. Keep track of the symptoms you experience and when you experience them. Think about your daily activities – work, hobbies, etc. – and make a note if you experience return of symptoms during any of them. It can also be helpful to enlist the help of friends and family members and ask them what they observe during your return of symptoms. Mike said Gail often noticed things he didn't realize were happening.

If you're not sure what to ask your doctor, here are some questions to help you frame the conversation:

1. What medications are available for return of symptoms?
2. What benefits were shown in clinical trials?
3. What were the side effects of the medications?
4. Can I take the medication by itself, or will I have to take multiple medications?
5. Are there pre-existing conditions that might prevent me from taking the medications?
6. Can I take the medications in conjunction with current medication(s) for other conditions?
7. Will my dose(s) have to be scaled up over time?

There are medications to help manage return of symptoms. The more information you share, the more your doctor can help you find the treatment option that's right for you.

This article was contributed by Acorda Therapeutics.



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RESEARCH SPOTLIGHT

Erin Foster, PhD, OTD, OTR/L



Erin Foster, PhD, OTD, OTR/L has been involved with APDA in various capacities for more than ten years. Her first associations were through her work and research at Washington University in St. Louis. “When I was a practicing clinician, I met APDA and learned about the great work they were doing for the Parkinson’s community. When I had a client with Parkinson disease (PD), it was important for me to connect them to the resources and programs that were available through APDA.”

Erin’s work eventually became more research based and she found another connection with APDA. “I had students in my lab who were interested in PD. I began reaching out to APDA to work together. We offered classes, attended events, and even gave talks to support groups or at Parkinson Education Programs. I even had a short stint leading an exercise group! I wanted to be involved because I thought APDA was a great organization and I wanted to help contribute my knowledge.” She also found collaboration with APDA to be beneficial to her students.

Eventually, Erin’s continued involvement led to her becoming a member of APDA Greater St. Louis Chapter’s Board of Directors. “I was honored and happy to serve on the board. It is a great opportunity for me and I also feel like it is a good fit for me to come in with a health professional background. I am able to help offer services that help people with PD in their daily lives.” Erin has big goals for APDA Greater St. Louis Chapter and has brought a new level of expertise to the programs and services we offer. “I think APDA is a really valuable organization and I want to see it grow. I want to see us develop and administer programs that are effective for people with PD. By generating the evidence and developing programs, we can help people with PD have a better quality of life.”

Historically, PD has been thought of as a movement disorder. However, we’re increasingly realizing that there a lot of non-motor symptoms that are associated with PD that actually might affect quality of life more than the motor-symptoms. But the tools to address those issues are limited. Erin’s primary research focus is on cognitive function—like memory, planning, processing information, etc.—and how changes in cognitive function can impact people’s ability to perform and participate in their meaningful daily activities. “I want to identify and develop interventions to mitigate the effects of cognitive dysfunction on daily life. Anything from individualized Occupational Therapy interventions to come up with specific strategies for an individual to group-based Cognitive Stimulation Therapy for people with more severe cognitive function. These interventions may help improve cognitive function, psycho social interactions, and daily life.”

Erin and her students continue to bring innovative programming to APDA to help people with PD live their best lives. “It’s a great opportunity for the students. They aren’t just sitting in the classroom learning about these conditions. They are actually out there being exposed to people with PD and their families and communities.” By working with APDA, Erin wants her students to have the opportunity to interact and learn from people living with PD directly—learning what their lived experiences are and what is important to them. The students also get the chance to give back to the community and share their skills, providing a positive and empowering educational experience for students. Erin believes it is important for her and her students to be a part of the PD community. “I want people to understand OT in general and my work is about helping people live their lives and do what they want to do in spite of having PD.”

Do-It-Yourself Optimism Event
VIRTUAL PEDALING 4 PARKINSON'S
 Aviston, Illinois



The 2020 version of **Pedaling 4 Parkinson's** looked a little different this year.

When the pandemic prevented large groups from gathering, Lynn Huegen and her committee had to make a decision – do we cancel the event or do we go virtual? Always up for a challenge, they decided raising money for the APDA – Greater St. Louis and Parkinson's disease awareness was too important, and they made the transition.

This is the third year Lynn and her committee have organized this event in honor of Lynn's father, Don Lampe. Thanks to amazing community support, the virtual event was a huge success and they were able to raise \$10,109.80! Lynn and her committee were motivated to fund raise in honor of her dad and family and friends of committee members who are battling Parkinson's disease. Raising awareness resulted in many others in the community sharing and revealing their own Parkinson connections.

LIVE STREAM EXERCISE CLASS SCHEDULE

apdaparkinson.org/greaterstlouis

DAY	TIME	CLASS	LEVEL	INSTRUCTION
MONDAY	10:00am	Strength & Cardio	Level 2	Marina Clements
MONDAY	1:00pm	Interval Training	Level 2	Jen Berger
TUESDAY	1:00pm	Seated Exercise	Level 1	Michelle Kinnett
TUESDAY (not live streamed)	posted weekly	Yoga and Meditation	All Levels	Ulrikke Malik
WEDNESDAY	1:00pm	Interval Training	Level 2	Michelle Kinnett
THURSDAY	1:00pm	Seated Exercise	Level 1	Jen Berger
FRIDAY	10:00am	Tai Chi	Level 1	Craig Miller
FRIDAY	11:00am	Tai Chi	Level 2	Craig Miller

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VIRTUAL

Midwest Parkinson Congress EXCEEDS EXPECTATIONS!

Thank you to everyone who made the 2020 Midwest Parkinson Congress a success. Over 1,300 people registered for the event, making it the largest Midwest Parkinson Congress ever – thank you to everyone who logged-on! We would like to thank our panel of esteemed speakers – Dr. Joel Perlmutter, Dr. Aesef Shaikh, Dr. Rebecca Gilbert, Dr. Jennifer Goldman and Dr. Tao Xie - for sharing their PD expertise with our audience, we are so grateful for their commitment to the PD community. Much appreciation goes to our loyal sponsors, without whom this event would not be possible:

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