apda AMERICAN PARKINSON DISEASE ASSOCIATION
GREATER ST. LOUIS CHAPTER
Strength in optimism. Hope in progress.

MAY/JUNE 2021

Why should I go to a Parkinson's disease support group?

Support groups play a vital role in the lives of many people with Parkinson's disease (PD) and APDA Greater St. Louis Chapter plays a vital role in providing access to support groups in Missouri and Illinois. In general terms, a support group is a collection of participants who meet on a regular basis, facilitated by a support group leader, to discuss issues of mutual concern – in this case, PD. Beyond that basic definition, there can be much potential variability in the makeup of the group, the type of facilitation, and the content of the meetings.

APDA hosts and facilitates many types of support groups (even online) and offers a unique psychosocial support model called the PRESS™ program (Parkinson's Roadmap for Education and Support Services). This is an eight-week standardized program for people who have been diagnosed for less than five years. It combines psychosocial support with basic PD education and covers topics that include medication management of PD, the importance of exercise in PD, the impact of PD on relationships, and tips for daily living.

We strongly suggest you connect with a support group as soon as possible after being diagnosed so you can start benefiting from the information and camaraderie right away, but you can join a support group at any time – whether you were diagnosed 10 days ago, or 10 years ago. Dr. Rebecca Gilbert, APDA's Vice President & Chief Scientific Officer, talks to three support group leaders to learn more about the benefits of support groups.

Rebecca: What do you observe are the reasons that people are drawn to participate in support groups for PD?

Ray: One of the most common reasons for attending a support group is a quest for knowledge: to understand more about Parkinson's. Many patients and families feel like it's not possible to have all their concerns and needs met within a 15–30-minute appointment with a healthcare provider, so they seek out support groups to learn more. I enjoy using my clinical and research background to answer questions for the group, but when more information is needed, APDA steps in with resources that I can provide. I also try to point to the plethora of educational symposia, research studies, expert panels, speakers, and awareness events that are happening around the states.

Sonja: I facilitate a group for individuals with Young Onset PD. Some of the participants are still working and may not have told employers, coworkers, or even friends of their diagnosis.

[continued on next page]

Volume 35, Issue 3

Participants in my support group report that they appreciate a space where they can speak uninhibited about their situation and struggles. Additionally, they value talking with people who "get it" – all the details of the medications, doctors, symptoms, etc.

Rebecca: So, it sounds like support groups offer education, community, and empathy from those who understand the struggles of PD.

Ray: Yes, I have found that attendees are able to speak to their personal experience and through that, uplift and educate others in a way that someone who isn't going through the experience is unable to do. A person may be able to talk about how they are handling a tough challenge – maybe the tremor they have is bothering them at work or during social gatherings, and someone else is going through that same experience. The way one person handles a tough issue like tremor for example, gives others a good idea of how they might handle the same issue.

Sonja: I agree, people who attend support groups gain a community. I know that participants from my groups talk between meetings and some have gotten together socially. Social connections like these can impact positively on health outcomes. The support group helps build and maintain those connections.

Gabrielle: I could not agree more. Support groups provide a secure and confidential space to discuss things that they might not feel comfortable discussing with anyone else, to share experiences – what works for them and what doesn't – as well as have the opportunity to ask questions that may only be answered by people who also live with PD. Your doctor and the internet can provide facts, but in a support group you can learn from other's actual experiences.

Rebecca: What can care partners hope to gain from a support group?

Ray: Care partners attend support groups because they want to seek answers about how to best help their loved one as well as gain from the experiences of others. But there are also support groups specifically designed for care partners to address the unique needs and challenges they face as they try to be the best support they can be for their loved ones. The support group provides resources and an outlet to share challenges, fears, and methods for success.

Tips and Takeaways:

- To find a support group near you, please call the office at **636.778.3377** or email **apdastlouis@apdaparkinson.org**
- Support groups offer educational opportunities as well as a sense of community.
- Support groups allow participants to learn from one another as they encounter similar struggles.
- Some support groups are segmented by age at diagnosis (ie, diagnosed at a young age) or by disease progression (i.e., newly diagnosed, or diagnosed within five years); other groups are more general. It may take more than one try to find a group that's right for you.
- Care partners need support too, and can often attend the regular groups, or seek out specialized groups tailored for their specific needs.

SPOTLIGHT ON MYRA CRANDALL

Myra Crandall purposely doesn't remember the exact date she was diagnosed with Parkinson's disease. Her diagnosis came as a shocking surprise. "No one in my family had ever had PD and I didn't know much about the disease. I had gone to several different doctors and no one could figure out what was going on with me." Myra finally went to a neurologist where the physician asked her to walk down a hallway. When Myra walked back, the physician told her she had Parkinson's disease.

Myra was relieved to finally have a diagnosis, but she was also frightened. After the shock wore off, Myra and her husband rallied to fight the disease and found the American Parkinson Disease Association-Greater St. Louis Chapter. "I first started with an APDA support group. Everyone was sharing their own Parkinson's journey and I thought it was great to have a group of people to discuss PD with since I didn't know anyone else with the disease. At my very first meeting, a woman came up after the meeting and gave me her name and phone number. It was so helpful to have the amazing support. We're more than just classmates, we're friends."

From there, Myra jumped into APDA's exercise programming. She has participated in a variety classes over the years, but she really loves the workouts that include balance and strength. "It was important for me to keep coming back to exercise for two reasons. I didn't want to miss my friends who I had become close with, but also when I didn't exercise, I could feel the difference. I would become stiffer and couldn't move as well. I felt exercise gave me spirit and helped with my positivity and outlook."

Even a global pandemic couldn't keep Myra from exercise! "I'm so glad APDA provides virtual exercise classes. I don't know what I would have done without these classes during the pandemic. Michelle and Jen cover everything in their online classes.

If Myra could share one piece of wisdom with someone who is newly diagnosed with PD, she would want people to know that they are not alone. "There are all kinds of people out there anxious to help you, like APDA-Greater St. Louis Chapter. Don't be afraid to ask lots of questions, get involved, and most importantly exercise, exercise, exercise. Continue to use all of the resources out there, connect with APDA, there is always something more out there."

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UPCOMING EVENTS

23rd ANNUAL APDA GOLF CLASSIC

Fore! Time to get a hole-in-one by supporting the APDA Golf Classic. Mark your calendars, the tournament will be held at Algonquin Golf Club on **Monday, June 21, 2021**.

If you or someone you know would like to play in this wonderful tournament, become a corporate or individual sponsor, we welcome your involvement. Please contact the APDA Greater St. Louis Chapter at **636.778.3377** or send an email to Director of Development, Melissa Skrivan - **mskrivan@apdaparkinson.org**.

The funds generated will assist those living with Parkinson's disease in our local communities as well as the researchers hard at work discovering causes and ultimately a cure for Parkinson's disease.

This year the golf tournament will look a little different. Due to COVID-19 and to keep everyone safe, there will not be a dinner following the golf tournament. APDA Greater St. Louis Chapter follows all recommended safety guidelines including social distancing, hand washing, mask wearing, and cleaning of surfaces.

— GREATER ST. LOUIS 5TH ANNUAL OPTIMISM WALK —

OPTIMISM WALK AMERICAN PARKINSON DISEASE ASSOCIATION

SAVE THE DATE!!

October 9, 2021
at Logan University

The American Parkinson Disease Association Greater St. Louis Chapter Optimism Walk raises funds to help people with Parkinson's live life to the fullest.

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 research. Your support of the Optimism Walk helps ensure these programs and services are there for people when they need them the most.

Lace up your sneakers and step up to help us put an end to Parkinson's disease!

VIRTUAL MIDWEST PARKINSON CONGRESS

Thank you to everyone who made the 4th Annual Midwest Parkinson Congress a success. Over 1,100 people registered for the event, making it one of the largest events ever – thank you to everyone who logged-on!

We would like to thank our panel of esteemed speakers – Joel Perlmutter, MD; Johanna Hartlein, RN, MSN; Stephanie Martinez, JD; Michael Mercury, Ph.D.; Tiffany Turner, MS, CCC-SLP, BCS-S; Kevin Klos, MD; and Lynda Nwabuobi, MD - for sharing their PD expertise with our audience, we are so grateful for their commitment to the PD community. We would also like to thank Heather Kennedy for delivering The Elliot and Mary Ann Stein Keynote Address and reminding everyone that living with Parkinson's disease takes courage and bravery.

THANK YOU TO OUR GENEROUS MIDWEST PARKINSON CONGRESS SPONSORS!

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Movement and Cueing Strategies to Thaw Freezing Events in Parkinson's Disease

By: Beth Crowner, Neurological Clinical Specialist at Washington University Physical Therapy

Some individuals with Parkinson's disease (PD) experience freezing of gait (FOG), which results in an inability to take a step or getting "stuck" while walking. This can be frustrating because it slows down walking, resulting in inefficiency. It can also lead to imbalance and falls. It is important to know common triggers for FOG as well as strategies to reduce freezes.

Freezing commonly occurs when a person first stands up and can't initiate the first step (start hesitation). FOG also commonly occurs with turning, walking through doorways, changes in flooring surface, or small spaces (crowds, walk-in closets, etc.). Knowing which "triggers" cause a person to freeze is important because strategies can be used before or during these events. Every person with PD that experiences freezing has different freezing severity and triggers. Additionally, each person responds distinctly to different movement strategies to reduce FOG. There are general principles that apply to everyone and person-specific movement strategies that will reduce FOG.

Three general principles that apply to everyone with FOG are reducing stress during a freezing event, avoiding quick turning, and reducing triggers as much as possible. Physical and emotional stress commonly increase all symptoms in PD. People often get upset or anxious when experiencing a freeze. It is important to avoid being stressed, getting upset, or trying to "push through" a FOG event. Doing so will often prolong a freeze or cause greater instability. People should try, as best as possible, to relax and avoid stress during a FOG event. Turning quickly will often trigger a freeze and often lead to imbalance or falls. When there is space available, a person should make a slow, wide-arc turn. Use of a "clock strategy" is also helpful for turning. This involves a person pretending to be in the middle of an imaginary clock and stepping to different, invisible points on the clock. For example, to complete a 180° clockwise turn, a person could step with their left leg to 12:00, then 2:00, then 4:00 and then 6:00. To reduce triggers, try to avoid having clutter in the home that causes a person to walk or turn in a narrow space. When walking through a doorway, look at an object in the distance in the next room, and avoid looking at the doorframe. While these general strategies work well for most people with FOG, there are effective movement or cueing strategies that can also be beneficial. However, the effectiveness of the type of cue used varies from person to person.

Types of cueing strategies include visual, auditory, attentional. Visual cues may involve stepping over someone's foot placed in front of the leg that is frozen or stepping on or over lines on the ground. Lines on the ground can be created by putting tape on the floor as a target in areas where freezing occurs. If freezing occurs in a room with tile or linoleum, the lines in the flooring can be used. Visual targets can also be created by a laser-emitted light that creates a line on the ground. The laser can be part of a cane or walker or a device attached to the shoelaces. Auditory cues use a real or imagined beat or rhythm that a person listens to. The beat can be created by using a metronome, listening to music, singing, or counting. Listening to or imagining a steady beat can help with freezing and also reduce the variability in walking pattern in someone with PD. Finally, attentional cues refer to creating BIG movements or taking BIG steps. Attentional cues involve thinking about taking long steps or strides or lifting knees up high while walking. Cueing can be performed prior to a situation that would likely trigger a freeze with a goal of preventing the FOG event. However, if freezing does still occur, the cues are often effective in shortening the duration of a freeze and, hopefully, reducing the frequency that they occur.

Because people respond very differently to each cueing strategy, people with PD are strongly encouraged to work with a physical therapist who has experience working with people with movement disorders to tailor the appropriate strategy to their needs and de-frost their troublesome freezes.

If you are interested in connecting with a physical therapist who has PD expertise, **you can contact the Washington University Program in Physical Therapy at 314-286-1940 to schedule an appointment.** If you would like to learn more about opportunities to participate in research, please call **314-286-1478**.

LIVE STREAM EXERCISE CLASS SCHEDULE

Please visit: bit.ly/APDAYouTube for exercise classes.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
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 Valenti
TUESDAY	posted weekly	Yoga & Meditation	All Levels	Ulrikke Malik
WEDNESDAY	1:00pm	Interval Training	Level 2	Michelle Valenti
THURSDAY	1:00pm	Seated Exercise	Level 1	Jen Berger
FRIDAY	10:00am	Tai Chi	Level 1	Craig Miller
FRIDAY	11:15am	Tai Chi	Level 2	Craig Miller

ZOOM EXERCISE CLASS SCHEDULE

For more information, please call 636.778.3377 or email apdastlouis@apdaparkinson.org.

DAY	TIME	CLASS	LEVEL	INSTRUCTOR
TUESDAY	9:00am	Seated Exercise	Level 1	Jen Berger
TUESDAY	10:00am	Strength & Cardio	Level 2	Jen Berger
THURSDAY	10:00am	Strength & Cardio	Level 2	Rachel Lehman
THURSDAY	11:00am	Seated Exercise	Level 1	Rachel Lehman
FRIDAY	10:00am	Strength & Cardio	Level 2	Michelle Valenti
FRIDAY	11:00am	Seated Exercise	Level 1	Michelle Valenti

VIRTUAL SUPPORT GROUP SCHEDULE

For more information, please call 636.778.3377 or email apdastlouis@apdaparkinson.org.

MISSOURI SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER
Chesterfield	First & Third Tuesday	11:00am	Carrie Burgraff
Chesterfield Caregivers	Second Monday	11:00am	Lynda Wiens & Jay Bender
Carthage	First Friday	2:00pm	Tericia Mixon
Kirkwood	Fourth Tuesday	6:30pm	Terri Hosto
South County	Fourth Wednesday	10:30am	Caitlin Jones
St. Peters	First Tuesday	1:00pm	Jodi Peterson
St. Louis Caregivers	Third Monday	1:00pm	Kathy Schroeder
YOPD	Every Wednesday	6:00pm	Karen Frank & Mike Mylenbusch

ILLINOIS SUPPORT GROUPS

LOCATION	DAY	TIME	SUPPORT GROUP LEADER
Carbondale	First Wednesday	1:00pm	Gala Lockwood
Edwardsville	First Tuesday	2:00pm	Pam Pinegar
Highland	Fourth Tuesday	2:00pm	Kayla Deerhake
Quincy	Saturdays	10:00am	Dave & Terri May

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UPDATE YOUR INFO WITH US!

Are you new to APDA? Have you moved recently, updated your email address or phone number? Do you want to receive weekly emails or receive this newsletter electronically? Let us know!

To update your contact information, call **636.778.3377** or email **apdastlouis@apdaparkinson.org**

OPTIMISM SOCIETY

In the fall of 2020, the APDA Greater St. Louis Chapter established the Optimism Society to honor those who provide annual support of $1,000 or more. Optimism Society members are a vital component of the Greater St. Louis Chapter, and each year we extend our gratitude to those who support us with a special Optimism Society celebration.

To join the Optimism Society, contact Director of Development, Melissa Skrivan at mskrivan@apdaparkinson.org or 636-778-3377.

APDA Community Resource Center

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