

MESSENGER SPRING 2025

APRIL IS: PARKINSON'S AWARENESS MONTH!

Hello Michigan Parkinson Foundation Community!

Parkinson's Awareness Month is always such a wonderful celebration. So much of this disease can be dark and difficult, but for this month, we have the opportunity to educate the broader public about Parkinson's and spotlight inspiring stories as well as the MPF programs and services that are here for you at every age and stage of your Parkinson's journey.

On a personal note, this is also a celebration of my work anniversary. I started working at MPF on April 11, 2022. I didn't know until closer to my start date that it was Parkinson's Awareness Day, but I thought it was such a great omen and I jumped right in. On my first day, my mom gave me a mug with a red tulip on it. I have used it just about every day since I started and it reminds me of how grateful I am to be a part of this tremendous community, and how inspired I am by the individuals and families I get to work with on a daily basis. Thank YOU!

We've got some great activities lined up for Parkinson's Awareness Month in this newsletter. Join us for exercise, education, book clubs, and more!

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HEALTH AND WELLNESS

Create the ultimate beginner walking workout

Aubrey Bailey, PT, DPT, CHT Reviewed by Amy Kwan, PT Posted on MeOverPD.org, December 2024

Walking is a great workout—especially for beginners. It's free and accessible, and it can help improve your heart health and lead to stronger muscles and bones.

The Physical Activity Guidelines for Americans manual recommends getting at least 150 minutes (2.5 hours) of moderate-intensity aerobic activity per week. Brisk walking counts toward that goal.

How to Create a Walking Workout

As with any new exercise program, check with your healthcare provider to make sure walking is a safe activity for you. Consider the following when creating a walking workout:

- Your pace (e.g., slow or brisk)
- How far you will walk
- How many days a week you'll walk
- The total amount of time you will walk each week

Experts recommend starting slowly and increasing your pace and frequency over time.

Outdoor Walking Plans

Walking outdoors provides a wide range of scenery and walking surfaces. Spending time in the sun also helps you get vitamin D. Research suggests that "green" exercising—outdoor activities in nature—can offer more mental health benefits than exercising in a gym.

When you're planning your outdoor walking, keep the following in mind:

- Be seen: Wear a reflective vest and carry a flashlight if you're walking in the early morning or evening.
- Bring your phone: Have a way to communicate in case of an emergency.
- Dress for the weather: Wear breathable fabrics and carry water to stay hydrated in the heat. In the cold, dress in layers.
- Plan your route: Pick a well-lit path with a flat, even surface.
- Stay off the road: If available, walk on sidewalks rather than the road. If you walk on the road, face oncoming traffic.

Indoor Walking Plans

You can walk indoors using a treadmill. If you don't have access to a treadmill, other options include:

- Doing laps around a mall or other large shopping centers
- Trying exercise videos with indoor routines structured around walking in place
- Walking at an indoor track or gymnasium



Why is Walking a Workout?

Walking is a great leg and core workout. If you walk at a brisk pace, this activity also increases your heart rate, which strengthens your heart muscle.

Over time, walking can improve your circulation and lower your blood pressure. Walking is a form of aerobic exercise that relies on oxygen as its primary energy source. Aerobic exercise is important for heart health.

It differs from anaerobic exercise, such as strength training, which you do in short bursts. Your body cannot provide enough oxygen to sustain anaerobic exercise for extended periods.

How to Intensify Your Walks

Once you have established a regular walking program, there are many different ways to intensify your workouts:

- Add extra weight: To increase the intensity of your workout, wear a weighted vest or backpack.
- Include some hills: Take an outdoor route that includes hills, or if you are using a treadmill, try the incline feature.
- Pick up the pace: Walk faster to make your workouts more challenging. You can do this in bursts—for example, walk for five minutes at your normal pace, walk briskly for one minute, and repeat.
- Sign up for a walk or race: Consider training for a 5K to make your walking routine more challenging.
- Take breaks for resistance exercises: Stop at specific time or distance intervals and do body weight

resistance strengthening exercises, such as squats, jumping jacks, lunges, or push-ups.

 Use walking poles: Walking with poles adds an upper body workout to your walking routine. These devices also help you maintain your balance on uneven surfaces

Tips to Enjoy Your Walking Workouts

Once you're ready to start walking, follow these tips to make the workouts more enjoyable:

- Add some entertainment: If you exercise alone, consider listening to music or audiobooks. If you walk indoors, do so while watching your favorite TV show.
- Find your footwear: Choose shoes that are made for walking. These are typically lightweight and well-cushioned to help protect your joints from the impact of walking.
- Recruit a friend: Walking with a partner can make your walk more enjoyable and help you stay accountable.
- Start slowly: Warm up your muscles by walking slowly for five minutes before you start your walking workout. Then, try to walk for 10 minutes at a pace that allows you to carry on a conversation. Cool down by walking slowly for another five minutes at the end of your workout.
- Track your progress: You could wear a pedometer or use an app on your phone or smartwatch to track your steps or track the amount of time you walk.

What's So Special About Urban Poling?

Deb Collng, Director of Fitness

Urban Poles are a fantastic tool to help individuals with Parkinson's walk with greater confidence and stability. When I first saw Urban Poling in action, I was immediately struck by how much support it provided, helping people move more securely and with improved posture.

Through my experience with Urban Poles, specifically the Activator Pole, I've learned that their benefits go beyond just stability. When used correctly, they can enhance:

- **Posture** Encouraging an upright stance
- Core and Back Engagement Activating key muscle groups
- Joint and Back Support Reducing strain while walking

Additional Benefits of Urban Poling:

- Assists with balance
- · Promotes natural arm swing
- · Turns walking into a full-body workout
- Improves gait and stride length
- · Can help increase walking speed

In honor of Parkinson's Awareness Month, we're excited to host a walking event featuring Urban Poles!

Check out more information on how to join on page 7.

For more information about Urban Poles, contact Deb Colling at 248-430-4206 or <u>dcolling@parkinsonsmi.org</u>.



Finding Strength in Community: The Power of Parkinson's Support Groups

Support groups offer numerous benefits for people living with Parkinson's, providing a sense of community, emotional support, and practical resources. Here are some key benefits:

1. Emotional Support & Connection

Living with Parkinson's can feel isolating, but support groups create a space where individuals can share experiences, challenges, and victories with people who truly understand.

2. Education & Resources

Many groups invite guest speakers, such as neurologists, physical therapists, or movement disorder specialists, to share the latest treatments, therapies, and research updates.

3. Motivation to Stay Active

Support groups often incorporate movement-based activities like exercise classes, dance, or yoga—helping members maintain mobility, balance, and overall wellbeing.

4. Coping Strategies & Practical Tips

Members share real-life advice on managing symptoms, medication side effects, and daily living challenges, providing insights that can improve quality of life.

5. Caregiver Support

Many groups welcome caregivers and family members, offering them guidance, emotional support, and strategies to better assist their loved ones.

6. A Sense of Hope

Connecting with others who are thriving despite Parkinson's can be incredibly encouraging. Support groups foster resilience and remind participants that they are not alone in their journey.

Whether in-person or virtual, joining a support group can be an empowering step toward managing Parkinson's with confidence and community.

Search for a support group near you! MPF has 76 support groups throughout Michigan's 83 counties. Visit <u>parkinsonsmi.org</u> to view a full list!

Support Group Facilitator Spotlight: Dianna Oates



I first became interested in learning more about Parkinson's Disease from a patient while I was working as a PTA in a nursing home. He had a book written by Dr. Abraham Lieberman that was very informative on the many facets of PD.

After leaving that nursing home, I worked with the Adrian Dominican Sisters and it was a personal goal of mine to start a support group. We invited the community PD group to join us as their leader was moving on. That was in 2000, so I have enjoyed being a facilitator of the Adrian Support Group for 25 years! I have met so many wonderful people in that time. Support groups are so helpful in journeying with PWP and caregivers through the stages of PD. Who is better to talk to than someone who may share the same symptoms and concerns as you?

I tell all of my PT patients and support group members who are newly diagnosed that PD is not a death sentence and you need to create a team to join you with your care and treatment. You need to learn as much as you can and be proactive in your treatment.

I live on a farm with my husband of 43 years. We have 3 kids and 7 of the best grandkids! They are my chief interest, but I play pickleball, love taking little trips with my group of gal pals, and take care of my aging Mom and Mom-in-law. I am certified as a PWR therapist and I love working with the PD community as patients and through the Support Group.

UPCOMING EDUCATIONAL EVENTS

Hope In Every Step Symposium

Presented by



In Partnership with



Healthcare Professionals earn 5 CE's

Friday, April 25, 2025 | Livonia, MI Register Online at: <u>bit.ly/MPFSymposium25</u>

PARKINSON'S SUMMER FORUM

Thursday, May 22, 2025 | Traverse City, MI

Presented by:



Register Online at: bit.ly/MPFSummerForum25



PARKINSON'S AWARENESS MONTH

april 1	Tuesday, 1:00 p.m. Webinar: A Lesson In Parkinson's History To kick off Parkinson's Awareness Month, the Independent Parkinson's Network is holding a webinar to discuss the history of Parkinson's over the last 200 years. Register online: <u>bit.ly/IPNWebinar25</u>
april 2	Wednesday, 10:00 a.m. PD 101: Newly Diagnosed Orientation Join our monthly orientation for newly diagnosed people with Parkinson's, care partners, and friends/family. Location: MPF Office in Bingham Farms, MI. Register by contacting Julia Wall at: jwall@parkinsonsmi.org.
april 10	Thursday, 7:00 p.m. Virtual Exercise Sampler Participate in a variety of exercise moves including boxing, PWR! Moves, and yoga with Grace Cummings, Deb Colling, and Michael Colling! Register online: <u>bit.ly/MPFExercise25</u>
april 11	Friday, All Day Parkinson's Awareness Day: Sit-to-Stand Challenge Join individuals and organizations from around the world in the commitment to stand up to Parkinson's by collectively completing 2,000,000 Sit to Stands in 24 hours! Find out how to log yours on the next page.
april 16	Wednesday, 7:00 p.m. Virtual Education Series Presented by: Eli Pollard, Executive Director at the World Parkinson Coalition. Register online: <u>bit.ly/VESApril25</u>
	Monday, 12:00 p.m.

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Exercise & Lunch Open House

21 Join us at our office for an afternoon of fun exercises with Angee Ludwa and Deb Colling and a chance to learn more about MPF! Register by contacting Deb at: <u>dcolling@parkinsonsmi.org</u>.

Join Our Virtual Book Cub!

APRIL

As we ramp up for our 2025 *Hope in Every Step* Symposium, we're holding a special book club to explore Dr. Michael S. Okun, our keynote speaker's book, *A Prescription for Action: Ending Parkinson's Disease!*

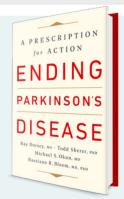
For more information on how to register, contact Julia Wall at jwall@parkinsonsmi.org.

The book will be divided into three parts and meetings:

March 21, 12:00 pm – Part 1: A Formidable Disease

April 4, 12:00 pm - Part 2: The Pact

April 18, 12:00 pm – Part 3: A Prescription for Action



2025 UPCOMING EVENTS



Friday, 8:00 a.m.

APRIL Hope In Every Step Symposium

25 This educational event is geared toward Parkinson's patients, care partners, and professionals with the goal of finding hope along your journey with Parkinson's. Location: Livonia, MI. Register online: <u>bit.ly/MPFSymposium25</u>

Tuesday, 9:30 a.m.

APRIL Virtual Mindfulness Workshop Begins

29 Join us for an eight-week Virtual Mindfulness Workshop with Dr. Barbara Pickut! Register online: <u>bit.ly/8WeekMindfulness</u>

Wednesday, 4:00 p.m.

APRIL Urban Poling With Deb Colling

30 Deb Colling, MPF Director of Fitness, will lead an urban poling walking event at Normandy Oaks Park in Royal Oak! Poles will be provided. Register by contacting Deb at: <u>dcolling@parkinsonsmi.org</u>.

Northern Michigan April Events:

APRIL 26 Chili Cookoff

Benefiting the Leelanau County Parkinson's Warriors walk team. Location: Leland Community United Methodist Church, from 12 - 2:00 p.m.

APRIL 29 Rock Climbing

Learn how to Rock Climb and unlock a new favorite exercise for Parkinson's! Rental gear included, no experience needed. Location: ELEV8 Climbing and Fitness, from 10 a.m. - 12 p.m.

To register, contact Torrey Davenport at tdavenport@parkinsonsmi.org

What is the Sit-to-Stand Challenge?

On Parkinson's Awareness Day, April 11, join individuals and organizations from around the world in the commitment to stand up to Parkinson's by collectively completing 2,000,000 Sit to Stands in 24 hours!

1. Complete as many sit to stands as you can in 24 hours on April 11, 2025!

2. Log your sit to stand number online at standuptoparkinsons.com or email Deb Colling at dcolling@parkinsonsmi.org and we can log them for you!

3. Share on social media! Share your count and encourage your community to join in on the fun using the hashtags #standup2pd and #sit2stand!

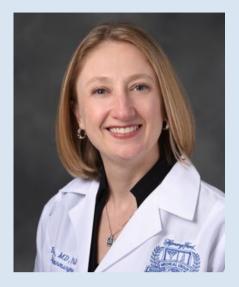


INNOVATIONS IN DEEP BRAIN STIMULATION

Ellen L. Air, MD, PhD, FAANS, FCNS Henry Ford Health

Deep Brain Stimulation (DBS) has become a core treatment for Parkinson's Disease, particularly when symptoms are not well controlled by medication alone. It involves implanting electrodes into specific brain areas, which send electrical impulses to help regulate abnormal brain activity. DBS is especially helpful for individuals who experience motor fluctuations, where their medication (like levodopa) becomes less effective or causes unwanted side effects. DBS can smooth out these fluctuations and help provide more consistent control of movement.

The approach to placing DBS electrodes has evolved significantly over the nearly 30 years since it was approved in the United States. Originally, a large frame was secured around a patient's head which provided 3-D reference to the brain anatomy, essentially giving GPS coordinates for electrode placement. However, the brain can subtly shift when the skull is opened, and each person has a unique anatomy. So, recordings of the brain, while the patient is awake, provide a second navigation tool to account for these factors and achieve the best placement. Advancements in brain imaging more precisely show each person's anatomy, opening the door to new approaches for DBS placement, including using real-time MRI guidance while the patient is asleep. In this procedure, a smaller aiming device is temporarily secured to the skull once the patient is asleep and positioned in an intraoperative MRI (iMRI). Real-time MRI imaging is then used to visualize the brain during surgery. This allows surgeons to optimize the electrode's trajectory before entering the brain and confirm final placement directly.



Henry Ford was the first in the region and third in the country to bring intraoperative MRI-guided DBS placement to patients. More than a decade later, the field has continued to evolve. Henry Ford is proud to bring yet another innovation to DBS surgery. The iMRI guidance technology has been enhanced to support intraoperative CT stereotactic guidance for neurosurgical procedures, including DBS lead placement. This allows for precision-guided neurosurgery in operating rooms without intraoperative MRI facilities.

Following FDA clearance in January, Henry Ford became the second in the country to bring this approach to patients. Compared to CT-supported, frame-based placement, the exact path of the lead can be imaged and optimized before it enters the brain. While frame-based DBS surgery will continue to have a role, this advancement broadens access to precision-guided neurosurgery and provides yet another option for patients with movement disorders. Henry Ford is excited to provide the full spectrum of options for patients and contribute to this ever-evolving field.

A MESSAGE FROM:



We hope this message finds you well and that you navigate through the winter season with ease. As we welcome the warmth of spring, with its warmer weather and blooming flowers, we are excited to honor Parkinson's Awareness Month this April.

At Quest Research, we have been diligently advancing our research initiatives, and we are thrilled to share some significant updates with you. We have recently been awarded six Parkinson's research studies, and we are actively enrolling participants for these groundbreaking projects!

- Gene Therapy If you are 45-75, and had a diagnosis of Parkinson's for 4-10 years, you may qualify to participate in Regenerate-PD, a gene therapy product that could stabilize or improve motor symptoms associated with Parkinson's. Gene therapy is a medical technique that involves delivering material into a person's cells to treat or prevent disease.
- Off-Time Oral medications that may to improve your on-time
- Diagnosed under 5 years Study focus is on medication designed to alleviate motor symptoms.
- Newly Diagnosed If you are 45-80 and received a Parkinson's diagnosis in last 2 years and are not currently taking Parkinson's medication. Studies may help slow disease progression.

We are also pleased to announce that Dr. Aaron Ellenbogen, our primary investigator is the President of the Michigan Parkinson's Foundation (MPF).

Additionally, we will be sponsoring and hosting a table at the MPF *Hope in Every Step* Symposium on Friday, April 25, 2025. We hope to see many of you there! We will also be at the MPF Parkinson's Hero Walk at Jimmy John's Field on September 13, 2025.



Interested in learning more about these studies? Please call 248-957-8940 and speak with one of our patient Liaison research specialists! No insurance is required and all study-related expenses are covered at no cost. Together we can make a difference!

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PARTNERS IN PARKINSON'S



An Education in PD

Vic Landa loves to learn. He is currently enrolled in the Foreign Policy Association's "Great Decisions" class through the Traverse Area District Library. Topics for the current session include such hearty subjects as "NATO's Future," "Climate Technology and Competition," and "Mideast Realignment." Vic looks forward to the weekly discussions and to learning about different points of view.

Vic first noticed symptoms of Parkinson's Disease around 2016. At the time, he thought his symptoms were related to a pinched nerve in his back. Post-diagnosis, Vic has applied his love of learning to manage PD.

Today, Vic's most prominent symptom relates to balance, and his propensity to fall. Over the years Vic has been surprised by how willing strangers are to help him when he falls in public. He's also been impressed by the warmth of the Parkinson's community in Northern Michigan. Vic is a member of the Leelanau County Parkinson's Support Group and has enjoyed the opportunity to talk with friends dealing with the same disease.

Vic's advice for others battling Parkinson's is "Don't fear the disease. Learn as much as you can about Parkinson's and use that information to build a team that will make the best decisions about your care." Vic also believes in the power of positive thinking. He warns that "negativity and fatigue can be very dangerous for someone with PD. Keeping a positive attitude is extremely important."

Ask for Help

Jeanne Kerner's husband, Eugene, lived with Parkinson's for seventeen years. Jeanne was his caregiver. Eugene initially sought medical care because he noticed that his little finger was twitching. He was only fiftyeight when he was diagnosed. "The diagnosis came as a shock," said Jeanne. "We didn't know much about Parkinson's disease at the time."

Jeanne and Gene learned a lot about PD over the years. Exercise was an important part of their journey. Joining a support group was also key. Jeanne's advice to other caregivers is to ask for help when things get hard. "You don't have to do it alone," she says.

Eugene passed away in February of 2024. Jeanne continues to support the work of the Michigan Parkinson Foundation in his memory.



Jeanne's husband, Eugene Partners in Parkinson's is a story-sharing project designed to highlight the ways in which Parkinson's impacts supporters of MPF.



Embrace the Good

Todd Gardner was diagnosed with Parkinson's disease at age 41. At first, Todd kept his diagnosis to himself, primarily because his daughter was too young to fully understand PD at the time. "Those were hard days," he says. Once Todd shared his diagnosis with family and friends, he was ready to do something that made a meaningful impact in the PD community.

Todd combined his love of golf with his desire to help others living with Parkinson's and organized a golf outing in the Lansing area. That golf outing became an annual event and, over the past twelve years, has raised a remarkable sum - over \$400,000. The funds have been used to create free Parkinson's-specific exercise classes at the Michigan Athletic Club in East Lansing, to support scholarships for the children of Parkinson's patients, and to support the Respite Care program at MPF.

Todd's advice to others with Parkinson's is to find an interest, passion, or hobby that keeps you motivated and active. Organizing the annual golf outing and playing golf with others in the Parkinson's community has provided Todd with an invaluable network of friends who support each other through the ups and downs of PD.

Todd continues to live his life according to a simple motto "I can't say being diagnosed with Parkinson's has been a good thing. But I can say, good things have happened to me because I have Parkinson's."

We want to hear from you! If you are interested in participating in the Partners in Parkinson's story-sharing project, please contact Lisa Anga at 248-232-0861 or <u>langa@parkinsonsmi.org</u>.



Register Today: MPF Fun Run 2025

June 4, 2025 | Lake St. Clair bit.ly/FunRunMPF25

