

Care, Support & Education for Parkinson's Disease in Michigan SINCE 1983

MESSENGER

WINTER 2024

From Winter to Spring: MPF's Commitment to Supporting Parkinson's Families

Dear Parkinson's Community,

I hope this news from MPF finds you well as we see the days slowly getting longer and the sun peaking out to remind us that warmer weather is just around the corner! And because we know that cold wintry days are not yet behind us, check out the article on cold weather and Parkinson's from our Professional Advisory Board member, Dr. Shana Krstevska.

We have an exciting year ahead at the Michigan Parkinson Foundation! From our Symposium to Parkinson's Awareness Month activities, to our regular programming, we hope you join us. We are here to support you and your family across the state of Michigan and beyond through our four pillars: community, exercise, education, and respite.

Community

Remember that in addition to over 70 support groups, we have a NEW! one-on-one mentorship program. Check out our new mentors within this issue and sign up with any of our 10 mentors on our website https://parkinsonsmi.org/grow/#ourmentorship

Exercise

I am happy to announce our NEW! Train the Trainer program. This is aimed at training instructors throughout the state so that they can bring you FREE exercise classes in your community. So far, we've been able to train teachers in Grand Rapids and Traverse City with Mt. Pleasant and Monroe and many more soon to come!

Winter weather keeping you inside? Check out our virtual exercise classes Monday—Saturday taught by physical therapists. https://parkinsonsmi.org/grow/#findaclass

In the Southfield area? Come to Angee Ludwa's in-person class at our office every Monday at 1 p.m.

Education

Join us for our in-person Symposium on April 5 at Laurel Manor in Livonia! Also, don't forget that we have Virtual Education Series lectures the 3rd Wednesday of each moth and Parkinson's Orientation for newly-diagnosed individuals the 1st Wednesday of each month.

Respite

Last year, we served a record number of families with respite care assistance. Please reach out to us for both respite care financial assistance and medication assistance at any time.

Our central message is that you are not alone, we are here to help at every age and stage of your Parkinson's journey. Call us, we can help.

Sincerely in Service, Kristin Rossi

Spring Into Action: Rejuvenating Your Routine for Parkinson's

By Angee Ludwa, Director of Exercise

As the sun graces us with its warmth and the snow melts away, it's the perfect time to revitalize our routines and embrace the benefits of movement, especially for those affected by Parkinson's Disease. Research consistently highlights the positive impact of exercise on managing Parkinson's symptoms, but knowing where to start and how to maintain momentum can be daunting. Fear not, for we're here to guide you on your journey to a more active and fulfilling lifestyle.

New to Exercise? Tips on Where to Begin:

- · Set realistic goals and commit to them.
- Start with simple exercises and gradually progress.
- Explore whether you prefer solitary workouts or group activities.
- Discover exercise classes available in your community via our website.
- Find a workout buddy for added motivation and accountability.
- Schedule your exercise sessions like important appointments.
- Remember to make it FUN!

Ready to Elevate Your Routine? Try These Tips:

- · Increase the intensity of aerobic exercises by adjusting speed or resistance.
- Incorporate hand weights to challenge your strength gradually.
- Monitor your heart rate to ensure you're hitting moderate to vigorous levels. The moderate to vigorous level is 70 to 80% max HR
- · Dive into high-intensity interval training (HIIT) classes for an exhilarating workout experience.
- Join Kim Wilkins every Thursday at 10 am live on zoom for an invigorating higher intensity workout.
- Remember: Consistency is key.



 Research underscores the importance of regular exercise for improving quality of life. Aim for a minimum of three days of exercise per week and strive for more whenever possible. If you don't know where to start, I highly recommend setting up an appointment with a neuro physical therapist so they can get you started in the right direction. Your journey with Parkinson's is unique, so listen to your body and seek support from healthcare professionals, loved ones and/or care partners to stay motivated. The Michigan Parkinson Foundation offers

free, live, zoom exercise classes

Monday through Saturday at 10 a.m. EST. These classes are taught by physical therapists that specialize in PD as well as certified yoga instructors. You can register for the classes via our website.

Health Tip: Incorporate overnight oats into your breakfast routine for a nutritious and convenient start to your day. Warm oatmeal is great in the winter but as spring approaches, don't rule out oatmeal as an option. I like to mix the ingredients in a 32 oz mason jar, put it in the refrigerator and pull it out to grab and eat.

Overnight Oats

Ingredients:

- Rolled oats
- Almond milk, or other type of liquid
- Greek yogurt
- Chia seeds
- Your choice of add-ins and toppings such as walnuts, almonds, bananas, berries, granola, maple syrup

Directions:

For the base recipe add a 1:1 ratio of oats to liquid and then half as much yogurt. Add a few tablespoons of chia seeds for a little fiber and protein, as well as your favorite add-ins. Once everything is together, mix and store in the refrigerator so the next day you can enjoy a healthy, tasty breakfast!



Stay tuned for more updates, tips, and resources to support your wellness journey. Let's embrace the beauty of spring as we move toward better health together!



April is Parkinson's Awareness Month

Come celebrate with us! Join us for the following activities throughout the month of April!

April 5 – Hope In Every Step Symposium See page seven for more information. Register online: bit.ly/MPFSymposium2024

April 11, 11 a.m. - 2 p.m. - In-person Open **House** hosted at the MPF office.

Neuroplasticity Talk at 12 p.m. with Quinn Hanses and Dr. Reza Amini, University of Michigan Flint

April 17, 6 p.m. – Painting for Parkinson's with Aimee Kahaian - In-person painting experience hosted at the MPF office. RSVP to Angee Ludwa at aludwa@parkinsonsmi.org. Spots are limited!

April 24, 7 p.m. - Virtual Education Series, via Zoom – Importance of Exercise with Dr. Amelia Heston, Movement Disorder Specialist at Michigan Medicine.

April 25, 7 p.m. - Virtual Exercise Sampler, via Zoom with Angee Ludwa, Ali Woerner, Mindy Eisenberg, and Deb Colling.



Empowering Yourself: Strategies for Adjusting to Life with Parkinson's

1. See a Specialist

If you haven't done so already, it's important to see a movement disorders specialist, especially if you have nagging symptoms that remain untreated despite your current therapies. This doesn't have to be your regular doctor or primary neurologist. A movement disorders specialist will be on top of new treatments and advances in therapies.

Call the Michigan Parkinson Foundation at (248) 433-1011 for our statewide neurology referral list.

2. Give Yourself Time to Adjust

Over time, you'll likely become an expert in Parkinson's disease — but right now, you're a newbie. Give yourself time for the diagnosis and it will all start to sink in. Then, get educated: join the Michigan Parkinson Foundation's Parkinson's Orientation on the 1st Wednesday of the month and our Virtual Education Series on the 3rd Wednesday of each month to stay up on all the latest information.

Contact our Director of Education at jwall@parkinsonsmi.org for more information!

3. Be Honest

While you need not tell everyone you know right away, try to avoid the impulse to totally hide your diagnosis. It's important for your long-term well-being to open up to friends, colleagues and loved ones.

Your family is most important, of course. If you don't already do so, set aside regular times to have conversations with your significant other about how things are going and what you both need.

Be honest with adult children about the reality of your diagnosis; they are an important part of your care. If your children are young, they need reassurance that the disease is not contagious, that they did nothing to cause it (a fear many children have when a parent becomes ill), and that you are still the same mom, dad or guardian you've always been. These are ongoing conversations.

Need help initiating these crucial conversations? Call us at at (248) 433-1011 to talk to our staff social worker who can help counsel you, provide information on the nearest support group to you, and/or help you reach out to one of our trained mentors.

4. Boost Activity

Don't wait until symptoms become more troubling before you try to counteract them with exercise or physical therapy.

If you change your life to be more active now, you'll increase your chances of staying active longer. Try to get active pursuits like biking, hiking, swimming and other forms of exercise, integrated into your lifestyle (if they aren't already), so that they become ingrained habits. If these seem boring, consider boxing, yoga or even dance classes designed for Parkinson's patients! The important thing is to find something you love to do and keep doing it.

This activity helps build a reserve against losing physical function as the disease progresses. It's normal for anyone to lose muscle mass, coordination and motor speed as they age, and it's even truer for people with Parkinson's. But if you have a baseline of being as fit and conditioned as you can, you'll do yourself a great service later on.

Contact our Director of Exercise at <u>aludwa@parkinsonsmi.org</u> to find exercise opportunities near you!

5. Stay Engaged

Mental and social engagement is similar to physical fitness — you use it, or you (gradually) lose it. Get together with friends and family, travel, and join clubs. Depending on where you are in your professional life, staying in the workforce can give you a sense of purpose and offers regular engagement with others.

That said, if work is too physically demanding, consider going on disability or retiring so you can focus more on social activities that keep you mentally active.

6. Track Your Symptoms

Pay attention to your body and how it reacts to medications and other treatments, and how you feel at certain times of the day or after specific activities. This is especially important as you receive new medications or have doses adjusted. It's up to you to tell your doctor what's working and what isn't. A chart, a notebook, a file on your computer, a spreadsheet — employ whatever system works for you.

7. Consider Research

While participating in research may directly help you physically (on the chance that you'll get into a study for a promising new treatment that works for you), it may also leave you better off just for having been a part of something that could improve the lives of other Parkinson's patients.

You will likely have a sense of purpose and something to get involved in. In addition, you often get additional care from doctors and researchers, and the benefit of networking with other patients. Find a research study that may suit you via Quest Diagnostics or ClinicalTrials.gov.

PARKINSON'S ORIENTATION 2024 First Wednesday of each month			
April 3	August 7		
May 1	September 4		
June 5	October 2		
July 3 Break no orientation this month	November 6		
	December 4		



Torrey has her Doctorate in Physical Therapy from Trine University and has been helping with our virtual exercise classes since 2021. In her new role as Northern Michigan Program Manager, she will be bringing in-person programming, exercise

classes and education events to rural areas of Michigan. She runs an in person PWR! Moves class and support group in Leelanau county.

Welcome Aboard

Torrey Davenport

In addition to working for MPF, Torrey is a physical therapist at Fyzical Therapy and Balance Centers and enjoys providing rehabilitation services to people with PD along with treating other orthopedic and neurologic conditions. Torrey lives in Traverse City with her husband, Justin, and together they have one daughter, Margo, and a golden retriever, Fitz. In her free time, she enjoys running, hiking, camping, reading and spending time exploring everything Traverse City has to offer.

Torrey is very excited to be joining MPF in a larger role and can't wait to lead this year's Traverse City Walkathon!

ASK THE DOCTOR!

Send your burning questions to director@parkinsonsmi.org with the Subject Line "Ask the Doctor" and we will ask our Professional Advisory Board to get you the best answer! We will select one question to highlight in the next newsletter.

Please keep these questions general information that would be helpful for others rather than a highly personalized question as the advice given will be general and not personalized.



Do You Have Parkinson's Disease (PD)?

CURRENTLY SEEKING VOLUNTEERS TO PARTICIPATE IN A QUALITY IMPROVEMENT PROJECT



Purpose

Better understand what it is like living with voice changes due to Parkinson's disease

Eligible Participants...

- Diagnosis of Parkinson's disease for at least one year
- Age of onset 50 years old or older
- Have you or others noticed changes in your voice
- Have attended speech therapy for voice changes
- Able to speak, read and understand English
- Have access to a computer or phone
- Currently residing in the US or Canada

The interview will take about **45 minutes.** It will be completed in a one-time interview over computer or phone.

The interview questions will address your experience with Parkinson's disease, speech therapy treatment and speech therapy techniques you use in daily life.

Your participation will impact the knowledge of nursing and speech language pathology communities with the intent to improve understanding of what it is like to live with Parkinson's disease. The intent is to better understand the impact of voice changes on quality of life and how to improve speech therapy outcomes.

If you are interested in participating and learning more, please contact us at patton29@msu.edu or brydejac@msu.edu

Hope in Every Step:

Unveiling Our Upcoming Symposium

April 5, 2024 Laurel Manor, Livonia, Michigan

We are thrilled to announce our much-anticipated symposium, "Hope in Every Step," scheduled to take place on April 5, 2024, at Laurel Manor in Livonia, Michigan. This event promises to be a beacon of inspiration and knowledge, bringing together thought leaders, experts, and enthusiasts in a celebration of hope and progress.

Join us for a day filled with engaging discussions, enlightening presentations, and valuable networking

opportunities. Our symposium aims to explore and amplify the many facets of hope that guide us through challenges and pave the way for a brighter future.

Join us on April 5th for a symposium that promises to be a catalyst for positive change. "Hope in Every Step" is not just an event; it's a movement toward a future where hope guides every stride. Please register by March 25, 2024. https://secure.qgiv.com/for/2024symposium/event/symposium2024/

\$65.00 per healthcare professional (5 CEU) \$30.00 per person

AGENDA

8:30 – 9:00 a.m.	Registration	12:00 – 12:45 p.m.	Lunch
9:00 – 9:20 a.m.	Interactive exercise with Deb Colling, Instructor	12:45 – 1:45 p.m.	Parkinson's is Not One Disease but Many: The Roadmap to Cures
9:20 – 9:30 a.m.	Welcome: Kristin Rossi, CEO Michigan Parkinson Foundation		Alberto Espay, MD, Move- ment Disorder Specialist, University of Cincinnati
9:30 – 10:30 a.m.	Orthostatic Hypotension and Cognition Across the Syndrome of PD	1:45 – 2:05 p.m.	Interactive exercise with Ali Woerner, Parkinson's
Abhimanyu Mahajan, MD Movement Disorders Spe- cialist, University of Cincinnati	Abhimanyu Mahajan, MD Movement Disorders Spe-	2:05 – 2:15 p.m.	Dance Break
	,	2:15 – 3:15 p.m.	To Sleep or Not to Sleep, That is The Question! (An overview of sleep issues in patients with Parkinson's Disease)
10:30 – 10:40 a.m.	Break		
10:40 – 11:00 a.m.	Interactive exercise with Angee Ludwa, PT		
11:00 a.m. – 12:00 p.m. (Danette Taylor, DO, Move- ment Disorder Specialist, Trinity Health, Hauenstein Neurosciences
	Shawn Bennis, MSN, RN, CHC, Faith Community Nurse, Henry Ford Health		
		3:15 p.m. –	Evaluations

Presented by







In Partnership with

Meet the Mentors!

Please give a warm MPF welcome to our newest mentors, **Deborah Farmer and Joe and Stephanie Staub!** Parkinson's, newly-diagnosed individuals, young-onset individuals, care partners and veterans. Reach out today at parkinsonsmi.org/grow/#ourmentorship or call us at (248) 433-1011.

Joe & Stephanie Staub

We were introduced to Parkinson's disease 35 years ago when my father was diagnosed. Prior to that we had barely heard of Parkinson's, let alone understood what it was. I was not his primary caregiver, rather I was a son taking on an ever-growing set of respon-

sibilities around his house so he could maintain his independence and quality of life.

Twenty years later, my mother-in-law was diagnosed. My wife, Stephanie, stepped into the role of primary caregiver, doing the shopping, banking, cleaning, laundry, coordinating doctor's visits and managing the medicine. Again, I assumed responsibilities around her house so she could maintain her independence.

Then eight years ago in 2015, I was diagnosed. I went home and crawled into bed for 2 days. Stephanie on the other hand went into action mode. Taking the lessons that we learned with our parents, we made an appointment at the Michigan Parkinson

Foundation, researched the right neurologists for us, and looked for clinical research trial opportunities.

We are a team! She understands the progression and changes I'm going through and adapts our lifestyle to accommodate. I am overwhelmed by her willingness to take on this challenge while keeping a positive outlook as we walk this journey together.

We live an active lifestyle, working part-time, visiting with friends, volunteering, golfing, camping, and exercising. We spent 3 months this past year traveling with our camper.

We realize we are not in control, but we keep a positive attitude and believe we can make a difference. We do that by volunteering at organizations and related events, working on committees, talking with students in physical therapy programs and participating in clinical research trials. It is our belief that without an understanding of the disease. diagnosis, slowing the progression, halting, and ultimately eliminating the disease will not be possible.

Feel free to reach out to Stephanie as a caregiver, or myself as a person living my best life with PD, or both of us as a team. We'd gladly share our experiences.

Deborah Farmer

September 19, 2020, a date I will always remember, the date was diagnosed with Parkinson's disease.

For me that word meant that my life was over. Here I was 67 years old with a disease, that there was no cure for, and I was going to spend the rest of my life

needing someone to take care of me. I was no longer going to be able to do the simple things in life that I took for granted.

I soon found out how wrong I was! I found a support group (Detroit Support Group). My neurologist

referred me to Speech Pathology, Physical Therapy and Occupational Therapy. I also started exercising 7 days a week for at least 1 hour a day.

The best medicine for PD is to get out and join groups to meet people that know and understand how you feel. I am now a part of Rock Steady Boxing (Parkinson's Movement Center), Motor City Upbeats Therapeutic Singing Club, Water Aerobics, and I also started a personal journal about my feelings concerning Parkinson's which I named Fear Knocking at My Door. My best support is my family, they have been with me since day one of my PD journey.

I am inviting you to join me in this journey, together we can slow this disease down if not stop it all together.

Parkinson's Disease and Cold Weather

By Shana Krstevska, MD

Dr. Krstevska is a movement disorders neurologist at Henry Ford Health and a proud member of the Michigan Parkinson Foundation Professional Advisory Board.

Our bodies are marvelously equipped to maintain a stable internal temperature—a process known as thermoregulation, which is crucial



for our survival. This regulation is managed by our autonomic nervous system, which automatically 6. Regularly inspect space heaters and electric adjusts to both chilly and hot environments. When we're exposed to cold, for example, our blood vessels constrict near the skin's surface to conserve heat, 7. If you must travel, do so during daylight hours which is essential for keeping our core temperature steady. When the cold is intense, shivering kicks in-a rapid contraction of muscles that generates additional warmth, helping us to reach the 9. Always carry extra medication when optimal temperature range necessary for our cells to function efficiently, typically between 97 to 99 degrees Fahrenheit.

Hypothermia, a potentially dangerous condition, arises when our body's heat production can't keep up with heat loss, leading to a drop in body temperature below 95 degrees Fahrenheit. This condition manifests through signs like confusion, shivering, labored breathing, drowsiness, and muscle stiffness. It can escalate to severe complications such as cardiac arrhythmia and even death if not promptly addressed.

Individuals with Parkinson's disease may find it particularly challenging to regulate their body temperature, often experiencing cold hands and feet. This is because their muscles, needing to contract to preserve heat, may not function as effectively. In fact, many neurological disorders that impede movement can reduce the ability to generate heat through muscle activity. Moreover, colder temperatures can exacerbate symptoms, increasing muscle rigidity, affecting movement and balance.

To safeguard against the cold and its effects, especially for those with mobility challenges and neurological conditions, consider the following proactive steps:

- 1. Arrange for mail delivery directly to your door to minimize exposure to the cold.
- 2. Utilize home delivery services for prescription medications.
- 3. Opt for food delivery to stock up on essentials without braving the cold.
- 4. Convert in-person medical appointments to telehealth sessions when possible.
- 5. Dress in layers, favoring materials like wool, and don't forget hats, scarves, and gloves.
- blankets for wear and tear, discarding them if they're damaged.
- and stay mindful of the temperature.
- 8. If temperatures plunge below freezing, it's best to remain indoors.
- leaving home.
- 10. Stock up on reading material to enjoy in the comfort and warmth of your home.
- 11. Maintain a gratitude journal, which can be a warming practice in itself.

By taking these precautions, you can stay warm, safe, and healthy, even when the thermometer dips.





Join the Movement: Michigan Parkinson Foundation's Hero Walks Return!

The Michigan Parkinson Foundation is gearing up for this year's Parkinson Hero Walks! The Parkinson Hero Walks (formerly I Gave My Sole for



Parkinson's Walks) are a team/ pledge walking event that helps allow MPF to continue critical programs and services free of charge. For individuals with Parkinson's, to care partners, healthcare professionals, family, friends, and loved ones: you are all our heroes

and your courage in facing this disease every day is truly exemplary.

The walks promise a day filled with community, camaraderie, and a shared commitment to raising awareness and funds for critical programs and

services. Whether walking in honor of a loved one. supporting a friend, or simply standing in solidarity with the Parkinson's community, every step taken at this event helps ensure that no person with the disease is without quality care and support.

To register, visit: https://bit.ly/2024walks and select your location!

Traverse City Walk: August 24, 2024 Civic Center in Traverse City, MI

Metro Detroit Walk: September 14, 2024 Jimmy John's Field in Utica, MI

Lansing Walk: September 21, 2024

People's Park, MSU Campus in East Lansing, MI

Grand Rapids: October 19, 2024

Alksnis Building, Aguinas College in Grand Rapids, MI



West Michigan Walk Renee



West Michigan individual



Lansing Walk at Finish sign



VETERANS WITH PARKINSON'S SUPPORT GROUP



We thank you for your service and we invite you to join us as we bring the Parkinson's Veteran community together in person each month. Together in service. Together in support.

When: 3rd Thursday of the month at 2:30 p.m.

Location: DC3S

7205 Sterling Ponds Ct. Sterling Heights, MI 48312

For more information or to join the group please contact

Nate Jolliff (248) 464-3258, or email natejolliff@comcast.net Marc Trail (586) 693-0434, or email mtrail@carepatrol.com

Join our group via Facebook



Upcoming Meeting Dates

January 18 April 18 February 15 **May 16** March 21 June 20

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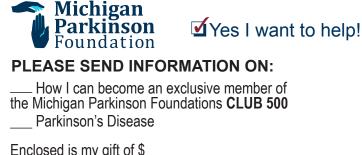
MPF provides the following services to those with Parkinson's and their families:

More than 76 Affiliated Support Groups • Medication Assistance • Information Literature • Exercise Programs • Subsidized Respite Care • Neurologist & Community Referral • Education Programs • Advocacy Consult your medical providers before acting on information in newsletter articles. This MPF publication offers information intended to be useful to people with Parkinson's, their caregivers and families, and the professionals who assist them, but they are not a substitute for qualified medical advice.

YOUR GENEROSITY IS GREATLY APPRECIATED. PLEASE HELP US NOW! No matter how large or how small, every donation helps. Return to MPF, 30400 Telegraph Road, Suite 150, Bingham Farms, MI 48025, or donate on-line at www.parkinsonsmi.org

CARE, SUPPORT & EDUCATION FOR

PARKINSON'S DISEASE IN MICHIGAN PLEASE CONTACT ME ABOUT:



How I can make a Recurring Donation (weekly, monthly, etc.) ____ How I might make a gift to MPF in my will, life insurance or other special means which may have tax advantages. Enclosed is my gift of \$_____ My Name _____ Visa___ Mastercard___ Discover___ Amex_ Address _____ Account # exp. City State Zip Card Security Code: County _____ Last 3 digits on back of card (4-digits on front of AMEX) In Memory of_____ Phone In Honor of I want to receive further mailings: Special Occasion of____ By e-mail at Please notify the following person of my gift: Name By regular mail Address DO NOT SEND further mailings _____ DO NOT INCLUDE my name in publications State___Zip___ City_

Your kind donation will be used whenever needed. Please make checks payable to: Michigan Parkinson Foundation.

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