



**MICHIGAN
PARKINSON
FOUNDATION**
Helping Families Since 1983

MESSENGER



**SPRING
2023**

Happy Spring MPF Community!

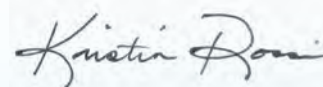
As the weather begins to change into bright, beautiful colors all around us, I am excited to share that our new website will be coming soon and will hopefully mimic the same transformation. Not only will our new site show vivacious colors, but we have also been working to make it more user-friendly and adaptive. We will have Zoom sessions available once our website is live so that we can help you navigate the new site and show you all the fun, new features it provides.

This edition of the newsletter is also very special to me as it marks one year with the Michigan Parkinson Foundation. I began working here on Parkinson's Awareness Day last year, something I've always taken as a great omen. Over the last year, I have had the wonderful opportunity to meet and work with so many of you. I thank you for every story shared, every idea and every note of encouragement sent my way. Thank you for welcoming me into your community and trusting me to lead our mission forward.

I am so proud to be a part of this influential organization which has been doing great work in the community since 1983. Cheers to 40 years, and here's to 40 more!

Thank you!

Sincerely,



Virtual Education Series

May

Tuesday, May 16, 7:00 p.m.,

Latest Clinical Trials

Dolly Niles, Executive Director
QUEST Research Institute



As the leader of Quest, Dolly Niles will be joining us to talk about the role that Quest Research Institute plays in the role of clinical trials and will explore upcoming opportunities for patient involvement. Here is some background from their website with more information! QUEST Research Institute is one of a few multi-specialty, dedicated research sites in the Metro Detroit area. Founded on the desire to bring the local community access to new treatments following strict, FDA guidelines, QUEST has flourished and is now a Preferred Provider with several Pharmaceutical Sponsors and Contract Research Organizations (CRO's). Our site includes ten investigators with extensive research experience in therapy areas such as Internal Medicine, Neurology, Rheumatology, Pain, Vaccines and Women's Health. We offer an in-patient facility and experienced clinical staff to support specialization

in complex, early phase clinical research in a variety of diseases, but also participate in later phase trials through Phase IV.

Prompt start-up, an experienced staff and strong recruitment and retention strategies are part of every trial we implement. Our tenured staff is educated on standard FDA requirements, respect for Volunteer's Rights and ICH/GCP Guidelines. Each research study is carefully planned and conducted to accommodate sponsor expectations and deadlines, while never compromising patient care.

Our hope is to continue to offer the local community access to new medical technology and cutting edge research to improve medicine for all. If you are a person considering a research study, I urge you to see the page for Study Participants. If you are an industry person considering our site as a partner in your important project, please see our Site Offerings page to get a better view of our offerings.

People like you are needed to improve the health of everyone and we are dedicated to improving health through research... one person at a time!

June

Tuesday, June 20, 7:00 p.m.,

Anesthesia and Parkinson's Disease

Nicholas Watson, M.D., Corewell Health

Dr. Nicholas C. Watson is an anesthesiologist in Grand Rapids, Michigan and is affiliated with multiple hospitals in the area, including Spectrum Health-Butterworth and Blodgett Campuses and Battle Creek Veterans Affairs Medical Center. He received his medical degree from University of Michigan Medical School and has been in practice for more than 20 years.



Particular anaesthetic problems in PD include old age, antiparkinsonian drug interaction with anaesthetic drugs and various alterations in the respiratory, cardiovascular, autonomic, and neurological systems and we look forward to

Dr. Watson exploring the intricacies with us in depth!

West Michigan Anesthesia PC – Grand Rapids

3333 Evergreen Dr NE

Grand Rapids, MI 49525

616.364.4200

Virtual Education Series

July

Tuesday, July 18, 7:00 p.m.

What Role A Physiatrist Plays with Parkinson's Disease

Dorin Deitch, D.O., RPM
Restorative Physical Medicine

Dorin Z. Deitch, DO, specializes in the treatment of movement disorders including Parkinson's disease, dystonia, and tremor. Dr. Deitch is one of the only physiatrists in the country to be formally trained in movement disorders. He decided to supplement his physiatry training to better care for Parkinson's and movement disorder patients from a rehabilitation and functional perspective. Trained by both physiatrists and neurologists, he is expertly qualified to care for



many diseases of the musculoskeletal and nervous systems.

Dr. Deitch focuses on the whole patient with individualized needs. He concentrates on restoring optimal function to people who have medical conditions related to the muscles, bones, tissues, or nervous system. Dr. Deitch provides every patient with a detailed consultation with a focus on collaborative and multidisciplinary care in order to improve their quality of life. Dr. Deitch is committed to offering patients the best in care and support.

Dr. Deitch accepts both in-office and telehealth appointments. To arrange a consultation, call (248) 697-2942.

Symposium

Our Symposium is back! For the first time since 2019, the Michigan Parkinson Foundation in partnership with Wayne State University present our in-person Symposium.

Living Your Best Life with Parkinson's

Novi Sheraton

May 13 | 8:30 a.m. – 3:00 p.m.

This event is for people with Parkinson's, care partners and professionals **5 CEUs and CMEs** available to qualifying individuals.

Register online at: bit.ly/2023MPFSymposium





Walk with us and make a difference for the Michigan Parkinson community!

Traverse City – August 12.

Register here today: <https://rb.gy/iduukr>

Detroit – September 23.

Register here today: <https://rb.gy/qh6yp9>

Lansing – September 30.

Register here today: <https://rb.gy/ymycba>

Grand Rapids – October 14.

Register here today: <https://rb.gy/npiirw>



Calling all Boaters! Fun Run on Lake St. Clair!

The Third Annual Fun Run benefitting Michigan Parkinson Foundation will be taking place Wednesday, June 7th on Lake St. Clair. The event will start promptly at 8:30AM and tickets start at \$600. Ticket price includes registration for (4) participants, breakfast, lunch, dinner, and five poker cards with the winner eligible to win a \$500 cash prize. Event is limited to 25 ft. boats and larger, though cruisers are welcome! In 2022 we had a turnout of 55 boats, 271 participants, and raised an incredible \$121,000. Thank you to the committee for continuing to make this event such a great success.

Register here: <https://rb.gy/nh7adq>

SHAKIN NOT STIRRED

Shakin not Stirred is not only the name of Jennifer Traver's nonprofit, but also how she lives her life with Parkinson's disease. Jennifer is kind, generous and unstoppable. These traits were never more evident than at Jennifer's 8th Annual Family Bowling Event on April 2 in Monroe, MI. This event is more than your average day at the bowling alley. You walk in to find a team of very well-coordinated volunteers checking people in, interesting



you in the many raffles, selling tickets for silent auction items, selling t-shirts—all to raise funds for Parkinson's disease awareness. These volunteers have been working with Jennifer for years, part of the reason this event is so well-run, and so well attended. This team knows what they're doing! This year alone, Shakin not Stirred raised over \$17,000—an amazing success!

When Jennifer was diagnosed with young-onset Parkinson's disease at age 42, her first question was for her kids who were 12 and 15 at the time. Indeed, Jennifer's overwhelming focus is on the 90,000 people who are diagnosed each year with Parkinson's. She wants to ensure that no one else has to live with Parkinson's and she also wants to make sure that the people who are living with Parkinson's are cared for. That's where the Michigan Parkinson Foundation comes in. MPF is proud to have been a partner and friend of Jennifer Traver and Shakin not Stirred over many years—a partnership that will undoubtedly continue to flourish into the future.

New Zoom Exercise Instructor: Alexa Gazda



Alexa is a physical therapist who works for Henry Ford Health outpatient with instructors Katie and Ashley. She graduated from Wayne State University and is a metro-Detroit local. She works with people with Parkinson's both

one-on-one and instructs an in-person class once a week. She is a firm believer exercise is medicine for people with Parkinson's. She has witnessed how exercise can increase both function and quality of life in people she has worked with. She became PWR! certified last year and enjoys using those foundational movements to help improve activity, flexibility, and power. When she is not working, she is usually playing with her dog Charlie, reading a thriller, or spending time with friends. She is excited to join the Michigan Parkinson Foundation team!

MPF 40th Anniversary Gala

Keeping our Parkinson's promise for 40 years, setting our sights on 40 more

SAVE THE DATE

November 3 at
The Henry Ford
Museum

For information go to:
<https://bit.ly/2023MPFGala>

Apathy and Parkinson's Disease



By Hadley Cameron-Carter, DO, and Laurie Boore-Clor, MD

“He just doesn’t want to do anything at all like he used to. We try so hard to help but nothing seems to work.”

Almost daily in our clinic we hear these words from our patients and their loved ones, and we assess apathy. Apathy is a common concern for people with Parkinson's disease or those with dementia. Apathy is typically defined as a lack of interest, motivation, feelings, and/or emotions (Merriman-webster dictionary, Oxford dictionary). It is common in Parkinson's disease and is estimated to occur in 40% of patients (Den Brok et al 2015). It is often mistaken as a normal

part of a mood disorder or disease progression, however, it can occur with or without depression, fatigue or worsening cognitive impairment (De Waele et al 2022). Apathetic symptoms in Parkinson's disease can cause significant stress to patients, their loved ones, and caretakers. Many caregivers feel helpless when it comes to managing this symptom. Apathy has been associated with increased caregiver burden (Mele et al 2019), decreased patient quality of life, higher motor symptom

burden, and increased risk for cognitive decline (De Waele et al 2022).

Currently, there is a limited understanding of the cause of apathy in Parkinson's disease and thus there are no FDA approved medications for management. There are a few studied medications, but there is a lack of consistent evidence for effectiveness (Liu et al 2019). Despite lack of consistent evidence, off label use is common because medication can be effective for some people.

Other barriers to treatment include lack of patient motivation and initiative (Mele et al 2019). However, regardless of these barriers, it has been found that patients and caregivers would prefer to have a diagnosis (Mele et al 2019).

Patients with apathy may not be diagnosed due to a lack of understanding and regular screening by physicians. Education and awareness are important for facilitating management (Mele et al 2019).

Thus, in order to promote screening, diagnosis, and research for more treatment options, it is important to educate the public and spread awareness about apathy in Parkinson's disease. Specialized physicians like geriatric psychiatrists are directly trained in identifying, managing, and treating apathy. As such, physicians and the health care team can work with patients and families to help decrease the burden and do their best to improve apathy symptoms.

4 Strategies for Dealing with Apathy

- 1) Tell them, don't ask them. Tell your loved one it is time to do a task, go to an event, or engage in self care. "We're going to church now." If you ask them to do something ("do you want to go to church with me?"), the loved one will just say, "no."
- 2) Ensure there is daily, consistent structure and routine so the loved one knows what to expect for the day.
- 3) Schedule regular activities and regular exercise. Consider adult day care or senior center attendance.
- 4) Talk to your doctor about medication options if other non medication strategies fail.



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Ruthy and Gary Bedard's 1936 Ford Coupe with Gary aka *Ruthless*.

A Ruthless Fight Against Parkinson's Disease

This is the story of Ruthy and Gary Bedard. The pair have been married for almost 23 years, together for 30, and binding them together throughout that time has been their shared love of classic cars and mutual support as they navigate Ruthy's Parkinson's disease. Their story is so compelling, it caught the attention of local documentary film maker Keith Famie, who met them at a car show and immediately wanted to feature them in his upcoming film, "Detroit: City of Hot Rods and Muscle Cars" premiering on June 19, 2023.

Ruthy and Gary's portion of the film opens to the tune of the classic rock song, *Black Betty*, a nod to their 1933 Ford Coupe that goes by the same name. The Bedard's *Black Betty* was expertly restored over

the course of only 11 months by Gary and two of his car-crazy buddies. From their start, they both knew they had struck love in this mutual hobby. For Gary it was when he saw Ruthy cruising by in her 1939 Ford Red Coupe early Saturday morning in South Lyon on the way to a car club event car show alone, the same car show Gary planned on driving his 1950 Mercury custom car alone the same day, where they spent time together. For Ruthy, it was seeing one of Gary's masterful car creations, a 1950 radical Mercury painted Ferrari red, that she fell for him.

It's clear when you meet Ruthy that she is a force of energy. She is constantly smiling and taking care of those around her. Despite any difficulty with

dyskinesias and speech, Ruthy jumps into conversation easily and routinely walks six laps at the track per day, keeping up her stamina and posture. Having Parkinson's disease for over 20 years hasn't stopped Ruthy from pursuing her car hobby either. Ruthy's car passion is in 1930's vintage hot rods—she loves the curves and the Bootie of the car styling era. It's appropriate, then, that Ruthy's favorite car to take cruising is her red 1936 Ford Coupe named Ruthless. That's Ruthy. Never giving up and never backing down from Parkinson's and doing it all with a beautiful, bright smile on her face. "It has been difficult" Ruthy says in the film. "But, the more I can learn about it, the better I can do at it."

Gary, too, is unrelenting in his love and care for Ruthy, and you get the sense after talking to the couple, that he will do anything to see that smile on her face. "She's my cruising buddy, I've gotta take care of her" says Gary. "She'd take care of me if it were the other way around. There's no doubt about it. So, it's my turn."

Ruthy is a sterling example to find what you love and pursue it. It will get you through the tough times and make the happy times that much happier.



Ruthy and Gary Bedard's *Black Betty*.



Ruthy and Gary Bedard's 1950 Mercury Custom Car *Big Red*.

Ruthy has been a member of the Cowtown Cruisers since 1988 and at the time was the only woman member. Just two years later, she was voted in as the President of the club. Gary is a 42-year member of the Spark Plugs Car Club which is one of seven car clubs in Michigan that makes up the Michigan Hot Rod Association. Catch the premiere of the film on June 19, 2023 at the Novi Emagine theatre, click here for details:

<https://detroitmusclecarfilm.com/>

Parkinson's Disease Health Marker Report Card Program Study

PURPOSE: Improve your confidence to manage your Parkinson's disease

Visit 1: (Spring/Summer 2023)
Complete balance/walking tests & take 3 surveys. Receive your 'report card' & information to improve/maintain your scores.

Visit 2: (Fall 2023)
Retesting and follow up support to improve/maintain your scores.

Visit 3: (Spring/Summer 2024)
Retesting & interview to share your experience with our program.



THE HERBERT H. &
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CENTRAL MICHIGAN
UNIVERSITY

Central Michigan University Department of Physical Therapy

Principal Investigator:
Dr. Jamie Haines, PT, DScPT
Associate Professor

Locations & Contact Person:

Mt. Pleasant: Central Michigan University
Contact: Meg Ready at ready1m@cmich.edu
or 616-502-6777

Alpena: Alpena Senior Citizen Center
Contact: Andrew Doubek
andrew.doubek@fyzical.com 989-884-2481

Houghton: Michigan Tech-CMU Program at
the ATDC (near Mineral Museum)
Contact: Caroline Gwaltney
gwalt1c@cmich.edu 906-487-3244

About Our Study

This study is supported by a generous grant from the Parkinson's Foundation Faculty Scholar Program.

All testing completed by doctoral physical therapy students supervised by licensed PTs.

There is no financial compensation.

Have questions? Contact:
Jamie Haines at 989-415-0418 or
haine1jj@cmich.edu.

Made with PosterMyWall.com

The Importance of Speech Therapy



Speech therapy is very important for people with Parkinson's not only to help with day-to-day communication, but also to help with future issues related to swallowing. Research shows that 89 percent of people with Parkinson's disease (PD) experience difficulty with speech. As a result, many people with PD sit out of conversations and social functions which further leads to isolation and diminishes quality of life.

Luckily, we're here to help you live your best life with Parkinson's. Check out our speech therapy offerings:

The Michigan Parkinson Foundation has partnered with the **Andrews University Speech and Hearing Clinic to deliver SPEAK OUT!® & The LOUD Crowd®**, a speech therapy program developed for people with Parkinson's.

The program is based on principles of motor learning. Participants are taught to transition speech from an automatic function to an intentional act. The program works on strengthening the muscles used for speaking and swallowing by combining individual speech therapy (SPEAK OUT!®) with ongoing group therapy (The LOUD Crowd®).

The program is offered **FREE OF CHARGE** to anyone with Parkinson's who lives in Michigan. The only requirement is you need access to the internet and an electronic device that has a camera on it such as a laptop, iPad, tablet or smart phone.



The program is two parts:

Part 1.

The participants complete a 12-session speech therapy program with speech-language pathologists from Andrews University, School of Communication Sciences & Disorders. The program is presented via Zoom.

Part 2.

The LOUD Crowd is a maintenance program that provides accountability and education, camaraderie and provides support and encouragement through weekly group sessions. SPEAK OUT! participants and graduates are invited to join the LOUD Crowd.

The 12-session program is administered by students and supervised by speech-language pathology professors from the Andrews University Speech and Hearing Clinic. The program is delivered through Zoom.

If you are interested in participating in this FREE program, complete the application on our website www.parkinsonsmi.org/mpf-programs/speech-therapy

And e-mail it to Michigan Parkinson Foundation, director@parkinsonsmi.org

Once you complete the Speak Out program above, we have another opportunity for you to engage with The LOUD Crowd@!

We have also partnered with Central Michigan University to bring you another The LOUD Crowd@, Friday mornings at 10 a.m. Email jwall@parkinsonsmi.org to sign up!

You are not alone with Parkinson's disease

Get Connected

- Support Groups
- Free virtual exercise offered 6 days a week
- Respite Care Assistance
- Education Programs
- Medication and Mobility Equipment Assistance
- A team that is here for YOU



What is the goal of uniting together?

Social connection is as fundamental as the need for water, food, and shelter. Social isolation has been tied to increased risk of depression, PD symptoms, heart problems, and more.

Statistics

Responded "yes" to "I am lonely" in Parkinson's disease study

55%



Statistics

Report depression at some point during course of Parkinson's disease

50%



We are better together. Connect with us today.





Support Group Facilitator Spotlight



In early 2017 two genealogists Judy Liptak and Alison Walters approached Director Diane Patterson about forming a Parkinson's group at the Cadillac Senior Center because both of their husbands were newly diagnosed. All three leaders think that the local groups are important because they make people feel less isolated and can help find answers to questions that they feel are too minor to ask a doctor.

Diane arranges most of the speakers, Judy handles the email communications and Alison handles the snail mail communications because about ten of the more than fifty members do not have email. Alison and Judy are in charge when the meeting is split into caregiver and patient groups. In early 2022 Diane was diagnosed with Parkinson's and has been actively promoting their support group throughout Cadillac.

All three leaders think that the local groups are so important because it make people feel less isolated and can find answers to questions that they feel are too minor to ask a doctor. They have also discovered that the simplest activities can be the most enjoyed. The group has scheduled walking at the community center (at no charge) and everyone enjoys walking in a safe, temperature controlled area which has seats around the perimeter and great sight lines so after the first lap everyone is walking at their own pace and talking with friends. These support group leaders understand the importance of socialization, movement and taking care of one another. Thank you Judy, Alison and Diane for all you do!

MPF in the Upper Peninsula

Come meet our staff social worker, Stephanie Woznak LMSW as she supports the following UP communities!

June 20th 1 pm

Marquette County — Negaunee
Negaunee Senior Center
410 Jackson St.
Negaunee, MI 49866

To RSVP contact 906-475-6266

June 21st 2 pm

Marquette County
Marquette Senior Center
300 West Spring St
Marquette MI 49855

To RSVP contact Stephanie Woznak at 248-419-7170

June 22nd 1pm

Dickinson County
First Presbyterian Church
395 Hamilton Ave.
Kingsford MI 49802

To RSVP contact Stephanie Woznak at 248-419-7170

June 26th 1pm

Luce County
Newberry Joy Hospital
502 W. Harrie St – Huron Room
Newberry, MI 49868

To RSVP contact Stephanie Woznak at 248-419-7170

June 27th 12pm

Chippewa County
Bayliss Public Library
541 Library Drive
Sault Ste. Marie, MI. 49783

To RSVP contact Stephanie Woznak at 248-419-7170 or sign up at the Library

LUCA STRONG

Putting the Hurt on Parkinson's

HIKE FOR PARKINSON'S

DATE: Saturday, June 10, 2023

TIME: 11am check-in, 12 pm 3 mile hike or 2 mile walk

COST: \$50 minimum donation to participate

WHERE: Holly Recreation Area - **Heron Beach**

8100 Grange Hall Road, Holly, MI

AFTER HIKE: Head to **River Rock Bar & Grill**, Holly, MI

For additional information and to register go to:

Eventbrite - LucaStrong Hike for Parkinson's or

CLICK HERE

REGISTRATION INCLUDES

- FREE T-SHIRT
- Complimentary
Appetizers at **River
Rock Bar & Grill**

***Must register by May 20th to
guarantee a t-shirt***

SPONSORSHIP OPPORTUNITIES

- \$250, \$500, \$1000, \$2000
Sponsorship levels are available
- Please contact Kristina Lucas
Bellas at (248) 930-4249 or go
to Eventbrite

Every dollar raised at the LucaStrong Hike will provide
financial assistance to promote health and exercise to those
with Parkinson's in Metro Detroit.



Our Littlest Supporter

We are proud to announce that first grader, Kerrigan Gorham was selected as the Livonia Youth Making a Difference award for her great work volunteering with and raising awareness and funds for people with Parkinson's disease. Kerrigan volunteers with the Livonia Parkinson's Support Group every month and along with her cousins raised \$346 creating

a Lemonade Stand fundraiser. Kerrigan comes by her work for the Parkinson's community honestly—she is the granddaughter of our very own Director of Education, Julia Butler Wall and great-granddaughter of MPF support group facilitator and early MPF supporter, Ruth Butler. Congratulations, Kerrigan! You are an inspiration.



Welcome to the team, Rita Dachs!

After volunteering for the Michigan Parkinson Foundation for 4 years, Rita Dachs had a great understanding of the mission and work of MPF. Rita's husband Terry was diagnosed with Parkinson's in 2011 and since then, they have been avid supporters and one of the Metro Detroit Parkinson's Walk's top teams raising over \$35,000 with Team Terry & Company. Rita and Terry have two kids, and love to walk, hike and be outside. One fun fact about Rita is that she is a first generation Maltese American. Rita will be helping with office and volunteer management. Please give Rita a warm MPF welcome!



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(800) 852-9781
www.parkinsonsmi.org

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

More than 73 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



Yes I want to help!



PLEASE SEND INFORMATION ON:

How I can become an exclusive member of the Michigan Parkinson Foundations **CLUB 500**
 Parkinson's Disease

Enclosed is my gift of \$ _____

Visa ___ Mastercard ___ Discover ___ Amex ___

Account # _____ exp. _____

Card Security Code: _____

Last 3 digits on back of card (4-digits on front of AMEX)

In Memory of _____

In Honor of _____

Special Occasion of _____

Please notify the following person of my gift:

Name _____

Address _____

City _____ State _____ Zip _____

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.

My Name _____

Address _____

City _____ State _____ Zip _____

County _____

Phone _____

I want to receive further mailings:

By e-mail at _____

By regular mail

DO NOT SEND further mailings

DO NOT INCLUDE my name in publications

Your kind donation will be used whenever needed. Please make checks payable to: Michigan Parkinson Foundation.
All gifts are tax deductible as provided by law. Michigan Solicitation License #8287