



# PARKINSON News

PUBLISHED BY THE PARKINSON ASSOCIATION OF GREATER DAYTONA BEACH (PAGDB)

## THE ACHES & PAINS OF PARKINSON'S DISEASE

Tuesday, November 14, 2023 • 2:00–3:30pm

Woodmark Pacifica Senior Living • 900 LPGA Blvd. Daytona Beach

The PAGDB is pleased to host Dr. Marina Mitry-Hana, DPT, PT, OTR/L, LSVT-BIG. Dr. Mitry-Hana works at Thomas Center for Physical Therapy, a locally owned clinic that has been in the Daytona Beach community since 1985. The Thomas Center for Physical Therapy offers specialized non-invasive patient care, provided in one-on-one direct treatment sessions with a therapist using hands-on manual therapy and targeted exercises catered to the individual patient's needs.



Dr. Marina Mitry-Hana

In her presentation **"The Aches and Pains of Parkinson's Disease"**, Dr. Mitry-Hana will provide attendees with education on common physical impairments that occur with PD (including the care providers of those with PD), such as back, shoulder, and knee pain, and the effect of PD on the treatment of these conditions. The benefits of Physical Therapy in effective conservative management of these issues with consideration of PD on exercise tolerance and interventions will also be discussed, with a demonstration of LSVT-BIG exercises which can be incorporated into treatment.

**This is an In-Person Only program.** To secure your seats please register online at: [www.parkinsondaytona.org/in-person-meetings](http://www.parkinsondaytona.org/in-person-meetings), or click the red button below or call 386-871-3879 and leave a message with your name and how many will be attending.

Register for In-Person Meeting

## Condolences

Longtime PAGDB member Jon Brand recently passed away – please join us in offering our thoughts, prayers, and condolences to Jon's wife Marianne and the entire Brand Family.

## DUCK RACE RESULTS

The PAGDB Team "PD Movers" adopted more ducks than any other team, **283 ducks - raising \$1,197.00.** Way to go Team PD Movers!

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## RECENT GIFTS & GRANTS

- ♥ Diane Castelli – Gift to PAGDB
- ♥ Helene Rice – Gift to PAGDB
- ♥ Anonymous – Gift to PAGDB in Memory of Jon Brand
- ♥ FOE Auxiliary 3800 – Grant to PAGDB

**A huge debt of gratitude to all those that donate to our cause. Your gifts and grants go a long way in enabling us to carry on. Thank You!**

There are two ways to make a gift in honor or memory of a loved one/friend, provide a grant, or to simply donate to the PAGDB – Online: visit our website [www.parkinsondaytona.org](http://www.parkinsondaytona.org) and click on the Donate link. By mail, please make checks payable to Parkinson Association of Daytona and mail to P.O. Box 4193 Ormond Beach, FL 32175.

DONATE

# 2024 PAGDB Fun Walk - Register Now!

Saturday February 24, 2024 • 10am-2pm

Mark your calendars and plan on attending the PAGDB's 15th Annual Sole Support for Parkinson's Fun Walk scheduled for Saturday February 24, 2024 from 10am-2pm at the City of Port Orange Lakeside Community Center & Amphitheater. **Register online at [www.parkinsondaytona.org](http://www.parkinsondaytona.org) or see the printable registration form on Page 8 in this newsletter.** Register early, and join in to support your local Parkinson Association. We hope to see you all there!

**REMINDER: NO MEETING IN DECEMBER!**



# WHOLISTIC MOVEMENT!

## NEW EXERCISE CLASS FOR PEOPLE WITH PARKINSON'S (PWP)

NEW DAY, TIME & LOCATION!



**GABRIELA TROTTA**  
INSTRUCTOR

Everyone knows that exercise is good for you, but it's especially good for PWP. The Parkinson Association of Greater Daytona Beach (PAGDB) is pleased to announce a new exercise program called **Wholistic Movement!**

**Wholistic Movement!** incorporates a combination of physical exercises designed to benefit the entire being; think of it like yoga, dancing, tai chi, stretching, and aerobics all rolled into one exercise session! Longtime PAGDB Dance & Exercise Instructor Gabriela Trotta will be facilitating this program. This class is open to any PAGDB member, including those with wheelchairs or walkers. Care providers are encouraged to attend and welcome to participate. This program is **Free of Charge** to all PAGDB members (attendees must sign in for every class).

**Wholistic Movement!** will be held every Thursday from 2:30pm-3:30pm at the Port Orange YMCA.

This program is made possible by Halifax Health/Brooks Rehab, The YMCA and the Parkinson Association of Greater Daytona Beach (PAGDB). For more information or any questions please contact Vince Kinsler at 386-871-3879.

 **THURSDAYS**  
**2:30-3:30PM**

 **PORT ORANGE YMCA**  
**4701 CITY CENTER PKWY.**  
**PORT ORANGE 32129**







# ROCK STEADY BOXING ORMOND BEACH IS BACK!

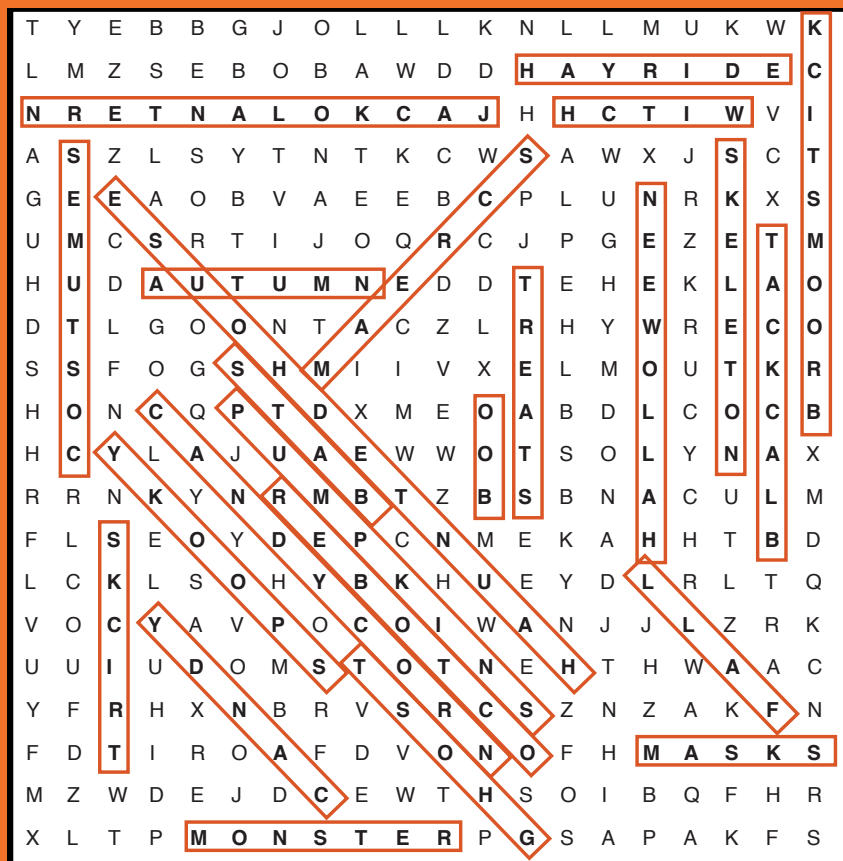
**TUESDAYS & THURSDAYS  
9:00 AM - 10:30 AM**

**BODY EXCHANGE BOXING GYM  
58 W. GRANADA BLVD · OB**

IF YOU ARE NEW OR CURIOUS ABOUT FIGHTING BACK AGAINST PARKINSON'S DISEASE, WE WELCOME YOU TO JOIN US AND SCHEDULE YOUR FREE ASSESSMENT REQUIRED TO GET YOU STARTED.

*\*ASSESSMENT DOES NOT INCLUDE BOXING GEAR.*

**386-314-6673**



## Halloween Word Search Answers

See **Page 7** in this newsletter for our Holiday Themed Word Search. Answers will be in the next newsletter edition.

Completing puzzles can strengthen the mind and help patients manage Parkinson's symptoms. Jigsaw puzzles, in particular, can increase skills of problem-solving, coordination, matching, and memory.

# COMMUNITY CALENDAR & EVENTS

## EAST & WEST VOLUSIA SUPPORT GROUPS

In conjunction with Halifax Health, the PAGDB is hosting Support Groups designed to provide a place for individuals with PD and their caregivers/loved one's to share their feelings, experiences, provide support and resources. These programs are offered free of and are facilitated by Anne Tracy, RN Community Relations Coordinator with Halifax Health Continuing Care and Hospice. **For more information please contact either Anne Tracy at 386-566-5728 Email: [annette.tracy@halifax.org](mailto:annette.tracy@halifax.org) or Vince Kinsler at 386-871-3879 Email: [yovinny57@aol.com](mailto:yovinny57@aol.com)**

### EAST VOLUSIA

4TH TUESDAY OF EACH MONTH FROM 2-3PM • WOODMARK • 900 LPGA BLVD. HOLLY HILL, FL  
**NEXT MEETING: Tuesday, November 28, 2023 • NO December Support Group**

### WEST VOLUSIA

2ND TUESDAY OF EACH MONTH FROM 2-3PM • WOODLAND TOWERS • 113 CHIPOLA AVE. DELAND, FL  
**NEXT MEETING: Tuesday, November 14, 2023 • Tuesday, December 12, 2023**

## FLAGLER SUPPORT GROUP

PALM COAST COMMUNITY CENTER • 305 PALM COAST PARKWAY NE, PALM COAST  
The Flagler/Palm Coast Support Group is hosting monthly meeting at the Palm Coast Community Center. For more information, please contact Renee Shoner at 386-503-2239 or email at: [Reneeshoner@gmail.com](mailto:Reneeshoner@gmail.com).

## ROCK STEADY BOXING

For more information on classes, times and to schedule an assessment 386-314-6673 | [www.inthiscorner.org](http://www.inthiscorner.org)

### NEW SMYRNA BEACH/EDGEWATER

MONDAY, WEDNESDAY & FRIDAYS • 201 SOUTH RIDGEWOOD AVE. SUITE 13 EDGEWATER, FL

### ORMOND BEACH

TUESDAYS & THURSDAYS 9-10:30AM • BODY EXCHANGE BOXING GYM • 58 WEST GRANADA BLVD.

## YOGA & DANCE NSB

TUESDAYS 1PM • 201 SOUTH RIDGEWOOD AVE. SUITE 13 EDGEWATER, FL

A combination yoga and dance class that is well choreographed to include warm up, upper/lower body, cardio, breathing exercises and a cool down. This class is instructed by Gabriella Trotta. **This class fills up quickly & seats are limited.** [www.inthiscorner.org](http://www.inthiscorner.org) | 386-314-6673

## WHOLISTIC MOVEMENT!

THURSDAYS 2:30-3:30 PM • PORT ORANGE YMCA

See flyer about this program in this newsletter for more information about this class.

## MOTION & MINDFULNESS

MONDAYS 2:30-3:30 PM • PICTONA

See flyer about this program in this newsletter for more information about this class.

## BROOKS REHAB

Brooks Rehab is offering an **Adaptive Sports & Recreation Programs (you do not need to be athletic to participate!) provided FREE of charge!** Brooks also offers Exercise & Wellness Programs at several YMCA locations throughout Volusia County. Cost for these programs is \$15.00 per month for YMCA members, and \$30.00 per month for non-YMCA members. **See flyers in this newsletter or our website for days, times and locations of these programs.**

## Pain in Parkinson's

If you live with Parkinson's disease (PD) and experience pain, you are not alone. Chronic pain is twice as common among people with PD as it is in people without it. In fact, more than 80 percent of people with PD report experiencing pain and many say it's their most troubling non-motor symptom. Fortunately, there are many ways to manage pain in PD. As with other aspects of the disease, there's no one-size-fits-all approach. The first step is to work with your healthcare team to understand what's causing the pain and then work together to find the best treatment plan for you.

### What Kinds of Pain Can Be Part of Parkinson's?

At its simplest, pain means the body hurts. When a person feels pain, nerves in the skin, joints and organs alert the brain to the location of an injury. Researchers have found that in early PD, there are already changes in the way that the body detects and regulates pain. Pain is complex and can take many forms. In PD, pain tends to affect the side of the body where motor symptoms first appeared. If your PD started with a tremor in the right hand, you're more likely to develop pain in the right shoulder, wrist or fingers. Here are a few common types.

### Musculoskeletal Pain

Musculoskeletal pain is experienced by up to 75 percent of people with PD and includes pain in the muscles, bones or skeleton. It is related to rigidity and decreased movement, and to arthritis. Many people with PD experience muscle cramps and tightness in the neck, spine and arms. Muscles may feel stiff or achy. Joint pain, especially in one shoulder, is also common. It's not uncommon for people with PD to be diagnosed with frozen shoulder or rotator cuff problems, and even undergo surgery.

### Dystonic Pain

Do you have painful curling of your foot, toes or hands? This is dystonia, a painful muscle spasm. Up to 50 percent of people with PD experience this at some stage of the disease. Foot dystonia is one of the most common sources of dystonic pain in early PD. Severe, painful spasms also can occur in the neck, face or throat muscles. Dystonia may occur spontaneously or may be triggered by certain movements, but is very often experienced in the early morning. It can also be related to fluctuations in PD medications. Report dystonia to your doctor for evaluation or recommendations.

### Neuropathic Pain

Also called radicular pain, neuropathic pain occurs when a nerve is crushed or inflamed. Between five and 30 percent of people with PD experience neuropathic pain. It feels sharp, electric, tingling or like coolness or numbness. In people with PD, changes in posture, as well as dystonia, can cause nerves to be crushed. A common type is sciatica - lower back pain that extends down one leg. People with PD may also experience peripheral neuropathy - injury to nerve endings that begins with numbness in the toes or fingertips.

### Central Pain

Central pain affects about 10 percent of people with PD at some point. It can be difficult to describe but may include a vague, constant boring sensation; abdominal pain, reflux, shortness of breath or feeling flushed; painful sensations around the mouth, genital or rectal areas or simply "pain all over."

### Treating Pain

How can you make a specialized plan for your PD pain? Build a team that includes a PD doctor, nurse, physical therapist, occupational therapist, pain management specialist and in some cases, an orthopedic specialist.

### Optimize PD Medications

It's critical to ensure your PD medications are working optimally. Your doctor may want to examine you immediately before and after you take PD medications. To increase, decrease or change your medication to extend its effectiveness.

### Exercise and Physical Therapy

Exercise is beneficial, particularly for musculoskeletal pain, but it can be a catch-22. It may be difficult to exercise when you're in pain, but if you're in pain and you stop moving, it gets worse! A physical therapist can recommend exercises or techniques to target the source of your pain. For example, if you experience neuropathic pain, the physical therapist can help improve your posture, which may alleviate pain.

### Other Medications

Your doctor can prescribe medications that target specific sources of pain. For example, muscle relaxants can help dystonia, as can deep brain stimulation (DBS) and botulinum toxin (Botox<sup>®</sup>). Medications for epilepsy and depression, such as gabapentin (Neurontin<sup>®</sup>) or nortriptyline (Pamelor<sup>®</sup>) may be helpful for neuropathic and central pain. Anti-inflammatory medications like ibuprofen may ease musculoskeletal pain.

### Treat Depression and Other Health Conditions

Chronic pain and depression are intertwined. If a person experiences depression, it may worsen pain and other PD symptoms. In addition, people who are depressed have a hard time taking medications properly, and this sets a vicious cycle in motion: with missed doses, medications don't work well, and a person feels worse. Treating depression is essential for managing pain. It's also important to treat other health conditions, such as osteoporosis or diabetes, that impact pain.

### Self-Management for Pain

If pain begins suddenly or an injury occurs, it is considered acute, especially if there is swelling or bruising. Apply cold packs for 15-10 minutes several times daily for the first 48-72 hours. Elevate the area to decrease swelling. If pain is long lasting (chronic), apply heat to the area for 15-20 minutes. Purchase a microwaveable hot pack that conforms to the area (or make your own with rice in a tube sock knotted at the opening). Heat pack according to directions; heat rice-filled sock for approximately two minutes in microwave. If muscles feel tense or "knotted," try self-massage. Apply pressure to the area with a tennis ball, using your body weight against it for deeper pressure. Knobby plastic massage tools or a Theracane can be used to get better leverage on hard-to-reach areas. An appointment with a massage therapist may also be helpful.

### Involving Your Team

When pain lasts longer than two weeks, interferes with sleep, or intensifies, it's time to involve your team. Keep track of WHEN the pain started, WHERE it hurts, HOW long it lasts and WHAT it feels like (achy, sharp). It will be useful to also track when the pain starts in relation to when you take your medication. This information will help your healthcare team work more efficiently with you in designing a treatment plan.

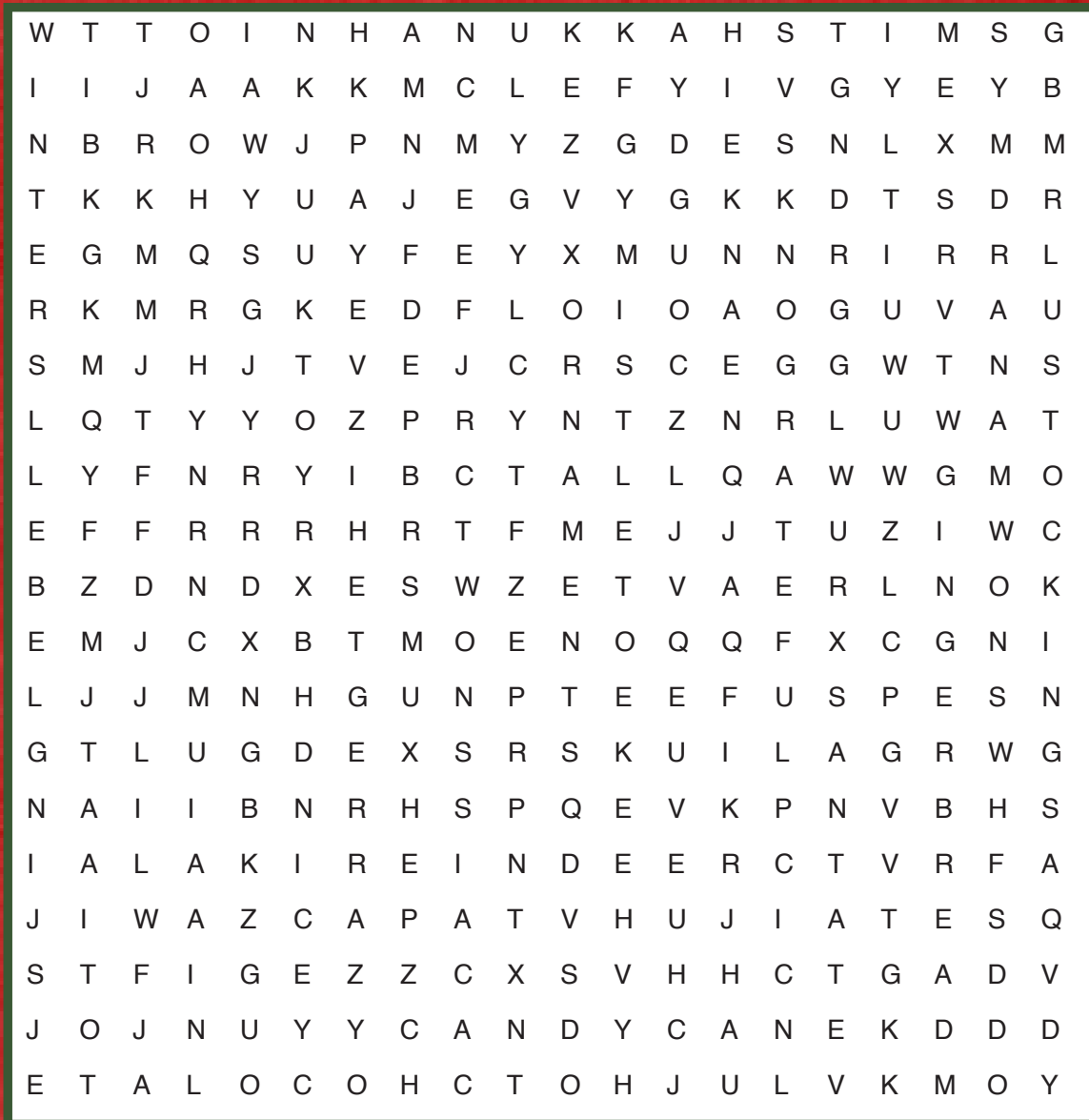
### Road to Recovery

Pain in PD is often overlooked and can have a significant impact on quality of life. The good news is that it can be managed. Tell your doctor about your pain so you can figure out what kind it is and find the best solutions for it. Once a cause is determined, you and your team can choose therapies that best fit your individual needs so you can feel your best.

Article reprinted from Parkinson's Foundation  
[www.parkinson.org](http://www.parkinson.org)



# Holiday Word Search



\* CANDLES  
\* CANDY CANE  
\* EGGNOG  
\* GIFTS  
\* GINGERBREAD  
\* GRATEFUL

\* HANUKKAH  
\* HOT CHOCOLATE  
\* JINGLE BELLS  
\* JOY  
\* LIGHTS  
\* MERRY

\* MISTLETOE  
\* NAUGHTY  
\* NICE  
\* ORNAMENTS  
\* REINDEER  
\* SANTA

\* SNOW  
\* SNOWMAN  
\* STOCKINGS  
\* TREE  
\* TURKEY  
\* WINTER



**15th ANNUAL “SOLE SUPPORT” FOR PARKINSON’S FUN WALK**  
Port Orange Lakeside Community Ctr. – Saturday February 24, 2024 - 10:00am-2pm  
\*\*Registration Begins at 9:00am

**-REGISTRATION FORM-**

**IMPORTANT:** This registration form must be filled out in its entirety, signed, and mailed with your \$25.00 check made payable to the Parkinson Association of Daytona to P.O. Box 4193 Ormond Beach, FL 32175 and be postmarked no later than February 2, 2024. Registration forms received after 2/4/24 cannot be guaranteed an event T-shirt/goody bag. For children 12 & under the registration fee is \$15.00. For all registrants less than 18 years of age, a parent or responsible adult must designate as a minor child by checking here: \_\_\_\_\_ and fill out this form in the minor’s name and sign on behalf of the minor child.

**PLEASE PRINT CLEARLY:**

Last Name: \_\_\_\_\_ First Name: \_\_\_\_\_

Address/City/State/Zip: \_\_\_\_\_

Phone: ( \_\_\_\_\_ ) \_\_\_\_\_ Email Address: \_\_\_\_\_

Age (if U-18): \_\_\_\_\_ T-Shirt Size: (circle one)    S            M            L            XL            XXL

**\*\*All registrants – MUST CHECK IN AT THE REGISTRATION TABLE PRIOR TO THE WALK – at check in you will receive a ticket for door prize drawings.**

**Participation Release (PR)**

By registering to participate in the Parkinson Fun Walk 2024 (event); I understand and agree, that participating in this event may involve risk of personal injury which may result from not only my own actions, inactions, or negligence, but also from the actions, inactions, or negligence of others, the condition of the facilities, equipment, or areas where the event is taking place, and or the parameters associated with the event itself. Being in full knowledge to the foregoing, I hereby release, indemnify, and hold harmless the City of Port Orange, the Parkinson Association of Greater Daytona Beach (PAGDB), and all individuals, agents, employees, volunteers, representatives, officers, directors, and insurance companies associated with the PAGDB, of and from any and all liability, claims, demands or causes of action whatsoever arising out of or related to any loss, damage, injury (up to and including death) that may be sustained by me or my property while participating in this event. I further agree, that by participating in this event, that if I suffer any injury or illness, I authorize the event facilitators to use their discretion to have me transported to a medical facility for treatment, and I assume full responsibility for this action. By signing below, I attest that I have read, understand, and agree to the entire content of this PR, that I am in good physical condition and have no medical condition that would be detrimental to my health or wellbeing by participating in this event. Further, I hereby grant full permission to the PAGDB, to use photos, videos, and any other record of me during this event for any purpose, and for which I agree to receive no compensation whatsoever in return. This PR shall be binding upon me, my heirs, my executors, legal representatives, and my assigns. This PR is construed to the laws of the state of Florida. **I agree that I am participating at my own risk.**

\_\_\_\_\_  
Signature of Registrant or Parent/Responsible Adult

\_\_\_\_\_  
Date

\_\_\_\_\_ **X here if you cannot participate** in the Parkinson’s Fun Walk 2024 **but would like to help support our cause;** all donations are gratefully accepted and much appreciated! Please make checks payable to the Parkinson Association of Daytona and mail to P.O. Box 4193 Ormond Beach, FL 32175. **Thank You!**

***The Fun Walk Will Take Place Rain or Shine!***

FW/2024



# THE WELLNESS CORNER



## Michael J. Fox Didn't Get Mad, He Got Motivated

**After a life-changing diagnosis, the actor and author has raised billions for Parkinson's research and personified grace under pressure. So why is he waiting for the other shoe to drop?**

A couple of years ago, Davis Guggenheim experienced a confounding emotion familiar to anyone who spends time with Michael J. Fox. The director was in Fox's Central Park West apartment, midway through his first day of interviewing the now 62-year-old actor and philanthropist for the 2023 biographical documentary *Still*.

Fox, who was diagnosed with Parkinson's disease in 1991, is not physically well, though he's lucky to be alive, having survived 33 years with an incurable degenerative disease that kills most patients within 20 years of diagnosis. In order to speak clearly, Fox takes pills to combat paralysis of facial muscles. The more the disease advances, the more medicine it takes to animate the muscles, until the inevitable point when the side effects outweigh the benefits of the medication, or it stops working altogether. One of the worst side effects of Fox's medication is dyskinesia—involuntary movements and tics. So, while the constant bobbing and careering may appear distressing for Fox, it is in fact the best version of himself available. He regularly acknowledges that he's long into the journey he once referred to as the "gradual paring away of my physical self."

And yet, after listening to Fox explain his outlook on the world, Guggenheim had a realization that he had encountered a man who had achieved a spiritual state known to few. He felt the need to confess. "I want what you have," Guggenheim told Fox.

Soon the director called for a break. "I walked 30 blocks to my hotel," Guggenheim recalls, "and the whole time I was like, 'Why do I feel this way? He's got this really tough diagnosis. I don't. But he has something that I wish I had.'" Fox recalls his rejoinder. "I told him, 'Be careful what you wish for.'" Still, Fox understands what Guggenheim was getting at. "It's very complicated," he says. "I've said Parkinson's is a gift. It's the gift that keeps on taking, but it has changed my life in so many positive ways."

Fox used to be a well-liked and funny TV and film star, a master pratfaller and teller of witty stories on talk show couches—a virtuoso of a light art. In the last 20 years he has evolved into something deeper: a philosopher, an exemplar of courage, and the exceedingly rare figure in this polarized moment that a country can unite behind. In a recent CBC TV profile, the journalist Harry Forestell, who was himself diagnosed with Parkinson's in 2015, characterized Fox's example using words only a fellow Parkinson's patient could, calling Fox's public reckoning with the disease "both futile and deeply inspiring." He is not only an inspiration to Parkinson's patients through his public appearances and the candor of his four moving memoirs, he's also the co-founder of the Michael J. Fox Foundation (...)

(...) for Parkinson's Research, which in its 23 years has funded nearly \$2 billion in research. He inspires not only his fans but his intimates. "They describe some people when playing a great sport as poetry in motion," says the novelist Harlan Coben, a close friend of more than a decade. "Mike's bravery in motion."

Few would have predicted this trajectory. After winning a couple of acting credits as a kid, Fox dropped out of high school in Burnaby, British Columbia, at 17 and drove to Hollywood. There were a couple of lean years spent landlord-ducking and dumpster-diving before Fox landed *Family Ties* in 1982, which begat *Back to the Future* three years later. Untold fame and riches arrived overnight. During his go-go '80s run, he was by his own admission a conspicuous consumer, a luxury automobile collector who recalls being able to light a cigarette in his Ferrari going 100 mph. "I'm sure that if you talked to him when he decided to drop out of high school, move to Hollywood, and become a movie star, that he had no intention of doing anything other than making money and being famous," Guggenheim says. "He didn't say, 'I'm going to make money, be famous, and inspire people.'"

Parkinson's didn't change Fox overnight. When he was diagnosed at 29, a doctor told him he probably had a decade before the symptoms would end his career. And by that point, as Fox admits in his 2002 book *Lucky Man*, his movie career was foundering. The *Back to the Future* franchise was over, and he'd made a series of box office flops like *Doc Hollywood* and *For Love or Money*. The diagnosis sometimes felt like the karmic price for his success, "the bill being brought to a sloppy table after an ill-deserved and underappreciated banquet," as he wrote.

Fox hid his Parkinson's, collected checks for movies that felt beneath his talents, and hit the pillow hammered every night. Predictably, a breakdown followed. He went to his first AA meeting and got sober. He found a Jungian analyst named Joyce and confessed that he felt as if his life were "in flames." Today he recalls the moment in the mid-'90s when he experienced an epiphany on Joyce's couch. "My therapist said, 'How are you feeling?'" he recalls. "I said, 'I'm just waiting for the other shoe to drop.' And she said, 'Michael, you have Parkinson's! The other shoe dropped a long time ago.'"

Difficult days, Fox understood, lay ahead. There was no better option than to surrender to appreciating the gifts of the present day.

His taxonomy of what mattered and what didn't was turned on its head. Family landed on top Fox and his wife, the actress Tracy Pollan, had been married only three years before his diagnosis. Divorce following a Parkinson's diagnosis is common, yet Pollan stuck around.

"Everybody says 'in sickness and in health,' but sometimes it's not that easy," says the couple's friend Cam Neely, the former hockey star and longtime president of the Boston Bruins. "Everybody thinks about what Mike goes through, but one can only imagine what Tracy goes through. You can just tell how much she loves him, but one thing about Tracy, she's a strong, tough woman, and doesn't put up with any BS." Fox had one request before he would allow Guggenheim to make a film about him. "No violins," he said, meaning no treacly music scoring scenes of his physical struggles. And Fox offered only one note after screening a rough cut of *Still*: "More family." *Still*'s most affecting scenes are those of Fox collapsing in joyful laughter when Pollan or one of his four kids ribs him.

Fox kept his Parkinson's a secret until 1998, when he made an announcement to Barbara Walters and *People*. It was made under duress: The *National Enquirer* was close to breaking the story of the health issue that was affecting the schedule of Fox's sitcom, *Spin City*. Despite the circumstances, the unburdening brought unexpected joy—and then an idea. "When I went public, I felt like I stood there naked in the town square and said, 'Look at me. This is what it is,'" he says. "What I didn't realize was how many other people had been dying to do that."

Overnight, various Parkinson's foundations clamored to land Fox as their spokesman. "Early on someone from a foundation gave me their pitch as to why I should come on," he says. Fox politely demurred, saying he appreciated the group's efforts. "But then they said the most unusual thing," he recalls. "They said, 'But if you don't help us, don't help them,' pointing to another foundation. I got so mad. I said, 'I've got to get in here and get this straightened out.'"

## "I'm of the mind that anything you want to do you can do."

In 2000 he founded the Michael J. Fox Foundation for Parkinson's Research with the goal of funneling money to scientists with the best shot of finding a cure. The monumental ambition of the mission didn't just occur to him.

"It seemed straightforward to me," he says. "I'm a short kid from Canada who at 17 moved to another country and somehow within five years was a millionaire. I'm of the mind that anything you want to do you can do." He went on a listening tour of scientists, politicians, and patient advocates. His conclusion: Foundations were mostly covering the unmet needs of patients while also lobbying the government to fund research. But despite these efforts the government wasn't coughing up enough money to make sufficient advances. "The science was ahead of the money," he says. "We just have to throw the money at the right people."

To find a CEO for his foundation, Fox met with candidate after highly qualified candidate from the nonprofit world, but he decided he wanted something different, someone who could innovate like a startup founder. After spending nine years making other people money at Goldman Sachs, Deborah Brooks was looking to do some good. "I thought, Wouldn't it be amazing if nonprofits were more efficient, if they were bolder?" Brooks tells me. Fox hired her after one meeting; she's both co-founder and CEO.

The pair agreed on a revolutionary fiscal philosophy. While many foundations rely on an endowment model, amassing a nest egg designed to assure long-term survival by parceling out small percentages to recipients, Fox's foundation would attempt to go broke annually. "The goal is to go out of business," Fox has said. In 2020 the foundation brought in \$199 million in private donations and the next year funded \$233 million in grants. According to Brooks, after spending nearly \$2 billion on research, the foundation in 2022 had allocated more on Parkinson's research than the U.S. government—and it seems to be paying off. In April, *Lancet Neurology* published the results of a decadelong Fox foundation-led study demonstrating that Parkinson's can now be detected in living people by locating a particular biomarker protein, abnormal alpha-synuclein, a discovery that has the potential to lead to a treatment that can delay, or even eliminate altogether, the onset of symptoms. "When I was diagnosed, it was like a drunk driving test," Fox says. "Now we can say, 'You have this protein, and we know that you have Parkinson's.' It opens the gates for pharmaceutical companies to come in and say, 'We've got a target and we're going to dump money into it,' and when they dump money into it, good things happen."

For many years the ability to turn lemons into lemonade was Fox's brand. His 2009 memoir, *Always Looking Up*, was subtitled *The Adventures of an Incurable Optimist*.

In 2018, when a spinal tumor unrelated to his Parkinson's threatened to paralyze him, he opted for surgery that required months of physical therapy to get him walking again. Freshly rehabilitated and finally on two feet, on a rare night alone in his apartment he tripped and did a header in the kitchen, breaking his upper arm. Fox recalls the words that he uttered while splayed on his floor: "I said, 'Fuck lemonade. I'm out of the lemonade business.'" He chronicled his medical misadventures and attendant depression two years later in his book *No Time Like the Future*. "That was nothing," he says now. He has since broken his other arm and shoulder, smashed his orbital bone and cheek, and broken his hand. "My hand got infected and then I almost lost it," he says. "It was a tsunami of misfortune."

But Fox is smiling. There's no self-pity in the litany, more pride in showing off battle scars. He often refers to himself as a "tough son of a bitch," a trait reflected by his daily training to remain ambulatory, despite the damage he faces from his now daily falls. I ask if anything scares him, and he thinks for a moment. "Anything that would put my family in jeopardy," he says. He has nightmares about falling into Tracy or one of the kids on the street, and them getting hit by a bus. But fear for himself, the future, the ultimate other shoe dropping? Not so much.

"One day I'll run out of gas," he says. "One day I'll just say, 'It's not going to happen. I'm not going out today.' If that comes, I'll allow myself that. I'm 62 years old. Certainly, if I were to pass away tomorrow, it would be premature, but it wouldn't be unheard of. And so, no, I don't fear that."

<https://www.townandcountrymag.com/society/money-and-power/a45549670/michael-j-fox-philanthropy-parkinsons-foundation-interview/>



## TAI CHI MAY SLOW PARKINSON'S SYMPTOMS FOR YEARS, STUDY FINDS

Tai chi may help slow down the symptoms of Parkinson's disease for several years, a Chinese study suggests.

Those who practised the martial art twice a week had fewer complications and better quality of life than those who didn't, the researchers say.

Parkinson's is a progressive brain disease which leads to tremors and slow movement, and there is no cure.

Experts say the findings back up previous studies on the benefits of exercise for those with Parkinson's.

The study, from Shanghai Jiao Tong University School of Medicine, monitored the health of hundreds of Parkinson's patients for up to five years.

One group of 147 people practised regular tai chi while another group of 187 did not.

The traditional Chinese exercise combines slow, gentle movements with deep breathing and relaxation.

The charity Parkinson's UK describes tai chi as a low-intensity physical activity that can "help to lift your mood and help you live well".

The researchers found that the disease progressed more slowly in the tai chi group on measurements of symptoms, movement and balance.

This group also saw fewer falls, less back pain and dizziness, with memory and concentration problems also lower than in the other group.

At the same time, sleep and quality of life continuously improved.

A previous trial of people with Parkinson's who practised tai chi for six months found greater improvements in walking, posture and balance than those not on the programme.

Writing in the Journal of Neurology Neurosurgery & Psychiatry, Dr Gen Li and co-authors say their study shows "that tai chi retains the long-term beneficial effect on Parkinson's disease".

They say tai chi could be used to manage Parkinson's on a long-term basis and prolong quality of life, while still helping to keep patients active.

But they also acknowledge that the study is relatively small and could not prove that tai chi was the reason for the positive outcomes experienced by one group.

### 'Positive Effects'

Prof K Ray Chaudhuri, professor of movement disorders and neurology at King's College London, said: "It is too early to claim any neuroprotection based on this study, although the positive effects on aspects of motor and non-motor functions are impressive."

He said ballet had also been found to have similar effects on Parkinson's.

Prof Alastair Noyce, professor in neurology and neuroepidemiology at Queen Mary University of London, called it "an important study" but said there were limitations in its design, and more trials were needed.

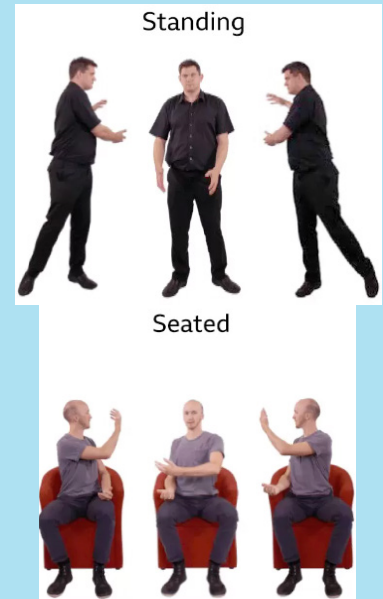
"We already recommend tai chi, as well as other forms of exercise, but understanding which forms of exercise are most beneficial is an important goal to enhance the long-term management of patients," he said.

<https://www.bbc.com/news/health-67208745>

## TAI CHI MOVES

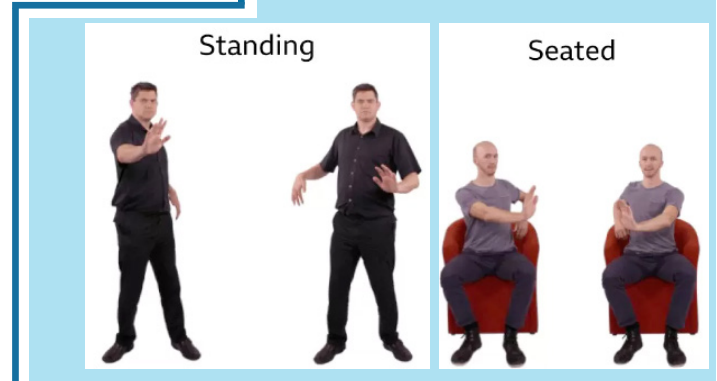
### Carrying The Moon

- Breathe in, turn your body towards the left from the waist
- Your shoulders are relaxed and your elbows slightly bent
- Now reach both arms towards the left with your head focusing on your hands
- Breathe out, bring hands down. Turn to right and repeat



### Twisting Waist and Push Palms

- Breathe in, draw palms to the waist facing upwards
- Breathe out, turn your body to the left at the waist. Keep the left elbow and wrist slightly bent and draw the elbow back
- At the same time, extend the right arm forward and push with the right palm facing forward (as if you are trying to stop traffic)
- Breathe in, return to the middle and spread your weight evenly before turning to the right, drawing your right arm back and extending your left arm with your palm facing forward.





# MOTION & MINDFULNESS



**JEN MOORE**  
INSTRUCTOR

Living with Parkinson's can present various challenges, but with the right strategies, you can maintain a safer more fulfilling life. Naturally, as we grow older, we often begin to experience balance issues and become more prone to falling. And gait and balance issues can be quite common in with people Parkinson's (PWP) which puts them at even greater risk for sustaining a fall – a double whammy!

It's no secret that one of the best ways to manage the movement symptoms associated with Parkinson's disease (PD) and reduce the risk of sustaining a fall is to MOVE - to consistently exercise. Movement and exercise is the **best medicine** for leading a higher quality of life living with PD.

Along with movement and exercise, it's equally important that we are mindful of what we are doing, and how we are doing it. Mindfulness is an important attribute to employ for anyone - especially those with PD.

**"Motion & Mindfulness"** incorporates a variety of exercises designed to strengthen the core and the lower extremities, while promoting flexibility to ultimately improve balance and gait. In this program, attendees will also be exposed to complimentary meditative practice, and guided imagery designed to enhance and strengthen their cognition and ability to employ mindfulness. Long time certified Dance for PD instructor and seasoned personal trainer, and group exercise instructor Jen Moore will be facilitating.

**"Motion & Mindfulness" is free of charge to all PAGDB members and will take place on Monday's from 2:30pm-3:30pm in the Senior Activity Center at Pictona.** This program is made possible by Florida Health Care, Halifax Health/Brooks Rehab, Pictona and the Parkinson Association of Greater Daytona Beach (PAGDB). For more information or any questions please contact Vince Kinsler at 386-871-3879.

 **MONDAYS**  
**2:30-3:30PM**

 **PICTONA**  
**1060 RIDGEWOOD AVE. (U.S. HWY. 1)**  
**HOLLY HILL, 32117**



OUTPATIENT REHABILITATION



An Independent Licensee of the Blue Cross and Blue Shield Association



# Halifax Health | Brooks Rehabilitation

## Adaptive Sports and Recreation - Daytona Beach

<b>MONDAY</b>	<b>Tai Chi</b> 3:00–4:00PM Pictona at Holly Hill 1060 Ridgewood Ave Holly Hill, FL 32117	
	<b>TUESDAY</b>	
<b>WEDNESDAY</b>	<b>On-Water Rowing</b> 8:00–10:00AM Halifax Rowing Boathouse 201 City Island Parkway Daytona Beach, FL 32114	<b>Rec Game Night</b> <small>[Rotating between Bocce Ball, Shuffle Board, Croquet and Horseshoes]</small> 4:15–5:15PM Pictona at Holly Hill 1060 Ridgewood Ave Holly Hill, FL 32117
	<b>THURSDAY</b>	
<b>FRIDAY</b>	<b>ERG Rowing</b> 3:00–5:00PM Halifax Rowing Boathouse 201 City Island Parkway Daytona Beach, FL 32114	<b>Adaptive Yoga</b> 1:30–2:30PM Port Orange Family YMCA 4701 City Center Parkway Port Orange, FL 32129
	ALTERNATES EVERY FRIDAY	
	<b>Bowling</b> 5:30–7:30PM Ormond Lanes 260 N US Highway 1 Ormond Beach, FL 32174	<b>Billiards</b> 4:30–6:30PM Uncle Waldo's Sports Pub 2454 Nova Road Daytona Beach, FL 32119

### FOR MORE INFORMATION:

386.871.3024

Christi.Dillard@Brooksrehab.org



CENTER FOR INPATIENT REHABILITATION

# Halifax Health | Brooks Rehabilitation

## Wellness Program Weekly Calendar

**MONDAY  
WEDNESDAY  
FRIDAY**

### Wellness Program

DeLand Family YMCA  
8:30-11:30am

### Wellness Program

Ormond Beach Family YMCA  
12:00-4:00pm

**TUESDAY  
THURSDAY**

### Wellness Program

Ormond Beach Family YMCA  
12:00-4:00pm

#### Ormond Beach Family YMCA:

500 Sterthaus Dr, Ormond Beach, FL

#### DeLand Family YMCA:

761 E International Speedway Blvd, DeLand, FL

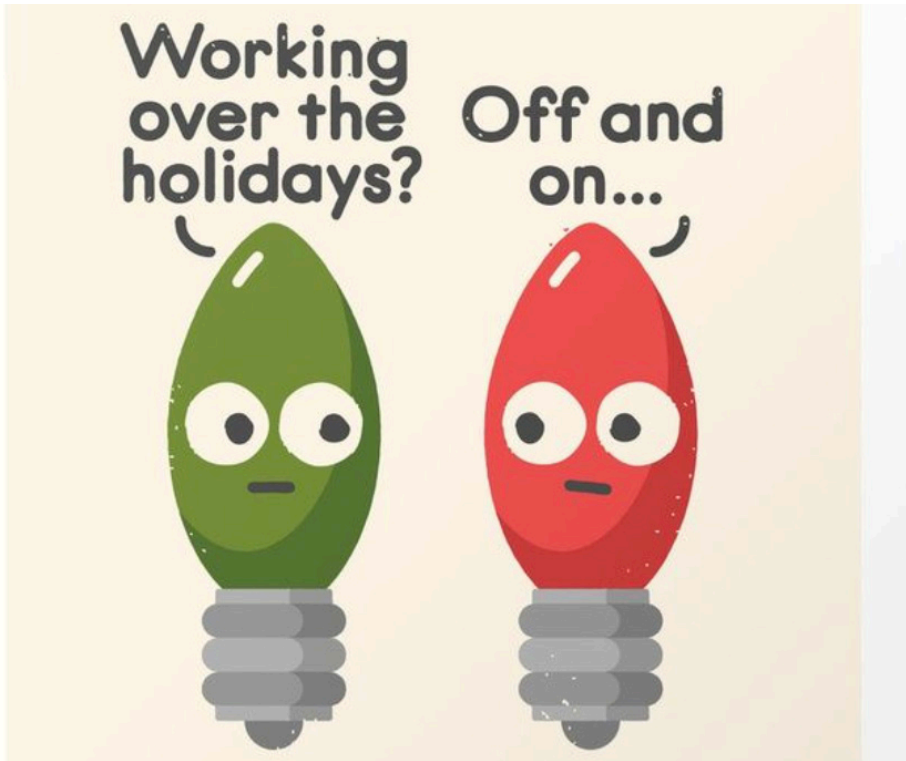
#### FOR MORE INFORMATION:

386.871.3024

[Christi.Dillard@Brooksrehab.org](mailto:Christi.Dillard@Brooksrehab.org)







**PAGDB**  
PO Box 4193  
Ormond Beach, FL 32175  
386-871-3879  
-  
[www.parkinsondaytona.org](http://www.parkinsondaytona.org)  
[parkinsondaytona@gmail.com](mailto:parkinsondaytona@gmail.com)

**Board of Directors**

**Vince Kinsler**  
*PAGDB Executive Director*  
[yovinny57@aol.com](mailto:yovinny57@aol.com)

**Alaine Keebaugh**  
*Boston Scientific*  
[Alaine.Keebaugh@bsci.com](mailto:Alaine.Keebaugh@bsci.com)

**Christina Atanasoski**  
PAGDB Admin & Designer

**Ellen Lauturner**  
[elauturn1@gmail.com](mailto:elauturn1@gmail.com)

**Ken Sipes, CPA**  
Treasurer

**Marianne Chapin**  
*Rock Steady Boxing*  
[mchapin130@gmail.com](mailto:mchapin130@gmail.com)

**Matt O'Malia**  
[matthew.omalia@gmail.com](mailto:matthew.omalia@gmail.com)

**Nancy Dawson**  
[ndawson0124@gmail.com](mailto:ndawson0124@gmail.com)

**Ursula O'Leary**  
[utrudeau@msn.com](mailto:utrudeau@msn.com)

**ONLINE  
BRAIN & BODY TRAINING**

Online Brain and Body Training for Alzheimer's, Parkinson's and Adults 50+

Total HealthWorks – an evidence-based virtual fitness platform created by the founders of Delay the Disease, the #1 Parkinson's group-exercise program in the country, is offering their Brain and Body Class **every Wednesday at 12:00 PM Noon EST via Zoom for FREE!**

**Fill out the form on their website and receive a link in your email to join** the online Brain and Body exercise class with Jackie Russell and David Zid. **Visit their website to learn more:** <https://totalhealthworks.com/free-online-class/>

Don't worry, if you can't join the class at the scheduled time, **you will receive a link in your email to watch the class whenever you'd like!**

**REGISTER**

**Parkinson's in Movement**  
with Andrew Carroll

Arts 4 All will be hosting their last session of their Parkinson's in Movement Class - Wednesday's at 11 am (via zoom or in person at USF).

Holiday: November 29, December 6 & December 13

**REGISTER**



 **SUBSCRIBE TO OUR YOUTUBE CHANNEL**

NOTE: The information in this newsletter and the information provided by our speakers is not intended as medical advice. Please consult your physician before trying anything new or different.