

Parkinson's Perspective

Summer 2017

Keep Moving Series



My name is Carol Kolls. I have Parkinson's disease. My diagnosis was made two years ago, and still there are mornings I wake

up and think it must be a bad dream. Initially researching the disease only frightened me more. There are so many different symptoms and paths Parkinson's can take. Medication works for some and not very well for others. There is not any set time table for its progression.

The area I live in is rural with a population of 10,000 people. Surprisingly, it was here that I found the most help and answers. We have a strong program at our local YMCA specifically for Parkinson's patients. It is an exercise class that meets twice a week and is overseen by physical therapy staff and YMCA coordination. A doctor's referral is needed to attend. I was able to meet other patients, find out what worked best, and see the disease in many different phases. The common thing is that we are all fighting. The staff gave me encouragement and reinforced some information I had learned on my own like keep hydrated, take your meds every day on time, and more importantly MOVE! Little by little the stiffness and ability to move improved and so did my outlook and frame of mind. Exercise and positive reinforcement have made all the difference. Thank you to my dedicated team.

There may not be a cure for Parkinson's disease during my lifetime, but I won't let it beat me. I will cope and learn to live with it with support from my caregivers and friends.



My name is Carl Grota. In 2013 Lee Dibble, a leading Parkinson's researcher, stated, "Many of our clients are discharged from insurance-reimbursed care

and left to fend for themselves in search for health, reduction of disability, and options for physical activity and exercise." I hope our class can help to change this. The Parkinson's and related disorders exercise class in Sturgeon Bay has been operational for six years. It is led by a physical therapist and personal trainer. Several volunteers and spouses assist as well. The focus of the program is to continue to reinforce formal clinic-based big to loud concepts, and instructions on a long-term basis, in order to maintain mobility and prevent social isolation.

The class focuses on BIG style exercises, tai chi for balance, posterior strength for posture, and an aerobic component. The aerobic component may include focused walking, NuStep, bike, or treadmill walking based on the individual's needs and ability. Each concept is grounded by research in the Parkinson's population.

In addition to the physical component of the program, we feel this is a great boost for socialization as well. Spouses are always welcome to join and participate or they can use this time as a respite. One of the reasons this program has been successful is the dedicated individuals and therapists who teach the class, and an excellent YMCA/Door County Medical Center relationship. Class sizes vary from 5-15 people and potential participants are encouraged to give it

a try for a session or two to try it out. We would encourage all people with PD to do some type of exercise that meets their needs and to join a class if they are having trouble self-motivating, or need some structure. Start early and don't wait until it's too late.



My name is Amy Pearce, and I am a physical therapist with UWHC at the Rehabilitation Clinic in Middleton. I work primarily with patients with neurological

conditions, including Parkinson's disease.

The benefits of physical activity for people with Parkinson's disease are well documented in the literature, including improvements in gait, balance, and quality of life. While many studies find that individual physical therapy provides the most benefit, we are often, unfortunately, limited by insurance. The current standard of care is to follow physical therapy with a home exercise program to be performed independently. However, it is very common for people with Parkinson's to lose motivation and discontinue their independent program after physical therapy is completed, which can lead to decline in function. Group classes can help to keep you motivated, and have been shown to result in more improvements in gait when compared with individual exercise. Finding a group class may be a great follow-up to physical therapy, or may even allow you to postpone the need for physical therapy.

From the President



As I stood among the hundreds of runners and walkers at the Parkinson's Half Marathon/5K/1 mile walk, from small children to trained athletes, I was overwhelmed with the sheer amount of effort that goes into making this event so successful every year. The first Parkinson's Half Marathon/5K/1 was held in 2012 and it continues to grow as a result of the tremendous dedication of Bob Nasett, his family and friends, and a growing contingency of community volunteers and sponsors. On the day of the event everyone is energized and friendly.

It is contagious. Bob opened this year's event with a moving speech about his recovery from knee surgery and pronounced his determination to reenter the 5K event next year. The two commemorative banners in memory of and in honor of loved ones were particularly moving and further demonstrated the important responsibility the Chapter has to our Parkinson's community. It was a beautiful spring day and a great way to launch another year of service. Thank you to Bob and his family, friends, volunteers, and sponsors for continuing to support the APDA Wisconsin Chapter.

Sheryl Hursh
APDA-Wisconsin Chapter President

From the Executive Director



The American Parkinson Disease Association has been extremely busy in 2017! In March, the APDA unveiled a new brand strategy that aims to increase the public's awareness of Parkinson's disease as a major health issue. APDA's reimagined brand begins with a fresh, relevant mission statement that speaks to the core of its purpose of ensuring improved quality of life for those facing PD as well as unraveling the scientific mysteries of this disease through outstanding science:

Every day, we provide the support, education, and research that will help everyone impacted by Parkinson's disease live life to the fullest.

To further illustrate the urgency of APDA's work, a new logo and tagline were designed to reflect APDA's dual mission to serve those impacted by Parkinson's disease and support innovative research to uncover the causes, treatment, and a cure for this disease.

With the largest grassroots network across the country, APDA is dedicated to fighting Parkinson's and aims to support every person and every family impacted by the disease. Through its nationwide system of Chapters and Information & Referral (I&R) Centers, APDA uniquely delivers education, support, and patient services to Americans with Parkinson's and their families each day.

APDA also proudly invests in eight Centers for Advanced Research and supports grants to fund the most promising science focused on discovering the cause(s) and finding the cure for Parkinson's disease. Since its founding in 1961, APDA has been a funding partner in most of the major PD scientific breakthroughs.

From the rebranding in March, we jumped right into April which is the busiest month as it is Parkinson's disease awareness month and the APDA holds two great fundraisers: Parkinson's Half Marathon/5k/1 mile walk and A Night of Hops & Vines: our wine and beer tasting fundraiser. We got lucky with weather and both days were sunny and beautiful. These fundraisers continue to prove to me the dedication the family and friends have for their loved ones with Parkinson's disease. Neither event would be possible without the committees. The Nasett family and friends and wine and beer tasting committee (especially committee chairs Chad Weick & Greg Chesmore) put in countless hours, time, and commitment to pull off these events. A Night of Hops & Vines raised approximately \$27,271 and the Parkinson's Half Marathon raised approximately \$66,549! It is clear that they are committed to making a difference in their loved one's life and the local Parkinson's community. I always end April feeling grateful and humbled to be a part of this amazing community.



New Class at Harbor Athletic Club coming in September

Sheryl Hursh's PD Rhythm class which was held on Mondays from 3:15–4:00 pm, will end on July 10. Starting on Monday, September 4, the class will be replaced with Tai Chi. The classes will be held on Mondays from 1:30–2:15 pm. Contact Harbor Wellness Studios at (608) 821-6501.

Learn to Row for Parkinson's Class JOIN US!

When: Tuesdays and Thursdays from 4:00-5:30 pm from July 11–August 4

Where: Bernard's Boathouse in James Madison Park (622 E Gorham St). Please come to the lake side of the building (big white boathouse next to the kayak rental place). Parking is available on Gorham or in one of the two parking lots at Blount and Gorham, or Gorham between Hancock and Butler.

Who: People with Parkinson's disease who are interested in other opportunities to remain active while learning the skills for rowing.

Cost: Free! (Sponsored by the APDA Wisconsin Chapter)

To officially register you can call Barbara Wiechers at (608) 513-2118. Please register by June 20.

UW Otolaryngology Research Study

Have you been diagnosed with Parkinson's disease within the last five years, and are your motor symptoms mild? Dr. Timothy McCulloch's research lab at the University of Wisconsin Hospital is recruiting subjects for a study evaluating changes to chewing, swallowing, voice, fine motor, and walking function in the early stages of Parkinson's disease, as well as healthy controls. Participation in this study lasts about two hours and participants are paid \$60. Contact study coordinator Dr. Suzan Abdelhalim at (608) 265-2470 or manometry@surgey.wisc.edu for more information.



Parkinson's Disease, and Learning to Cast a Fly Rod...

June 7 from 10:00 am until 1:00 pm

Fishing will be available at Lake Wingra and the Vilas Park ponds. For this outing we can host a maximum of 20 people so please sign up early. If more are interested, we can hold additional classes. Please call Jordan Mooney at (608) 345-7938 to reserve your place. Any questions, please call Jon at (608) 206-9597.

For more information on other area programs and services, contact APDA Wisconsin Chapter 5900 Monona Drive, Suite 407, Monona, WI 53716 (608) 345-7938

Join Us for Our Optimism Walk Kick-Off Party at Hybrid Athletic Club

**Thursday, June 8
from 9:00–10:00 am**

2881 Commerce Drive, Fitchburg, WI

RSVP TODAY: (608) 345-7938
or jmooney@apdaparkinson.org

What's New in PD Research?

Earlier this month Microsoft unveiled a watch that they believe can help control tremors associated with Parkinson's disease. The Emma watch, created by Microsoft Research innovation director Haiyan Zhang uses small motors to vibrate the skin and relay sensations to the brain. Zhang believes that this activity is "short-circuiting whatever feedback loop there is between the brain and the hand that's causing the tremors." Although the watch is only a prototype, the technology presents promising therapeutic benefits for controlling tremor.

The watch was specifically designed for and named after Emma Lawton, a friend of Zhang's who suffers from Parkinson's disease. The device does not seem to completely stop tremor, however, it significantly improved fine-motor control to the point where Lawton was able to write her name legibly, an otherwise arduous task for her. She states, "It makes me forget that I have a tremor."

Perspective

The effects of the watch are not known biologically or physiologically. The hypothesis that the vibrations somehow "distract" the brain from producing tremors may be true, and provide some insight into how this works mechanistically. The receptors of the skin detect sensations, such as touch, vibration, pain, and temperature. There is a specific receptor for each sensation that, when activated sends a message to

the brain informing it of what is going on. In turn, this typically leads to a response from the brain telling the body what to do.

For example, when you touch something hot that message is sent to the brain and is responded with a motor command to remove your hand from the hot surface. However, there are compensatory signals that are also involved with sensory receptors. Let's say you are out rowing while participating in the Rowing for PD class on Lake Mendota. You accidentally hit your knee with the oar, what do you do? Typically our first instinct is to aggressively rub our knee, which we've been taught takes the pain away (even more than a kiss). This works because the receptors that detect and signal "touch" to the brain actually inhibits or distracts from the activation and signaling of "pain" receptors. Therefore, you can dampen the pain signal by activating touch. By thinking of how skin receptors may regulate brain-to-hand signaling we may start to understand how vibrations given off by the Emma watch may control the severity of tremor. Based on our perspective, we can see how Zhang might conclude that a compensatory or "distracting" phenomenon is taking place. This technology is very recent and not fully understood, yet it provides hope that an effective therapeutic device may be readily available in the near future.

Giuseppe Cortese

HYBRID ATHLETIC CLUB'S ROCK STEADY BOXING PROGRAM

Hybrid Athletic Club in Fitchburg, Wisconsin offers a program for people battling Parkinson's disease called Rock Steady Boxing. This is not just a standard boxing class that people with Parkinson's disease attend. Rather, this program is unlike anything in South Central Wisconsin and is designed to directly address the unique challenges that Parkinson's presents.

Boxers condition for optimal agility, speed, muscular endurance, accuracy, hand-eye coordination, footwork, and overall strength to defend against and overcome opponents. At Hybrid's Rock Steady Boxing classes, Parkinson's disease is the opponent. Exercises vary in purpose and form, but share one common trait: they are rigorous and intended to extend the capabilities of the participant. Academic institutions, such as University of Indianapolis and Butler University, are reporting and documenting the improved quality of life among our boxers – and our Hybrid Athletic Club Rock Steady Boxers are living proof!



ADDITIONAL ROCK STEADY BOXING CLASSES BEGINNING JUNE 2017

Hybrid Athletic Club currently offers our Rock Steady Boxing program Tuesday and Thursday from 10:00–11:30 am. We are excited to announce that we will be expanding the program to four days a week beginning June 5, 2017. You heard right! Rock Steady Boxing will be offered Mondays, Tuesdays, Wednesdays, and Thursdays from 10:00 am to 11:30 am. The expanded schedule will allow us to serve a greater number of athletes and will provide more flexibility for our boxers.

SPINNING AGAINST PARKINSON'S

Hybrid Athletic Club is also excited to announce our Spinning Against Parkinson's class – a spinning class specifically designed for people with Parkinson's disease. Bicycling has been shown to alleviate a variety of Parkinson's symptoms, such as freezing gait and we are excited by the potential!

This one-hour program will be offered every Friday at 10:00 am beginning in June. The fee per class is \$10 and it is instructed by the same great trainer who is in charge of our Rock Steady Boxing program. Come and check it out!



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PARKINSON DISEASE
ASSOCIATION



Wisconsin
August 27, 2017

Warner Park
1625 Northport Drive
Madison, WI 53704

Check-in: 10:00 am

Walk: 11:00 am

Register online today!

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ph: 608-345-7938

What is an Optimism Walk?

- A fun-filled fundraising event!
- A short non-competitive walk with family-friendly activities!

Raise \$100 or more and get a free Optimism Walk T-shirt!

Why Walk?

- Every nine minutes someone is diagnosed with Parkinson's disease.
- Funds raised provide local support, education and research.
- **The more funds we raise, the more people we can help.**

Walk with us and help put an end to Parkinson's disease!

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Ask the Doctor

Do you have an unanswered question about managing Parkinson's disease? Email the APDA Wisconsin Chapter at apdawi@apdaparkinson.org and we will try our best to have your question answered by our health care experts. Today's question is answered by Dr. Teresa Mangin.

Dr. Mangin is a movement disorders trained neurologist specializing in the care of patients with Parkinson's disease. She completed medical school and a neurology residency at the University of Pennsylvania in Philadelphia, PA. She went on to train in movement disorders at Oregon Health and Science University (OHSU), a National Parkinson Foundation Center of Excellence, and the Portland VAMC. During her time at OHSU, she also completed the Human Investigations Program in clinical research. Dr. Mangin practiced at the Dean Clinic from 2010 to 2015, where she specialized in movement disorders and dementia, ran Dean's Memory Assessment Clinic, and served as co-chair for the St. Mary's Hospital Ethics Committee. Dr. Mangin joined the neurology department at UW-Madison in 2015 as a clinical assistant professor. In addition to movement disorders and dementia, Dr. Mangin has an interest in palliative care for these disorders and has completed the Palliative Care Education and Practice course through Harvard Medical School. She lives in Madison with her husband, two sons, and two daughters.

Question: "How common is constipation in Parkinson's and what can I do to help my constipation?"

Answer: Constipation is very common in Parkinson's disease, although many people have been living with it for so long, it may not be recognized as a problem. The slowing down of the GI tract is one of the changes of Parkinson's that can occur years or even decades before more obvious symptoms like tremor or gait changes develop. Once PD is diagnosed, some of the medications we use to treat it can exacerbate or cause constipation. There are various definitions for constipation, but generally if you are having fewer than 3 bowel movements per week, are going longer than 2-3 days between bowel movements, or are having hard, difficult to pass stools, you are constipated. You are also in good company: 50-60 percent or more of people living with PD share your experience. It is important to address this, not only for quality of life reasons (constipation can be miserably uncomfortable!), but also to prevent potentially serious complications like a bowel perforation.

As with many things, an ounce of prevention is worth a pound of cure. Drinking plenty of fluids (48-64 oz per day) and getting regular exercise both play key roles in keeping your bowels moving. The diet should contain plenty of fiber in the form of fresh fruits and veggies; whole grains like steel cut oats, whole wheat, brown rice; nuts; even popcorn. Aim for at least 20-30 grams of dietary fiber per day. Try to limit or avoid overly processed, sugary foods and cheese. Prunes or "power pudding" recipes can be helpful, as can my personal favorite: a strong cup of coffee.

If these simpler measures are not sufficient, talk with your doctor about appropriate next steps for you. Stool softeners like docusate (Colace) and the osmotic laxative polyethylene glycol (Miralax) can be obtained over the counter and are safe for most people to take daily. Bulk-forming laxatives such as Metamucil can actually exacerbate the type of constipation some patients with PD have, because the slow moving gut will draw more water out of the stool which is now bulked up by the Metamucil, making it even more difficult to pass. Stimulant laxatives and suppositories or enemas are more of a last resort.

Recipes:

Power Pudding

1 cup each of bran cereal or Miller's wheat bran, applesauce, and prune juice. Mix and store in refrigerated airtight container. Use 1-2 Tbsp daily.



Yakima Valley Anti Constipation Fruit Paste

1 lb pitted prunes

4 ozs senna tea leaves (at health foods store)

1 lb raisins

1 lb figs

1 cup lemon juice

1. Prepare tea; use about 2 1/2 cups boiled water, add to tea leaves and steep for 5 minutes.
2. Strain tea and remove tea leaves.
3. Place 2 cups of tea, or amount left, in large pot.
4. Add all of the fruit to the tea.
5. Boil fruit and tea for 15-20 minutes, until soft.
6. Remove from heat and add lemon juice. Allow to cool.
7. Use hand mixer/blender or food processor to turn fruit and tea mix into a paste.
8. Place in glass jars or Tupperware and place in freezer (paste will not freeze but will keep forever in freezer also very long in fridge).

DOSAGE: 1 - 2 Tablespoons per day

2017 Marathon Thank you!

Greetings,

To all of the 2017 Parkinson's Half Marathon and 5K event participants, volunteers, and sponsors – THANK YOU on behalf of our family committee for making this event once again a huge success on such a wonderful day. We had over 1,500 people attending the event and as a result we will be sending approximately \$66,549 to the APDA Wisconsin Chapter. Check our website: <https://parkinsonshalfmarathon.wordpress.com/>.

The Parkinson's Half Marathon and 5K event funding supports the APDA Wisconsin Chapter, but the event means so much more. The event is built on a foundation of family, friends, love, and fellowship all coming together to make a difference.

There are so many examples of inspiration and love that make this event so rewarding. Each year the event has shown this time and time again. Every family and friend hour is volunteered, each coming with love and fellowship.

We are humbled, blessed, honored, and grateful with your involvement in the event in your own way. From all the families and friends who live with the disease on a daily basis, we say THANK YOU with all our hearts!

Bob (Roth)- you will be forever missed and never forgotten! To all of you who may have lost a loved one to this disease, our thoughts are with you.

We look forward to next year's Parkinson's Half Marathon/5k/1 mile walk on April 14, 2018. All our best to you and your loved ones!

Kindest Regards,

Alyssa Greiber
Bonnie Coy
Brooke Coy
Christina and Nate Nasett
Debbie and Tom Coy
Debbie and Bob Nasett
Joel Clark
Jordan Mooney
Julie and Jerry Walther
Mandy Nasett
Stacy and Ryan Hastings
Stephanie and Brian Sauer
Sue and Mark Harvey



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Parkinson's Perspective

This newsletter is published four times a year for Parkinson's patients, their families and caregivers by the APDA Information & Referral Center and the APDA-Wisconsin Chapter.

If you would like to subscribe or unsubscribe, please contact Jordan at (608) 345-7938 or jmooney@apdaparkinson.org.

The newsletter is intended for educational purposes only and should not be interpreted as providing medical recommendations. Patients are advised not to change their treatment without the advice and consent of their treating physician. Newsletter content is the sole responsibility of the editors.

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