

Parkinson's Perspective

Spring 2017

Keep Moving Series



My name is Phil Helmke. At the age of 74, I find that a scheduled, weekly exercise class helps to maintain my motivation to do daily exercises and

makes me feel better. I was initially diagnosed as having Parkinson's disease four years ago but in retrospect I was experiencing some symptoms as long as 10 years ago. As an accomplished ballroom dancer, I initially noticed the fluidity of my movements were decreasing with time and my posture was impaired. This was especially evident when I reviewed video recordings of my dancing over time.

My main symptoms of Parkinson's disease are muscle rigidity, restless leg syndrome, and balance issues. For most of 2016, I have been participating in a weekly class sponsored by the Stoughton Senior Center and Stoughton Hospital and led by Emily Devine, DPT. While not a cure, the stretching and movement exercises and balance routines done in class and the corresponding written directions provided for home use improve my symptoms. The class is small, six to 15 participants, allowing for individual attention.

The exercises promoted as the BIG group are especially helpful in maintaining flexibility and coordination. The weekly introduction of new routines motivates me to do the exercises daily and to vary the specific exercises. I am generally very active with woodworking, yard work, and operating a family farm, but these activities are no substitute for structured exercises.



Hi, my name is Emily Devine, and I have been a physical therapist for Stoughton Hospital since 2008. Over the years I have had the opportunity to

work with people at the Stoughton Hospital Outpatient Clinic who have Parkinson's disease.

The focus in clinic is to improve movement and quality of life using Parkinson's Wellness Recovery (PWR) techniques as well as Lee Silverman Voice Training – BIG (LSVT- BIG) treatment techniques which I am certified in providing. The remarkable benefits that physical activity can have especially for people with Parkinson's disease has been shown over and over again. Performing exercises daily that are specific to Parkinson's disease symptoms can help slow the progression of symptoms. Group sessions and getting to know other people with similar difficulties with movement can also help to motivate people to exercise.

Due to this, I have been working in collaboration with the Stoughton Senior Center since 2012 leading a community based exercise class for people who have Parkinson's disease.

A group class not only promotes physical activity but also allows participants to motivate each other with similar challenges to move. The classes are meant to improve overall function, mood, mobility, quality of life, and fall reduction, as well as work on cardiovascular fitness in a fun, open environment. The group usually includes an age range from the 60s to the 80s.

The class runs for 3 sessions: fall, winter, and spring, with summers off, every Friday from 1:00 to 1:45 p.m. at the Stoughton Senior Center. Class size is limited. Interested participants need to be able to walk independently or with an assistive device as well as tolerate both standing and sitting positions. Participants can contact Stoughton Physical Therapy at (608) 873-2313 or the Stoughton Senior Center (608) 873-8585 to learn more about this local community class.



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.

As evidence demonstrates many beneficial effects on the brain and body, we highly recommend physical activity, especially for people with Parkinson's disease. There is currently an ongoing clinical study of some 5,500 participants by the National Parkinson Foundation, called the Quality Improvement Initiative (part of the Parkinson's Outcome Project). Early results show that people with PD who exercise more than 2.5 hours per week have lower degrees of mobility impairment, caregiver burden, and impairment in everyday activities. Results also show that those who start exercising earlier experience a significantly slower decline in quality of life than those who start later. This is good motivation to begin exercising today, regardless of your age or ability level!

From the President



The APDA finished 2016 with a strong turnout at our annual symposium. We hope to expand this event and continue to bring our Parkinson's and professional communities together. If you were unable to attend, we will be posting highlights of the event on the APDA Wisconsin Chapter

website. I'm sure you will find the question and answer session with the panel of experts as well as our keynote speaker's presentation full of valuable information.

In addition, the exercise committee is currently developing a partnership to expand the availability of PWR! exercise classes to communities throughout Wisconsin. The Chapter is supporting this initiative by investing in the training of fitness professionals. This is exactly the kind of broad reaching goals the Chapter is dedicated to and I want to thank Phil Schleicher and his committee for their vision and follow-through. We

have also established a research committee headed by Dr. Giuseppe Cortese and Corinne Jones. The goal of the research committee is to provide a bridge between Parkinson's research and the Parkinson's community through a statewide outreach program. I am very excited to see the direction these two dedicated and talented researchers take this initiative.

Lastly, I encourage you to join us in our efforts to serve the Parkinson's community by joining one of our committees, registering for an upcoming event, or sponsoring one of our events. Please join us for **A Night of Hops & Vines** and the **Parkinson's Half Marathon/5k/1 Mile Walk**, both coming up in April. Each of our events provide valuable funds that allow the Chapter to bring quality programs throughout Wisconsin.

Happy New Year,

Sheryl Hursh

APDA-Wisconsin Chapter President

From the Executive Director



As we begin 2017, the American Parkinson Disease Association Wisconsin Chapter looks forward to continuing to support individuals affected by Parkinson's disease in the community. Whether you are newly diagnosed or have had the disease for years, I am available to

you for educational materials, finding a local support group or exercise group in your area, or even if you just need someone to simply listen. If you have questions on a certain topic or are struggling with an aspect of the disease, please reach out to me. I have set up some excellent presenters at support groups thanks to feedback from the participants. I strive to have your needs met and enjoy the feedback on how to continue to improve.

2017 is going to be a very big year for the American Parkinson Disease Association. We have a lot of exciting projects in the works. I have been working with a number of health care professionals in the field to create a pilot study for an eight-week program for those who have been diagnosed with Parkinson's disease within the last five years. I am searching for a health care professional (example: social worker, nurse, counselor, etc.) who has experience running groups and would be willing to help lead this project, which is a paid position. If you are an individual with Parkinson's

disease diagnosed within the last five years or a health care professional who is interested in this new program, please contact me.

Our chapter continues to strive to help the whole family affected by Parkinson's disease. We continue to offer grants up to \$750 for caregiver respite to encourage the caregiver to receive some additional help at home and take some time off. The Dane County Area on Aging has a great teleconnection support group flyer for caregivers who can't make it to a caregiver support group in person. If you are interested in the flyer, please call me or the Dane County Area Agency on Aging at (608) 261-5679.

I encourage you this year to reach out and become active in our Parkinson's community. Attend one of our local events such as the **Parkinson's Half Marathon/5k/1 Mile Walk** on April 1, or our **A Night of Hops & Vines** on April 22 at Blackhawk Country Club. Volunteers are always needed for these events as they require countless hours of planning. Try out a local support group or exercise class. Throughout the year, please remember that I am always available to you and look forward to continuing to assist you with any of your questions or concerns. Thank you!

Jordan Mooney

APDA-Wisconsin Chapter Executive Director

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@surgery.wisc.edu
for more information.



Save the Date

SATURDAY, APRIL 22

ANNUAL WINE AND BEER TASTING
BENEFITTING THE AMERICAN PARKINSON
DISEASE ASSOCIATION WISCONSIN CHAPTER

Blackhawk Country Club, Madison, Wisconsin



Save the Date

Parkinson's Half Marathon, 5k, 1 Mile Walk

April 1, 2017

Cottage Grove, Wisconsin

Want to get involved?
Call the APDA-Wisconsin Chapter today!

(608) 345-7938

UW Health Moving Forward Topics

MOVING FORWARD, an educational series for patients with movement disorders, will continue in 2017 on the second Monday of each month starting in February. The event is at the Alliant Energy Center (1919 Alliant Energy Way) from 6:30-8:00 p.m. The event is free and also has free handicapped parking. The sessions are now recorded, and if you miss them you can view them online at:

www.uwhealth.org/neurology/moving-forward/49095



February 13

Goop Soup: A Nervous System Breakdown

**Kathleen Shannon, MD, UW Health,
Department of Neurology**

Are you dizzy? Do you have an “anxious” bladder or constipation? The autonomic nervous system (ANS) takes care of all the things you don’t think about (blood pressure, bowel and bladder function, sweating). For many people with Parkinson’s disease, the ANS seems to be “missing in action.” Learn how the autonomic nervous system misbehaves in Parkinson’s disease and what can be done to make things better.

March 13

Should I be Driving?

**Peggy Nied, OT, UW Health Rehab Department;
Teresa Mangin, MD, UW Health Movement Disorders
Clinic; and Steve Pazynski, Department of Transportation**

Do you have the physical and mental ability to drive? Who helps to decide whether you should be behind the wheel? What happens in a driving evaluation? Can restrictions be placed on my driver’s license? Join in a discussion with this panel of experts to see if you should still be driving.



April 10

Help! I'm Falling!

Kathleen Walsh, MD, UW Health Faint and Falls Clinic

Do you lose your balance? Have you been falling? Does dizziness affect your ability to move? What causes your falls and what can you do to prevent them? Learn from Dr. Walsh what may be the reasons for your falls and what can be done to treat them.

May 8

What about My Teeth?

Jane Busch, retired DDS

Parkinson’s disease affects the entire body including the mouth. Challenges may include difficulty in mouth opening, dry mouth, and drooling. Dental treatment may be affected by Parkinson’s medications. This presentation will address these concerns and include tips for optimal oral health.

June 12

Exercise and Parkinson’s Disease

**Kristen Pickett, PhD, UW-Madison,
Department of Kinesiology**

Everyone talks about exercise being good for us. What does research tell us about the benefits of routine exercise? What kind of exercise should that be? Dr. Pickett will share her research at UW-Madison and help you learn what exercise can do for you.

July 10

A Night at the Opera: Music, Diction, and Your Voice

**Wendy Rowe, Soprano and Professor of Opera at UW-
Milwaukee and Sue Capp, MPT, retired Physical
Therapist and person with Parkinson’s disease.**

Let your voice be heard. Improve your facial expression. A new approach to communication blends principles of neurorehab and opera. Wendy and Sue will provide a fun and interactive session with practical take-home tips. (Ability to carry a tune is not required.)



August 14

Normal Aging Brain or Dementia?

Laura Hancock, PhD
University of Wisconsin Department of Neuroscience
and Neurology

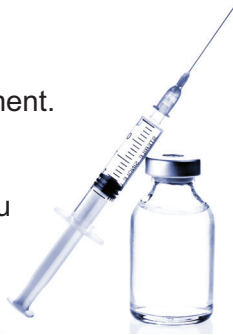
You are becoming more forgetful and at times confused. What is the problem? A medication side effect? Depression? Normal aging? Dementia? Find out from Dr. Hancock what symptoms are normal with aging and what may be an indication of a more serious problem.

September 11

Botox: Not Just for Wrinkles

Laura Buyan-Dent, PhD, MD
UW Health Movement Disorders Clinic

Botox is no longer just a cosmetic treatment. It is used to treat many symptoms of Parkinson's disease and dystonia. Cramping toes...pain...drooling...did you know that Botox can offer help in the treatment of many symptoms? Dr. Dent will explain how Botox works and how it is used to improve the symptoms of PD.



October 9

Vision and PD

Judy Chen, MD, Neuro-ophthalmologist, UW Health
Department of Ophthalmology

Parkinson's patients tend to experience more eye symptoms than other elderly. This presentation will give you an overview of common visual problems related to Parkinson's disease, as well as a few tips that may help you to alleviate those eye symptoms and improve your ability to see.

November 13

Whoever Said Caregiving was Easy?

Amy Scharmer, MSSW
UW Health Neurology Clinic

Caregiving is the most challenging job you will have. It is normal and common to feel overwhelmed and exhausted when providing care for someone. Learn more about caregiver fatigue and what community resources might be available to help you.

Upcoming Exercise Classes

Boxing at Ford's Gym

2114 Winnebago Street, Madison, WI

The next eight-week session will be 2:00 p.m. to 2:45 p.m., January 5 – March 2 with no class on January 26.

Rhythm at Harbor Athletic Club

2529 Allen Blvd, Middleton, WI

The next 12-week session starts January 23. Rhythm is at 3:15 p.m. on Mondays.

Zumba at Harbor Athletic Club

2529 Allen Blvd, Middleton, WI

The next 12-week session starts January 15. Zumba is at 1:30 p.m. on Wednesdays.



Brand-New Program Seeks Participants!

Were you diagnosed with PD in the last five years?

**Then the PRESS program is for you!
(Parkinson's Roadmap for Education and Support Services)**

We are currently seeking 15–20 participants for an exciting new program designed to give you a roadmap on your journey with Parkinson's disease.

This eight-week program conducted in a support group format will help you feel empowered, in control, and optimistic. The program is designed to provide emotional support and a safe place to share coping strategies to live the best life with PD.

Topics covered will be:

- What's next after diagnosis?
- How to best manage your medications
- Building your healthcare team
- Dealing with physical symptoms and emotional stress
- The impact of PD on daily coping and relationships
- Tips for daily living
- And more!

This is an APDA program, built specifically to empower those newly coping with PD. It will be evaluated for its effectiveness and benefit to you at the completion of the eight weeks.

The program:

- Program is free of charge for participants
- Must attend all sessions to gain full benefit of the group
- For those newly coping (diagnosed within the last five years)
- Led by a healthcare professional
- Care partners welcomed
- Closed group after second session
- Share coping strategies and resources
- Education regarding PD as part of group discussion
- Speakers invited to present on specific topics

First Responders Parkinson's Disease Awareness Program



I am very excited to announce that the First Responders Parkinson's Disease Awareness Training Program has been launched on the APDA website and several other state learning sites.

APDA partnered with the Office of Continuing Professional Education (OCPE) at Rutgers, The State University of New Jersey to provide a web-based, user-friendly program for police officers, fire fighters, and emergency medical service providers to help them recognize the unique symptoms and needs of those with Parkinson's disease, enabling them to provide the best and most appropriate care.

The Parkinson's Awareness Training program meets the educational goals in Section 4b4 of the New Jersey Parkinson's Disease Public Awareness and Education Act (A-2576.) The statute signed into New Jersey state law in December 2014 was driven by APDA's New Jersey Chapter and called specifically for the development of an educational program to educate and empower first responders to not only know the signs and symptoms to look for, but to know how to best treat and care for people living with Parkinson's disease. With a new diagnosis of Parkinson's disease every nine minutes, this training is critically important.

The New Jersey Chapter of the American Parkinson Disease Association worked for nine years to pass this law. Chapter President, Allan Bleich, a retired police officer of 25 years, who was diagnosed with Parkinson's disease at age 45, was instrumental in leading the charge. "After my diagnosis I realized that it was vital that first responders be educated about the disease so they could recognize the symptoms and effectively work with an individual impacted by Parkinson's. For example, an EMT treating someone who has undergone deep brain stimulation (DBS), which is a device implanted in the brain to help combat Parkinson's symptoms, must understand the implications of the device otherwise the person's life could inadvertently be at stake."

The web program is a 1–2 hour course with instructional videos intended to provide overall education on Parkinson's disease and information on

protocols for the first responder when interacting with a person who shows the signs of Parkinson's. To date the program has been posted on training websites in New Jersey, Pennsylvania, New Hampshire, and South Carolina. Other states will be adding the program in the coming year; CEUs may be available through these states' websites.

A non-CEU version of the program is available on the APDA website and can be found at : www.apdaparkinson.org/EMTtrainingcourse/presentation.html.

Very special thanks to Dr. Lawrence Golbe, Rutgers Robert Wood Johnson Medical Center; Cathi A. Thomas, RN, MS, CNRN – Program Director, Boston University Medical Center; and Laura Lieb, RN, MPH, MSN, Nurse Coordinator, University of Alabama Medical Center; who served as expert consultants to the project.

The program provides an excellent overview of Parkinson's disease and can be used as a training tool for lay and professional volunteers working with your APDA Chapter or Center.

APDA will provide the content for free to state learning websites. We will be in touch with Chapters and I and R Centers with tools to reach out to your state site.

Congratulations to the New Jersey Chapter on their efforts to bring this important program to an important audience.

*Robin Kornhaber
Vice President, Programs and Services*

APDA of Wisconsin

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Parkinson's Perspective

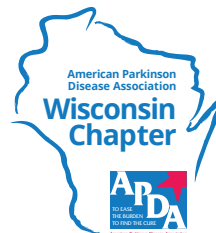
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If you would like to subscribe or unsubscribe, please contact Jordan at (608) 345-7938 or jmooney@apdaparkinson.org.

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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