



WISCONSIN
PARKINSON
ASSOCIATION

STRONGER together

COMMUNITY ♡ EDUCATION ♡ HOPE

Read about support and exercise groups
around the state – **AND BEYOND!**

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Credits

The Network is a publication for people with Parkinson disease, their families and friends, and any interested individuals and groups. It is published by the Wisconsin Parkinson Association.

Information provided concerning medical diagnosis, treatment, and research is not intended to answer individual problems but to report and explain current information about Parkinson disease. You should always ask your physician about specific treatment issues.

If you do not receive *The Network* quarterly, join our mailing list at wiparkinson.org. You will receive this magazine, as well as periodic information about educational events, support & exercise groups, and other resources in your area. This magazine is funded by your donations. Your support helps those living with Parkinson disease by allowing us to enhance and expand our services to them and their families. For more information, visit wiparkinson.org.

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Letter from the Executive Director



Gary Garland
Executive Director

Happy January!

Okay, I admit it just does not have the same joyous ring as “Merry Christmas!”

or “Happy Holidays!” If we’re honest, by the time this part of winter rolls around in Wisconsin – we’re done. That beautiful first snow – a distant memory. Snow angels – I don’t think so! Hot cocoa by a warm fire – Bah Humbug!

But wait, don’t give up, this challenging and chilly time can get so much warmer! That’s the theme of this issue of *The Network*. Parkinson disease can make you feel alone and physically weakened, but there are proven ways to fight back, and many are right outside your door.

There are over 130 support and exercise groups in Wisconsin whose sole purpose is to build community and help you build some muscle. Spending time in community with others and exercising are shown to have real benefits for all of us. It matters less which you choose to do, the important decision is to do something.

Take a look at some of the groups highlighted here, and then feel free to connect with them through our website – or call us if you have questions. With so many choices, I am confident you can find one that fits your personality and needs. This issue is just a snapshot of a few groups, and many others have been profiled over the last few years. You can view past issues of this magazine on our website to learn about other groups!

You’ll also read about some of our holiday and winter happenings – it was a busy time! We were so proud to spearhead the visit from Dr. Matt Havrda of the Geisel School of Medicine at Dartmouth-Hitchcock in New Hampshire. Matt spread some hope of his own as he spoke about the research his team is conducting with donated brain tissue, most of which came from the kindness of WPA supporters and families. For me, it was powerful to hear from him and meet some of those whose loved ones made his work possible.

So grit your teeth, bundle up and get ready to kick Jack Frost right in the... Never mind, let’s just get out, get to work and fight back!

Thanks,
Gary
garyg@wiparkinson.org

You may notice that some exercise classes charge a fee to participate. **If the cost is a hindrance for you or to your group, CONTACT WPA!** We have dollars set aside to assist YOU and your group moving forward. We want to connect you with the resources you need, whether that means helping with the class fee for a boxing or cycling class, supporting you in buying some equipment, or something else. **We are here for you – please contact us and tell how we can help!**



Dr. Matt Havrda sharing updates with the medical and general Parkinson’s community.



Members of the Stoughton support group enjoying a fly fishing clinic.



Terry Sexton and his daughter Caitlin after a half-marathon in Austin, Texas.

Researcher **Dr. Matt Havrda** Visits WPA

In December, WPA was honored to have arranged a three day visit by Dr. Matt Havrda from the Geisel School of Medicine at Dartmouth-Hitchcock in New Hampshire. Dr. Havrda and his team have been performing research on brain tissue that was donated by compassionate WPA supporters. The goal of the visit was to share updates on his research with both the local Parkinson's medical community and the general Parkinson's community. We were especially touched that several members of tissue donor families were able to hear Dr. Havrda, and better understand the importance of their loved one's gift.



Dr. Matt Havrda speaking to the Parkinson's community.

Dr. Havrda started his whirlwind journey to southeast Wisconsin by meeting with Dr. Karen Blindauer (a member of our Medical Advisory Committee) and Dr. Ryan Brennan, both Movement Disorder Specialists at Froedtert & the Medical College of Wisconsin. He then spent the next day presenting to a group of about 100 at a well-received lunch event at Aurora Hospital System Conference Center with two other members of our Medical Advisory Committee, Dr. Taylor Finseth and Dr. Kathryn Gaines, before we hauled him away to share his work with two other members of our Medical Advisory Committee prior to our annual Holiday Reception. On the third and final day of his trip, the staff and members of the WPA board spent a couple hours discussing with Dr. Havrda ways in which he and WPA can continue to partner moving forward.



Dr. Taylor Finseth, Medical Advisory Committee member.

Dr. Havrda's research focuses on inflammation and how it occurs in the Central Nervous System and how this may impact the diagnosis and treatment of Parkinson disease. He hopes, that if all progresses with the teams' research it could lead to improved diagnostic and therapeutic tools in PD in the coming years.

The feedback we received from those who had a chance to hear Dr. Havrda speak was overwhelmingly positive. It was certainly an exciting opportunity for WPA to showcase how we continue to build and leverage partnerships in order to bring the most important information to the local Parkinson community. A big thank you to Dr. Havrda for taking the time to share his work, and its possibilities, with so many!



WPA'S ROLE with Groups



By **Jeremy Otte** • Director of Outreach & Education

In my five years with Wisconsin Parkinson Association, I have seen many groups adapt and change with the times. When I first started, many support groups relied on medical professionals to present to their groups and share expertise. As the health care industry has changed, facilitators have adapted and often utilize speakers who aren't Parkinson disease specific, but cover issues faced by people with PD, such as insurance, exercise and other community resources.

As we enter 2018, groups continue to change and evolve. More groups are focusing on "sharing" meetings over speaker-focused meetings. This kind of meeting provides members a chance to share their current situation, learn more about others' experiences and discover community resources for Parkinson disease. Another change I see is the growth and variety of exercise groups throughout the state. As a member of an exercise class at a local YMCA said to me recently, "We view ourselves as a support group, who happens to exercise." That made me stop and think – and realize the incredible sense of community they have built!

At WPA, our role is to assist groups and facilitators through these changes, and provide support and training to meeting facilitators. We do this through yearly trainings, visiting and meeting with groups regularly, and providing materials and resources for group members. When members request a specific topic, we will help identify potential content experts and local resources to meet these needs. Also, we promote these groups to local medical experts, as well as people with Parkinson disease, through our website, Facebook page, brochures, and press releases to local media.

In addition to providing support to over 130 facilitators and groups, we also facilitate support groups in Brookfield and Oconomowoc. This active involvement keeps us more personally aware of the issues faced by people in the Parkinson community. It also allows us to experience the regular management of running a support group, and

provides hands-on experience when facilitators come to us with questions and concerns. By running our own groups, it allows us to have direct experience and provide examples that are current – not theoretical support based on how things should or could be developed.

As I run these two groups, I have learned about the programs and services in our area, and also what resonates with those impacted by PD. About three years ago, several members of one of my groups passed away. During our discussions later, their spouses shared that they wished they had known about palliative care and hospice care, and what each means. After that discussion, we decided to bring in a speaker every year for an overview and discussion on palliative and hospice care. Similarly, we annually have speakers from the Waukesha County Aging & Disability Resource Center, information on Medicare around the Open Enrollment Period, and various exercise opportunities.

Running these two groups has allowed me to experience the challenges all facilitators face with their groups – changing attendance, finding speakers, and keeping members engaged. Thankfully, I can take these experiences and share my successes and challenges with other facilitators, and we can work together to improve the quality and significance of our groups.

Finally, I appreciate the importance support groups have in assisting you in your everyday life with PD. They provide you with a sense of community and shared experiences. They offer you a chance to receive monthly in-person education and resources related to PD. Support groups provide you a way to be active in your diagnosis and care. They provide you and your care partner with tools to understand, manage and care for your PD.

Thank you to the facilitators and members who help others connect with WPA. You all provide support and resources to people with PD in ways big and small. Keep up the great work and let me know how we can further assist support groups to further impact the Parkinson population!

Ask the doctor!

Have a question you'd like our Medical Advisory Committee to address in a future issue? Send it to mail@wiparkinson.org and put "Ask the Doctor" in the subject line.

Ask the Doctors

The Scoop on Poop... and Other Awkward Topics, Part 2

More and more focus has been on the non-motor symptoms of Parkinson disease. This is because not only can they predate the motor symptoms, but at times, they can also affect quality of life even more than the motor symptoms. Some of these non-motor symptoms include things like changes in blood pressure, urinary symptoms, constipation, memory, sleep problems, hallucinations and mood.

Some symptoms are easier to talk about than others, so we asked several members of our Medical Advisory Committee to tackle a few of these topics. Last issue addressed gastrointestinal problems, abnormal bladder and sexual dysfunction. Visit wiparkinson.org to read that article. This issue will address hallucinations, anxiety and depression.

Hallucinations

Michael B. Schonberger, DO, Gundersen Health Systems, La Crosse, WI: Hallucinations in Parkinson disease provide an extra challenge to handle in the daily life of PD patients

and their loved ones/caregivers. Hallucinations themselves can be a consequence of being on too much levodopa and/or dopamine agonist therapy, or potentially a manifestation of what is now being referred to as "Parkinson Disease Psychosis" (PDP). According to one website, over fifty percent of patients with PD will experience hallucinations and/or delusions over the course of their disease.

Besides the obvious difficulties that hallucinations cause for people with PD, there has historically been an unfortunate stigma when it comes to dealing with these issues, mainly because people are uncomfortable discussing symptoms that presumptively have to do with their "mind". Many patients sadly think that if they experience hallucinations that they are progressing "beyond the point of no return" or that they are "losing their mind." However, it is important for everyone

to know that PDP is becoming more recognized as a true medical entity, and neither something to be ashamed of nor embarrassed by.

Generally speaking, my philosophy in treating hallucinations in PD has been dependent on the answer to two questions posed to the patients and their loved ones/caregivers:

- 1 Does the patient find the hallucinations bothersome, frightening, etc.?
- 2 Does the patient and/or other people think that the hallucinations pose a risk to the safety of the patient or others around them? Stated another way: Do they think the patient is more likely to harm themselves (i.e. by falling) due to the hallucinations than due to the symptoms PD itself?

If the answer to both is "yes", then we simply must intervene.

In the past, we had to rely on traditional anti-psychotic therapies to fight hallucinations, which for the most part carried with them the possibility of worsening the parkinsonian symptoms themselves. Fortunately, more recently, a medicine called pimavanserin (trade name

Nuplazid) has been released. It works differently than the previously used anti-psychotics, in that it addresses the hallucinations without risk to worsening PD features. This medication is designed to try to lessen the severity and/or frequency of the hallucinations themselves. While 100% obliteration of hallucinations is unlikely, many patients who have tried this medication have found that their hallucinations are easier to deal with, either because they are less frightening or happen less frequently, allowing for the patient to develop more insight into the fact that what they are experiencing is not real.

Again, hallucinations in PD are not uncommon, and thanks to more medical knowledge and updated means of treatment, we are able to help many patients carry on with one less thing to worry about. If you or a loved one is experiencing hallucinations and/or delusions, please talk to your neurologist about intervention options.

Anxiety and Depression

Katie Spangler, MD,
Marshfield Clinic,
Wausau, WI: Anxiety and/or depression are the most prevalent mood problems in Parkinson disease. They

can be present in up to 50% (and some report even more) of all patients with Parkinson disease.

Depression can manifest in different ways, which can include hypersomnolence or insomnia. It also can show through a change in eating habits, or appetite. Some patients may lose their appetite, while others may have an enhanced appetite. Often patients with depression lose interest in things that they normally would find enjoyment in. They can often become withdrawn. This is different, but can sometimes be confused with something called apathy which is also present in people with Parkinson disease. Apathy is a lack of motivation. It does not cause eating or sleeping changes. It often is not bothersome to the patient who has it, but is more bothersome to their caregiver and loved ones. With depression, often eating or sleeping changes occur. With apathy, patients will still find enjoyment in things, but don't have initiative or motivation to start them.

Anxiety is a heightened state of worry. It often can produce physical symptoms such as headaches, insomnia, sweating, palpitations/heart racing, GI upset and nausea.

Both depression and anxiety can be successfully treated if they are present and affect a patient's quality of life. We often use the same medicines that would be used in patients without Parkinson disease. These medications are called SSRIs (selective serotonin reuptake inhibitors) or SNRIs (selective serotonin and norepinephrine reuptake inhibitors). These include medications such as escitalopram, citalopram, sertraline, paroxetine, venlafaxine, desvenlafaxine, among others. Other medications can be used such as Buspirone or Bupropion as well. Most of these medications often take at least 4-6 weeks for efficacy and noticeable clinical benefit, although some patients report benefit earlier. Although the mood components of the non-motor symptoms are primarily separate from the motor symptoms of Parkinson disease, there is more data showing that perhaps they are more linked than previously thought. For example, patients whose motor symptoms are not being optimized or treated may have more depression and anxiety. So instead of treating the depression/anxiety, perhaps treat the motor symptoms with dopamine medications first to see if this helps with the mood. Patients who have more freezing episodes, also tend to have more anxiety. In addition, patients that have more anxiety may have more motor symptoms (such as freezing of gait and tremor). So again, depression/anxiety may be more linked to the motor symptoms than what we first thought.



Regardless, although the mood symptoms can be prevalent and can affect quality of life, they are treatable and most patients do very well on medications combined with psychotherapy if necessary. I would encourage patients to talk with their neurologists if they or their loved ones are struggling with depression and/or anxiety. It is common, but can be successfully treated.

NORTHSHORE

Many support groups have just one facilitator, or perhaps two co-facilitators to plan the meetings. But the group that meets at the Jewish Community Center in the Northshore area of Milwaukee is lucky enough to have three co-facilitators that work really well together!

With different life circumstances, they all have different amounts of time to contribute to facilitating, so it works very well for all of them to share the responsibilities.

In order to help everyone feel comfortable, they open meetings with introductions and an “icebreaker” question.

“It can be comforting to just belong to a group where others are walking the same path as you.”

– Margaret Sohm

Margaret Sohm, Lucia Francis, and Bonnie Barr are approaching two years of facilitating together, and have been hard at work over that time. “We each bring different strengths,” said Lucia. “Bonnie is the idea person, Margaret is our organizer, and I help with the creativity and technology!”

In addition to having different strengths, they also have different perspectives on Parkinson disease. Bonnie and Lucia both have been diagnosed with PD, and Margaret cared for her late husband who had the disease.

Often the questions will relate to the meeting topic. For example, an exercise speaker may ask about what kind of exercises attendees did in the last week. For their meeting in November, they asked members to share a favorite Thanksgiving memory – which turned into members sharing the misadventures of previous Thanksgivings! Other icebreaker questions have included members’ first cars, “2 truths and a lie” (where members share three details about themselves, and the others have to guess which two are true and which is made up), and questions about careers.

“It’s been very informative to learn more about our members,” shared Margaret. “We didn’t know that much about what they did in their “previous lives”, so it was a great way to build trust and get to know one another better.” Bonnie agreed, “It also gives everyone a chance to talk, which they might not get otherwise.”

The facilitators want to make sure group members know they don’t take the word ‘support’ lightly. “It can be comforting to just belong to a group where others are walking the same path as you are,” said Margaret.



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APPLETON YOUNG-ONSET



Dennis Lange and Gary Rademan enjoy the benefits of their workouts at 9Round.

The Young-Onset support group in Appleton has always been an active group, and a few months ago, the group visited 9Round, a specialized gym dedicated to circuit training with an emphasis on kickboxing fitness training. 9Round's fitness program incorporates functional, interval, cardiovascular, and circuit training regimens. It consists of nine challenging workout stations. Every 3 minutes, participants move to a new station, and after 30 minutes they have completed a full-body workout.

Last April, 9Round helped increase awareness of life with Parkinson's by providing exercise stations that demonstrated what it might be like for someone exercising with common PD symptoms. Stations included uneven surfaces, balance training, and uneven weights to mimic affected vs. unaffected unilateral symptoms.

The support group took an outing recently, and 9Round closed down for the evening so that group members and their caregivers could feel comfortable trying out the exercise routines. Owner Breanna McKenny and her team of personal trainers adapted the exercises to each individual's abilities, and the group really enjoyed it.

After that session, two group members joined the club, and have committed to regular intensive exercise to improve symptom control in managing their PD. Gary Rademan and Dennis Lange both feel their symptoms have improved as a result of regular workouts, and they have encouraged others to get up and move. Group co-facilitator Michele Wuest was already a member of the club, and loves these workouts. "We take less medication than we would without the regular exercise," she said. "And the bonus of hitting something really hard is tough to beat!"

"There is something scary and exhilarating about working out at a gym geared to kickboxing," said Gary. "Scary because you haven't done it before, and exhilarating because you can do most of it." The staff at 9Round work with Gary, Dennis and Michele to modify challenging exercises to ensure they get the benefit without risk. "We're not pounding the bags or kicking very hard but we do feel better after we workout. Everyone is there to do better. It's a positive place to make new friends."

Sandy Lange, Dennis's wife, is glad to see them going several times a week. "Everything we read about Parkinson's is to keep moving and stay positive. This program fulfills both. Does it need to be 9round? No, but it is small and personal without the expense of a private workout."

If you're interested in joining Dennis, Gary and Michele for a workout, stop in to talk with them more at their next support group meeting!



Brookdale Senior Living Solutions

5800 Pennsylvania Avenue
Appleton, WI 54914 • 920-312-1555



MEETING TIME:

2nd Thursday at 6:00 pm

STOUGHTON

A support group's activities are driven by the interests of facilitators and members, and the support group in Stoughton is no different.



Members of the Stoughton support group discuss fly fishing techniques.

Jon Hill, a co-facilitator for the group, is a fly fisherman. Not one to let his Parkinson's diagnosis slow him down, Jon wanted to share his passion with the rest of his group. In July 2016, Jon and Dennis Owen, co-facilitator, led a group of people with Parkinson's and their caregivers in a fly fishing clinic outside Oregon, Wisconsin.

Jon realized that fly fishing was something that would help his Parkinson's symptoms so he was happy to coordinate this outing. "Fly fishing has always been cathartic for me, and a great way to clear my head – even before my PD diagnosis," said Jon. "After I was diagnosed, I knew I had to keep up with my hobby, and I'm glad to share it with others."

With spring coming soon, Jon will be working with WPA to hold a fly fishing clinic in the area between Milwaukee and Madison. The outing will last 3 hours or so, and Jon will serve as an instructor, along with volunteers from Trout Unlimited and Project Healing Waters Fly Fishing.

Trout Unlimited is an organization dedicated to the conservation of freshwater streams, rivers, and habitats for trout, salmon, and other aquatic species. Project Healing Waters is an organization dedicated to the physical and emotional rehabilitation of disabled active military service personnel and disabled veterans through fly fishing and associated activities including education and outings.

The clinic will be limited to 20, including any interested caregivers, so that each individual will have an opportunity to try their hand. **Watch for more details and registration coming soon to wiparkinson.org.**



Group members work with volunteers to learn about casting.



"Fly fishing and casting, and everything that goes along with it can be really good for people with PD," he said. "We know we need to make big movements, and being outside instead of sitting on the couch watching TV is good for all of us!"

The Stoughton support group has other activities and meetings planned – join them for a meeting to learn more.



Stoughton Area Senior Center

248 W. Main Street
Stoughton, WI 53589 • 608-206-9597



MEETING TIME:

4th Wednesday from 1:30 - 3:00 pm

SHAWANO



When your support group facilitator is a registered nurse, you can bet your meetings won't just be sedentary meetings. Joyce Hagen, RN, has facilitated a support group in Shawano for almost 5 years, and recently added an exercise component to each group meeting.

The third lap around the room, of course, everyone stops at the snack table (brought in by different members each month), and then they all have a seat for the “business portion” of the meetings before guest speakers begin. “Business” includes upcoming meeting dates, speakers, and who will be bringing in the treats!

The group's guest speakers often also have emphasis on exercise and movement as well as many other topics. Recent speakers have included therapists leading LSVT BIG & LOUD, local social service organizations sharing available resources, and a representative from their Senior Center. They also have had pharmaceutical reps talking about available medications and how they can affect each individual, and someone talking about other exercises and how you can find a combination of what you like and what works well for you.

“Of the three treatments for Parkinson's: medication, exercise, and deep brain stimulation, exercise is the only one without negative side effects!”

– Joyce Hagen, RN

“We stress that exercise isn't just an option – it's a necessity when you have Parkinson's,” said Joyce. “Of the three treatments for Parkinson's: medication, exercise, and deep brain stimulation, exercise is the only one without negative side effects!”

Each 90 minute meeting starts with 15 minutes of movement. During the first lap around the room, group members focus on raising their feet and taking high steps. On the second lap, they aim for elongated steps, and on the third lap, they incorporate arm swings with their long high steps.

“Often the speakers join in the exercise,” shared Joyce, who is also certified to teach Silver Sneakers, a fitness program for seniors. “It's just a fun way to start our meetings!”



City Hall, River Room

127 S. Sawyer
Shawano, WI 54166 • 715-526-5104



MEETING TIME:

2nd Tuesday at 10:00 am

Tremble Clefs

Nearly every variety of exercise can be adapted for people with Parkinson's – including vocal exercise! LSVT LOUD classes and sessions with speech therapists are always an option, and for the “musically inclined” – there may be Tremble Clefs in your area!

.....
“I knew that singing was good for people with Parkinson's, so I thought ‘why not form a singing group?’”

–Jeff Obst, Group Facilitator
.....

Tremble Clefs is a nationwide program for people with Parkinson's and their care partners. The program establishes singing groups to bring people together to participate in a joyful activity with therapeutic results while working toward a common goal. Participation in a Tremble Clefs singing program can help address voice and communication problems through breathing, stretching and posture activities, vocal exercise, rhythm and movement, and a strong social support system.

Caitlin Ward, MS, CCC-SLP is a speech therapist at Beaver Dam Community Hospital. She started a Tremble Clefs group there two years ago. The group consistently has half a dozen participants, and has had as many as 15 at times. Almost all participants have Parkinson's, and most usually bring significant others or caregivers with them.

“This is a different kind of support group for people with PD and other neurological disorders. It is led by a speech therapist and physical therapist with therapeutic singing and moving,” said Caitlin. “Our group is an ‘exercise support group’, and we also talk about current events and issues that people want to discuss.”

Caitlin feels the biggest benefits for participants are the social aspects, as well as other ideas for exercises and how to stay active at home. “We provide resources for other therapies and activities that we have heard of. They keep coming back because they enjoy the songs, stretches and movements, and they like laughing with others!”

The “Bay Area” of Wisconsin, in the northern part of the state near Bayfield and Ashland, has hosted a support group since 2010. Jeff Obst, facilitator for that group, remembers hearing about alternative ways of lessening the symptoms of Parkinson's several years ago, including boxing, dancing and more. “I knew that singing was good for people with Parkinson's, so I thought ‘why not form a singing group?’” He contacted Tremble Clefs to learn more about their methods, but with only 5 of the 20 participants in the singing group actually having Parkinson's, they aren't officially affiliated with the program.

“In a town as small as Bayfield, we knew we wouldn't all be people with Parkinson's,” Jeff said. “So we opened the group to relatives and friends of people with Parkinson's, as well as other supporters.”

The group practices twice a month, and they put on four “concerts” each year for assisted living and nursing home residents. It's a great way for the people with PD in the group to get some vocal exercises, and a wonderful service to members of their community! The “Bay Area” group meetings rotate monthly between Bayfield, Washburn and Ashland. **Call 715-209-0807 for date and location information.**



Stone Terrace Apartment Building

819 S. University Avenue –
2nd Floor Community Room
Beaver Dam, WI 53916 • 920-887-4039



MEETING TIME:

2nd Thursday from 6:00 - 7:00 pm

PARKINSON DANCE CLASS

One of the great ways people with Parkinson's in Wisconsin can "get moving" is by joining a Parkinson's Dance Class. A dance class may sound scary to someone who has never participated before, but don't be concerned! The class focuses on movement of all kinds, and is easily adaptable depending on participants' abilities. Chairs are often incorporated, and seated dances include arm and leg movements.

"Dance has so much to offer physically, mentally and emotionally. The artistic process is at the core and that is where the magic happens."

– Susanne Carter

Susanne Carter leads the Wauwatosa Parkinson's Dance Class during their recital.



Susanne Carter leads dance classes in Whitefish Bay and Wauwatosa, and many of her students say her passion and enthusiasm for dance is contagious. She starts each class with a huge smile and energy that invites everyone to participate and move along to the music.

For nearly a decade, Susanne and her team have been teaching people with PD about the benefits of dance, not just for their PD, but for their overall health and spirit. At each class, people with PD and their caregivers are challenged to have fun and be creative, while trying something new. In this class setting, you find yourself free to explore and try new things, all the while improving your mind, mood and movement.

"We started The Parkinson's Dance Class in 2009," remembers Susanne. "It is still vivid in my mind. I was a little nervous and a little excited for our first class! As soon as we were seated, the music got started and when I saw the look on people's faces and the way they moved – I was hooked!"

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Kate Mann leads the Parkinson's Dance Class at the Fond du Lac Senior Center.

ST. FRANCIS

The support group at St. Ann Center for Intergenerational Care in St. Francis averages 15-18 lively, active members at its monthly meetings. The group is comprised of both people with Parkinson's and caregivers, and they have had wonderful speakers who graced them with knowledge and sensitivity. Group member Sister Rose Martin Weldgen said, "Our speakers have also shared in our conviction that we must never give up on new research and embrace the future with positive thinking, while facing the need to keep exercising and being hopeful."



Terry and his friend Jennifer Richardson ran in the Zero Prostate Cancer 5K in Austin, Texas.

One group member, Terry Sexton, has shared his story and passions with the group. Terry was a runner in high school and athletically inclined, which contributed to his coping with the challenges of his PD diagnosis four years ago. Motivated by his sensitivity to helping others, he chose to participate in a 5K Run hosted by Carthage College, with the proceeds benefiting the Kenosha Boys & Girls Club.

He has run this 5K for the last 5 years, and on May 12, 2017, he took 2nd place in the "Senior Over 60" category!



Terry runs in the Cullen Run for Heart Health at Willow Way in Wauwatosa, Wisconsin.

Terry proudly showed off his silver medal with the memorable imprinted message: Every Kid Needs a Superhero. He shared his journey with his support group, and Sister Rose Martin said "Warm emotion showed in his smile and conviction that this is a sacred heart-filled value to have embraced in repeated actions!"

It took Terry thirty-five minutes to reach his dream and many meaningful hours of practice to achieve it. He feels he can collect enough winnings to purchase sports equipment for the kids at the Boys & Girls Club. In a few words, he said "I feel I have slowed down my Parkinson's with these goals in my heart. I encourage everyone to run or walk with a goal in mind!"

Sister Rose Martin shared "May each of you as readers, dreamers, and miracle workers continue to share in your own way by doing whatever you can to experience joy and giving as Terry has. You can be sure that each member of our group stands tall with other groups to witness to the beautiful example of giving to others in such a God giving, loving, healing way."



St. Ann Center for Intergenerational Care
2801 E. Morgan Avenue
St. Francis, WI 53207 • 414-212-8255



MEETING TIME:
3rd Tuesday at 1:30 pm

DULUTH, MINNESOTA

WPA knows that state lines don't stop you from accessing the services and resources you need. In addition to serving groups and individuals in the state of Wisconsin, WPA also serves people who may live in Wisconsin and travel to surrounding states for group meetings, medical appointments and other services.

One support group we partner with is in Duluth, Minnesota. Located just a few miles from Superior, Wisconsin, this group is made up of members from both states, and is led by three facilitators: Joan Setterlund, Catharine Larsen, and Bonnie Niemi. Joan and Catharine have been involved in the group for a number of years, and have been leading together for the last 4 years or so. Bonnie is a good friend who started helping out in the last year.

“Get involved, and manage your own health. Know WHY you're taking the medications you are – be responsible for your disease.”

– Joan Setterlund

“After I received my Parkinson's diagnosis, I didn't join a support group right away,” said Joan. “After the shock of finding out – I just wasn't ready to face it yet.” Joan's perspective is common among newly diagnosed. She knows that many others are like her, which makes her even more passionate about the support group. “I wasn't ready to face it yet, but I know the group would have been helpful to me earlier on.”

Group members mainly come from the Duluth area, but some have come from as far as Lake Nebagamon and Ashland. Meeting attendance ranges from 20-35 or so, depending on the topic and time of year. For 2018, their goal is to have more “sharing” meetings. “The group really wants more discussion time, especially the care partners who attend,” said Joan. “We often divide up for discussion, and the care partners group might be led by Bonnie, or by my husband Jack. Catharine is a retired psychologist, so she's great at leading discussions as well.”

Meeting topics have varied throughout the last year. The group has brought in speakers on exercise, depression, medications, hallucinations and more. Local physical therapists and speech pathologists have also been invited in, and their speaker this month is an attorney talking about health care directives and estate planning, specifically geared to people with a chronic illness like PD.

The facilitators have worked hard to emphasize the importance of learning more about your disease. “Be informed, be connected!” says Joan. “Get involved, and manage your own health. Know WHY you're taking the medications you are – be responsible for your disease.”



Primrose Retirement Community of Duluth

724 Maple Grove Road
Duluth, MN 55811 • 218-728-4986



MEETING TIME:

3rd Monday from 10:00 - 11:30 am

CEDAR GROVE

Barb Skutka was recently diagnosed with Young-Onset PD, and was disappointed when she found that all of the groups in her area met during the day – a challenge since she works full-time. Through conversations with WPA staff, Barb and her husband Sean decided to start a support group in Cedar Grove.

“I felt it was too long to wait a month between gatherings, and it’s hard to get to know each other when you only meet monthly, so we added Connections.”

– Barb Skutka

Barb and Sean welcomed over 30 people at their first meeting, and many of them went out of their way to thank Barb for taking the lead and holding meetings in the evening – which is easier for many of them to attend. At the second meeting, Barb shared a handout on exercise she had gotten from WPA. The handout led to discussion on exercise, and to keep conversation moving, Barb passed out some “conversation prompts” written on index cards. One side was topics relating to care support, the other was more Parkinson’s specific.

For their November meeting, Barb invited Attorney Carole Knuppel to speak about estate planning and topics like wills, trusts, health care and financial powers of attorney, and irrevocable trusts. Carole allowed plenty of time to answer questions, and she also met with a couple of group members privately after the meeting.



After holding a couple meetings, the Skutkas wanted to build a stronger connection among group members, and started hosting a gathering called “Connections” at their home from 6:30-8 pm one evening mid-month. No RSVP is necessary, and there is no agenda or plan. The first meeting brought one member to their house. For the second meeting, 14 people came!

“I felt it was too long to wait a month between gatherings, and it’s hard to get to know each other when you only meet monthly, so we added Connections,” said Barb. “And although our disease is invariably a topic of conversation, the hope is to talk about something OTHER THAN Parkinson’s!”



Cedar Grove Public Library

131 Van Altona Avenue
Cedar Grove, WI 53013 • 920-889-9154

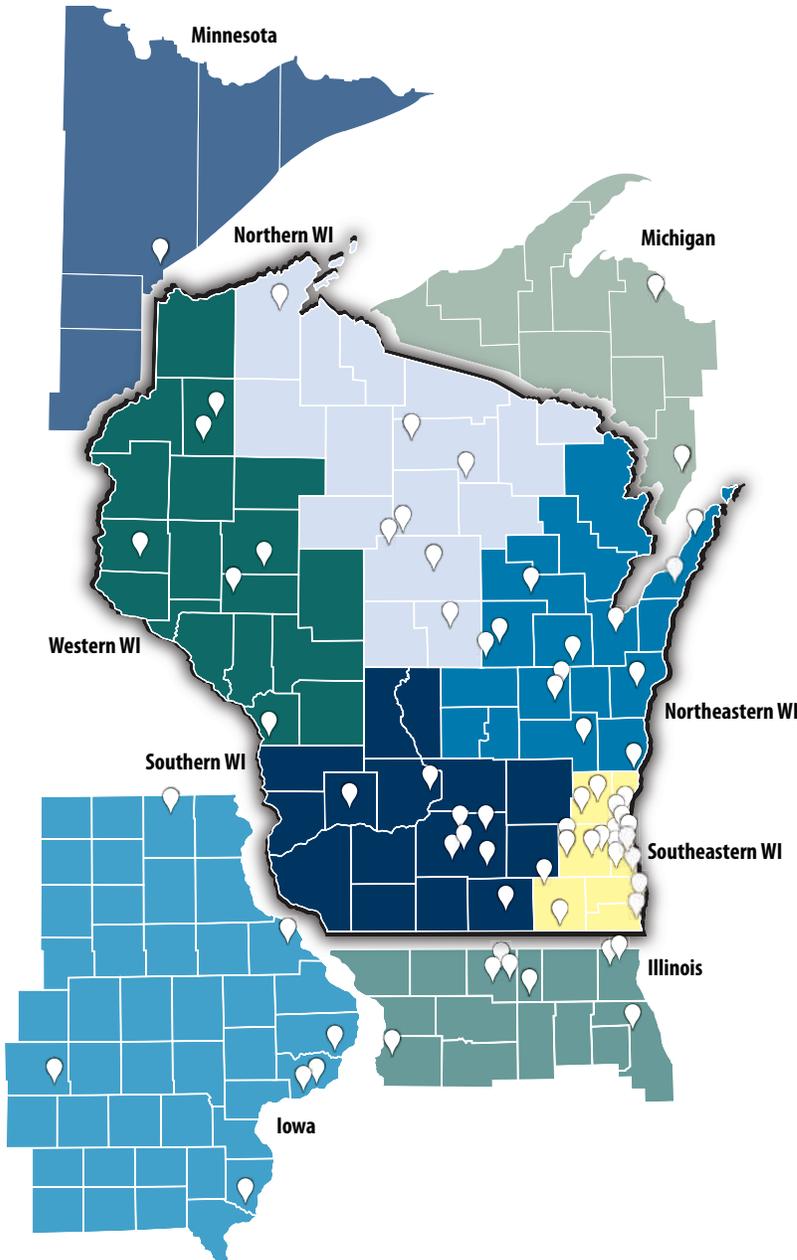


MEETING TIME:

4th Monday from 6:30 - 8:00 pm

Support Groups & Exercise Groups

WPA works with groups around Wisconsin and in surrounding areas. Groups include support groups, exercise groups, caregiver groups, and young-onset groups. Most groups are run by volunteer facilitators.



Northeastern Wisconsin

- Appleton
- Cedar Grove
- Fish Creek
- Fond du Lac
- Green Bay
- King
- Manitowoc
- Neenah
- Oshkosh
- Shawano
- Sturgeon Bay
- Waupaca

- Mequon
- Milwaukee
- Oconomowoc
- Racine
- St. Francis
- Summit
- Waukesha
- Wauwatosa
- West Allis
- West Bend
- Whitefish Bay
- Whitewater

Northern Wisconsin

- Athens
- Bayfield/Apostle Islands
- Colby
- Marshfield
- Minocqua
- Rhineland
- Stevens Point

Southern Wisconsin

- Baraboo
- Janesville
- Madison
- Richland Center
- Stoughton
- Sun Prairie
- Verona
- Waunakee

Southeastern Wisconsin

- Brookfield
- Brown Deer
- Grafton
- Greenfield
- Hartford
- Kenosha
- Lake Geneva

Western Wisconsin

- Chippewa Falls
- Eau Claire
- Hudson
- La Crosse
- Shell Lake
- Spencer

Illinois

- Belvidere
- Lake Forest
- Libertyville
- Lindenhurst
- Loves Park
- Moline
- Rockford
- Roscoe

- Clinton
- Davenport
- Decorah
- Dubuque
- Newton

Michigan

- Menominee
- Negaunee

Iowa

- Bettendorf
- Burlington

Minnesota

- Duluth



For more information
on groups in your area,
visit wiparkinson.org
or call 414-312-6990.

Support Group

NORTHSHORE

Recognizing that different group members have different needs, they often have breakout sessions for caregivers at meetings. Some of their best attended meetings have had these breakout meetings planned, where the group might watch a video clip to start discussion, then split into two groups. Attendees in both groups know what they say will be confidential, and it helps them to discuss their separate experiences.

As the trio plans for the first half of 2018, they have set goals to improve communication among group members. They want members to feel comfortable connecting to each other outside of their meetings, and know that the icebreakers and other group activities help build those relationships. “If someone misses a few months in a row, we want to call them and check in,” said Bonnie. “We want to find out what’s going on, and make sure they are ok.”

Lucia, Bonnie, and Margaret also want to make sure all group members are taking an active role in the management of their disease, and want all participants to read *The Network* magazine each quarter (**group members beware: they may quiz you on this article!**)



Jewish Community Center
6255 N. Santa Monica Boulevard
Room 1M50 • Whitefish Bay, WI 53217
414-805-5223



MEETING TIME:
2nd Wednesday from 3:00 - 4:30 pm

PARKINSON DANCE CLASS



In addition to the physical and mental benefits of weekly classes, Susanne’s classes also build up to a recital that families can attend. The recital is the culmination of months of proactive community building and provides the opportunity to highlight improvements and explore the movements participants have learned. It is a fun experience to witness!

Susanne is passionate about bringing dance to people with PD because the classes are taught by professional dancers who have been studying dance for many years. “This brings an array of dance and movement talents that are helpful to those with PD,” said Susanne. “Dance has so much to offer physically, mentally and emotionally. The artistic process is at the core and that is where the magic happens.”

Cathy Loomans is the Senior Center Director in Fond du Lac, where WPA hosted a series of dance classes last fall. “What an awesome program. We are so fortunate to be a part of this wonderful activity – thank you for bringing this to Fond du Lac!”



Whitefish Bay | Harry & Rose Samson Family Jewish Community Center
6255 North Santa Monica Boulevard
Milwaukee, WI 53217 • 414-871-1523



MEETING TIME:
Fridays from 2:15 - 3:30 pm



Wauwatosa | West Suburban YMCA
2420 N. 124th Street
Wauwatosa, WI 53226 • 414-454-4645



MEETING TIME:
Thursdays from 1:00 - 2:00 pm

Fond du Lac & Kenosha | Spring dates to be announced soon • 414-312-6990



Fee may be associated

WPA News



New Board Member

WPA welcomed Ronald Mohorek to its board of directors recently. Ron has over 30 years of experience in the health care industry with concentrated effort in the legal, strategic, business and operational aspects of health care delivery. He is also a member of our board's Governance Committee.

RECENT EVENT

Holiday Reception

On December 6, over 120 WPA supporters came to Westmoor Country Club in Brookfield for our annual Holiday Reception. **Thank YOU** for making 2017 a successful year – and here's to a bigger and better 2018!



Punt Parkinson's with the Pack

For the last 5 years, the Barbian Family has planned "Sam's GDPD Open & Punt Parkinson's with the Pack." With the golf outing and Green Bay Packers party in honor of Sam Barbian, who has young-onset PD, this wonderful family and their friends have raised over \$40,000 for education, support and exercise groups, and awareness of Parkinson's.



Samantha Barbian and Gary Garland,
WPA's Executive Director

Would you like to receive *The Network* magazine?

If you do not receive *The Network* quarterly, join our mailing list at wiparkinson.org. You will receive this magazine, as well as periodic information about educational events, support & exercise groups, and other resources in your area. This magazine is funded by your donations. Your support helps those living with Parkinson disease by allowing us to enhance and expand our services to you and your families. For more information, visit wiparkinson.org.

The mission of the Wisconsin Parkinson Association is to expand medical professional and public awareness and understanding about Parkinson disease that will lead to maximum support, the best individual healthcare, assistance for caregivers and families, and increased funding for research.



WISCONSIN
PARKINSON
ASSOCIATION

414-312-6990
wiparkinson.org
mail@wiparkinson.org

Wisconsin Parkinson Association
2819 W. Highland Boulevard
Milwaukee, WI 53208

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Upcoming Events

March 7

Milwaukee Admirals Hockey
Game benefitting WPA

March 9

Parkinson Disease: Living Well
Oconomowoc

March 16

Parkinson Disease: Living Well
Appleton

April

Parkinson's Awareness Month

April 27

Parkinson Disease: Living Well
Rothschild/Wausau

June 21

Support Group Facilitator Training
Milwaukee



More programs
are being planned
around the state.

**Visit wiparkinson.org
for more information!**

June 22

32nd Annual Parkinson
Disease Symposium
Milwaukee