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**Cover photo:** Residents of Milwaukee Catholic Home regularly gather in the solarium for tai chi exercises. Although she is in a wheelchair, Mary, front, participates with modified tai chi moves.
Dear Friends of the WPA,

I was delighted to meet and talk with many of you at the Kenton Kilmer Parkinson Disease Symposium on June 27 in Pewaukee. It was a perfect opportunity for the other board members and me to listen to your stories, your concerns, and your triumphs.

The symposium positively hummed with activity, as more than 250 persons attended on a perfect Wisconsin summer day. A continental breakfast greeted participants, and the conference started with a talk by Paul A. Nausieda, M.D., about the cause and natural progression rate of Parkinson disease. Then audience members chose one of four breakout sessions – hour-long talks given by experts in their fields – to attend in the morning: “Let’s Talk about Stress!” by Lynda Markut from the Alzheimer’s Association of Southeastern Wisconsin, “Preventing Falls for Patients with Parkinson Disease” by Lisa Hass-Peters of Froedtert and The Medical College of Wisconsin, “Young-onset Parkinson Disease” by Thomas Fritsch of the Parkinson Research Institute, and “Navigating Senior Living and Care Options” by Pam Foti and Jenny Wagner of Vesta Senior Network.

After lunch in the Grand Salon of Country Springs Hotel and Conference Center, the WPA presented its Tulip Award to representatives of Craig High School. Please turn to page 6 to read more about the ceremony and this organization’s remarkable awareness and fund-raising campaign.

In the afternoon, attendees chose one of four completely different breakout sessions: “Sleep Disruption in Parkinson Disease” by Dacy Reimer of the Regional Parkinson Center, “Resources and Networking for Caregivers” by Kathy Gale of Interfaith Senior Programs of Waukesha County, “Basic Estate Planning Issues: Help Yourself, Help Your Family” by Jerry Zimmerman of Zimmerman & Steber Legal Group, and “Practical and Inexpensive Tips to Adapting Your Home for Safety and Convenience” by Ruth Busalacchi of Synergy HomeCare.

After each talk, the audience enjoyed refreshment breaks and visited exhibitor booths, where they learned about products and services to assist those living with Parkinson’s. The symposium’s final presentation was a spirited panel discussion on exercise programs that featured Ann Brophy of Spinal Dynamics of Wisconsin, Susan Goulet of the Milwaukee Yoga Center, and Erica Vitek, an occupational therapist at Aurora Sinai Medical Center.

We do our very best to bring a wealth of information and expertise to you, our members. The Kenton Kilmer Symposium is our signature annual education event, and attendees’ input helps to determine the content. Each conference participant completed an evaluation that lets us know what went well, what didn’t, and what topics we should consider including next year.

We hope you found the education conference to be of value and that you gleaned information that will help you in your journey with Parkinson’s. Education, outreach, and research form the focus of our services to you. If you have any questions or if we can help, please give us a call. We look forward to seeing you at next year’s symposium.

Sincerely,

Richard Schumann
One of the best parts of my job is meeting the individuals involved in supporting WPA’s mission – to expand medical professional and public awareness and understanding about Parkinson disease that will lead to maximum support, the best individual health care, assistance for caregivers and families, and increased funding for research. Though there is only one mission, there are many individuals who support the WPA in their own special ways. There is no right way to help, and the only wrong way is to not help or not use your unique skills.

The WPA has been “uniquely” supported through monies raised at cookouts and car shows, bowling and golf tournaments, Elvis tributes, motorcycle rides, runs/walks, formal galas, informal parties, and the sales of beautiful artistry products. Other ways include in-kind donations of artwork, computer software, and professional expertise or by being named the beneficiary of an estate or private foundation fund. It is the coming together of all these various ways of support that makes the WPA a community, a viable, local nonprofit providing much-needed education and support for those affected by Parkinson disease.

Each of us has a talent, interest, connection, or passion that we can use to help the WPA. The avenues of support are as unique and varied as our members. For example, one of the WPA’s members, Norma, not only facilitates two support groups and gives of her time and energy but, additionally, she collaborated with a local brewery to acquire several of their beer growlers, on which she painted beautiful nature- and sport-themed pictures and then donated all the financial proceeds to the WPA. Another example: Ed, who serves on the board of directors, is involved with committee work, and is a regular sponsor of WPA events – but he also has established a private memorial fund at the Greater Milwaukee Foundation that provides some financial assistance to the WPA/PRI Brain Bank and its ongoing expenses related to Parkinson disease research. Though Ed will tell you it is easy to set up such a fund (he invites you to call him at 262-542-7654) and that the Greater Milwaukee Foundation makes contributing to the WPA almost a painless form of giving, it was his unique gifts and interests and following through that have led to this beneficial support of the WPA. Those are only two examples of the many I wish I could share with you because each is uniquely interesting and needed.

So my challenge to each of us is to ask ourselves – what am I uniquely in a position to do to support the WPA? For some, it might be that you are in a position financially to write that big check to help fund a research project at the WPA/PRI. For others, maybe you have the gift of time and can start a new support group or volunteer to chair next year’s WPA gala or plan your own community fund-raising event involving your hobby or professional organization. I look forward to meeting the unique you and learning about how you uniquely are supporting the WPA.
Events Calendar

**Tuesday, September 16**
WPA Open against Parkinson Disease
Presented by HeatTek, Inc.
The Legend at Brandybrook (Wales, WI)
Registration and information: 414-219-7061

**Thursday, September 18**
WPA Newly Diagnosed Workshop, free presentation
Milwaukee Heart Institute of Aurora Sinai Medical Center (Milwaukee, WI)
Registration and information: Jeremy at 414-219-7065

**Friday, October 10**
WPA “Living Well” Conference, free presentation
Rockford, IL
Registration and information: Jeremy at 414-219-7065

**Wednesday, December 10**
WPA Annual Board Meeting
Milwaukee, WI
Open to WPA members; details: 414-219-7061

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**On Tuesday, September 16, the third annual WPA Open against Parkinson Disease, held at The Legend at Brandybrook, one of the most beautiful golf courses in Wisconsin, will offer:**

- limited field of golfers – reply early to ensure your inclusion
- 18 holes with golf cart
- choice of flights – best ball or scramble format
- limited on-course events to focus on quality golfing
- cookout lunch, on-course beverages, cocktail hour, and plated dinner
- silent auction and wine pull
- shotgun start at 12:00 noon; event ends by 7:30 p.m.

**For WPA Open guests:** a bed-and-breakfast package at The Delafield Hotel with a courtesy shuttle to and from the golf course.

Don’t golf? Come for the elegant dinner, or share this information with a friend!

**For more information and to register for this event, call 414-219-7061!**
Would You Like to Receive The Network?

If you enjoy reading The Network, find it to be a valuable resource, and would like to receive future magazines, act now! See the donation envelope included in this issue for details.

The Membership Tulips ARE IN BLOOM!

A special thank you and welcome to our new Tulip Club members who have joined the WPA at the membership level of $250 or greater. We appreciate your joining with us in support of those with Parkinson disease, and we look forward to seeing you at a special thank-you reception this fall.

If you are not yet a member of the WPA, we invite you to join us – and if you are, consider increasing your membership to become part of the Tulip Club.

The Tulip Club ($250 or more) includes:

Ron and Nancy Muehlhausen
Harold Nigbor
Cheryl Prescott
George and Judi Prescott
Donald and Beverly Randall
Betsy and Bill Reilly
Jean Rinka
Roger Ritzow
George and Sandra Roemer
Wayne and Barbara Sommer
Ed Vojtk
Peter and Irene Weber
Mark and Virginia Wooster

YOUR LOGO HERE!

Become a Sponsor of The Network!

Published four times a year, the WPA’s magazine reaches a readership specifically interested in addressing the issues and challenges of Parkinson disease.

Have your business name affiliated with philanthropy by sponsoring The Network through a charitable contribution to support the WPA’s mission.

For more details, please contact Jeanine Bly at 414-219-7024 or jeanineb@wiparkinson.org.
The Kenton Kilmer Symposium on June 27 attracted approximately 250 attendees and 30 exhibitors at the Country Springs Hotel and Conference Center in Pewaukee. In addition to talks given throughout the day, the WPA presented its 2014 Tulip Award to representatives of Craig High School for their Pace for Parkinson’s run/walk.

The Wisconsin Parkinson Association created the Tulip Award in 2009 to recognize a worthy individual, couple, family, or group that has shown through their actions a dedication and commitment toward helping people with Parkinson disease, educating the public about Parkinson disease, and supporting research to discover the cause, cure, and better treatment options.

Pace for Parkinson’s organizers Cherie Farrell, Tricia Jones, and Michelle Meier accepted the award.

In 2011, staff and students of Craig High School in Janesville, Wisconsin, inaugurated Pace for Parkinson’s to honor their retiring principal, Dr. Michael Kuehne. In a closing goodbye assembly, Dr. Kuehne informed the staff that he had been diagnosed with Parkinson’s. Two staff friends, Cherie Farrell and Emily Dresen, knew they had to do something to raise awareness of this disease, “so we joined forces with an amazing committee” and started Pace for Parkinson’s, a 5K run and 1-mile family fun walk held in Riverside Park, Janesville.

The first year began with a little more than 100 participants; this year, the fourth, drew more than 300.

The high school’s Craig Cougar mascot and Snappy the Turtle were joined by the Milwaukee Brewers Famous Racing Sausages at the event, which was followed by a volleyball tournament and additional fund-raising activities. The cumulative total raised over the past four years is nearly $40,000.

Cherie and Emily say, “This committee wanted to raise awareness, help others, give support, and honor an amazing man who will always mean so much to us. We are already planning the fifth annual Pace for Parkinson’s and can’t wait!”

Every step of the way, the event has been a community endeavor, involving not only the school’s students, teachers, and staff but individuals, families, and area businesses as well. Craig High School has unquestionably raised awareness of Parkinson’s, created goodwill in the community, and generously financed education, support services, and research to help others who live with Parkinson disease.
Community Fund-raisers

Support the Work of the WPA

Generous community efforts help the work of the Wisconsin Parkinson Association, a charitable nonprofit organization, in delivering information and services to those living with Parkinson’s. Over the years the WPA has received donations from – regular readers of this magazine will recognize the names – “All Shook Up” for Parkinson’s, Kenny’s Kettle Moraine Run/Walk for Parkinson’s, Reuben Orr’s “Bowling for a Cure,” and the Gordon Ferguson Yackle .10K Run against Parkinson’s. We will always remember with gratitude the bigheartedness of the people who have organized these events. You have raised money, awareness, and hope.

On May 17, the annual LaVerne Brewer Memorial Golf Outing to benefit the Wisconsin Parkinson Association made its seventeenth and final appearance on the links. The event at Ironwood Golf Course was again successful and well-attended, but the Brewer family has decided that the outing had achieved what it set out to do – honor their mother’s memory and raise money to help others – and it was time to put the clubs away. During those years, the golf outing grossed a total of approximately $300,000. To the Brewer family, our profound thanks.

A new event “entered the building” June 5 through 8 at The Reel Inn in Necedah, Wisconsin. “Rockin’ with the King,” an Elvis tribute artist competition with a Memphis-style barbeque and classic car show, was hosted by Elaine Bomback Wesley – whose father has Parkinson’s – and her husband, Garry. It attracted more than 300 people even though the car show was cancelled due to rain. The WPA’s board president, Richard Schumann, was on hand to accept the donation. Thank you, Elvis artists, fans, and people of Necedah. You are rock stars!

On April 26, with Craig High School’s own Craig Cougar and Snappy the Turtle, Pace for Parkinson’s runners and walkers were joined by the Milwaukee Brewers Famous Racing Sausages at Riverside Park in Janesville. (Coincidentally, the Chorizo Sausage was a graduate of Craig High School.) In the fourth year of this fund-raiser, 317 people participated, and the event raised more than $13,000 for Parkinson’s education, support, and research. On behalf of those who are challenged by movement, thank you for running, walking, and smiling.
What is the Progression Rate in Parkinson Disease?

by: Paul A. Nausieda, M.D.
Medical Director
Regional Parkinson Center

Getting a diagnosis of Parkinson disease is only the first step in dealing with this disorder. Every patient has probably heard the classic trilogy of comments that follow diagnosis: it is incurable, it is treatable, it is progressive. The first two items are pretty straightforward in most diseases; the third comment tends to be most controversial, and, unfortunately, that is the issue most relevant to patient and family. You think we would have a definite answer to how progressive Parkinson disease really is, but multiple studies come up with very divergent information on this topic. Let me review what has been said in the medical literature.

Initial studies in the 1970s following the introduction of levodopa treatment stated that life expectancy had been restored to normal. Prior to an effective treatment, data suggested an eight-year decline in life expectancy in Parkinson disease, so this was a major change in prognosis. In the late 1970s, a number of studies suggested that disability progressed even in the face of levodopa treatment, though it was unclear how much disability was due to the disease itself or the limitations in treatment that were caused by side effects of levodopa. The other factor that was ignored was the effect of advancing age – the average age of patients in most of these studies was 75 to 80 when data collection started, so most patients were quite elderly during the period of analysis. Progressive disability is not a prominent feature in studies looking at young-onset Parkinson disease, and some recent studies suggest that aging is the basis of most of the declines in performance seen in older patients.

Most of these studies involved relatively small numbers of patients. When the Medicare database became available for analysis, very interesting data was generated. In one study done about four years ago in a population of 500,000 patients who were age- and disease-matched to a control group (that is, a group that was the same age, sex, and had the same disease codes as the Parkinson group), it was found that the Parkinson group had longer life expectancy than the control population during the subsequent fifteen-year period of follow up. Life expectancy differences were less at fifteen years, but this population was 80 years old at this point. A second study found that Parkinson patients had a significant reduction in life expectancy if dementia was present, and survival beyond five years was unusual in this subgroup. Given the limitations of using data from Medicare, it was impossible to draw any further information from the data that lacked clinical information of the treatments being used or the overall condition of the patients. Autopsy confirmation of the diagnosis was not available nor was the specific cause of death.

In the last ten years, a hypothesis was developed about the cause and course of Parkinson disease based on autopsy data in 41 patients with Parkinson disease, cases of 69 patients without symptoms of PD who had autopsy findings consistent with the diagnosis, and 58 autopsies in patients without symptoms of PD and no pathologic findings to suggest the diagnosis. Based on this material, German anatomist Heiko Braak and colleagues suggested that PD might be due to a prion (an infectious agent similar to the one that causes mad cow disease) that enters the brain via the gastrointestinal tract or nose, then invades the brain through nerve cells in the gut or olfactory system, and progressively spreads in the brain. Without going into all the details of the studies, the theory would suggest that all cases of PD relentlessly progress once they start and...
ultimately result in dementia as the disease invades the cerebral cortex of the victim. In various papers, Braak and his colleagues suggest that dementia would occur in ten to fifteen years preceded by significant disability and ultimately resulting in death. This hypothesis has been very popular with neurologists in spite of the lack of data to support its validity. Exactly why this should be the case is an interesting question. It has been used to justify the early use of invasive treatment approaches such as deep brain stimulator placement as well as potentially hazardous experimental treatments such as fetal cell implantation or genetic manipulation of various brain areas. It is impossible to know how much this has influenced the reception of this hypothesis, but Braak’s theory comes in handy for justifying less-conservative treatment approaches. Let me just say that Braak’s data is not entirely consistent with his hypothesis, and PD has never been shown to be transmissible – a feature consistently shown to be true in other prion-related disorders.

In this issue, we are showing you data derived from our own patient database and our Brain Bank series. We have the advantage of being able to analyze data from our own center rather than relying on information from outside sources, and our clinical data in each case is far more extensive than that available in any other study conducted. If Braak and his colleagues are correct, our data should be consistent with their hypothesis, and it is not. The data suggests that dementia does have an important effect on outcome and is consistent with the Medicare studies noted above. It also shows that many patients can have Parkinson disease for periods longer than Braak would predict. In that sense, it is consistent with the observation that PD patients may have a longer life expectancy than individuals who do not have the disorder. You will see that dementia is noted in almost two-thirds of the cases in our autopsy series, but this is probably because families taking care of patients with dementia seem more inclined to participate in the Brain Bank registration program (as do families of patients with non-Parkinson disease syndromes), so these cases are overrepresented in this series. Our cases also exclude those in which Alzheimer’s disease was thought to be present based on the post-mortem findings.

Overall, I think that our own data fails to support the premise that Parkinson disease is a relentlessly progressive disorder with a uniformly grim prognosis. Clinically, many cases of Parkinson disease seem to stabilize after a period of five to ten years and no longer increase in severity. The fact that antiparkinson medications have side effects that increase in frequency after longer periods of administration is a distinct problem, which is the focus of our trials of experimental treatment agents to control this complication, but this is an independent issue that is amenable to treatment. One of the biggest problems we deal with in long-term management is the patient who “gives up.” The Braak model does nothing to reduce this problem and can facilitate its development. For this reason alone, I think that clinicians who attribute every difficulty encountered in the course of Parkinson disease to progression of the disease itself miss the opportunity to find better treatment options and fail to work with patients and families to maintain independence and an active life in their patients. The support of patients and families in our research programs and the Brain Bank have been invaluable to our ability to analyze this significant issue and are an example of how continued research can help clarify our knowledge of Parkinson disease.
Ask the Doctor

by: Kathryn Gaines, D.O.
Neurologist
Aurora Advanced Healthcare

Disclaimer: Below are brief answers to people who have written in with questions; however, please note that my advice should not take the place of having a conversation and formulating a treatment plan with one’s own neurologist or treating physician.

Why am I so tired all of the time? Is it condition-related? Is it medicine-related? Probably both. It takes a lot more effort to maneuver about one’s day with Parkinson disease. Simple tasks we often take for granted become more challenging to one with PD because one has to overcome the slowness of movement, tremor oftentimes, and stiffness that hallmark the diagnosis. And if tremor is excessive, this is constant, uncontrolled activity that expends energy and effort. The same can be said for medication-induced movements known as dyskinesia. Add on top of that the loss of dexterity, which can be frustrating and energy expending.

Sleep issues as well may cause fragmented sleep or non-restful sleep for various reasons, and thus daytime sleepiness becomes an issue.

Most of the Parkinson’s medications can cause sleepiness; some are more problematic than others. If the sleepiness ensues after the introduction of a new medication and is significant, rethinking the new medication is in order.

Parkinson’s disease is no proverbial walk in the park.

A focused approach to maximize sleep at night, proper nutrition and exercise to build endurance, and titration of medication with an effort to gain the most benefit and limit side effects is recommended. When all else fails, it helps to try to time the most important activities of the day to be completed during one’s anticipated best “on” time and best anticipated energy level of the day.

What exactly is freezing, and what does it mean for me? Commonly, the term “freezing” refers to one’s inability to smoothly ambulate or turn without having episodes during which the feet (or foot) seem to get stuck to the floor momentarily. Sometimes this episode of freezing just lasts a split second, but sometimes people can get “stuck” for more than a few minutes. Of course, this is very frustrating and can be dangerous because the freezing often accompanies loss of balance and falling. Various techniques are employed to overcome the freezing. These are “tricks” that are learned through trial and error; however, the most effective approach to freezing includes a regimen of physical therapy we often refer to as BiG therapy. It is difficult to treat freezing with medication alone, although there are instances in which freezing clearly is responsive to Parkinson’s medicine. Freezing does not occur only when one is walking but can happen with various other tasks, including even speech – but by far the most common type of freezing I see involves walking.

Ask the doctor! Send your questions about Parkinson disease by mail to “Ask the Doctor,” Wisconsin Parkinson Association, 945 N. 12th Street, Suite 4602, Milwaukee, WI 53233 or email to mail@wiparkinson.org and put “Ask the Doctor” in the subject line.
I just love summer and fall for the bounty they bring. People often ask me, “What is floating in your water bottle?” because I enjoy plucking spearmint from my garden to freshen my water along with a wedge of lime. I’m not one for those artificially flavored waters or drops because pure foods just make me feel healthier. That mint floating in my water has opened many conversations on herbs and natural medicine with my patients that I don’t think would have come up on a typical visit. I would like to share some of those discussions on complementary medicines with you.

People tend to assume that homeopathic remedies are more natural and less toxic. In fact, many patients omit them when discussing their medication list assuming that they have no relevance to prescribed drugs. This couldn’t be further from the truth. You may not be aware, but there are many herb/herb or herb/drug interactions. Many medicines are derived from plants and are extremely toxic. Take belladonna, for example. My daughter read that using teething gel with benzocaine (used to numb the gums) was not good for a baby. Instead she confidently picked up a homeopathic brand and began using it. I asked to see the label and it contained belladonna. This would have been great if we were still in the Middle Ages when it was used for surgical anesthetic; however, it caught me by surprise since to this day belladonna (known as “deadly nightshade”) is the most poisonous plant in the Northern Hemisphere. Mothers would shudder at the thought of putting it into a baby’s mouth if more details were listed, but with “homeopathic” on the label, it is assumed to be safe.

Whether plant or pill, once ingested, the body breaks it down into enzymes it can use. This can get pretty complicated and I will not give you a crash course on pharmacology, but the enzyme system each one uses is important, especially if it is cytochrome P450 3A4. This is a common enzyme found in the liver and intestine. Combinations of certain plants/herbals (and even grapefruit juice) can significantly increase or decrease the potency of medications. Below is a list of potential interactions with frequently used Parkinson, anxiety, and depression medications and their effects.

**S-Adenosyl-L-methionine (SAMe)** Studied for use in depression, but the research is inconclusive; sold as a dietary supplement. Results of a study completed in January 2013 comparing SAMe versus citalopram versus placebo in Parkinson’s have not been released to date.

- **Decreases** the effects of levodopa in treating Parkinson disease
- **Increases** the effects of antidepressants and St. John’s wort

**Kava** Part of the pepper family. Thought to help anxiety. USDA issued a warning against use due to liver damage.

- **Increases** the effects of PD medications.
  Associated with an increase in involuntary movements and dystonia (painful muscle cramping)
St. John’s wort Marketed to treat depression. Combining St. John’s wort and certain antidepressants can lead to a potentially life-threatening increase in serotonin levels (called serotonin syndrome).
  - Increases the risk for psychosis in bipolar disorder
  - Decreases the effects of antidepressants, digoxin (a heart medication), some cancer medications, and warfarin and other blood thinners; also, can increase feelings of anxiety because it is a stimulant

Valerian root Marketed to treat insomnia and anxiety. Research shows it may be useful to treat insomnia for short periods – four to six weeks – but there is not enough evidence to support claims that it helps anxiety (anything that sedates you will have the potential to calm you). Long-term safety is unknown.

In seeking natural treatment, I think it is important to point out that the most natural medicine we use in treating Parkinson disease is levodopa. Levodopa is a naturally occurring amino acid found in some foods and converted in the brain to dopamine. It is the most potent treatment for Parkinson disease for that very reason. If you are diabetic and your body no longer produces insulin, you need to replace it via injections. If you are low on calcium, vitamin D, or thyroid, you take supplements to replace them. Levodopa is the same concept. Dopamine agonists such as Requip (ropinirole), Mirapex (pramipexole), and Neupro (rotigotine) are not naturally occurring agents and are synthetically made.

Powdered cowhage (also known as cowitch, cowitch plant, kapi kacchu, mucuna, Mucuna pruriens, and velvet bean) Sold as an alternative to taking carbidopa/levodopa. Studies show there is insufficient reliable evidence. Be careful not to let the claims that 30 mg of one is better than 1,000 mg of levodopa. It just sounds like less; however, the claim states it is just as potent – but the claim omits toxicity information.

There are many manufacturers of a variety of levodopa powders, and the problem is in the variance of dosage. These products are not under the scrutiny of the FDA for strength, dose consistency, or side effects. In fact, one of the uses for powdered cowhage or velvet bean is to induce vomiting. Therefore, the purpose of carbidopa in carbidopa/levodopa is to block the effect of vomiting and allow greater uptake of the amino acid levodopa. My suggestion is neither to reinvent the wheel nor play chemist. Many years of research have gone into levodopa treatment, and the side effects and dosages are known. If you have a strong leaning toward natural therapeutics, take carbidopa/levodopa into consideration over these alternative options.

This list is not comprehensive. It is a sample of some of the herbals I have been recently asked about. To learn more, the U.S. Department of Health and Human Services, National Institutes of Health, National Center for Complementary and Alternative Medicine (NCCAM) has a comprehensive site summarizing current research on all complementary medicines, exercise, and treatment. Visit http://nccam.nih.gov/. I encourage you to investigate all plant or herbal treatments prior to use to check for any interaction and validity of claims, and please report use to your care providers.

In the next issue of The Network, I will be discussing each of the antiparkinson medications and the drug-to-drug interactions you should know about to stay healthy. Stay well! 🌿
With soft music playing in the background, the man moves smoothly and with purpose, bending his knees, shifting his weight carefully from one foot to the other. Everyone else in the tai chi class is raising and lowering their arms in the same way, but for him it is different – he has Parkinson disease, which for years has made any kind of movement a challenge for him.

Tai chi is an ancient martial art that promotes calmness of mind and body. It can be practiced safely without special equipment and in any space, alone or with others. One of the most problematic symptoms of Parkinson’s is a loss of balance, which leads to falls that can cause severe injury. People living with Parkinson disease have discovered the benefits of the controlled stretches, strengthening, and fluid motions that help to alleviate anxiety and may potentially improve balance.

Ann Brophy, a physical therapist with Spinal Dynamics of Wisconsin in Wauwatosa, has a special interest in spinal rehabilitation for Parkinson patients and integrates some key movement patterns from tai chi into her clients’ home exercise programs. Because challenges for those with Parkinson’s include single leg balance, rotational movements, and maintaining upright balanced posture, Ann says, “I pick and choose those movements that are part of the tai chi form – mostly basic weight shifting and hip mobility movements – that are appropriate for patients’ needs. I encourage them to use the back of a chair or countertop if balance is a safety issue.” She incorporates the tai chi movements because “the literature supports improvements in balance and coordination, lower extremity strength, ankle range of motion, and even a mild aerobic benefit.”

Claire Walchli, T.C.I., is a Level 3 certified tai chi instructor with Tai Chi Fundamentals in Milwaukee; she also is an instructor at Waukesha County Technical College. Claire modifies her tai chi teaching so that those with physical challenges can benefit from the discipline. Participants begin seated in chairs for warm-up exercises; after several minutes, they have the option of standing with a chair nearby for support or continuing the exercises seated. In addition to gentle stretching and range-of-motion movements, Claire includes visualizations – “moving meditation,” she calls it, and she creates an atmosphere of peace and positivity to go along with the physical actions.
Mary, who attends Claire’s weekly class at Milwaukee Catholic Home, has had Parkinson’s for seven years. “I practice this every day because it relaxes me and helps with anxiety,” she says.

Claire also offers modified tai chi to seniors at the Regency in Brookfield and at San Camillo in Wauwatosa. Dolores, a resident at the Regency, thought she’d try out tai chi after living with Parkinson’s for fourteen years. Even after only about seven weeks, Dolores said she notices that her handwriting has improved a little. She also says, “Sometimes I get into trouble (with movement) because I’m in too big a hurry, and I’m calmer after this class.”

Beverly and her husband, Gene, have lived at San Camillo for four years. Gene says, “With the amount of physical activity we do here, we probably have better stamina now than when we first arrived.” Beverly, who has had Parkinson’s since 2002, says of the class, “There are people here who are nearly one hundred years old. If they can do it, I can do it!” And she does. She holds onto her walker or a chair for support, but she stands and moves her arms in concert with Claire’s. Gene noted that while Beverly had fallen seventy-seven times in 2013, she has had only about two falls per month this year.

Two recent studies have found tai chi to be beneficial to people with Parkinson’s. Funded by the National Institute of Neurological Disorders and Stroke of the National Institutes of Health, The New England Journal of Medicine published in 2012 a study that found improvement in patients’ postural stability and reduced incidence of falls.\(^1\) A peer-reviewed study in ISRN Neurology in 2013 noted improvement in some aspects of motor function – reaction time and balance – and improved ability to complete activities of daily living.\(^2\)

Tai chi could be helpful to you. Its potential benefits include enhanced well-being, improved circulation, a sense of calmness, strengthened muscles, and possibly improved balance. As with any exercise program, two things: Be sure to check with your doctor first! And remember that consistency with any exercise program is important; tai chi is a discipline, and the benefits tend to pay off with regular practice. \textit{Zi jian!}

— Juliette Hayes

Special thanks to Claire Walchli for her generous help with preparation for this article and for her dedication to her clients. Visit her at www.taichifun.com.


Recently, a member of the WPA called us looking for medical equipment for her husband that their insurance wouldn’t cover. They were looking at paying $800 out of pocket for a stripped down version of what he needed. They contacted the WPA requesting resources to assist with the cost. Since the out-of-pocket cost would stretch their limits, I gave them names of some organizations that provide refurbished equipment. I heard back from them a couple of days later. They got the item they needed, with the extra features, for $210. They were ecstatic about the cost savings and the condition of the equipment.

With ever-changing insurance coverage, fewer medical equipment companies to choose from, and cost being an issue, you can often find yourself feeling frustrated getting equipment you need. Often, you can forgo the frustration and reach out to local agencies that will either provide the equipment to you on loan or for purchase at reduced prices.

A “loan closet” is exactly what it sounds like. You borrow equipment for a period of time and then return it to the organization you borrowed it from. This is a great option if you need something only short term but is not great if you need an item for your everyday life. If you are looking for a long-term need, there are a few organizations you can contact. These organizations deal with canes, walkers, wheelchairs, lift chairs, commodes, and more. It is best to go to their websites or contact them to learn about what they have in stock, as this changes daily.

The following organizations can assist you in getting the medical equipment you or your loved one needs. They offer refurbished equipment, host loan closets, or provide referrals.

- **IndependenceFirst Mobility Store.** With stores in Milwaukee and Madison, IndependenceFirst collaborates with statewide independent living centers to provide equipment all over Wisconsin. You can reach the greater Milwaukee-area store at 414-988-5333 or the Madison-area store at 608-243-1785 or via their website at www.independencefirst.org. They sell refurbished items and will take donated medical equipment you no longer need.

- **Katy’s Kloset** is an organization that accepts donations of used durable medical equipment and provides it on loan to people in need of items. You can contact them at 262-746-9034 or www.TeamUpWithFamilies.org to learn more about their program.

- **The Aging and Disability Resource Center (ADRC)** can provide local contact information and resources on loan closets or other refurbished equipment organizations. You can find your local ADRC at www.dhs.wisconsin.gov/adrc/customer/Map/index.htm.

- There are eight independent living centers in Wisconsin. When you contact them, they can provide referrals to loan closets or other refurbished equipment organizations in your area. To find the one in your area, go to www.dhs.wisconsin.gov/disabilities/physical/ilcs.htm.

Remember that the WPA is here to answer your questions and provide referrals when needed. If you have questions on this topic or other areas we cover, please contact me at jeremyo@wiparkinson.org or 414-219-7065.
More than sixty support groups throughout the WPA’s service area meet regularly to provide education and peer support to those negotiating the challenges of Parkinson’s. We wish to introduce you to these support groups here and in future issues of The Network. **What do support groups do? Why go to one?** We talked with members to find out what a support group offers to them.

Minocqua, “the island city” of 4,300 people, is located about 65 miles from the southern shore of Lake Superior. Norma Semling and Dennis Leith both have Parkinson’s and started the support group in 2006; people come in from surrounding towns. The group is small, but the meetings – often discussion-based – provide a forum for sharing and inspiration.

Mark Strosahl knew soon after his 2009 diagnosis that he wanted as much information as possible. As a director of human services for three counties, he knew the value of support systems; within one month, he joined a support group. "Knowledge is power," says Mark. “Everything I’ve learned thus far has been useful in dealing with the path I am on.” While things he learns in the support groups may be upsetting – not all of the information is happy and optimistic – and although he may not agree with everything he hears, he feels it is important to know as much as possible about Parkinson’s. He says, “My involvement is preparing me for my future,” and his interaction with others, as well as the support and education, have been nothing but positive.

**Minocqua Support Group**
Ascension Lutheran Church
Highway 51 South, Minocqua
2nd Tuesday at 10:00 a.m.
**Contact:** Dennis Leith at 715-358-2207
or Norma Semling at 715-545-3414

Neenah, a city of 25,000, rests on the banks of the Fox River, Lake Winnebago, and Little Lake Butte des Morts in Wisconsin. The Neenah support group has a regular attendance of twenty-five to thirty. The group previously met in Appleton where it was facilitated by Mary Peters; since moving the meetings to Neenah in 2009, it has been run by Patrick Pelkey who, himself, has Parkinson’s.

Jim Hakes was diagnosed in Atlanta six years ago and attended two support groups there. Before he and his wife moved to Neenah in 2012 to be near a grandchild, he did some research to see whether a Parkinson’s support group would be nearby. “My wife, Jean, comes with me. It’s good to be with other people who have the same challenge of Parkinson’s. We are equals, we give mutual encouragement, share information, and learn things.” He does what he can to help others because “men sometimes don’t want to admit they can’t handle this on their own.”

While Jim and Jean are relative newcomers to the Neenah group, Joanne Dekarske and her husband, Gerald, have been coming for almost fourteen years. Joanne recalls how they started out. “The doctor made the diagnosis, Gerald got pills, and we went home and thought, ‘What else is there to life besides this?’ Then we heard about a support group. The presentations are helpful. You get warm feelings and are with people who understand where you are coming from. One thing leads to another, and you become friends. Gerald and I rarely miss a meeting.”

**Neenah Support Group**
Neuroscience Group
1305 W. American Drive, Neenah
4th Thursday at 2:00 p.m.
**Contact:** Patrick Pelkey at 920-538-0144
The percentage of people with Parkinson disease who experience bothersome bladder symptoms can be debated, but the negative impact on quality of life can be profound, not only for the person experiencing the problem but also for the care partner. In previous articles, I have described conservative, one-on-one therapy treatment programs – referred to as pelvic-floor therapy – performed by a specially trained therapist with postgraduate work in pelvic health and pelvic-floor muscle function. In this issue, I would like to discuss a new medical treatment approach called “intradetrusor onabotulinum toxin A” injections, more commonly known as Botox. Botox has emerged as a safe and effective way to treat common bladder complaints experienced by people with Parkinson disease and other neurologic disorders.

The most frequent bladder complaints reported by people with Parkinson disease are included on the list of indications for bladder Botox treatment. What will benefit from the use of Botox are urinary urgency and frequency (urinating more than eight times during wake hours and more than one time during sleep hours), urinary incontinence (involuntary loss of urine), urinary incontinence associated with strong urgency (a need to get to the bathroom quickly), and small voided/urinated volumes (typically less than 150 cc or 5 oz).

When Botox is injected into the bladder muscle (detrusor), it causes a portion of the nerves to become temporarily inactive. The injection can be performed as an in-office procedure, is typically available in most urologic practices, and generally is well tolerated. A urologist would first assess the bladder using a test, such as urodynamics, an in-office study, to confirm bladder dysfunction: how the bladder and urethra (the tube that exits the bladder to empty urine) are performing their job of storing and releasing urine. The test can identify a diagnosis of neurogenic overactive bladder (NOAB)/neurogenic detrusor overactivity (NDO). NOAB/NDO are typically defined as bladder dysfunction associated with interference with the normal nerve pathways that allow for storage and release of urine. The affected bladder produces involuntary bladder contractions (squeezing of the bladder), which we feel as urgency to urinate because the nerves are no longer working correctly to calm or inhibit the contractions. The bladder is dependent on two types of nerves that help with control. In simple terms, sensory nerves help in allowing us to become aware when the bladder is full and needs to be emptied. Motor nerves trigger the bladder muscle movement/contraction to allow bladder emptying. The condition of NOAB/NDO is such that the muscle of the bladder (detrusor) does not relax enough to allow the bladder to fill with large volumes of urine, then causing premature urgency that is sometimes so strong that it results in urinary incontinence.

The results that one can expect with the use of Botox include decreasing urinary incontinence episodes; increasing volumes voided (larger amounts of urine filling the bladder); increasing bladder compliance/stretching to decrease pressure in the bladder, which reduces urgency and protects the upper urinary tract (kidneys); and improving quality of life, which supports independent living. Another important purpose for use of Botox is to take the place of bladder medications that are typically not well tolerated by people with Parkinson disease. These medications may fail to have an adequate or effective response and have undesirable side effects including dry mouth, constipation, blurry vision, and confusion. Additionally, self-catheterization may have been initiated by a physician as treatment for NOAB/NDO and failed or was ineffective.

Risk factors and complications include urinary retention (compromised bladder emptying – this is the most concerning risk but appears to be related to the size of the dose injected), urinary tract infections, fever, distant spread of the toxin (rare), and required intermittent self-catheterization, which may be the most intimidating side effect and must be discussed prior to the initiation of treatment. The effects of the Botox wear off as the nerves...
A chief concern of patients is how Parkinson disease (PD) will progress. In his article on page 8, Dr. Nausieda outlined three theories about disease progression. Here we focus on Dr. Heiko Braak’s theory of PD staging, using data from the PRI Brain Bank. According to Braak, once the illness makes its way into the brain, it progresses from the central-lower brain areas to the cerebral cortex, ending in the frontal cortex, which is immediately behind the forehead. If true, persons experiencing the full progression of PD will develop a PD dementia – memory and thinking problems and decline in self-care abilities.

If Braak and his colleagues are correct and PD spreads relentlessly to higher centers of the brain, one would expect to see changes in the cerebral cortex in patients with long-standing symptoms, and dementia should be evident clinically. Lewy bodies (LBs), the cellular inclusions that occur in the substantia nigra neurons controlling movement, would be anticipated to be seen in cells of the cerebral cortex. Our autopsy collection is now large enough to see whether our data supports such a theory. In this analysis, we did not include autopsy material resulting in Alzheimer’s disease, a frequent discovery in patients with dementia. In those cases, it appears that individuals developed two independent disorders, since the chemistry of Alzheimer’s is distinct from that of PD. The present sample is relatively “pure” in the sense that only PD autopsies are included in the analysis.

Continued on page 19

**FIGURE 1** The light-gray bars indicate the duration of PD symptoms in each individual, while the dark gray segments of each bar identify when dementia was present on clinical examination (or on the basis of neuropsychological test results).
The age of onset for each patient is not shown on the graph (average age was 64 years, consistent with PD data), nor was the cause of death indicated, though most patients died of other medical complications rather than PD. Notable is the wide variability in the duration of the disorder ranging from just under three years to over twenty-five years. Braak’s theory establishes an average life expectancy of twenty years for patients diagnosed at age 60. This number, shown in Figure 1, is based on gender, presence of tremor, age of onset, type of treatment, and delay of diagnosis from onset of motor symptoms for those diagnosed at age 60. Two-thirds of the cases show evidence of a dementia at some point in the course of the disorder, though the period of time before this became apparent varies a great deal. This percentage is rather high relative to other published studies but may reflect a selection bias due to the greater likelihood of autopsies performed in individuals with cognitive problems. Once dementia was present, there appears to be a higher chance of death in the ensuing few years, consistent with other studies that report a higher mortality rate in patients with dementia. Interestingly, the duration of the disease does not appear to correlate with the appearance of dementia, which occurs at variable intervals during the course of PD. If the Braak theory is correct, one would expect to see dementia in a more predictable pattern in individuals with longer symptomatic periods. The data shows some individuals with long periods of symptoms who never developed signs of dementia during life, while dementia appeared much earlier in other patients. Of course, one could speculate that the spread of the disease is highly variable, though this fails to explain cases in which dementia never appeared after many years of symptoms.

Every autopsy completed in our series contains a number of slides from sections of the cerebral cortex. Examination of the pathologic changes in the cortex should explain the cause of the dementia. According to Braak and fellow researchers, one would expect to see LBs and evidence of disease within the nerve cells of these areas. Interestingly, our cases fail to show pathologic involvement of the cortex in those patients who were demented, and the cause of the cognitive problems would appear to be related to some other process. One process could be the side effect of medications and therefore would not be reflected in pathologic changes in the cortex. The other explanation may be related to the neurochemical changes that are related to the damage to the dopamine system (or another neurochemical pathway that is damaged in the course of the disease). While the dopamine system is usually associated with movement control, damage to this pathway does produce behavioral changes in experimental animals, suggesting that it functions in cognitive processing as well as movement. While a large number of dopamine neurons send processes into motor control areas of the brain, the lower portion of the dopamine system projects into the frontal cortex of the brain, which is thought to control judgment and decision-making processes. We know that other neurochemical systems can be damaged in PD, and it is possible that depletion of norepinephrine, acetylcholine, or serotonin results in cognitive changes that might be thought to reflect dementia during life.

Unfortunately, cognitive processes are the most complex of human behaviors, and while we can identify that there is a problem clinically, the origin of that problem is not as obvious. While it is easy enough
to postulate that the processes causing cell damage in the dopamine system ultimately damage cells in the cortex, this does not appear to be the case in the multiple cases from our Brain Bank. This suggests that Braak’s theory is erroneous. It should also be noted that the diagnosis of “dementia” is often made on the basis of performance on neuropsychological tests. In some of these patients, the test data seems more abnormal than the patient’s clinical expression would suggest. There is a possibility that certain patterns of test performance reflect the underlying pathology of the disease and result from neurochemical changes rather than cellular damage. While we recognize that certain patterns of test performance are seen in patients with clear-cut toxicity from their medications, it is difficult to exclude the possibility that intellectual processes are interfered with as a result of neurotransmitter depletion or changes related to the administration of therapeutic doses of antiparkinson medications. A recent article in The New Yorker (April 2014) by a prominent author who has had PD for twenty years highlights this issue. While obviously a talented writer, this patient was distressed to be told he was “demented” on the basis of his performance on neuropsychological testing. Being demented on a test may not equate to the kinds of behavioral deterioration we usually associate with dementing illnesses, and we need to scrutinize our data in more detail before offering an opinion on this potential variable.

The PRI Brain Bank is an invaluable resource in trying to understand PD. Parkinson disease occurs only in humans. Animal models of PD are all flawed by the fact that damage needs to be induced by a toxin administered to the animal. There are very few autopsy collections in which detailed information about the patient is available for study along with the pathologic material. This is an obvious flaw in the Braak hypothesis, which lacks detailed information about the history of the patient during life. Our data fails to support the belief that PD is relentlessly progressive and suggests that cognitive problems, which obviously shorten life expectancy when detected, may be amenable to more specific treatment. Since the cerebral cortex cells appear to be intact in these patients, finding a way to restore them to normal function would appear to be a logical area of further investigation. The dramatic depletion of acetylcholine that has been noted in PD autopsies may have more to do with cognitive changes than currently believed. Acetylcholine depletion is known to alter memory function and forms the basis for treatment of Alzheimer’s dementia. Since we retain autopsy material, it would be valuable to look at the areas of the brain that produce this neurotransmitter (optic nucleus of Meynert and the septal nucleus) to see whether any correlation exists between the extent of damage noted and the clinical status of the patient. This area is not routinely examined in autopsies, but our data suggests that this deserves further exploration. The success in using drugs that increase acetylcholine suggests that manipulation of this chemical system offers a therapeutic approach for symptoms of dementia, and further exploration of how damage to these areas occurs might prove valuable clinically.

We are grateful to all the patients and families who have supported our work by registering in the Brain Bank program. Without their cooperation, original research like that presented here would not be possible. For information on the Brain Bank program, please contact Maggie Wallendal at 414-219-7485. 🌸
This list is current as at July 30, 2014. Please contact Raven Hamilton at 414-219-5768 or ravenh@wiparkinson.org with any changes.

To find Lewy body dementia support groups in your area, call the Lewy Body Dementia Association at 800-539-9767.

### illinois Support Groups

**Belvidere, IL**  
**exercice group**  
Keen Age Center  
2141 Henry Luckow Lane  
Tuesdays from 9:15 - 10:00 a.m.  
(fee associated)  
**Contact:** 815-544-9893

**Dixon, IL**  
Town Square Center  
102 S. Hennepin, 2nd Floor Community Room  
2nd Thursday at 1:00 p.m.  
**Contact:** 815-285-5575

**Libertyville, IL**  
Lake County Parkinson Support Group  
Condell Medical Center/Conference Center  
Condell Drive & Milwaukee Avenue (Rt. #21)  
3rd Tuesday from 7:00 – 8:30 p.m.  
**Contact:** 847-332-6497

**Northfield, IL**  
North Shore Senior Center  
161 Northfield  
Every Wednesday at 1:00 p.m.  
**Contact:** Michele Corrado at 847-784-6038

**Rockford, IL**  
**support group**  
Wesley Willows  
4141 N. Rockton Avenue  
2nd Wednesday at 10:00 a.m.  
**Contact:** Faye Ford at 815-885-4897 or Joyce Reiland at 815-229-3078

**Roscoe, IL**  
**exercise group**  
Pedaling for Parkinson’s  
Stateline Family YMCA, Roscoe Branch  
9901 Main Street  
Mondays, Wednesdays, Fridays at 11:00 a.m. (free)  
**Contact:** Ann Hankins at 608-365-2261

**young-onset group**  
Gloria Dei Lutheran Church  
4700 Augustana Drive  
3rd Tuesday at 7:00 p.m.  
Dinner meetings at 6:30 p.m.  
**Contact:** Sharon Habling at 815-398-1720

**support groups • exercise groups**  

### iowa Support Groups

**Bettendorf, IA**  
**Lewy body dementia support group**  
Trinity Medical Center  
4500 Ullica Ridge Road  
Lower Level Classroom A and B  
3rd Tuesday from 7:00 – 8:30 p.m.  
**Contact:** Elizabeth Saelens at 309-523-3880

**Burlington, IA**  
Great River Medical Center  
1225 Gear Avenue  
Blackhawk Room  
3rd Thursday at 2:00 p.m.  
**Contact:** Ruth & Bill Newton at 217-453-2481

**Clinton, IA**  
Merry Medical Center  
638 S. Bluff Boulevard  
South Campus Board Room  
2nd Saturday at 10:00 a.m.  
**Contact:** Don & Rita Schneider at 563-243-5585

**Davenport, IA**  
Center for Active Seniors  
1035 W. Kimberly Road  
3rd Saturday from 10:00 a.m. – Noon  
**Contact:** Eileen Benson at 563-332-6497

**Decorah, IA**  
Winnereskie Medical Center  
901 Montgomery Street  
4th Wednesday at 1:30 p.m.  
**Contact:** Linda Klimesh at 563-387-3038 or Dawn Milligan at 563-387-3146

### indiana Support Groups

**Notre Dame/South Bend, IN**  
Michiana Parkinson Support Group  
Holy Cross Village, Andre Place  
54515 State Road 933 North  
1st Monday from 1:00 – 3:00 p.m.  
**Contact:** Dawn Hatch at 574-262-1739

### michigan Support Groups

**Calumet, MI**  
Aspirus Keweenaw Home Health & Hospice  
311 Sixth Street  
2nd Monday at 1:00 p.m.  
**Contact:** Sarah Baratono at 906-337-5708

**Menominee, MI/Marinette, WI**  
Harbors  
1110 Tenth Avenue  
3rd Thursday at 10:00 a.m.  
**Contact:** Patricia Ihler at 906-863-9445

### wisconsin Support Groups

**Appleton, WI**  
**support group**  
Touchmark at West Prospect  
2601 Touchmark Drive  
3rd Thursday at 2:00 p.m.  
**Contact:** Rachel Watkins-Peterson at 920-832-9100  
**young-onset group**  
Emeritus at Fox River  
5800 Pennsylvania Avenue  
2nd Thursday at 6:00 p.m.  
**Contact:** Margaret Foth at 920-735-0477 or Margaret Kaspar at 920-915-5488

**Baraboo, WI**  
**support group**  
First Congregational United Church of Christ  
131 Sixth Avenue  
3rd Monday at 2:00 p.m.  
**Contact:** Sylvia Kriegl at 608-356-7096 or Geri Schoenoff at 608-356-3473

**Dubuque, IA**  
Stonehill Adult Daycare Center  
3485 Windsor Avenue  
4th Saturday at 10:00 a.m.  
**Contact:** Gerald Osterhaus at 563-582-7313

**Newton, IA**  
Wesley Park Center  
500 First Street North  
Garden Room  
3rd Monday at 1:30 p.m.  
**Contact:** Eloise Prater at 641-791-1018 or Maralyn Stull at 641-791-2299

**Washington, IA**  
United Presbyterian Home  
1203 E. Washington Street  
2nd Tuesday at 3:30 p.m.  
**Contact:** Amy Kleese at 319-653-5473

### All Groups

**Appleton, WI**  
**support group**  
Touchmark at West Prospect  
2601 Touchmark Drive  
3rd Thursday at 2:00 p.m.  
**Contact:** Rachel Watkins-Peterson at 920-832-9100  
**young-onset group**  
Emeritus at Fox River  
5800 Pennsylvania Avenue  
2nd Thursday at 6:00 p.m.  
**Contact:** Margaret Foth at 920-735-0477 or Margaret Kaspar at 920-915-5488

**Baraboo, WI**  
**support group**  
First Congregational United Church of Christ  
131 Sixth Avenue  
3rd Monday at 2:00 p.m.  
**Contact:** Sylvia Kriegl at 608-356-7096 or Geri Schoenoff at 608-356-3473
Bayfield–Apostle Islands, WI
support group
Location and meeting times vary; call for information
Contact: Jeff Obst at 715-209-0807

Brookfield, WI
support group
Brookfield Regency
777 N. Brookfield Road
1st Thursday at 2:30 p.m.
Contact: Jeremy Otte at 414-219-7065

support group
Brookfield Public Library
1900 N. Calhoun Road
3rd Tuesday from 2:30 – 4:00 p.m.
Contact: 414-805-8326

exercise group
Brookfield Senior Community Center
2000 N. Calhoun Road
Tuesdays & Thursdays at 10:30 a.m.
(fee associated)
Contact: Lisa Glenn at 262-796-6675

Brown Deer, WI
exercise group
Rite-Hite YMCA
9250 N. Green Bay Road
Tuesdays & Thursdays at 1:30 or 2:00 p.m.
(fee associated)
Contact: Megan Radowski or Liz Paly, PT, at 414-354-9622

Chippewa Falls, WI
support group
Trinity United Methodist Church
201 W. Central Street
1st Wednesday at 1:30 p.m.
Contact: Ursula Whelan at 715-723-3726

Eau Claire, WI
support group
Sacred Heart Hospital
900 W. Clairemont Avenue
Conference Room 15
3rd Tuesday; call for time
Contact: Elizabeth Milanowski, RN, at 715-831-1045

Fish Creek, WI
exercise group
Door County YMCA
3866 Gibraltar Road
Tuesdays & Thursdays at 11:00 a.m.
(fee associated)
Contact: Carol Ash, PT, at 920-868-3660

Fond du Lac, WI
support group
Aurora Health Center
210 Wisconsin American Drive
2nd Floor Meeting Room
2nd Monday at 10:00 a.m.
Contact: Cheryl Leonard at 920-477-5222
or Cathy Foster at 920-907-0117

exercise group
YMCA
90 W. Second Street
Tuesdays & Thursdays from 1:00 – 2:30 p.m.
(fee associated)
Contact: Celia Crespo, PT, DPF, at 920-921-3330 x 337

Grafton, WI
exercise group
Form & Fitness
2020 Cheyenne Court
Tuesdays & Thursdays at 2:00 p.m.
(fee associated)
Contact: Teresa Steffen, PT, at 262-512-0206

Green Bay, WI
support group
Aging & Disability Resource Center
300 S. Adams Street
2nd Tuesday at 1:00 p.m.
Contact: Mary Beth Fumelle at 920-655-3715

support group
SS. Edward and Isidore Parish
3667 Flinthill Road
4th Wednesday from 10:00 – 11:30 a.m.
Contact: Carol Mueller at 920-655-0451

exercise group
The Aquatic Center for CP
2801 S. Webster Avenue
Mondays & Wednesdays from 11:00 – 11:45 a.m.
(fee associated)
Contact: 920-403-7665

exercise group
PWR! Fitness
Aurora BayCare Sports Medicine Center
1160 Kepler Drive
Mondays, Wednesdays, Fridays
at 10:00 a.m. ($5 per class)
Contact: Kelly Geri, PT, at 920-288-5400

Greenfield, WI
exercise group
Southwest YMCA
11311 W. Howard Avenue
Mondays & Thursdays at 1:00 p.m.
(fee associated)
Contact: J.T. Mathwig, PT, or MaryEllen Humpal, PT, at 414-546-9622

Hartford, WI
exercise group
Aurora Medical Center Washington County
1032 E. Sumner Street
Rehab Department
Tuesdays & Thursdays at 12:30 p.m.
(fee associated)
Contact: Kim Beimel, PTA, or Meg Bowen, PTA, at 262-670-7233

Hudson, WI
support group
Hudson Hospital and Clinics
405 Stageline Road
2nd Tuesday at 10:00 a.m.
Contact: Marilyn Schuchman at 715-386-1849

Janesville, WI
support group
Cedar Crest
1702 S. River Road
1st Wednesday at 2:00 p.m.
Contact: Darlene Larson at 608-754-4549

exercise group
SOL Fitness
4113 Whitney Street
Wednesdays from 9:00 – 9:45 a.m.
(fee associated)
Contact: Connie Udell at 608-302-7088

Kenosha, WI
support group
Brookside Care Center
3506 Washington Road
Southport Room
1st Wednesday at 2:00 p.m.
Contact: Julie Topolovec at 262-657-7276
or Dave Gourdoux at 262-694-6156

King, WI
support group
Wisconsin Veterans Home at King
422 Bell Avenue
3rd Wednesday at 1:15 p.m.
Contact: Michael Izzo at 715-252-2592

La Crosse, WI
support group
Gundersen Lutheran Hospital
1900 South Avenue
4th Tuesday at 2:00 p.m.
Contact: Julie Holzwarth at 608-782-7300

The Network, summer 2014
Wisconsin Parkinson Association
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<thead>
<tr>
<th>Location</th>
<th>Group Type</th>
<th>Meeting Details</th>
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<tr>
<td>Madison, WI</td>
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<td>4th Wednesday at 3:00 p.m.</td>
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<td>Contact:</td>
<td>Katie Lowe at 608-663-8600</td>
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<td>3527 University Avenue</td>
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<tr>
<td></td>
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<td>Fridays from 2:00 – 2:45 p.m.</td>
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<tr>
<td></td>
<td>(fee associated)</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>608-233-2577</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Harbor Athletic Club</td>
</tr>
<tr>
<td></td>
<td></td>
<td>2529 Allen Boulevard, Middleton</td>
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<tr>
<td></td>
<td></td>
<td>Multiple meeting days and times for PD</td>
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<tr>
<td></td>
<td></td>
<td>exercise, Zumba, PDGlee, PD in Motion</td>
</tr>
<tr>
<td></td>
<td>(fee associated)</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>608-831-6500</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Madison Senior Center</td>
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<tr>
<td></td>
<td></td>
<td>330 W. Mifflin Street</td>
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<tr>
<td></td>
<td></td>
<td>Tuesdays at 10:30 a.m. (fee associated)</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>608-266-6581</td>
</tr>
<tr>
<td></td>
<td>exercise group</td>
<td>UW Health Sports Medicine Center</td>
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<td></td>
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<td>Research Park Fitness Center</td>
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<td>621 Science Drive</td>
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<td></td>
<td></td>
<td>Tuesdays &amp; Thursdays from 12:40 – 2:10 p.m. (fee associated)</td>
</tr>
<tr>
<td></td>
<td>Contact:</td>
<td>Melissa Mattioda, PT, at 608-265-8303</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Ascension Lutheran Church</td>
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<tr>
<td></td>
<td></td>
<td>3330 Custer Street</td>
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<td></td>
<td></td>
<td>4th Thursday at 1:30 p.m.</td>
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<tr>
<td></td>
<td>No meeting July or August</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Vicki Rathsack at 920-726-4626</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Holy Family Memorial Wellness Center</td>
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<tr>
<td></td>
<td></td>
<td>1650 S. 41st Street</td>
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<tr>
<td></td>
<td></td>
<td>Tuesdays &amp; Fridays at 2:00 p.m.</td>
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<td></td>
<td>(fee associated)</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Pamela Posvic, PTA at 920-320-4600</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Wesley United Methodist Church</td>
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<tr>
<td></td>
<td></td>
<td>205 S. Maple Street</td>
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<tr>
<td></td>
<td></td>
<td>3rd Thursday at 1:00 p.m.</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Marilyn Seidl-Kramer at 715-305-8224</td>
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<tr>
<td></td>
<td>social group</td>
<td>YPPT: Young Parkinson Professionals Together</td>
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<tr>
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<td></td>
<td>Meeting dates and places vary; for the latest information, go to meetup.com/</td>
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<td></td>
<td></td>
<td>young-parkinson-professioners-together/ or contact Bob Norman at 414-550-1031</td>
</tr>
<tr>
<td></td>
<td></td>
<td>or <a href="mailto:ypptbob@gmail.com">ypptbob@gmail.com</a></td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Group Yoga Therapy (safe for those with PD)</td>
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<td></td>
<td></td>
<td>Invivo Wellness</td>
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<td></td>
<td></td>
<td>2060 N. Humboldt Avenue</td>
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<td></td>
<td>Wednesdays from 9:00 - 10:30 a.m.</td>
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<td></td>
<td>(fee associated)</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Tina Romenesko, PYT, RYT, at 414-265-5606</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Yoga for Parkinson’s</td>
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<tr>
<td></td>
<td></td>
<td>Milwaukee Yoga Center</td>
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<td></td>
<td></td>
<td>3514 N. Oakland Avenue</td>
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<td></td>
<td>Fridays from 1:30 – 3:00 p.m.</td>
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<td></td>
<td>(fee associated)</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Susan Goulet at 414-332-3551</td>
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<tr>
<td></td>
<td>veterans’ PD group</td>
<td>Clement J. Zablocki VA Medical Center</td>
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<td></td>
<td></td>
<td>5000 W. National, 3rd Floor</td>
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<td></td>
<td></td>
<td>1st Thursday from 11:30 a.m. – 1:00 p.m.</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>414-805-8326</td>
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<td></td>
<td>exercise group</td>
<td>Ascension Lutheran Church</td>
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<td></td>
<td></td>
<td>Highway 51 South</td>
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<td></td>
<td>2nd Tuesday at 10:00 a.m.</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Dennis Leith at 715-358-2207 or Norma Semling at 715-545-3414</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Monroe Clinic</td>
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<td></td>
<td></td>
<td>515 – 22nd Avenue</td>
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<td></td>
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<td>3rd Saturday; call for time</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Shelley Kimble-Welch and Steve Welch at 608-966-1398</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Mount Horeb Public Library</td>
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<td></td>
<td></td>
<td>105 Perimeter Street</td>
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<td></td>
<td>3rd Tuesday from 10:00 a.m. – Noon</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>608-229-7628</td>
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<tr>
<td></td>
<td>exercise group</td>
<td>Neuroscience Group</td>
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<td></td>
<td></td>
<td>1305 W. American Drive</td>
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<td></td>
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<td>2nd Floor Classroom</td>
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<td>4th Thursday at 2:00 p.m.</td>
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<td></td>
<td>(fee associated)</td>
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<td></td>
<td>Contact:</td>
<td>Kathy Hergert at 920-720-1617</td>
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<td></td>
<td>exercise group</td>
<td>Pabst Farms YMCA</td>
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<td></td>
<td></td>
<td>1750 E. Valley Road</td>
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<td>Wednesdays from 1:00 p.m.</td>
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<td>(fee associated)</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Ashley Knuth, PT, DPT, at 262-567-7251</td>
</tr>
<tr>
<td></td>
<td>exercise group</td>
<td>Oconomowoc Memorial Hospital</td>
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<td></td>
<td>791 Summit Avenue</td>
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<td></td>
<td>3rd Friday at 2:00 p.m.</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Peg Theder at 920-261-9805</td>
</tr>
<tr>
<td></td>
<td>veterans’ PD group</td>
<td>Pabst Farms YMCA</td>
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<td>1750 E. Valley Road</td>
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<td>Wednesdays &amp; Fridays at 1:00 p.m.</td>
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<tr>
<td></td>
<td>Contact:</td>
<td>Ashley Knuth, PT, DPT, at 262-567-7251</td>
</tr>
</tbody>
</table>
Oshkosh, WI
support group
Oshkosh Seniors Center, South Building
200 N. Campbell Road
3rd Tuesday at 2:00 p.m.
Contact: Carrie Ottum or Paula Seeley at 920-232-5300

Richland Center, WI
support group
Richland Center Community/Senior Center
1050 Orange Street
4th Wednesday at 10:00 a.m.
Contact: Maureen Smith, PT, at 608-647-2623
or Jo Wenzler at 608-653-0200

St. Francis, WI
support group
St. Ann Center for Intergenerational Care
Adult Day Services Unit
2801 E. Morgan Avenue
3rd Tuesday at 1:30 p.m.
Contact: Hattie Goodman at 414-744-5654

Seymour, WI
support group
Good Shepherd Services
607 E. Bronson Road, Community Center
1st Tuesday at 1:30 p.m.
Contact: Lori Tesch-Janke at 920-538-2071
or Carol Janke at 715-752-4247

Shawano, WI
support group
City Hall
127 S. Sawyer, River Room
2nd Tuesday at 1:30 p.m.
Contact: Joyce Hagen at 715-526-5104

exercise group
Total Fitness
212 E. Green Bay Street
Mondays & Thursdays at 1:15 p.m.
(fee associated)
Contact: Jean Darling, PT, or Jamie Mursaw, PTA, at 715-526-2899

Sheboygan, WI
support group
Sunny Ridge Health & Rehabilitation Center
3014 Erie Avenue
3rd Tuesday at 2:00 p.m.
Contact: Louis Borth at 920-400-1336 or Kristin Barts at 920-889-2602

Shell Lake, WI
support group
Northwest Wisconsin Parkinson’s Support Group
St. Joseph’s Catholic Church
201 N. Second Street, Lower Level
1st Thursday at 1:00 p.m.
Contact: Joelle Colburn at 715-255-0357

Stoughton, WI
support group
Stoughton Area Senior Center
248 W. Main Street
4th Wednesday at 1:00 p.m.
Contact: Ellen Grys at 715-343-6294

Sturgeon Bay, WI
support group
United Methodist Church
836 Michigan Street
1st Thursday from 12:30 - 2:00 p.m.
Contact: Carol Moellenberndt at 920-743-3476

exercise group
Door County YMCA, Sturgeon Bay
1900 Michigan Street
Tuesdays & Thursdays at 2:15 p.m.
(fee associated)
Contact: Carl Grota, PT, or Shawn Hanrahan, PTA, at 920-743-4949

Summit, WI
exercise group
Aurora Medical Center Summit
36500 Aurora Drive
Outpatient Rehabilitation Gym
Every Monday at 6:00 p.m. (free)
Contact: Ashley Knuth, PT, DPT, at 262-434-2600
**Sun Prairie, WI**  
**support group**  
Colonial Club Senior Center  
301 Blankenheim Lane  
Therapy Room  
4th Monday at 1:00 p.m.  
**Contact:** 608-229-7628

**exercise group**  
YMCA of Dane County  
1470 Don Simon Drive  
Wednesdays at 11:00 a.m.  
(fee associated)  
**Contact:** 608-837-8221

**Verona, WI**  
**support group**  
Verona Senior Center  
108 Paoli Street  
3rd Friday at 10:00 a.m.  
**Contact:** Becky Losby at 608-845-7471

**caregiver group**  
Verona Senior Center  
108 Paoli Street  
3rd Tuesday at 10:30 a.m.  
**Contact:** Becky Losby at 608-845-7471

**Waukesha, WI**  
**exercise group**  
Waukesha Family YMCA  
320 E. Broadway  
Mondays & Thursdays at 1:00 or 1:30 p.m.  
(fee associated)  
**Contact:** Kristine DeKarske, PT, at 262-542-2557

**Waunakee, WI**  
**support group**  
Village Center of Waunakee  
Senior Center Stage  
333 S. Madison Street  
4th Tuesday at 2:00 p.m.  
**Contact:** 608-229-7628

**exercise group**  
Waunakee Senior Center  
333 S. Madison Street  
Tuesdays from 1:30 – 2:15 p.m.  
(fee associated)  
**Contact:** Kristine DeKarske, PT, at 262-542-2557

**Wauwatosa, WI**  
**young-onset group**  
Community Conference Center  
8700 Watertown Plank Road  
Lower Level, east side of WAC  
3rd Wednesday from 6:30 – 8:00 p.m.  
**Contact:** 414-805-8326

**caregiver group**  
Community Conference Center  
8700 Watertown Plank Road  
Lower Level, east side of WAC  
2nd Saturday from 1:00 – 2:30 p.m.  
**Contact:** 414-805-8326

**men’s group**  
San Camillo, 10200 W. Bluemound Road  
2nd Monday at 1:30 p.m.  
**Contact:** Mitchell Smith at 262-796-1935

**women’s group**  
San Camillo, 10200 W. Bluemound Road  
4th Monday at 1:30 p.m.  
**Contact:** Gail Mellinger at 414-259-4521  
or Pat Mueller at 414-545-1487

**exercise group**  
Group Yoga Therapy (safe for those with PD)  
Haleybird Yoga Studios  
9207 W. Center Street  
Fridays from Noon – 1:15 p.m.  
(fee associated)  
Elevator access is not available in this building.  
**Contact:** Biz Casmer at 612-801-0188

**West Allis, WI**  
**support group**  
Aurora West Allis Medical Center  
8901 W. Lincoln Avenue, Meeting Room 1  
4th Tuesday at 7:00 p.m.  
**Contact:** Dale & Ellen Jante at 262-492-2439  
Judy Tharman at 262-691-7342, or  
Mary Donovan at 414-817-0192

**exercise group**  
Parkinson’s Dance Class  
Jewish Community Center, Studio B  
6255 N. Santa Monica Boulevard  
Every Friday from 2:15 – 3:30 p.m.  
(fee associated)  
**Contact:** Susanne Carter at 414-871-1523

**exercise group**  
Mercy Fitness & Aquatic Center  
580 S. Elizabeth  
Call for meeting days and times  
(fee associated)  
**Contact:** 262-473-4900

**West Bend, WI**  
**support group**  
Cedar Ridge Retirement Campus  
113 Cedar Ridge Drive  
3rd Monday at 1:00 p.m.  
**Contact:** Kathy Stultz at 262-338-2821

**exercise group**  
Kettle Moraine YMCA at River Shores  
705 Village Green Way, Suite 201  
Tuesdays & Fridays at 2:00 or 2:30 p.m.  
(fee associated)  
**Contact:** Beth Dieringer, PT, or Anne Langenfeld Smith, PT, at 262-247-1050

**Wisconsin Rapids, WI**  
**support group**  
Riverview Hospital Association  
410 Dewey Street  
4th Monday at 6:00 p.m.  
**Contact:** Randy & Jane Santora at 715-887-3805
We are grateful to the following donors for their support of those living with Parkinson disease. This list reflects gifts received from April 22 to July 22, 2014; contributions of $250 or more are shown. While space considerations hinder our ability to list all donors, please know that we deeply appreciate every gift. Donors whose names appear in italics have designated their gifts for research. Tribute gifts appear collectively under the name of the honored or memorialized person.

**$2,500 or more**
- Craig High School/“Pace for Parkinson’s”
- Elaine and Garry Wesley/“Rockin’ with the King!” Elvis Fest Jamboree
- Mark and Virginia Wooster

**$999 to $250**
- Don and Barbara Abrams
- Ron and Darla Becker
- John and Lynn Binder
- Claire Boles
- Burczyk Creative Group
- Neal and Helen Buteyn
- Thomas Cassidy
- Community Health Charities
- William Jambrek
- Richard and Linda Lundin
- Kathleen Miller
- Ron and Nancy Muehlhausen
- Harold Nigbor
- Cheryl Prescott
- George and Judi Prescott
- Donald and Beverly Randall
- Betsy and Bill Reilly
- Jean Rinka
- Roger Ritzow
- Norma Semling/Tribute—Brewing Company Taphouse
- Ed Voytik

**Gifts made in honor of:**
- Knut Apitz’s 75th Birthday
- Bob DeMotts
- Alan and Karen Katz
- Lois Richards
- Julie Van Strattn

**Gifts made in memory of:**
- Richard J. “Dick” Banach, Sr.
- Antonia Beecher
- Donald Bins
- William Oscar Boles
- Donald Brew
- Rick Briggs
- Edward W. Burgess
- Sam Castagna
- Robert Terence “Terry” Cox
- Patricia “Patty” Davidson
- Robert Donaj
- Elsie L. Eddy
- Willa Fordyce
- Bernhardt Goldader
- Arthur L. Hass
- Doris Heidschmidt
- Eldred Heidschmidt
- Jo Carolyn Hill
- Lenora Jaeger
- Adeline Johnson
- Donald Larmouth
- Everett Larsen
- Anthony Lesch
- Bernadine “Berdie” Lesch
- kennard “Ken” Lubbs
- Enzo Lucarelli
- Shirley Marcus
- Joseph McDonough
- David Morgan
- Gail Nigbor
- Clayton Noyes
- Betty Lou Palubicki
- Dorothy M. Poelzer
- Derek Rack
- Joseph Rathsock
- Joanne Romero
- Judge Leo F. Schlaefer
- Gary Swensen, Sr.
- Curtis Teetzen
- William H. Toppan

**Is Your Bladder Bothering You?**

(continued from page 17)

grow back/regenerate; therefore, both the positive and negative side effects experienced are eliminated. This means that to achieve the positive effects, repeat injections are required.

In 2009 came the first report of Botox improving NOAB/NDO in Parkinsonian patients (Parkinson disease and multiple system atrophy) when following up with these patients three months later. In a 2011 study, Botox treatment was given to eight people with Parkinson disease. The findings were a decrease in daytime and nighttime urinary frequency, a decrease in the number of urinary incontinence episodes, an increase in quality of life, and improved urodynamic findings (decreased overactive bladder symptoms and increased bladder capacity/storage). Improvements lasted at least six months when the patients were assessed in the clinic and via urodynamic reassessment. In 2013, a study of 416 patients looked at Botox versus placebo in improving quality of life in patients with neurologic disorders who had been diagnosed with NOAB/NDO. The study found significant positive changes in the treatment groups (two different dosing levels of Botox) versus the placebo, or non-treatment, group. Changes noted were a reduction in bothersome urinary frequency, improvement in quality of life – including more engagement in social activities, travel, and relationships – improvements in sleep, and a reduction in feelings of social embarrassment. Additionally, in 2013, a study completed repeat Botox injections up to five times in the same patient and observed that the risk of adverse side effects did not increase over repeated injections. The patients were able to see sustained decreases in urinary incontinence, increases in voided volume, and improvements in quality of life.

Talk to your doctor about any symptoms you might be experiencing with your bladder. There are many conservative treatment options available. Don’t let your bladder be the boss of how you live your life.
Would you like to become a member of the WPA and receive The Network magazine?

If you do not receive this magazine regularly, please consider joining our membership.

Your becoming a member helps those living with Parkinson disease by allowing us to enhance and expand our services to them and their families. Annual membership provides you with four issues of The Network, announcements of our education events, and information about local education and support programs so that you can contact others in your area.

For more information about membership with the Wisconsin Parkinson Association, please call Juliette Hayes at 414-219-7060.