



WISCONSIN PARKINSON

MAGAZINE

ISSUE NO. 103 | 2019

HOPE
SUPPORT
COMMUNITY
RESOURCES



P.6

ASK THE DOCTOR:
DEEP BRAIN STIMULATION

P.8

ENJOY WINTER
IN WISCONSIN!

P.12

HOME CARE
AGENCY VS.
INDEPENDENT
CARE: WHAT
MAKES SENSE
FOR YOU?

In this Issue...

- | | |
|--|--|
| 4
What is the DaTscan? | 14
Charitable Gifting Options |
| 5
Senior Care for Veterans | 16
WPA Open |
| 6
Ask the Doctor:
Deep Brain Stimulation | 17
Support Groups & Exercise Groups |
| 8
Enjoy Winter in
Wisconsin | 18
Welcome Mary Spidell-Wood |
| 10
What is the Role of
a Nurse Practitioner | 18
Support/Exercise Group Feature:
Lake Geneva Rock Steady Boxing |
| 11
Preventing Falls | 19
WPA Happenings |
| 12
Home Care Agency vs.
Independent Caregiver:
What Makes Sense for You? | |

Credits

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

Staff

Gary Garland
Executive Director
garryg@wiparkinson.org

Laurie Couillard
Director of Group Engagement
lauriec@wiparkinson.org

Carolyn Hahn
Director of Communications
carolynh@wiparkinson.org

Raven Hamilton
Director of
Administrative Services
ravenh@wiparkinson.org

Jeremy Otte

Director of Outreach & Education
jeremyo@wiparkinson.org

Mary Spidell-Wood
Exercise Coordinator
maryw@wiparkinson.org

Board of Directors

President
Jim Cantrell

Vice President
Fred Moseley

Secretary
Bob Norman

Treasurer

Rob McDonald

Past President

Dick Cosentino

Board Members

Omar Andrade

Tom Brandt

Kate Brewer

Kristine Everson

Ken Foster

Peter Ginn

Kate McDonald

Ron Mohorek

Cheryl Prescott

Joe Schlicher

Emeritus Members

Knut Apitz

Keith Brewer

Dick Schumann

Medical Advisory Committee

Rachel Biemiller, MD

Gundersen Health System

Karen Blindauer, MD

Froedtert & the Medical College
of Wisconsin

Ryan Brennan, MD

Froedtert & the Medical College
of Wisconsin

Taylor Finseth, MD

Aurora Health Care

Kathryn Gaines, DO

Aurora Health Care

Lisa Kokontis, MD

Neuroscience Group

Michael Schonberger, DO

Gundersen Health System

Katie Spangler, MD

Marshfield Clinic

Letter from the Executive Director



Happy Fall!

I hope this magazine finds you reading on one of those sunny, crisp and cool perfect Wisconsin days that make this my favorite season! Sure, we all know what is around the corner weather-wise in a few weeks, but fall helps us live in the moment. Even if today isn't ideal in some way, I hope this edition of the Wisconsin Parkinson Magazine gives you a lift.

Inside you will find a lot of helpful and practical information. One of the things that makes WPA so unique is the connections we have built with so many people allowing for the variety of voices that you will find here. A doctor talking about Deep Brain Stimulation, a nurse practitioner sharing how those in her role are essential members of your health care team, our friends in the senior living community helping you understand VA benefits and your eligibility and the differences in home care agencies and independent aides, and two members of our Caregiver Committee who have lived the Parkinson's journey sharing great travel tips.

This issue of Wisconsin Parkinson Magazine will also introduce you to Mary Spidell-Wood, WPA's new part-time Exercise Coordinator. We are so excited to have Mary in this brand new position – her wealth of experience and upbeat personality will allow us to continue building a Parkinson exercise program that brings affordable, high-quality exercise to brand new parts of the state. Welcome Mary!

While our publications regularly keep you updated on national and international Parkinson's news, our commitment to bringing you the best information from the brightest **local** minds is what makes our mission so unique.

Thank you for making it all possible!

Gary

Gary Garland
Executive Director
garyg@wiparkinson.org

Ken Pipping shows off the comfort bird he won from WPA. These beautiful comfort birds were donated by woodcarver Patrick Pelkey, who has Parkinson's.



What is the DaTscan?

WPA exists to be a resource for people with Parkinson's and their loved ones. When you read about a topic, or hear another support group member ask a question, we want to make sure we are able to help you find the answers!

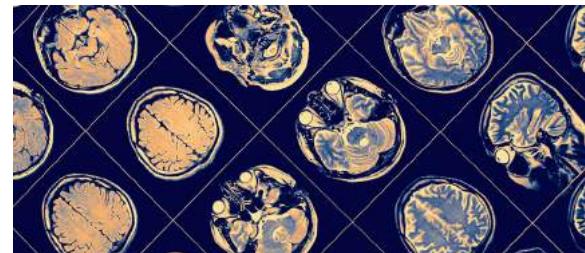
Laurie Couillard, our director of group engagement, spends a lot of time meeting with support groups and exercise groups across Wisconsin and hearing about topics our Parkinson's community is interested in learning more about. She compiled a summary of what the DaTscan imaging tool is, why and when it may be used by physicians, and a bit about the process involved in performing a DaTscan on a patient exhibiting some symptoms of PD.

"In cases where the expert is not sure of the diagnosis – is it essential tremor or Parkinson's, for example – or where a potentially risky procedure is being considered (e.g. deep brain stimulation surgery), it is reasonable for your doctor to recommend a DaTscan. For a person with classic motor symptoms (tremor, slowness, stiffness) who benefits from treatment with medication, the diagnosis is already made. Unless the disease progresses in a way that calls the diagnosis into question, DaTscan is likely unnecessary." (Okun, 2012)

The procedure is as follows: the patient receives an injection given via IV of the imaging agent, and

will need to wait 3-6 hours for the body to absorb the compound. "The substance 'tags' a part of a neuron in the brain where dopamine attaches to it, something called the dopamine transporter (DaT), showing the density of healthy dopamine neurons." (Okun, 2012) Next, the compound is visualized by a gamma camera, and the areas of the images captured that then "light up" symbolize more surviving brain cells. If the parts of the brain where dopamine cells should be remains dark instead, an expert reader may diagnose early brain degeneration. This could mean either Parkinson's disease or parkinsonism. The side effects of a DaTscan are minimal (e.g. injection site pain, headache, dizziness, nausea, dry mouth, hives and skin rash).

"DaT/SPECT scans examine the 'function' of the brain rather than its anatomy. This is an important point because unlike in strokes and tumors, the brain anatomy of a Parkinson's disease patient is largely normal. These scans can show changes in brain chemistry, such as a decrease in dopamine, which identify



Parkinson's disease and other kinds of parkinsonism." (Okun, 2012).

Finally, a determination will be made as to the severity of the brain cell loss. But patients and their families need to be aware that these scans cannot reliably separate Parkinson's disease from parkinsonism (multiple system atrophy- MSA, corticobasal degeneration, progressive supranuclear palsy- PSP). "The DaTscan is presently being used as a tool to determine if dopamine degeneration is present, suggestive of a diagnosis of PD, MSA, PSP, or other variants." (Seifert & Wiener, 2013) Interpretations are not clear cut, and once a scan is determined to be normal or abnormal, the expert will determine if the scan follows the pattern of Parkinson's disease.

As always, if you have questions about the DaTscan or any Parkinson's treatment, talk to your doctor.



References

1. <https://movementdisorders.ufhealth.org/2012/04/11/should-i-get-a-dat-scan-to-confirm-my-parkinsons-disease/>
2. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3601468/>

Senior Care for *Veterans*: The Aid and Attendance Benefit

By D.R. Salerno, Amada Senior Care of Greater Milwaukee

As of 2015, the total number of Americans over the age of 65 was about 47.8 million. Of that population, more than 10 million consisted of war veterans, their surviving spouses or both. This means that almost 25% of Americans over the age of 65 may be eligible to receive a VA Pension, such as the Veterans Aid and Attendance Benefit.

There are four basic points that qualify someone to receive the Veterans Aid and Attendance Benefit:

1 Military service – The veteran is required to have at least 90 days of active duty on his or her service record, with at least one day of service within a wartime period. The reason for leaving the service can be anything but a dishonorable discharge. A surviving spouse is also eligible as long as the marriage was ended by the veteran's death.

The VA recognizes wartime periods to determine eligibility for VA Pension benefits as:

- World War II (December 7, 1941 – December 31, 1946)
- Korean Conflict (June 27, 1950 – January 31, 1955)

- Vietnam War (February 28, 1961 – May 7, 1975 for veterans who served in the Republic of Vietnam during that period; otherwise August 5, 1964 – May 7, 1975)
- Gulf War (August 2, 1990 – through a future date to be set by law or Presidential Proclamation)

2 Veteran's state of health – A doctor needs to certify that the veteran's health has declined to where he or she needs assistance from another person. To qualify, one specifically must need assistance with activities of daily living (ADLs) like eating, bathing, and getting dressed. Other qualifications include blindness or living in a nursing home or assisted-living facility.

3 Monthly income/medical expenses – Is the veteran spending the majority of his or her monthly income on health care expenses? The veteran's net worth limitations and net income come into play, but there is no set amount to qualify. The Aid and Attendance Benefit can provide up to \$1,788 per month for a single veteran; \$1,149 for a surviving spouse; and \$2,120 for a married veteran.

4 Veteran's age – The older the veteran, the less he or she will receive from the benefit in most cases. Due to lower life expectancy as age increases, the VA will most likely decline older veterans if they have a higher amount of income and assets.

Amada Senior Care of Greater Milwaukee can direct veterans and their families to programs like the VA Pension that provide significant financial assistance to help pay for in-home senior care.

Managing the Aid and Attendance benefit can be a difficult process because there are many things to consider such as military service, age, health, income, and assets. Amada works to help families understand this potential financial resource and act as an advocate for the senior veteran to access the benefit.

It's generally good to speak to someone who's familiar with the intricacies and details of these types of programs. At Amada, we can help people find the right resources and connect them with others who are equipped to handle these situations. 

D.R. Salerno owns Amada Senior Care of Greater Milwaukee.
Contact Amada Senior Care at 262-395-7928 to learn more about
Veterans Benefits.



Ask the Doctor:

Deep Brain Stimulation

By Teresa Mangin, MD, UW Health



How do I know if I'm a candidate for Deep Brain Stimulation (DBS)?

You may be a candidate for DBS if you 1) have a firm diagnosis of idiopathic Parkinson disease (not just parkinsonism), 2) respond to PD medications, 3) have symptoms that are not sufficiently controlled with medications alone, and 4) do not have excessive surgical risks, like a bleeding disorder or serious heart or lung disease. A response to PD medications would be defined as physical symptoms that improve (at least in some ways) after taking medications like carbidopa/levodopa or dopamine agonists. The response may not be long enough or predictable enough, or it may come with unwanted side effects like dyskinesia (extra wiggly movements that occur when your PD meds are in your system). However, if medications do not help your symptoms at all, they may be due to a condition other than PD and therefore not respond well to DBS therapy either.

At what stage of the disease would my doctor consider DBS?

A common misconception about DBS is that it is a treatment of "last resort." In fact, for many patients there is a

window of time lasting several years where DBS could be an option, but waiting too long can result in missing that window. Patients whose PD has become quite advanced are not only more vulnerable to complications of surgery, but are also less likely to see a significant benefit from the stimulation therapy.

Although there have been clinical trials investigating DBS therapy earlier in the course of Parkinson disease, DBS is most often considered several years into the diagnosis. At this point, we have a sense of how well you are responding to medications. This is important for two reasons: 1) we need to be as confident as possible that your symptoms are due to Parkinson disease rather than an atypical form of parkinsonism, which would NOT benefit from DBS therapy, and 2) medication response is our best predictor of how well you would respond to the stimulation therapy. A frequently repeated DBS aphorism is: "DBS won't get you better than your best on [medications]." The one exception to the medication response rule is that patients with medically-refractory PD tremor can usually achieve good tremor control with surgery.



Your provider may begin to discuss DBS with you when your medication regimen is not adequately controlling your PD symptoms. This may occur because the meds are wearing off too quickly or too unpredictably, or because you are experiencing bothersome dyskinesia from the medications, or because you are having some difficulty tolerating a sufficient dose of medications due to other side effects, like nausea or sleepiness. If medications are managing your symptoms well, without too much wearing off between doses or bothersome side effects, then DBS may not be necessary. (Although the risks of DBS are relatively small, taking on any unnecessary surgical risks at all may not be justified if you are happy with your symptom control.)

Are there long-term considerations or maintenance to plan for when considering DBS?

Embarking on DBS therapy requires a commitment on the part of the patient, the care partner, and the treatment team. Early on, you can plan on frequent programming visits and adjustments with your provider to get the optimal settings dialed in. These visits will serve to maximize the benefit you are receiving from the stimulation, while minimizing any stimulation-related side effects, such as slurred speech, tingling sensations, or stimulation-induced dyskinesia. During those early programming visits, you will also be educated on how to use your patient access controller. This device allows you to turn the DBS on and off, and to make limited adjustments on your own at home.

Once the DBS settings are optimized, your visits to your treatment team may decrease in frequency. However, it is important to check in periodically to monitor the battery voltage. Depending on the strength of your DBS settings, batteries tend to last 3-5 years on average. When the battery voltage declines below a certain point, a replacement is scheduled with the goal of avoiding any lapse in therapy. Battery replacement surgery is typically an outpatient surgery, during which your DBS surgeon opens up the prior incision in the chest (usually just under

the collarbone) and removes the old generator, replacing it with the new one and reconnecting the leads. Some patients opt for a rechargeable battery. This shifts the burden a bit more onto the patient and care partner to check the battery daily and to recharge at appropriate intervals.

Choosing DBS means you will have a long-term relationship with your movement disorders team. Proximity to the DBS center and ability to get back and forth to appointments should go into your decision about whether DBS is right for you. 

Teresa Mangin, MD

is a neurologist at the University of Wisconsin School of Medicine and Public Health where she specializes in movement disorders.

GE Healthcare



Ask your doctor about

**DatScan™
Ioflupane I123 Injection**



© 2019 General Electric Company.
GE, the GE Monogram, and DatScan are trademarks of GE Healthcare.
Any third-party trademarks are the property of their respective owners.

October 2019 JB71186US

Enjoy Winter in Wisconsin

Tips for Traveling with Parkinson Disease

By Jo Ann Hagner & Ginger Wooster

Living in Wisconsin, we are fortunate to experience the wonders and beauty our four seasons offer us. Over the next several months, we will experience a wide range of variations in our weather from a late Indian summer in November to the snow and frigid cold that comes with late December through February, and into March.

Our ability to enjoy the great outdoors is not only hampered by changing weather conditions, but also by our mobility issues. People with Parkinson's are well aware of the issues rigidity and balance create in getting out and about during more weather-friendly months of late spring and summer. For many, the late fall and winter months bring on a well-founded concern of falls and a sense of confinement. Activities that were once enjoyed – hiking, skiing – are thought to be lost in the past. Many are unaware of the many late fall and winter outdoor activities that are available to those with mobility issues.

Cross-Country Skiing – State Parks with Sit Skis

Sit skis provide the balanced stability needed to more fully enjoy our Wisconsin winters. The state parks noted on the next page have one sit ski on site and maintain well groomed trails. Sit skis are available at the rental office at each park – at no charge – on a first come first serve basis. Please call about availability and trail conditions prior to going to the state park.



Hiking Trails - State Park Accessible Trails

Preserve	City	Trail	Phone
Hartman Creek State Park	Waupaca	G, GR, P	715-258-2372
Schmeeckle Reserve (Free)	Stevens Point	B, GR	715-346-4992
Big Bay State Park	Madeline Island	B	715-747-6425
Lion's Den Gorge Nature Preserve	Grafton	B	262-284-8257
Sentinel Trail - Peninsula State Park	Fish Creek	GR	920-868-3258
Bearskin State Trail	Minocqua	CG	715-539-2035
Green Tree Loop - Schlitz Audubon Center	Milwaukee	GR	414-352-2880

Key for trail construction:

- B** – Boardwalk
- CG** – Compacted Granite
- G** – Grass
- GR** – Gravel (compact)
- P** – Pavement

For a listing of all state park hiking trails and their accessibility go to: <https://dnr.wi.gov/topic/parks/activities/hike.html>

Find a park map: <https://dnr.wi.gov/topic/parks/findapark.html>

An annual or daily vehicle admission sticker is required for State Parks. **For more information on admission fees:** <https://dnr.wi.gov/topic/parks/admission.html>

Hours: All listed state parks are open from 6 am - 11 pm year-round. Check other locations for hours and fees.



Jane Schmieding using one of the cross-country sit skis at Governor Nelson State Park. Jane has MS which restricts her ability to walk.

The following parks have sit skis available: Buckhorn State Park in Necedah, Governor Nelson State Park in Waunakee, Harrington Beach State Park in Belgium, Kettle Moraine State Forest – Lapham Peak Unit in Delafield, Mirror Lake State Park in Baraboo, and Richard Bong State Recreation Area in Kansaville.

Trekking Poles for Balance

Using two trekking poles helps to keep you balanced and avoid falls. They afford you the ability to stand in a more upright position, helping to improve your posture. The metal tips grip the snow and ice. Rubber tips are available for indoor use.



Staying Warm and Safe While Enjoying a Winter Outing

The Wisconsin DNR website offers a myriad of helpful suggestions and winter weather cautions that will help to make your winter outing more enjoyable when visiting state parks during the winter season. Here are some tips that will help prevent cold weather issues whether you are strolling through your favorite park or around your neighborhood.

- ✿ Dress to stay warm by dressing in layers that trap your body heat, keeping you warm. Layering your clothes allows you the flexibility to remove or add layers as the temperature changes throughout your outing.
- ✿ Wear a winter hat. You can lose up to 70% of your body heat from your exposed head. Wearing a winter scarf helps to keep your neck warm, and can easily be adjusted to protect your nose and ears from a chilly wind.
- ✿ Wear mittens with long cuffs. Your fingers will help to keep each other warm. The long cuff tucked into your coat or jacket sleeve will keep your wrists covered and warm.

✿ Layer your socks to create warm air pockets around your feet and calves. Socks that are too tight will prevent good blood circulation leading to cold feet.

✿ Have an insulated pad or pillow for sitting on if you are traveling in a wheelchair, or you might want to sit down along the way. The insulation will protect your bottom from the winter cold.

✿ Crampons are necessary for snowy or icy paths or walkways to prevent slipping and falling. They are made with spikes that grip the ice and snow. Crampons can be easily fastened to your foot wear.



Pack a "Go Bag"

No outing in Wisconsin is complete without refreshments. Often state park concessions close for the colder months, so consider keeping a handy "go bag" that is always stocked with any supplies you need. Many favorite snacks such as trail mix, crackers, and cookies will stay fresh for a long while. Keep the bag stocked with cups, plastic utensils, and napkins. Then, just before you go, make a thermos of hot coffee or hot chocolate and add any other perishable goodies like fruit or cheese to the bag. Include any medical supplies you need, and don't forget to bring along your medications. Save previous empty prescription bottles from the pharmacy and split the new refill into two portions, each still correctly labeled - one for home, a smaller amount for the portion in the go bag. It's a good idea to keep a blanket in the bag. Keep warm!

Other Tips

To ensure you get the most enjoyment from your outdoor excursion, get as much information as possible in advance about where you want to go or what you want to do.

Outings are often more fun in a group. The social aspect combined with a healthy dose of fresh air adds to the fun. It also doesn't hurt to have extra hands to help each other.

Don't be fearful of trying something new. Start your activity in small increments to see what you enjoy. Set realistic expectations.

(continued on page 15)

What is the Role of a Nurse Practitioner in Parkinson's Care?

By Kelly Tritz, RN, MSN, AGACNP, Aurora Neuroscience Innovation Institute

Nurse practitioners (NPs) are excellent assets to neurology clinics. The world of medicine continues to grow, and clinics continue to get busier. By expanding the clinic to include NPs, patients can be seen on a more frequent basis and clinics are better able to accommodate urgent appointment requests to address bothersome symptoms or medication side effects that cannot be accurately or adequately described over the phone. Additionally, having a team that includes multiple providers allows for a diverse assessment of your disease process and treatment regimen. The physician and nurse practitioner work as a team and your plan of care is a collaborative effort.

Nurse practitioners are trained and licensed to assess, diagnose, treat, and manage diseases. They have the ability to prescribe and manage medications. In addition to medical knowledge and management, the education model for both nurses and NPs is based in comprehensive and holistic patient care. Your psychological and emotional well-being, as well as support for your family, are equally as important as medical management. NPs receive formal education to become licensed, and also undergo training with their physician to ensure that there is continuity of care regardless of who you may see for your appointments. This includes on the job training and observation, specialized training courses for procedures, and numerous

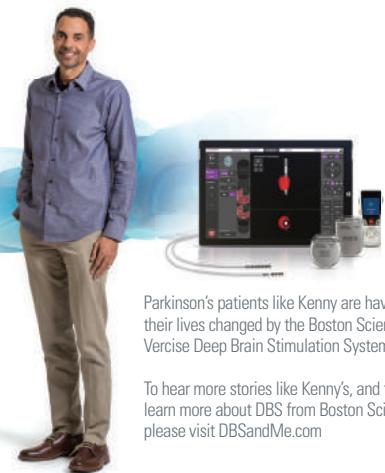
continuing education activities such as conferences and online training programs. In regards to Parkinson's specific care, NPs can manage medication adjustments, suggest and order different therapy modalities, and also perform specialized assessments and interventions like deep brain stimulation programming. Nurse practitioners can be an integral part of your health care team. They work closely with the physician to provide high level neurological care in a variety of ways. 

VERCISE™
Deep Brain Stimulation Systems

Boston Scientific
Advancing science for life™

*"DBS has helped me tremendously. This cutting edge technology has increased my quality of life by providing me with more consistent control of my symptoms, [allowing] me more time to engage in the activities that I love."**

**Kenny H.
Boston Scientific DBS Patient**



Parkinson's patients like Kenny are having their lives changed by the Boston Scientific Vercise Deep Brain Stimulation Systems.

To hear more stories like Kenny's, and to learn more about DBS from Boston Scientific, please visit [DBSandMe.com](#)

Kelly Tritz, RN, MSN, AGACNP

is a neurology nurse practitioner at Aurora Neuroscience Innovation Institute in Milwaukee. To learn more about Parkinson's care at Aurora, visit [aurora.org](#).

*Results from case studies are not necessarily predictive of results in other cases. Results in other cases may vary. Indications for Use: The Vercise™ Deep Brain Stimulation (DBS) Systems are indicated for use in bilateral stimulation of the subthalamic nucleus (STN) as adjunctive therapies in reducing some of the symptoms of moderate to advanced levodopa-responsive Parkinson's disease (PD) that are not adequately controlled with medication. Contraindications: The Vercise DBS Systems are not recommended for patients who will be exposed to the following procedures: Diathermy as either a treatment for a medical condition or as part of a surgical procedure, Electroconvulsive Therapy (ECT) and Transcranial Magnetic Stimulation (TMS). The safety of these therapies in patients implanted with Vercise DBS Systems has not been established. Patients implanted with Vercise DBS Systems should not have Magnetic Resonance Imaging (MRI). Vercise DBS Systems is not recommended for patients who are unable to operate the system, are poor surgical candidates or who experience unsuccessful test stimulation. Warnings: Unauthorized modification to the medical devices is prohibited. You should not be exposed to high stimulation levels. High level of stimulation may damage brain tissue. Patients implanted with Vercise DBS Systems may be at risk for intracranial hemorrhages (bleeding in the brain) during DBS lead placement. Strong electromagnetic fields, such as power generators, security screeners or theft detections systems, can potentially turn the stimulator off, or cause unpredictable changes in stimulation. The system should not be charged while sleeping. If you notice changes in mood or behavior or have thoughts of suicide contact your physician immediately. Chemical burns may result if the Stimulator housing is ruptured or pierced. The Deep Brain Stimulation System may interfere with the operation of implanted stimulation devices, such as cardiac pacemakers, implanted cardioverter defibrillators, or medication delivery pumps. Patients should operate motorized vehicles or potentially dangerous machinery with caution. It is unknown if the device may hurt an unborn baby. Your doctor may be able to provide additional information on the Boston Scientific Vercise DBS Systems. For complete indications for use, contraindications, warnings, precautions, and side effects, call 833-DBS-INFO or 833-327-4636. CAUTION: U.S. Federal law restricts this device to sale by or on the order of a physician. All trademarks are the property of their respective owners. NM-588706-AA © 2019 Boston Scientific or its affiliates. All rights reserved.

Preventing Falls

This Fall Season and Beyond

By Nancy Johll Pearson, PT, Greenfield Rehabilitation Agency



While here in Wisconsin we would like to be known for our beloved Brewers, Badgers or Packers leading the nation, in truth Wisconsin tops the nation in highest rate of deadly falls among the elderly, according to a 2018 study completed by the Centers for Disease Control and Prevention.

The good news is there are many ways to prevent falls, from practical changes in your home that can be completed today, to incorporating a healthy lifestyle, which begins with moving your body in ways to decrease stiffness and improve endurance, strength, and balance. Research has shown that making multiple interventions is the best way to prevent falls.

Let's get started!

- **Improve safety in your home:** The first thing you can do is to clear pathways and clean up clutter. Remove anything that could cause tripping while walking, such as rugs at sinks or in entryways. Use non-slip items in the bathroom and avoid wet floors. Use extra caution at night, making sure the path to the bathroom is well lit. Avoid wearing loose fitting clothing that can be caught on items in your home and wear properly fitting, supportive shoes with nonskid soles. If you have experienced a fall in your home you may want to consider asking your doctor for a referral to an

occupational therapist to brainstorm fall prevention strategies specific to your living environment. Most solutions are practical, relatively inexpensive, and/or easily installed.

- **Make an appointment with your doctor.** Review medications with your doctor that make you overly tired, affect your thinking, or affect your balance. Have your vision checked routinely, and if required, wear your prescription glasses when you are up and moving about your home. Discuss any health conditions that bother you when walking – for example, do you feel dizzy, experience joint pain, shortness of breath, or numbness in your feet? Do you find yourself rushing to the bathroom due to urge incontinence? Your doctor may be able to help you address these issues.

- **Begin exercising TODAY:** Exercise plays an essential role in keeping a person with Parkinson disease healthy and able to participate in activities of daily living. Start with any physical activity that you

feel is safe and that you enjoy. Consider yoga or tai chi, or classes provided at your local Senior Center such as dancing and aerobic classes, or visit wiparkinson.org for a list of Parkinson's classes in your area. Begin slowly with the goal of increasing exertion level over time. Research has shown that exercise that requires your attention, concentration, and focus on movement may serve to protect the nerve cells from damage and possibly slow progression of Parkinson's. If you are avoiding physical activity because of pain or fear of falling, consider asking your doctor for a referral to a physical therapist, who can address your specific concerns and customize an exercise program based on your needs. 

Nancy Johll Pearson, PT

is the director of outpatient services at Greenfield Rehabilitation Agency. To learn more, visit grawi.com.

Home Care Agency vs. Independent Caregiver:

By John Becwar, Oasis Senior Advisors

As a Certified Senior Advisor, I consult and educate clients on the costs and benefits of senior living options, both in-home and in independent or assisted living communities. If a family chooses for their loved one to remain at home to receive care, I am often asked if I recommend hiring an independent caregiver or one employed by a home care agency. There are many advantages and disadvantages to both options and I will explore both in the hope that your family will make the decision that is right for you and your loved ones.

Before providing an assessment of the benefits and considerations for the two types of caregiver services, I'd like to share a basic description of home care agencies and private caregivers:

- **Home Care Agency** – They are licensed businesses that employ caregivers and send them to private residences for non-medical care services for their clients. Non-medical services, also referred to as personal care, consists of assistance with Activities of Daily Living (ADLs), such as bathing, dressing, and eating. Other non-medical services often provided include shopping, housework, running errands, and companionship. Agencies provide training to their caregivers, but not necessarily professional training with certifications such as Certified Nursing Assistants (CNAs).

- **Independent or Private Caregivers**
They can provide all the services described above, perhaps more

depending on their background and training, but are employed directly by the family. There is no intermediary agency between the care recipient and the caregiver.

In the comparisons below, I provide the positive aspects, or pros, and the considerations/concerns, or cons, for each of the service options. Although I use the term con, not all considerations or concerns are negative. For example, I list consistency as a con for agencies, but some clients may prefer the variety of meeting new caregivers on a regular basis. With those distinctions, here are the pros and cons to consider when deciding between hiring an agency or an independent caregiver:

HOME CARE AGENCY - PROS:

- **Convenience** – In the metro Milwaukee area alone, there are over 170 home care agencies, so the process of locating and hiring one is a simple one.
- **Scheduling and Back-up Care** – Although most agencies have minimum hourly requirements, they can accommodate most requests for scheduling and have back-ups in case the regular provider can't make it to work.
- **Background Checks** – Every home care agency I've encountered over the years performs background checks on their caregivers, although some more extensively than others. Do they check all of their employment and criminal history or just for the state of Wisconsin?
- **Liability & Bonding Insurance** – The majority of home care agencies are franchises and therefore, require their franchisees to have professional liability insurance and bonding insurance in order to compensate clients if an employee is found stealing.

HOME CARE AGENCY - CONS:

- **Cost** – I've seen hourly rates as low as \$22 per hour for clients requiring 24/7 care and as high as \$30 per hour for only an hour of care per visit. On average though, the rates usually range from \$24-\$27 per hour. Also, most agencies have minimum hourly requirements, usually 2-3 hours per visit. If you or your loved one requires multiple visits per day, please consider whether they are cost efficient.
- **Consistency** – Typically, the less amount of time a client requires for care, the more challenging it is for agencies to consistently schedule caregivers assigned and preferred by the family.
- **Range of Support** – Agency caregivers can provide ample non-medical support for most individual clients, but due to liability issues, agencies have stricter rules on what their caregivers may and may not do. For example, an agency caregiver may be allowed to run errands, but not drive the care recipient to medical appointments, shopping, or other social activities.

What Makes Sense For You?

In summary, neither home care agencies nor private caregivers can boast an advantage in providing a higher quality of care than the other. Quality of care is dependent on the individual providing the care. There will be independent caregivers,

as well as caregivers from agencies, that provide excellent care, but also individuals from both options that provide less attentive care and fail to meet expectations. 

Cautionary Notes:

- ① Regardless of whether an individual chooses a private caregiver or a home care agency, as I indicated earlier, in-home care is a private pay service. It's especially important to monitor the cost of that care if financial resources are limited. When an individual's care costs exceed their monthly income and eventually spend down their savings and investments, many families assume Medicaid will either pick up those home care costs or that they can transition their loved one to an assisted living community under the same preface. Unfortunately, when financial resources are depleted, care options become limited. Most assisted living communities do accept Medicaid, but only after residents have met their minimum financial requirement, typically private pay over the course of two years or more. Obviously, most seniors prefer in-home care when at all possible. The caution is to avoid spending down limited financial resources as the cost of care begins to exceed your loved one's monthly income. Seek the advice of a senior advisor.
- ② As you read in the comparisons below, the costs for in-home care are significant. As you consider these options, please note that the cost of home care services are NOT covered under Medicare insurance. Therefore, families need to understand that they will be paying privately for these services.

John Becwar

is a certified senior advisor for Oasis Senior

Advisors. Since John opened Oasis Senior Advisors, the first Oasis franchise in the country, in 2014, he has advised and guided hundreds of seniors and families on senior living options. Learn more at senioradvisorsmilwaukee.com.

INDEPENDENT CAREGIVER - PROS:

- **Less Expensive** – Compensation for independent caregivers vary, but typically is in the range of \$14-\$18 per hour.
- **More Control** - Families can be more selective about caregivers because they're choosing them specifically rather than having an agency representative make that match for them.
- **Broader Range of Support** – This is not always the case, but if the caregiver has a medical background for example, such as a retired nurse, they can provide more services than non-medical home care agency caregivers.
- **Flexibility** – An independent caregiver is often more flexible with their schedule, adjusting to needs of families for shorter or longer shifts, weekends, and holidays.
- **Consistency** – If working with a single independent caregiver, familiarity with the client's daily needs and expectations is something seniors and their families value greatly in most cases.

INDEPENDENT CAREGIVER - CONS:

- **Care Coordination** – If you're working with a single caregiver, what happens if that person is sick, injured, or unable to work for whatever reason? Who will take their place? It's important to have a plan for back-up care.
- **Finding Candidates** – I find most families choose private caregivers through friends, neighbors, and religious groups, but others turn to services such as Craigslist. Regardless of the source, it's important to interview, call multiple references, and run background checks.
- **Employer Responsibilities** – Although many families pay independent caregivers under the table, it is illegal. Therefore, the family must take on the responsibility of an employer, such as deducting social security and other taxes, or pay for a 3rd party service that manages caregiver payroll.
- **Liability** – Most independent caregivers don't have professional liability insurance. It's important to check on what your homeowner's insurance policy does and does not cover in the event there is an accident in the home. Are you covered if the caregiver injures themselves in your home?

Charitable Gifting Options: PART 1

By Jim Cantrell, Financial Strategies, Inc.

None of us are meant to be alone. Even the Lone Ranger had his best friend by his side everywhere he went. The Bible tells us that God created a partner for the first man because it was not good for him to be alone. We coexist, we develop friendships, we encourage one another, we watch each other's back, and we help each other. Whether it's holding a door open when someone's arms are full, or cutting our neighbor's grass when they are sick, or helping those less fortunate than ourselves, I believe we have an internal desire to help each other because we don't want to be alone in this world.

In light of this, it makes sense that we might want to share our financial resources. Giving to a good cause makes us feel like we are making the world a little better. If we are inclined to give to charity, there may be strategies to make our giving more efficient. For example, if you can save taxes when you give, you can afford to give a little more. The extra amount you would have paid in tax could be given to charity. If a \$10,000 charitable gift saves you \$3,000 in taxes, you could give the \$3,000 to charity or use it to enhance life for your family. You could turn that gift into a \$13,000 gift, or you could give the \$10,000, but your cost is only \$7,000 due to tax savings. Either way you look at it, you win.

If there is a way to give to charity and save taxes in the process, of course you

should do it. There are several ways you can do this.

Qualified Charitable Distribution (QCD)

Individuals over 70½ with an IRA can consider a Qualified Charitable Distribution (QCD). If you want to give to charity and are taking your Required Minimum Distributions (RMD) from your IRA, you could give money directly from your IRA to a qualified charity. You will need to work with your IRA custodian to be sure the check is made out to the charity and not to you. The great part is that this gift can count as part, or all, of your RMD.

Even if you don't itemize deductions (many taxpayers do not under the new tax rules), the QCD portion of your IRA distribution is not included in your taxable income. The only bad news is that the IRS limits your QCD amount to \$100,000 per year, so if you wanted to give a million dollars to your charity from your IRA, you would have to split it up over a ten-year period. It bears repeating, the check must be made payable directly to the charity in order for this strategy to work.

Gift of Appreciated Assets

Instead of writing a check to your favorite charity, you could give stock or mutual fund shares (or any assets) that have increased in value. Usually, when

you sell appreciated assets, you will pay a capital gain tax on appreciation in value. For example, if you buy a mutual fund share for \$10 and sell it for \$15, you will likely pay tax on the \$5 gain. If instead, you gift the share to charity, you have not sold, so you do not pay a tax. The charity will then sell the share, and being a charity, they typically do not pay tax on the gain.

If you are itemizing deductions on your tax return, you have an added benefit. You would deduct the value of the shares at the average share price on the day they were removed from your account and transferred to the charity. In our example, \$15. This takes a little paperwork, so it probably is not worth it if you are giving a few dollars. However, it can be well worth it if you're giving a few thousand dollars or more.

Donor Advised Fund (DAF)

If you have a larger sum you would like to give to charity but would rather the charity did not get the money all at once, or you have not decided to which charities the money will go, you should consider a Donor Advised Fund. A DAF is a fund to which you irrevocably gift money and distribute those assets to the 501(c)(3) public charities of your choice. The assets can be invested until you distribute them to charity. The administrators of these funds typically charge 0.6-1.0% per year for



This article will be continued in Issue 104.

administration. Additionally, there may be investment fees. DAF's tend to be more effective for larger donations.

Bunching

As mentioned earlier in this article, many taxpayers no longer itemize deductions. This is due to the much higher standard deduction and the elimination of some deductions (such as financial advisor fees and tax preparation fees, etc.). If you give substantially to charity each year, but not enough to exceed the

standard deduction, you should consider bunching your contributions. Instead of giving a smaller amount in one year, give two, three or more years' worth of giving in one year. For example, if you typically give \$15,000 to your favorite charity each year, you could consider giving \$30,000 this year and not giving anything next year. You have given the same amount over two years but did it all in one year. This allows you to exceed the standard deduction and pay less tax every other year. Be sure to let the

charity know this is your intent, so they can plan appropriately.

You could bunch for several years, giving three or more years' worth of donations in one year. If you do this and it becomes a large sum, you could consider using a Donor Advised Fund to hold the assets. You would still get the tax deduction in the year of the gift to the DAF, then distribute the money to the charity on an annual basis. This may help the charities in their budgeting process. 

Jim Cantrell

is a certified financial planning professional with 30 years of experience. He is the president of Financial Strategies, Inc. a fee-only, comprehensive wealth management and financial planning firm in Brookfield, WI. He has been a member of NAPFA (National Association of Personal Financial Advisors) since

1996 and has served as chair and president of the NAPFA Midwest Regional Board and served on NAPFA's national board of directors. Jim currently serves as president of Wisconsin Parkinson Association's board of directors.

(continued from page 9)

Tips for Traveling with Parkinson Disease

There is no need to go five miles your first time on the sit ski - if you only make it 100 yards on the first go, it is a success. Even if it is going smoothly, don't overdo. You can always come again. Also, when the activity is finished and everyone still has some energy left, how about a stop for a treat on the way home. If energy is waning, a drive-thru is a good option. Try to make the outing a truly fun activity. If so, you will look forward to your next adventure.

In some cases, the caregiver will do most of the planning so it may be a little more work for them, but if you can make a great memory for your loved one and find something you can do together, it's worth every minute.

Above all – go out and enjoy the beauty our Wisconsin winters have to offer. 

Jo Ann Hagner & Ginger Wooster

both love to travel and are members of WPA's Caregiver Committee. They also recently discussed this topic on an episode of WPA's podcast. Listen to the podcast under the Resources tab at wiparkinson.org.

WPA Open Against Parkinson Disease

Presented by Financial Strategies, Inc. & HeatTek, Inc.

Raising nearly \$150,000 to ensure that all of WPA's programs and services remain FREE, the 2019 WPA Open was a great success! Thank you to all of our sponsors, donors, golfers, and dinner guests for participating in this wonderful day!



1



2



3



4



5



6



7



8

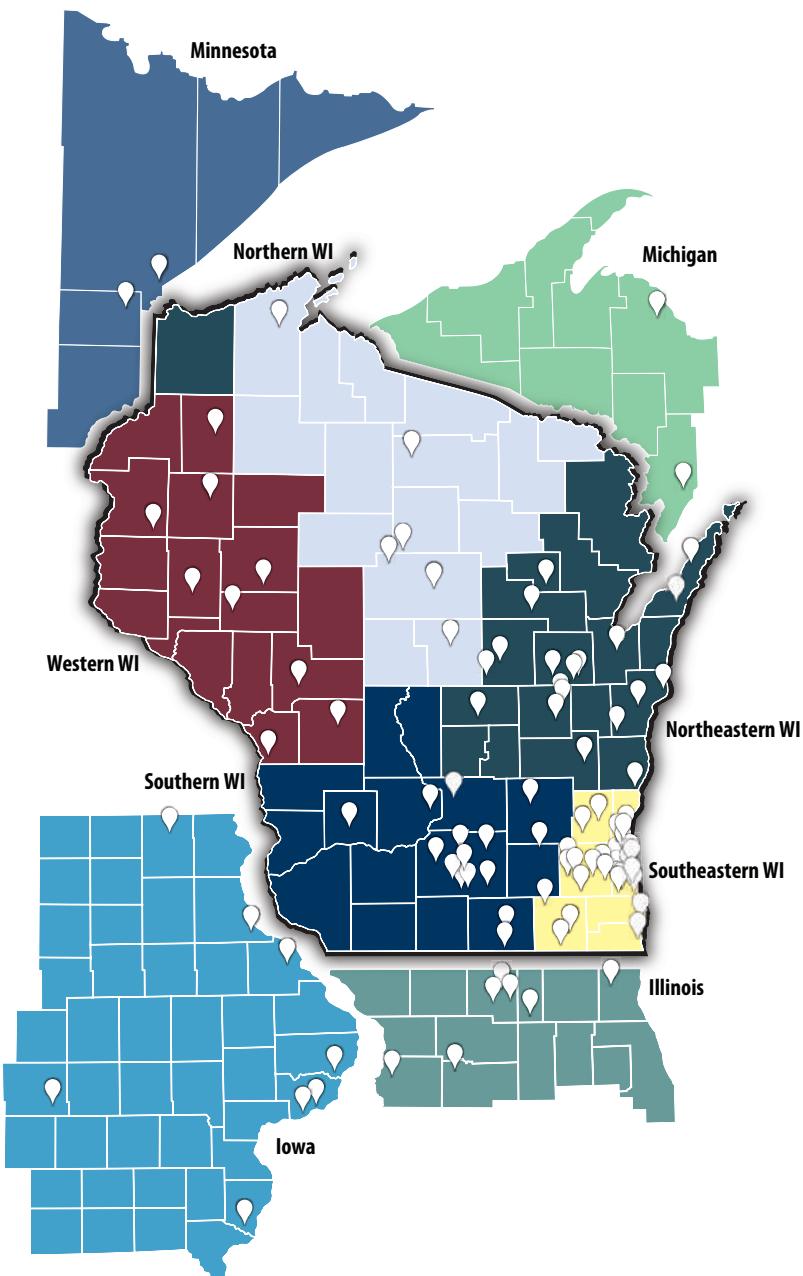
- 1 The highlight of the day was Dan Winkler's hole-in-one! Dan has Parkinson's, and this was his first year golfing with us.
- 2 Kim Murray, Lamon Elrod, Kevin King, and Dr. Dan Murray
- 3 Russell Doolittle, Marcia Doolittle, WPA board member Ken Foster, and Ken Bjurstrom

- 4 Tom Smoody, Bob Rusk, and Amy-Mae Miller
- 5 Maureen & Dan Winkler, and Patty & Joe Schlicher. Joe is a WPA board member.
- 6 Laurie Dulitz, Kris Natalizio, Denise DiChristopher, and Kate Brewer. Kate is a WPA board member.

- 7 Unique auction items included this autographed Green Bay Packers football featuring the 1994 team.
- 8 Anna Warren shared her story about living with early-onset Parkinson disease and the positive impact WPA has had on her life. Anna is a member of the Rock Steady Boxing class in New Berlin that received a grant from WPA to support intake assessments and equipment for their initial class of boxers.

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
Greenville
Keshena
Kiel
Kimberly
King
Manitowoc
Menasha
Neenah
Oshkosh
Shawano
Sheboygan
Sturgeon Bay
Waupaca
Wautoma

Northern Wisconsin

Athens
Bayfield/Apostle Islands
Colby
Marshfield
Minocqua
Stevens Point
Wausau

Southeastern Wisconsin

Brookfield
Brown Deer
Burlington
Cudahy
Franklin
Grafton
Greendale
Greenfield
Hartford
Hartland
Kenosha
Lake Geneva
Mequon

Illinois

Dixon
Lake Forest
Lindenhurst
Loves Park
Moline
Rockford
Roscoe

Iowa

Bettendorf
Burlington
Clinton

Milwaukee
Mukwonago
New Berlin
Oak Creek
Oconomowoc
Racine
St. Francis
Summit
Thiensville
Waukesha
Wauwatosa
West Allis
West Bend
Whitefish Bay
Whitewater

Southern Wisconsin

Baraboo
Beaver Dam
Beloit
Fitchburg
Janesville
Madison
Middleton
Oregon
Portage
Richland Center
Stoughton
Sun Prairie
Verona
Watertown
Waunakee

Western Wisconsin

Black River Falls
Chippewa Falls
Clear Lake
Eau Claire
La Crosse
Menomonie
Rice Lake
Spooner
Tomah

Davenport
Decorah
Dubuque
Guttenberg
Newton

Menominee
Negaunee

Cloquet
Duluth



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

Welcome Mary Spidell-Wood!

Mary Spidell-Wood just joined WPA as part-time Exercise Coordinator! We are thrilled to have her join our team!

In 2009, Mary was an instructor at the Wisconsin Athletic Club (WAC). When a member with PD inquired about starting up a PD exercise class, Mary stepped up! She researched and knew this was something she wanted to do. She became certified through Delay the Disease in Columbus Ohio, and has been instructing classes since, and this has become her passion!

She has brought PD exercise classes to various recreation departments throughout the Milwaukee area.

In this new role, Mary will assist in the development, training, and instruction of Parkinson's Exercise Classes in under-served areas.

Three new classes have already started up – in Watertown, Burlington, and Cudahy. She will continue to carry out WPA's goals of building a strong network of exercise opportunities for Parkinson's communities across the state.

Connect with her at maryw@wiparkinson.org and learn more about her classes at wiparkinson.org.



SUPPORT/EXERCISE GROUP FEATURE: Lake Geneva Rock Steady Boxing



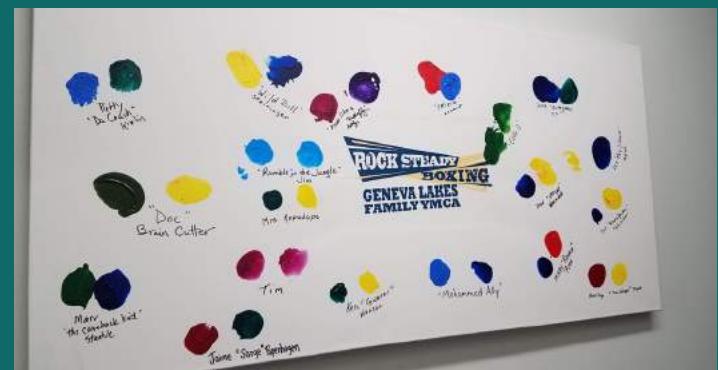
It all started with two friends, Pat Olson and Pauline Malsch. Both of their husbands had Parkinson disease. Pat and her husband, John, went to Florida in the winter of 2015. While down there, they found an exercise class designed for people with Parkinson's called Rock Steady Boxing. They thought it was a great program.

Pauline Malsch (left), with Pat Olson.

When they got back to Wisconsin in the spring, Pauline and her husband, Les, took them to a Rock Steady Boxing class in Madison, WI. It was a good class, but too far to travel twice a week from Lake Geneva. Together, they decided to try to start a class locally. Pat knew a board member at the Geneva Lakes Family YMCA. The board approved the idea. Next, they needed financial

support. So Pat and Pauline, along with the YMCA, contacted local businesses and raised enough money to send two staff members to Indianapolis to get certified as Rock Steady Boxing instructors.

The class started in September 2016 as a work out, and officially became Rock Steady Boxing in January 2017. The group started with six boxers, and today there are 25 and still growing! This would not have happened without the perseverance of two friends, Pat and Pauline.



WPA Happenings



Punt Parkinson's with the Pack

80% of our funding comes from individuals like you. We are so honored when families choose to raise money to support WPA's program and services.

The Barbian/Felder Family has held "Punt Parkinson's with the Pack" for the last seven years. This golf outing and Packer viewing party raised \$13,186 this year! Over the last seven years, they have brought in over \$63,000!

Thank you to Sam & Derek, Darlene & Craig, and all of their wonderful friends and family for supporting this work!

Pictured: Gary Garland, WPA executive director with Sam Felder.



Movement & Music: Parkinson Disease Exercise

WPA has launched new exercise classes in Watertown, Burlington, and Cudahy! These FREE classes incorporate stretches, strength training, posture, balance and walking drills, as well as vocal exercises. Learn more about these new classes at wiparkinson.org or by calling 414-312-6990.

Pictured: Chippewa Falls Movement & Music Class

WPA's Annual Holiday Reception!

December 4, 2019 | 4:30-7:00pm

Embassy Suites Brookfield

No charge to attend. | Donations welcome.

Register at wiparkinson.org or call 414-312-6990.



Would you like to receive Wisconsin Parkinson Magazine?

If you do not receive *Wisconsin Parkinson Magazine* 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.

Wisconsin Parkinson Association provides hope, community, support, and resources for people with Parkinson's and their loved ones.



WISCONSIN
PARKINSON
ASSOCIATION

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

Wisconsin Parkinson Association
16655 W. Bluemound Road, Suite 330
Brookfield, WI 53005

NON-PROFIT
U.S. POSTAGE PAID
TWIN CITIES, MN
PERMIT NO. 31688

Upcoming Programs

November 21

Working Professionals with Parkinson's
Iron Horse Hotel - Milwaukee

December 4

Holiday Reception
Embassy Suites Hotel - Brookfield

January 14

Working Professionals with Parkinson's
Revere's Wells Street Tavern - Delafield

Save the Date:

Renew! Retreat - March 28, 2020
Ingleside Hotel - Pewaukee

June 19

Parkinson Disease Symposium
Red Lion Hotel Paper Valley - Appleton

**More 2020 programs
will be announced soon!**

