

support
COMMUNITY
hope
RESOURCES



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WISCONSIN
PARKINSON
ASSOCIATION

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Credits

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

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

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

Staff

Gary Garland
Executive Director
garyg@wiparkinson.org

Carolyn Hahn
Marketing Communications Manager
carolynh@wiparkinson.org

Raven Hamilton
Administrative Services Manager
ravenh@wiparkinson.org

Jeremy Otte
Director of Outreach & Education
jeremyo@wiparkinson.org

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Letter from the Executive Director

• • •



Gary Garland

Executive Director

Welcome to the spring 2018 edition of *The Network* magazine!

While you are, hopefully, more aware of the season change as you look out the window, WPA is working hard to ensure tens of thousands around our state are more aware of Parkinson disease as April launches Parkinson Awareness month. Our plans for educational events, billboards, radio interviews, newspaper spots, and social media outreach make certain that this April, more people than ever before in our community will learn more about Parkinson's – and where to get help! Thank you for helping to make that possible.

Part of our Parkinson's awareness raising includes sharing our revamped mission statement:

**Providing hope, community, support,
and resources for people with Parkinson's
and their loved ones.**

It is a simple snapshot of who we are – with and for you.

In this, and every issue of *The Network*, we strive to put that mission statement into action. I am confident that as you make your way through the pages that follow, you will find yourself better informed, more inspired, and more connected to a strong and hopeful community.

Finally, I hope you will join us for our Annual Parkinson Disease Symposium on Friday, June 22. If you have attended in the past you know what a special program this is, and we expect the 2018 Symposium to be the best yet! It will be held at the Italian Community Center in Milwaukee, and for the first time ever, it will be free of charge! That means now all of our services – dynamic educational programs, this magazine, ongoing Parkinson's group support, great publications, a user friendly website, and prompt phone and email answers – come without cost. It is our desire that there is never any financial barrier for anyone who needs to get help on their Parkinson's journey.

**Thank you for sharing in, and making possible,
that mission!**

Thanks,
Gary
garyg@wiparkinson.org



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

Exciting News about the

32nd Annual Parkinson Disease Symposium

For the Parkinson community in Wisconsin for many years, there has been one constant: Wisconsin Parkinson Association's Annual Parkinson Disease Symposium. The Symposium offers opportunities to learn more about managing PD, new and emerging treatments, and access tips and tools for caregivers. This year will be no different in that regard, but there are some exciting changes for our upcoming Symposium on Friday, June 22.

First, the venue has changed. We will be at the Italian Community Center in Milwaukee. Why the move? Because of you. Last year, we had over 300 people who wanted to attend, but we only had space for 280 attendees. Due to the overwhelming demand, we knew we needed a larger space with greater capacity to hold everyone who wants to take charge of their Parkinson care.

The next change is the one we are most excited about. The cost for this year's event is FREE. You will still get a continental breakfast, a plated lunch, and snacks throughout the day, and more importantly, you will still get a handout with all 8 presentations included (even for the breakout sessions you don't attend). Because of this change, registration is required and walk-ins will not be admitted.

Our promise to you is that the Parkinson Disease Symposium will be a day of learning, connecting, and inclusion. The breakout sessions during the day will focus on exercise and staying active, tools for caregivers, and topics specific to your Parkinson disease care. The main sessions will focus on cognitive changes and mental health issues that can be associated with Parkinson disease, as well as other topics that you know you won't want to miss! 

"I can't wait
**FOR NEXT
YEAR!"**

"This was my first time attending and I enjoyed this conference so much."

"Your programs get better every year and translate into understanding and useful knowledge for living with Parkinson disease."

**THANK
YOU!**
Very informative day, glad I came."

"As my mom's caregiver, there are so many things she doesn't know I can help her with... We appreciate you opening up the conversation for us!"

To register, visit wiparkinson.org, or call 414-312-6990.

Ask the doctor!

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

Ask the Doctor

Taylor Finseth, MD

Taylor Finseth, MD is a neurologist at Aurora Health Care in Milwaukee, providing management of movement disorders including Parkinson disease, tremor, dystonia, and restless leg.

There have been several new PD medications introduced recently. Can you explain the differences and functions of these new medications?

There are four new medications introduced for addressing medication fluctuations, a problem where patients have inconsistent medication benefit throughout the day with periods of "ON time" where medicines work well, periods of "OFF time" where medications have worn off, and periods of dyskinesia where excess movements are induced by the medication.

Starting with most recent, these four medications are: Amantadine ER (brand name Gocovri™), Safinamide (brand name Xadago®), Carbidopa/Levodopa ER (brand name Rytary™) and Carbidopa/Levodopa enteral suspension (brand name Duopa™).

Gocovri showed improvement in OFF time and dyskinesia in the clinical trial and appeared to be well tolerated in most individuals, though some patients had hallucinations, dizziness or insomnia. It has not been studied head-to-head with generic immediate release amantadine and so it is difficult to compare the two, but theoretically the extended release version might offer more consistent benefit.

Xadago was approved for treatment of motor fluctuations in Parkinson's and appeared to show similar benefit to related medications like rasagiline by reducing OFF time, and while it was not studied head-to-head with rasagiline, it appeared that it caused less dyskinesia compared to rasagiline.

Rytary and Duopa have both been around a few years now and are two new long-acting formulations of carbidopa/

levodopa. Rytary is a capsule that lasts 4-8 hours and can both decrease OFF time and decrease dyskinesia compared to carbidopa/levodopa immediate release (Sinemet®). Duopa is a continuous infusion into the intestine that provides very steady medication levels, and comparably better control of motor fluctuations, but requires placement of a J-tube (a tube placed through the stomach wall and led into the upper intestine) and for the patient to have an external pump device to deliver the medicine.

For non-motor symptoms of PD, Pimavanserin (brand name Nuplazid®) was approved by the FDA for PD psychosis, which is a syndrome of hallucinations and/or delusions that can be seen in certain patients with PD. Medications like donepezil or quetiapine were typically used off-label for psychosis and are still utilized by some practitioners. Nuplazid appeared to be effective in trials and was relatively well tolerated. Importantly, Nuplazid did not appear to worsen movement problems in treated patients, as is common with traditional antipsychotic medications.

Another medication, called mirabegron (brand name Myrbetriq®), has come out in the last few years to help with overactive bladder symptoms. While this is not specifically for PD, it is quite useful for patients with PD and overactive bladder because it can help the bladder symptoms without worsening thinking and memory like other bladder medications can do.

These different options can be overwhelming, so be sure to discuss all questions and concerns in depth with your Parkinson's doctor. 

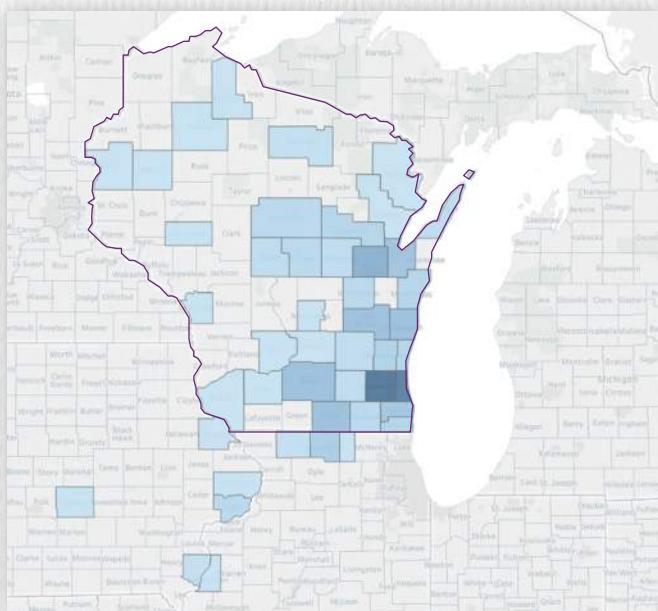
2017

SURVEY RESULTS

In October 2017, we included a survey in *The Network* magazine, and through our emails, asking readers for their input in an effort to improve our programming and outreach. You were asked a variety of questions related to demographics, your relationship to PD, and the needs you may have related to PD.

We received 251 responses from individuals across Wisconsin, Illinois, and Iowa.

Area	Number of Respondents	% of Respondents
Southeast WI	92	36.65%
Northeast WI	74	29.48%
Southwest WI	33	13.15%
North Central WI	22	8.76%
Unknown	17	6.77%
Iowa	9	3.59%
Illinois	4	1.59%
Total	251	100.00%



Basic Demographics

All respondents:

- Represented **45 counties** across Wisconsin, Illinois, and Iowa.
- Slightly **more than half** of respondents completed survey online.
- Seventy percent** of respondents identified having Parkinson disease.

Respondents that reported having PD:

- Slightly **more than half** are male.
- Seventy percent** are between the ages of 61 and 80.
- Fifty percent self-reported a mobility need and **27%** reported needing transportation assistance.
- More than **40%** travel farther than 16 miles to receive care.
- The primary caregiver is a spouse or partner (**70%**).
- The timeframe for diagnosis varied: Less than a year ago (**11%**), one to ten years ago (**66%**), and more than ten years ago (**22%**).

Key Findings

The purpose of using the survey to gather feedback was to better understand the people we serve – we wanted to learn more about who you are and what you need.

When asked what types of support WPA could provide, respondents with PD reported the following:

- Education programs in my area – **73%**
- Exercise groups/classes in my area – **57%**
- Literature and resources – **52%**
- Support groups in my area – **47%**
- Opportunities for social interaction – **25%**
- Webinars – **20%**
- Respite care – **7%**

Taking a deeper look at these needs by different attributes, we saw that they did not particularly change by geography.

Support Requested	IA	IL	North Central WI	Northeast WI	Southeast WI	Southwest WI	Unknown	Total
Education programs in my area	71.43%	100.00%	76.47%	79.63%	71.43%	58.82%	60.00%	73.17%
Exercise group/classes in my area	28.57%	33.33%	58.82%	62.96%	53.57%	70.59%	40.00%	56.71%
Literature and resources	71.43%	33.33%	47.06%	51.85%	44.64%	64.71%	70.00%	51.83%
Opportunities for social interaction	14.29%	66.67%	35.29%	27.78%	17.86%	23.53%	30.00%	25.00%
Respite care	—	33.33%	5.88%	9.26%	8.93%	—	—	7.32%
Support groups in my area	42.86%	33.33%	35.29%	57.41%	41.07%	52.94%	40.00%	46.95%
Webinars	14.29%	33.33%	23.53%	20.37%	17.86%	29.41%	10.00%	20.12%

But there were some notable differences when these responses are looked at by age group. Education programs are important, but less so to individuals with PD between the ages of 41-50. Opportunities for social interaction become decreasingly important for older individuals.

Support Requested	31-40	41-50	51-60	61-70	71-80	80+	Total
Education programs in my area	100.00%	25.00%	82.35%	84.21%	66.67%	62.96%	73.01%
Exercise group/classes in my area	—	75.00%	70.59%	59.65%	49.12%	59.26%	57.06%
Literature and resources	—	50.00%	58.82%	54.39%	42.11%	62.96%	51.53%
Opportunities for social interaction	100.00%	50.00%	35.29%	28.07%	24.56%	7.41%	25.15%
Respite care	—	25.00%	5.88%	3.51%	7.02%	14.81%	7.36%
Support groups in my area	100.00%	75.00%	52.94%	45.61%	45.61%	44.44%	47.24%
Webinars	—	—	29.41%	28.07%	14.04%	14.81%	20.25%

The length of time respondents have been living with a PD diagnosis also impacts their needs. Those who have lived with the disease the longest are seeking exercise and education over everything else, whereas those who haven't lived with the disease as long seem to want more information in the form of education programs and resources.

Support Requested	Less than a year ago	1-5 years ago	6-10 years ago	11-15 years ago	20+ years ago	Total
Education programs in my area	88.89%	76.27%	74.00%	57.69%	60.00%	73.01%
Exercise group/classes in my area	61.11%	67.80%	48.00%	42.31%	70.00%	57.06%
Literature and resources	66.67%	49.15%	46.00%	57.69%	50.00%	51.53%
Opportunities for social interaction	38.89%	15.25%	32.00%	19.23%	40.00%	25.15%
Respite care	5.56%	3.39%	10.00%	15.38%	0	7.36%
Support groups in my area	50.00%	50.85%	42.00%	50.00%	40.00%	47.24%
Webinars	38.89%	28.81%	12.00%	11.54%	—	20.25%

Next Steps

Thank you to all of the survey participants for taking the time to complete the survey. Surveys are one way we can learn from those we serve and we will use the responses to design and implement programming for the PD community. We will also be conducting another survey this fall.

If you have any questions or would like to provide additional feedback, please reach out to Carolyn Hahn, marketing communications manager at carolynh@wiparkinson.org or 414-312-6990. 

Deep Brain Stimulation

for Parkinson Disease

By Ryan T. Brennan, DO, Medical College of Wisconsin

Ryan T. Brennan, DO is an assistant professor in the Department of Neurology at Medical College of Wisconsin.

Deep brain stimulation (DBS) is an advanced therapy for patients with Parkinson disease (PD) suffering from complications of carbidopa/levodopa treatment. It has been FDA approved for use in PD since 2002 and for tremor prior to that. DBS involves the surgical implantation of a device with electrodes that deliver electrical signals to specific areas within the brain. Once the electrodes are placed, they are then connected to an implanted pulse generator (battery) which is placed under the skin, typically in the chest. When the device is activated, it delivers regular electrical pulses to that area of the brain and results in improvement of PD symptoms. The exact mechanisms of how DBS improves symptoms are not known. However, we do know that it disrupts pathological signals that occur within the brain of PD patients.

Currently, DBS is approved for those patients with a diagnosis of idiopathic PD, who have had symptoms for four or more years and suffer from motor complications that are not controlled with medications. Motor complications refer to the medications not lasting as long (wearing off), levodopa induced dyskinesias (extra, abnormal and involuntary movements) and dose failures.

Individuals who would not benefit from DBS are those with atypical forms of PD, those with signs of dementia and those whose symptoms do not improve with levodopa. Depression and anxiety do not preclude someone from receiving DBS, but these should be addressed, treated and well controlled prior to proceeding.

The process of implanting DBS for patients is a lengthy process. It involves careful pre-surgical screening, two

or three surgeries and many follow up programming appointments. The first step is what is called an “Off/On Test.” For this test, the patient comes to an appointment with the neurologist after not taking PD medications from the night before. The patient is then examined in this “Off” medication state. Then, the patient receives a higher than usual dose of carbidopa/levodopa and is re-examined once those take effect.

The next step is to have a formal neuropsychological evaluation performed. This evaluation typically takes about half a day and includes extensive testing of memory, language and other cognitive abilities. Once these two preliminary evaluations are complete, most DBS centers hold a multidisciplinary case conference to discuss the results and the patient’s candidacy for DBS surgery. If there are no contraindications to surgery, the patient will meet with the neurosurgeon who reviews the procedure and the potential risk of surgery. Often times, an additional pre-operative medical evaluation is also required to screen for other medical conditions that could pose additional surgical risks or potential complications. The patient also receives a pre-surgical MRI of the brain to assist with placement of the DBS electrodes.

“Depression and anxiety do not preclude someone from receiving DBS, but these should be addressed, treated and well controlled prior to proceeding.”

—Ryan T. Brennan, DO



Most centers perform DBS implantation in two or three individual surgeries. After the DBS device is implanted, the patient then returns to the clinic to turn the device on, typically after three or four weeks. The number of programming appointments needed varies from one patient to the next but can take 6-12 months to reach optimal settings. The battery is checked at routine follow-up appointments and depending on which device is implanted, the battery will need to be replaced from time to time.

Not all symptoms of PD will improve with DBS therapy. The general rule of thumb is if particular symptoms improve after taking carbidopa/levodopa then those symptoms can be expected to improve with DBS. The caveat to this rule are refractory tremors. Tremor in PD can often be resistant to carbidopa/levodopa, but responds well to DBS. In addition, DBS can significantly reduce problems with medication

wearing off and dyskinesias. Walking difficulties in PD can be varied and complex. Some of these may respond to DBS but many do not, including balance. Therefore, patients should consult with their DBS physician prior to surgery in regard to their specific walking issues.

Symptoms that are unlikely to improve with DBS are those symptoms that worsen with levodopa, balance, memory problems, speech and swallowing difficulties. DBS can also allow the reduction of some of the PD medications, although it is not realistic to expect to stop all PD related medications after surgery.

It is important to understand that DBS is not a cure, however it is very effective at treating many motor symptoms of PD and improving quality of life. 



WPA'S CAREGIVER COMMITTEE



By Carolyn Hahn, Marketing Communications Manager

Over the last 35 years, WPA has worked hard to meet the needs of people with Parkinson's. Through educational programs, support and exercise groups, this magazine, our website and more, we have provided support, resources, hope, and a sense of community for the people fighting this disease.

Now we are broadening even more – to also provide support, resources, hope, and a sense of community for those of you who CARE for someone with Parkinson's. With this goal in mind, we started with a roundtable discussion last fall, where we invited feedback on what caregivers wish they had known when first caring for someone with PD, what WPA has (and hasn't) provided for caregivers in the past, and ideas on how we could help people in their position moving forward.

After several roundtable discussions, we have come up with some ways that we will be improving our support to this often over-looked group over the next few months.



Incorporate a caregiver-related article into each issue of *The Network* magazine



Include a caregiver-related article in each edition of our monthly e-newsletter



Create an area on wiparkinson.org solely dedicated to caregiver resources, including relevant publications and links to other organizations that can help

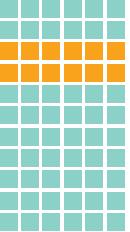


Post more caregiver information and resources on our Facebook page



Develop a caregiver survey, similar to the program survey we conducted in 2017 (see pages 6-7), to hear from a larger group of caregivers around the state

As with all of our programs, we need your feedback for this to be successful. If you have ideas on ways to improve on these ideas, or to start something new – please reach out! You can email me at carolynh@wiparkinson.org or call our office at 414-312-6990.



300 Tips FOR MAKING LIFE EASIER

Here are some ideas from the book "Parkinson Disease: 300 Tips for Making Life Easier" by Shelley Peterman Schwartz. Some tips have been shortened for the purpose of this article.

Looking Good, Feeling Better

- 1 | Dress during your "on time"** – it will be easier.
 - 2 | Allow enough time so that you don't feel rushed.** Gather all your clothing items together before you start to dress, or lay your clothes out the night before.
 - 3 | If your balance is unsteady,** sit on the bed or in a sturdy chair with armrests while you dress, do your hair, shave, or apply makeup.
- ## Grooming
- 4 | Substitute a wash mitt, soft or long-handled sponge for the usual washcloth.**
 - 5 | Pour shampoo onto a sponge,** then rub the sponge on your hair. The shampoo is less likely to run into your eyes, and there's no chance of dropping a slippery bottle.
 - 6 | Keep undergarments in a drawer** in the bathroom so you can change into them after you shower.
 - 7 | Cut your toenails right after you bathe,** since they are less brittle and easier to cut, using a toenail clipper or scissors with short blades. If your nails are too thick, consider having your toenails cut by a pedicurist or podiatrist.
 - 8 | Use an electric toothbrush** if you have tremors. Conserve energy by brushing sitting down.
 - 9 | Buy dental floss "swords"** or try a WaterPik that will massage your gums and rinse food debris from your mouth.
 - 10 | Use an electric razor** if you experience tremors. They come in all shapes and sizes, so test out how they feel in your hand before you buy one.
 - 11 | Use pump bottles for lotions and liquid soap.** It's easier to press down on a pump top than to squeeze a bottle or grasp a bar of soap.

Choosing the Right Clothing

- 12 | Replace clothes that are hard to put on** with easy-on/easy-off clothing. Consider buying clothing one size larger than you normally wear.
 - 13 | Choose satin or nylon tricot sleepwear and underwear.** This will make turning over in bed easier, as well as pulling slacks and trousers up and down.
 - 14 | Choose shirts with multiple colors and patterns.** If you tend to spill when eating, most spills won't show up.
 - 15 | Choose clothing with elastic waistbands or Velcro closures** instead of zippers or buttons. Wear pullover tops to eliminate fastening.
- ## Dressing Tips
- 16 | Always dress a weaker limb or your stiffer side first,** and to undress, take the garment off the stronger side first.
 - 17 | Dress in front of a mirror** to help you find sleeves and match buttons with buttonholes.
 - 18 | If you're wearing layers,** put the inner layer into the outer layer before putting it on, so you only have to expend the energy to put the garment on once.

Dressing Aids and Simple Clothing Adaptations

- 19 | Replace buttons and fasteners with Velcro.**
- 20 | Make your own zipper pull** by screwing a small cup hook into a dowel.
- 21 | Sew loops of bias tape inside the waistbands of pants** to help pull them up and down.

continued on page 16

SKIN ISSUES IN PARKINSON'S

By Joseph Jankovic, MD

Skin, the largest organ of the body with a total area of about 20 square feet, protects us from infection and environmental elements, helps regulate body temperature, and mediates various sensations, including touch and temperature. Skin can be involved in many diseases including Parkinson's disease (PD).

One of the most common dermatological conditions associated with PD is seborrhea, manifested by greasy and flaking skin, oily hair and dandruff. Seborrheic dermatitis, one of the most common non-motor manifestations of PD, typically affects the face but may involve other parts of the body. The cause of this condition is not well understood, but skin infection with yeast, such as *Malassezia globosa*, has been implicated. This presumably results in inflammation of sebaceous glands under the skin which then leads to over-secretion of oil, especially in the scalp, forehead, eyebrows, and around the nose. In addition to oiliness and redness the seborrheic dermatitis may cause itching. Keeping the skin clean and dry is an essential element in the treatment of seborrhea. This may need to be supplemented with topical steroids or injecting the affected skin areas with botulinum toxin (e.g. Botox).

Some individuals with PD complain of dry skin while others experience excessive sweating (hyperhidrosis), the so called "drenching sweats of PD." These typically occur at night or during wearing off periods in patients with levodopa-related motor fluctuations. In addition to dopaminergic drugs, patients with hyperhidrosis may benefit from medications such as propranolol, aluminum chloride hexahydrate, and anticholinergics (e.g., glycopyrrolate) as well as skin injections with botulinum toxin.

Drooling (sialorrhea) can also cause skin problems especially of the lips and the chin as a result of local irritation by the saliva and frequent wiping of the area around the mouth.

Another dermatologic problem associated with PD is skin picking (dermatillomania), which may be a manifestation of impulsive or compulsive behavior and it may occur even before the onset of motor symptoms [Che et al, 2016].

There are certain medications used to treat various PD-related symptoms that can affect the skin. For example, the yellow dye in Sinemet 25/100 used to be associated with allergic skin reactions in rare cases. Also, dopamine agonists such as pramipexole, ropinirole, and rotigotine, can cause swelling of ankles and other body parts because of skin edema. Furthermore, amantadine can cause livedo reticularis giving rise to mottled pattern of a lace-like purplish discoloration of the skin. It particularly affects the legs but, except for the abnormal appearance, it usually does not cause any symptoms. Anticholinergics, such as trihexyphenidyl and benztrapine, occasionally used to treat PD-related tremor can also cause dry skin.

"There is growing research interest in skin not only because of its symptomatic involvement in PD but also as a potential diagnostic biomarker."

—Joseph Jankovic, MD

The most serious skin disease in PD is melanoma. This malignant form of skin cancer can spread (metastasize) to internal organs and the brain and is associated with high mortality. We and others have found that while PD patients have a relatively low risk for most cancers, they have up to 7 fold increase in the frequency of melanoma compared to general population.

Joseph Jankovic, MD is Professor of Neurology and Distinguished Chair in Movement Disorders; Director, Parkinson's Disease Center and Movement Disorders Clinic, Department of Neurology, Baylor College of Medicine. In 1977, he joined the faculty at BCM and became a founder and director of the Parkinson's Disease Center and Movement Disorders Clinic, recognized as a "Center of Excellence" by the National Parkinson Foundation and the Huntington Disease Society of America. Dr. Jankovic has published over 900 original articles and chapters and has edited or co-edited over 50 books and volumes including several standard textbooks.



As a result, the American Academy of Neurology recommends that all patients with PD are screened for melanoma at least annually. The relationship between PD and melanoma is still not fully understood but research at Baylor College of Medicine Parkinson's Disease Center has provided some insight. For example, in one of our studies we found that the synthesis of the pigment melanin is impaired not only in the brains of patients with PD (substantia nigra) but also in their skin, thus increasing the susceptibility of PD patients to melanoma [Pan et al, 2011]. We further postulated that α -synuclein, the abnormal toxic protein that accumulates in the brains of patients with PD, may also accumulate in the skin and interfere with melanin synthesis, thus depleting the skin of the pigment that normally protects it against the damaging effects of ultra-violet radiation [Pan et al, 2012]. Subsequent studies confirmed that individuals with PD are more likely to develop melanoma and melanoma patients have a higher risk of developing PD [Inzelberg et al, 2016]. Interestingly, PD risk is influenced also by pigmentation in the hair and studies have found increased risk of PD with decreasing darkness of hair color; thus blonds and redheads have been found to have the highest risk for PD. Despite warnings against using levodopa in patients with history of melanoma, it is unlikely that levodopa increases the risk of melanoma.

There is growing research interest in skin not only because of its symptomatic involvement in PD but also as a potential diagnostic biomarker [Jankovic, 2017]. Several studies have demonstrated abnormally high levels of α -synuclein in the skin of patients with PD. In one study of 28 patients with PD and 23 healthy participants α -synuclein was found to be significantly more represented in the skin of PD patients compared to the normal controls, and this difference distinguished the two groups with a high (>90%) sensitivity and specificity [Gibbons et al, 2016]. This observation has led to measuring α -synuclein in skin biopsies as a potential biomarker for the diagnosis of PD [Lee et al, 2017]. Thus the clue to PD may lie just under the skin! 

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TIPS FOR VISITING SOMEONE in a nursing home

By the GWAAR Legal Services Team

Summer can be a time for travel, catching up with family and friends, and spending time outdoors. It can also mean more time and ability to visit loved ones in nursing homes. However, many people put off visiting friends and relatives in nursing homes because they are nervous, have had difficulty with visits in the past, or don't know how to act.

Here are ten tips that may help you or someone you know make nursing home visits enjoyable for everyone:

- 1. Plan your visit.** Know when you're going, the home's visiting hours policies, and the activity schedule.
- 2. Time your visit carefully.** Ask the person you are visiting and the nurses when is a good time to visit. For example, some people are more alert and energized in the morning.
- 3. Make your visit brief, if needed.** There's no ideal length for a visit. Consider a half hour of warm connection rather than sitting in silence for twice that time. Often people in nursing homes tire quickly, so shorter visits are better.
- 4. Try not to feel intimidated.** It's natural to feel self-conscious about how you're "supposed" to act in a new situation. Consider it a gift to your loved one to set your own feelings aside.
- 5. Don't be intimidated by dementia.** Try not to turn a visit with a person with dementia into a series of challenging questions, where they feel put on the spot to remember or come up with the "right" answer. Instead try the phrase, "Tell me about..."



- 6. Talk about yourself.** Talking may take a lot of energy and tire the person out – listening may be an easier (and more pleasant) way to spend time together.
- 7. Go outdoors.** If possible, go for a short walk, take a drive, or sit outside on a bench.
- 8. Bring items to talk about.** Some examples include pictures, videos, cards or drawings from children, or other objects with great memories to spur conversation.
- 9. Don't be afraid of physical contact.** You don't have to talk the whole time – you can just spend time expressing that you care in other ways. Consider going at meal time to share a meal or help with feeding; give a shoulder or foot massage or a manicure; just sit quietly and hold hands.
- 10. Know that your presence can be a source of comfort and reassurance.** 

WHEN SUMMER BEGINS,

Outside Workouts Don't Have to End

You have been loyal to your outdoor exercise program for months; walking, even when your muscles ached or biking, even when your Parkinson's acted up. Due to your dedication, your body is strong, your health is good and your endurance is better than ever, then summer approaches and the environmental thermostat begins to rise. Does that mean your beloved outdoor workout has to end when those warm months roll around? Only in your dreams, because with proper precautions, you can keep on trucking and workout in the summer heat.

Tips for Working Out in the Heat:

1 Check weather reports. What you are mainly concerned about is not only the temperature, but also the humidity. High heat and humidity can cause exhaustion, heat cramps or worse. When there's a lot of moisture in the air, the body isn't able to rid itself of heat as well as in a drier environment because the body can't evaporate sweat, so watch humidity levels.

2 Notice your body's signals. Indications that the body is straining itself during a workout include: a higher heart rate than normal, nausea, excessive sweating or inability to sweat and lightheadedness. Take these symptoms seriously and slow down.

3 Hydrate yourself. If you feel thirsty, your body may already be experiencing dehydration. Drink a minimum of 8 ounces of water, 20 minutes before a workout and at least 4 ounces of water every 15 minutes during activity.

4 Consider working out in the early morning or evening and still watch the humidity.

5 Know your heat tolerance. People can adapt to their climate so heat tolerances vary. If you are accustomed to working out in a high humidity climate, you may be OK during high heat, high humidity days. But, if you are a vacationer from Arizona trying to work out in the humidity of Florida, you may find yourself in trouble.

6 Wear light-colored, loose-fitting clothing and a hat to keep your face and head cool. There are specially manufactured materials in stores that you can buy to help keep moisture away from the skin.

7 Wear a specially formulated sunscreen for participating in sports. They tend to be less greasy and stay on better. Also, wear UV protecting sunglasses to guard against ultraviolet radiation.

8 If you feel especially fatigued, slow down. Even top-notch athletes know when to say, "uncle". If you still feel depleted, take a cool shower.

9 If you are experiencing heat cramps, which are less severe than regular cramps, it may be a sign your body is having problems with the heat so lower the intensity.

10 Stay away from highly sweetened waters during activity because they may upset your stomach. Also, carbonated drinks during a workout may cause a dehydrating effect so consider sticking with regular water. 

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300 Tips FOR MAKING LIFE EASIER

Hosiery and Footwear

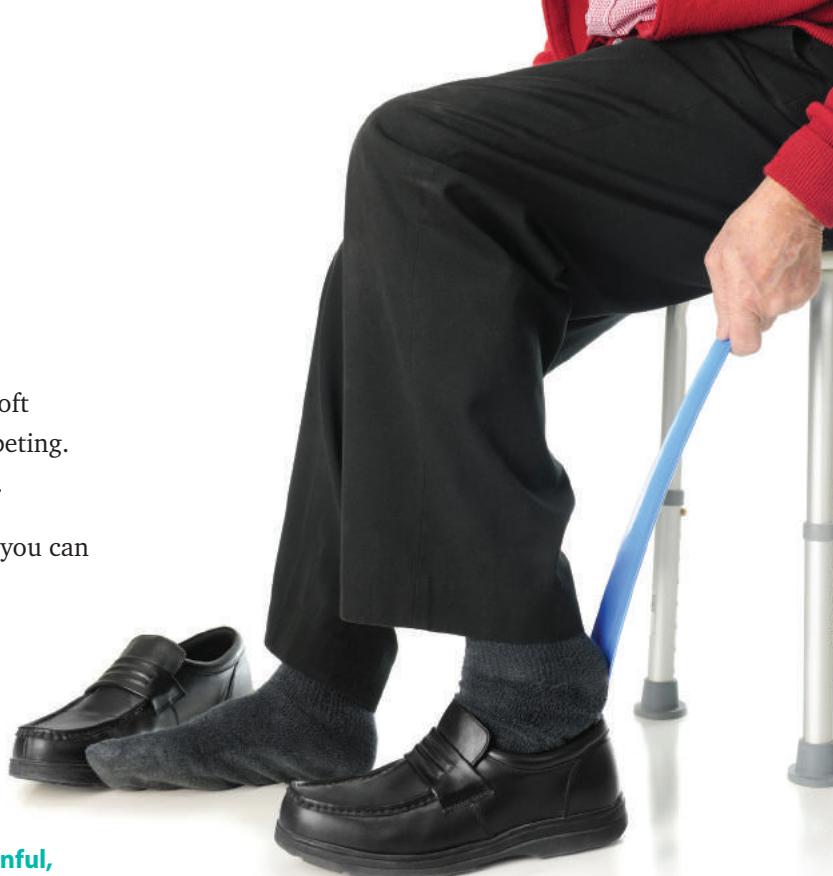
22 | Choose the right shoes. If you have a shuffling gait, soft rubber soles make walking more difficult, especially on carpeting. Hard leather soles can be slippery on linoleum or tile floors.

23 | Use elastic shoelaces in place of normal laces so that you can just slip your shoes on and off.

24 | Use a long-handled shoehorn to minimize bending and reaching.

25 | Wear tube socks – they are easier to put on than traditional socks.

26 | Support hose and compression socks may relieve painful, swollen feet. Putting them on requires some strength and practice, and you may need assistance. 



MOVING FORWARD TOGETHER

Parkinson Disease SYMPOSIUM

a community education program on Parkinson disease

June 22, 2018
8:00 am - 3:30 pm

Italian Community Center
Milwaukee

brought to you by:



WISCONSIN
PARKINSON
ASSOCIATION

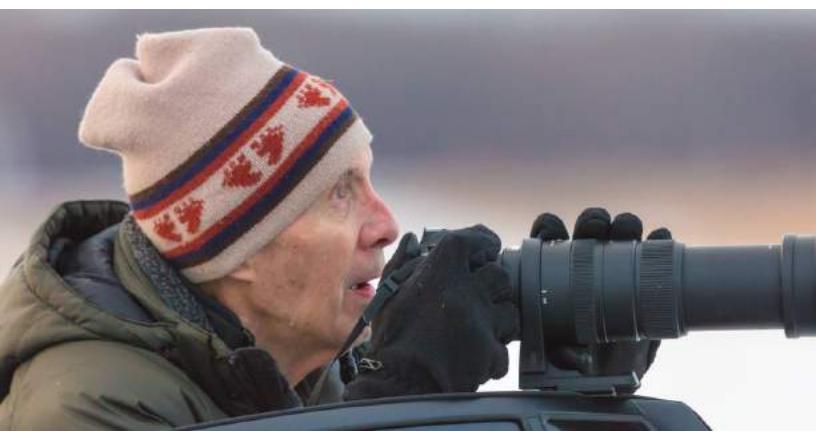
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US WorldMeds

Registration is FREE!
Learn more and register at
wiparkinson.org or 414-312-6990.

jim edwards: PHOTOGRAPHER



Jim Edwards is a husband, a father, and a grandfather. He is also a retired financial planner, a photographer, and someone living with Parkinson's. He recently shared his beautiful photographs with the Appleton Support Group.

WPA: How long have you been a photographer, and what kinds of photos do you most enjoy taking?

Jim: I've been taking pictures for a long time. I was a financial planner, and retired about 7 years ago. There's not a lot of room for creativity in financial planning, so photography gave me that outlet. It really brings me joy to take pretty pictures and share them! I like to give them to people who have gone out of their way to help me, or others. I've given out several hundred pictures to people in our community, at our church, and in our neighborhood. I like taking scenic pictures of nature, animals and birds.

WPA: Where do you find inspiration for your photos?

Jim: I carry my camera with me a lot when I go out, and I have a mentor and friend who is a photographer, and he and I will often head to a wildlife refuge about a half hour away to take pictures. There are several great places in

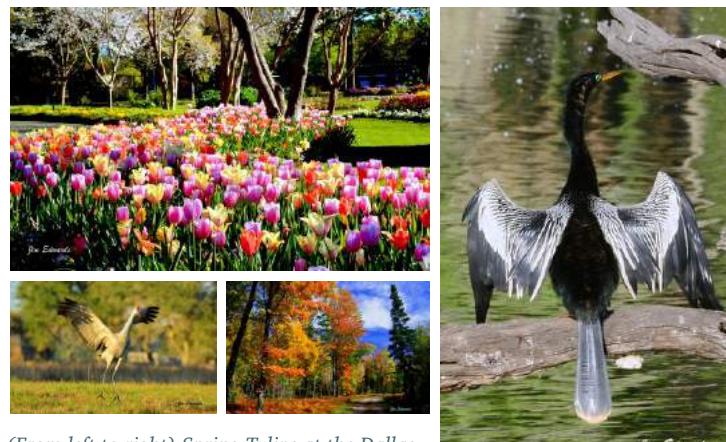
Wisconsin: nature preserves and other similar areas. We're blessed here to have land set aside for wetlands and conservation through the Northeast Wisconsin Land Trust.



My wife Rachel and I used to live in Dallas, and one of our three children lives in Houston, so we travel down to Texas nearly every year. The Dallas Arboretum & Botanical Garden has over 500,000 tulips in bloom every year, so this tulip photo (below) was taken in 2016.

WPA: Tell us about your connection to Parkinson's.

Jim: I was diagnosed with Parkinson's about 15 years ago, at age 65. In 2011, we moved to Appleton to be closer to family, and I joined the Appleton Support Group about 5 years ago. My voice has gotten a little softer, and my gait is about two-thirds of what it was, but I don't have a tremor. I know the importance of exercise, and I like to walk at least three times a week, and go to the gym too.



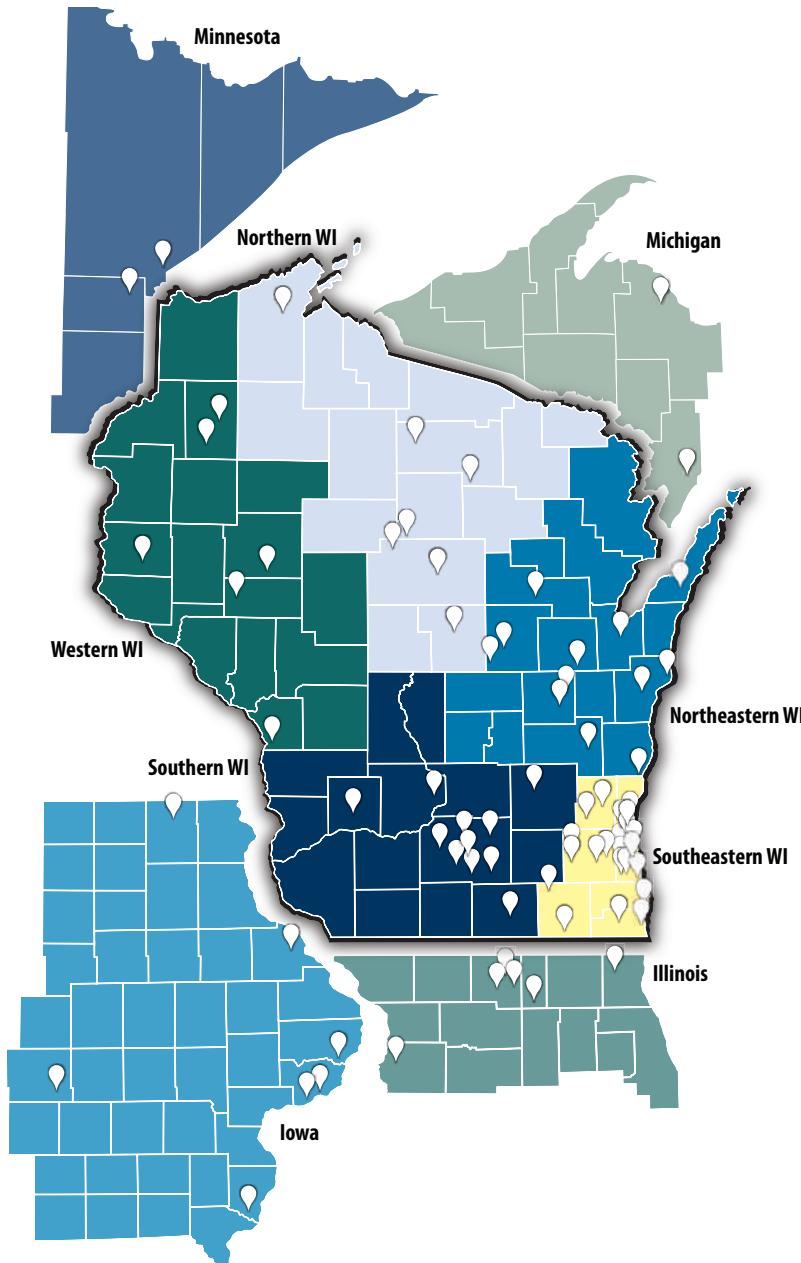
(From left to right) Spring Tulips at the Dallas Arboretum; Anhinga drying feathers in the sun; Sandhill Crane dancing to start the day; Curve in the Road in Michigan's UP

WPA: Any advice to share with other people with Parkinson's?

Jim: Find a hobby and keep being active. If you don't use your mobility, you will lose it. And once you've lost it, you can't get it back! 

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
Fond du Lac
Green Bay
King
Manitowoc
Neenah
Oshkosh
Shawano
Sheboygan
Sturgeon Bay
Waupaca

Northern Wisconsin

Athens
Bayfield/Apostle Islands
Colby
Marshfield
Minocqua
Rhineland
Stevens Point

Southeastern Wisconsin

Brookfield
Brown Deer
Franklin
Grafton
Greenfield
Hartford
Kenosha
Lake Geneva
Mequon
Milwaukee

Illinois

Lake Forest
Lindenhurst
Loves Park
Moline
Rockford
Roscoe

Iowa

Bettendorf
Burlington
Clinton

Oconomowoc

Racine
St. Francis
Somers
Summit
Thiensville
Waukesha
Wauwatosa
West Allis
West Bend
Whitefish Bay
Whitewater

Southern Wisconsin

Baraboo
Beaver Dam
Fitchburg
Janesville
Madison
Middleton
Richland Center
Stoughton
Sun Prairie
Verona
Waunakee

Western Wisconsin

Chippewa Falls
Eau Claire
Hudson
La Crosse
Shell Lake
Spooner

Davenport

Decorah
Dubuque
Newton

Michigan

Menominee
Negaunee

Minnesota

Cloquet
Duluth



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

Working Professionals With Parkinson's

We know that balancing a career, family, life, and Parkinson disease can be challenging, so we are coordinating a series of 3 "after work" events for working professionals with Parkinson's to get together and network. Registration is requested – visit wiparkinson.org for all the details!

April 5 | Wine Maniacs, Oconomowoc • May 10 | Red Dot, Wauwatosa • June 7 | World of Beer, Wauwatosa

RECENT EVENT

Parkinson Disease: Living Well

WPA recently hosted "Parkinson Disease: Living Well" in Oconomowoc and in Appleton. This 3-hour program features three different speakers on topics like the non-motor symptoms of Parkinson's, adapting your home for safety & convenience, resources for driving safely, and more.



Thanks to our recent speakers: Taylor Finseth, MD, Kyle Swanson, MD, Ruth Busalacchi, Lisa Kokontis, MD, David Neuenfeldt, DPT, and Carrie Campbell, OTR.

Movers & Shakers Golf Classic



The 4th Annual Movers & Shakers Golf Classic is set for Saturday, June 2 at Evergreen Golf Club in Elkhorn, WI. This family-oriented golf and dinner event is run by Joe Schlicher and his family and friends as a community fundraiser for WPA. The event includes golf and dinner, or the option to come just for dinner. There will be an extensive silent auction assortment as well as a raffle and live auction items. We hope you can join the event this year! Visit wiparkinson.org for details on how you can get involved!



WPA was so honored to receive a \$15,000 donation recently from the Krainz Foundation. This private family foundation was founded by Robert Krainz, and is now managed by his family.

Pictured: Dale Martin, president and director of the Krainz Foundation; Gary Garland, executive director of Wisconsin Parkinson Association; Dick Cosentino, board president of Wisconsin Parkinson Association.

Would you like to receive *The Network* magazine?

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

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
2819 W. Highland Boulevard
Milwaukee, WI 53208

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Upcoming Events

April

Parkinson's Awareness Month

April 27

Parkinson Disease: Living Well
Rothschild/Wausau

May 10

Working Professionals
with Parkinson's:
Cocktails & Conversations
Wauwatosa

May 23

Fly Fishing Clinic
Palmyra

June 2

Movers & Shakers
Golf Classic
Elkhorn

June 7

Working Professionals
with Parkinson's:
Cocktails & Conversations
Wauwatosa

June 21

Support Group
Facilitator Training
Milwaukee

June 22

32nd Annual Parkinson
Disease Symposium
Milwaukee

July 29

The Bottle Milwaukee
Softball Tournament
Milwaukee

September 11

WPA Open Golf Outing
& Dinner
Hartland

September 26

Parkinson Disease: Living Well
Green Bay



More programs are being
planned around the state.
Visit wiparkinson.org
for more information!