



WISCONSIN PARKINSON

MAGAZINE ISSUE NO. 105 | 2020

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RESOURCES



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Please help us keep this magazine – and ALL WPA programs – 100% free for everyone who needs them, by sending your generous gift today.

Thank you!

Letter from the Executive Director

Dear Friends,

I hope this finds you and your loved ones safe and well!

You know, I have started hundreds of letters with that exact greeting, and never have I worried about how you are doing as much as I do today. These days are beyond strange, and I really do hope you and your loved ones are finding ways to thrive and stay healthy.

Things have been difficult for all of us since March when our worlds were turned upside down by a previously unknown virus. And when our lives have been shaken – we all seek and need anchors.

I hope you have those anchors – whether it's your **family**, your **friends**, your **work life**, or your **faith** community. Wisconsin Parkinson Association wants to be an anchor in your life, and especially on your journey with Parkinson's.

I hope you have enjoyed some of the great programs our staff has created since the need to "go virtual" started in March. I am so proud of our entire staff. Before Wisconsin's "Safer at Home" order was even put into place, WPA had begun delivering our programs virtually. We went into action so quickly, because of our commitment to serve you and the entire Parkinson's community. You'll read a lot more about our recent efforts in this issue of Wisconsin Parkinson Magazine.

So, as we launched virtual programming... We pivoted... We tried things out... We learned a lot... We took risks... Sometimes we failed... We learned some more... And we tried again.

That's the model we will keep using in these uncertain times – whether this strange season lasts three more months or another year.

WE ARE HERE FOR YOU AND YOUR FAMILY FOR THE LONG RUN!

Finally, more than ever due to canceled programs and hard economic times brought by COVID-19, we ask you to consider a generous gift. In the fiscal year that ended August 31st, we saw \$80,000 less revenue than we had projected. Despite deep cuts to our expenses, we still saw a significant deficit. With over 80% of our support coming from individuals just like you, your help is our lifeline. You can use the envelope provided here, or donate easily online at wiparkinson.org.

As always, if you have any questions or comments about WPA's work, please reach out to me at garyg@wiparkinson.org or 414-312-6990.

Stay well!

Gary

Gary Garland



Delivering Local Programs and Local Answers During a Global Health Crisis

With the changes in our world, country, and state this year, WPA has “pivoted,” “adapted,” and “adjusted” nearly everything we do. It still isn’t safe to gather in large groups, so welcoming 500 people to our Annual Symposium this summer was obviously out of the question. So what’s new from WPA over the last six months?

Have been providing **weekly** emails featuring information and resources from across the country, as well as from local experts, including your doctors and therapists.

Hosted our Annual Parkinson Disease Symposium over **3** days, where **449** people (from **14** states) signed up to hear **9** presentations about medications, nutrition, caregiving, driving safety, and MORE. If you missed out, view the recordings at wiparkinson.org/program-videos/

Held **5 VIRTUAL** half-day programs welcoming speakers from places like Wausau, La Crosse, Appleton, Milwaukee, Madison, Racine, and Green Bay. If you missed out, view the recordings at wiparkinson.org/program-videos/

Launched “**Movement & Music**” classes LIVE on Facebook – which continue **3x** a week on Facebook Live and Zoom! You can also download or view recordings at wiparkinson.org and our YouTube page. Join us at facebook.com/groups/wpamovementandmusic

Made over **550** phone calls to people who don’t receive our email communications, and we were concerned about being isolated during this difficult time.

Interviewed **22** of Wisconsin’s top health care professionals and experts on topics like home care, motor fluctuations, estate planning, medications, and so much more. View all of these videos at wiparkinson.org/video-resources

Created a list of **at-home** exercise options for you to do from the **comfort** and **safety** of your living room. See page 18 for a sample.

Continued to have our staff available to you via phone and email to **answer your questions** or **point you to resources** you were looking for.

Our mission remains the same: providing hope, community, support, and resources for people with Parkinson’s and their loved ones. Even if that looks a little different right now, WPA remains here for you!

2020 Parkinson Disease

Symposium



The 2020 Parkinson Disease Symposium looked a lot different this year! Instead of one day packed full of education, it was three days packed full of education. Instead of enjoying a beautiful banquet facility and a catered lunch, participants watched from the safety and comfort of their own homes. Instead of being in a big conference room with doctors, therapists, and care providers, attendees welcomed the speakers onto their computers and into their living rooms!

All sessions were recorded and can be viewed at wiparkinson.org/program-videos/. The next few pages also include summaries of some of the sessions, written by the presenters.

Using a program called Hopin, attendees were able to visit with exhibitors and vendors, just like they do at WPA's in-person programs. Thanks to these sponsors for making the Symposium possible:

AbbVie

Bader Philanthropies

Kyowa Kirin

Medtronic

Adamas

Boston Scientific

Lundbeck

Supernus

"Thanks to WPA, vendors, and presenters for staring COVID in the eye and not backing down! These 3 days were excellent!"

"All good speakers, covering a wide range of topics – some I hadn't thought of before. Such a good week!"


"Since listening to the presentation on research, I have since signed up to see if I'm a candidate to help."

"I hope you have this online again! Not everyone can come to your location, so this is a great way to reach people!"

Bladder, Bowel, and Sexual Health

Erica Vitek, MOT, OTR
Aurora Health Care



 Bladder, bowel, and sexual health concerns can be very challenging to manage especially on top of the movement challenges those with Parkinson disease face. The prevalence of all of these concerns varies in literature, however it is noted to be well over 50%. Urgent bladder, night time frequency of urination, lack of interest, or physical ability to participate in sexual relations tend to be the most common.

Knowledge about normal functioning can be empowering to help in analysis of the pelvic challenges the person with Parkinson's is facing. For example, the bladder should hold a fair amount of urine before the urge to void comes into one's awareness, additionally, being able to hold the urge until it is socially appropriate to empty. There is a complex interworking in the brain that helps our bodies maintain this normal function. When the brain is depleted of the chemical dopamine from Parkinson disease, the bladder begins to be uninhibited, meaning it becomes overactive. This may result in voiding frequently throughout the day, greater than eight times.

Another example is with bowel function; daily bowel movements are especially important to keeping the bowel system from becoming backed up and uncomfortable. Potentially, one may have been able to get up for work every day, have a cup of coffee, and easily have a daily bowel movement without giving it a second thought. When the brain and colon system is depleted of dopamine, it results in slow transit of waste through the system and additionally makes it difficult to evacuate the stool.


Lastly, the sexual system relies on dopamine in the brain for allowing the optimal environment for desire to participate in sexually related activity. Adding this to the challenges of movement and positioning and potential bed separation with one's partner due to sleeping difficulties are just a few examples of how this may negatively impact one's sexual health.

There are many simple lifestyle changes one can try in order to get a handle on these challenges.

For the bladder: 1. Consider eliminating irritants such as caffeine, carbonation, and acidic juice. 2. Drinking enough water throughout the day, ½ body weight in ounces. 3. Having a daily bowel movement gives the bladder space for proper filling. 4. Limit fluids at least two hours before bedtime. 5. Relax and do not strain during urination to ensure emptying the bladder completely.

For the bowels: 1. Sit on the toilet at the same time each day to attempt a bowel movement. 2. Use a stool under the feet and leaning over with elbows on thighs while sitting in the toilet. 3. Eat a balanced diet of fiber and water intake daily. 4. Exercise! 5. Never ignore the urge to have a bowel movement.

For sexual health: 1. Consider sexual activity during on times. 2. Find intimacy in everyday activities, potentially showering together. 3. Use of intimacy tools, music to set the mood and/or lubricants to help with desire and sensations. 4. Use of non-verbal cues to communicate with your partner about interest to minimize the potential of flat affect/facial expression. 5. Good sleep hygiene to recharge the body and sexual organs.

Pelvic health rehabilitation can be key to working through these challenges, significantly lessening the burden and potentially eliminating these concerns. The pelvic floor muscle plays a role in the ability to maintain continence, allow for ease of bowel movements, our core support of balance and stability, as well as participates in sexual pleasure. Completing exercises with the pelvic floor muscles and surrounding larger muscle groups can be key to normalizing the pelvic functions. 

Erica Vitek, MOT, OTR

is board certified in biofeedback for pelvic muscle dysfunction, and a board certified pelvic rehabilitation practitioner. She is a senior occupational therapist at Aurora Sinai Medical Center in Milwaukee, WI.

How to Balance Driving Safety with Independence

Laurie Misslich, OTR/L, CDRS, LDI

Many adults associate their independence and even their identity with driving. The prospect of being dependent upon other people can be life changing and frightening. Driving is a privilege that is bestowed on us when we complete the proper training and testing. It is natural to assume that abilities change over time. Medical events such as Parkinson's, a heart attack, or even any surgery can affect someone's driving safety. Chronic medical problems like diabetes, respiratory disease, and renal failure can also decrease operational abilities. Aging causes changes to vision, mobility, and reaction time. All of these issues can also be compounded by memory deficits. You owe it to yourself and others to ensure that you are safe to be driving.

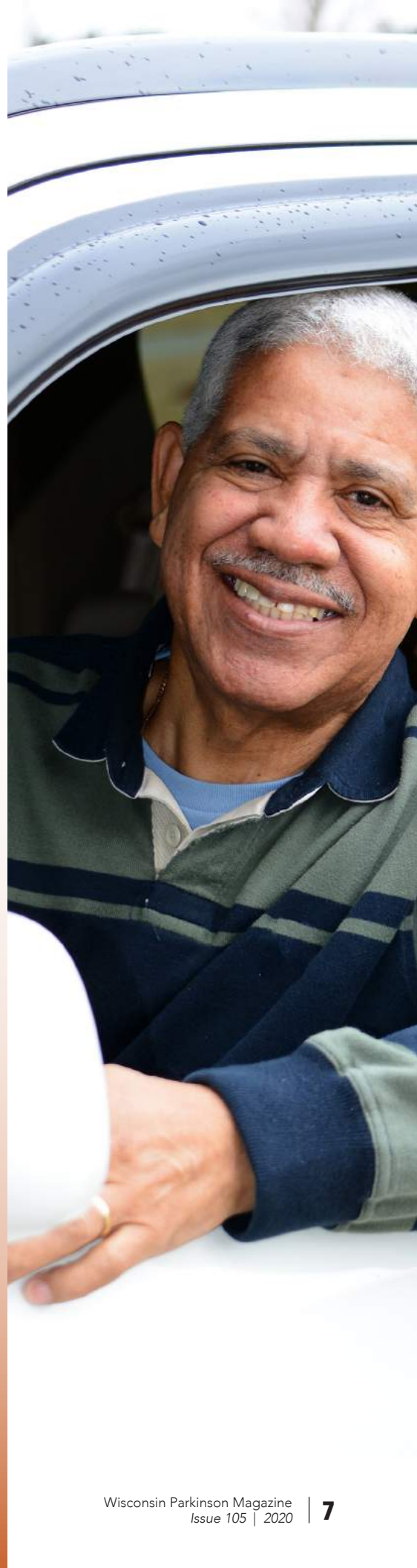
There are warning signs that will present themselves when your driving safety is reduced. These signs are important for you and your loved ones. Is it difficult to turn when you are backing up? Do you use mirrors instead of a visual blind spot check? Driving slowly seems like it is more safe but are other drivers acting aggressively or honking when you are on the road? It is not safe to drive and have the passenger be your copilot. Are left turns causing increased anxiety? Be honest with yourself and your family.

A driving evaluation can help you to ensure that you are safe to drive. Ask your doctor for an order for occupational therapy for a driving evaluation. There are many clinics that are able to provide a clinical evaluation for driving. Driving evaluations are completed using tests that provide information about driving skills. The majority of people are then referred for a road test.

A road test can be completed with a certified driving rehabilitation specialist that is also an occupational therapist (OT). The road test can be tailored to your needs. An OT is able to understand any medical conditions that you may have, including Parkinson's, and how they can affect driving safety. Often, it is not an all-or-nothing proposition. Many people can continue their driving in a limited format by staying close to home during the day. Training can also be offered.

The key is awareness. Be aware of driving skills that are getting difficult for you and reach out to find compensations that can increase your safety and time behind the wheel. If someone you love is starting to worry you, talk about your concerns with their driving. An occupational therapist can help. Our goal is to keep you independent. 🍷

Laurie Misslich OTR, CDRS, LDI owns Adaptive Driving LLC. She is also supervisor rehab services, OP Neuro Rehab Program at Aurora West Allis Medical Center in West Allis, WI. To learn more, contact her at adaptivedrivingllc@gmail.com or 414-721-8636.



The Role of Care Partners in Parkinson Disease - Part 1

Michael B. Schonberger, DO, MBA
Gundersen Health System, La Crosse, WI



*****SPOILER: Yes, you read it right; this is Part 1. I was asked to summarize my recent presentation at WPA's Symposium, and since much of the content is based on my experience (and since I don't know how to keep things brief), we decided to break this into two parts!*****

Over the course of my time in health care (both as provider and patient), I've learned that I've been guilty of having certain prejudices about how patients are "supposed to act" if they are truly interested in receiving care. That got dispelled rather quickly – especially as I encountered more patients who were not able to convey what has been going on in their lives. Unfortunately, many such patients arrive alone without any presence of support. To that end, those appointed as "Care Partners" become critical elements to making sure the correct, high-quality care is provided to their loved one.

The beginning of a Care Partner's role is usually earlier than they realize, and usually takes the form of an "epiphany" that something is not right with their loved one. However, having been in that position myself, I can say that it may seem sudden, but it ultimately is overcoming denial of something you already knew and just weren't yet ready to accept.

When going to the health care provider's office, the more you prepare ahead of time, the more productive the

visit. It begins with the history, and here is when some Care Partners make the first mistake: They often feel the need to be the first to speak. However, as the provider, I gently remind everyone that the patient needs to go first. Here are a few reasons why:

- 1 The "History" is crucial in making the right diagnosis and deciding on the appropriate treatment options, which requires the patient to be able to convey:
 - a. Why they were referred
 - b. What the initial symptom(s) were/when they started
 - c. Timeline of symptoms (motor versus non-motor)
 - d. Previous testing and/or treatment attempts (conservative and/or medication)
 - e. Other important details (symptoms patients are scared to bring up [i.e. hallucinations, memory/mood changes], family history, safety concerns (i.e. driving)
 - f. Social history (substance use/abuse, sexual activity, "socially inappropriate/unacceptable behavior(s)")


- 2 When asked why they were referred to see me, not everyone can explain; some are able to relay what the other provider wanted them assessed for, others can only state their "chief complaint" (a certain symptom, such as tremors or imbalance), and others simply stare at me and say nothing.
- 3 When it comes to separating PD from the atypical parkinsonian syndromes, knowing the first symptom to occur, how long the symptom has been there, how quickly things have progressed, and in what order other associated symptoms appeared can be the key to getting the right diagnosis.
- 4 When it comes to verifying medications, not everyone can relay what they are taking or why. Keeping a list of medications, doses and times, prescribers, and why you are taking them can be a big help to all concerned. Alternatively, you can bring all of your bottles to the appointment. The main point here: I am not yet good enough to be able to tell which medicine a patient is referring to when they say "You know, the little round pink one."

Michael B. Schonberger, DO, MBA is a neurologist at the Parkinson's Disease and Movement Disorders Center at Gundersen Health System, La Crosse, WI. He is also a member of WPA's Medical Advisory Committee.

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The Search for Better Treatment Options

Eric Jackowiak, MD
Froedtert & the Medical College of Wisconsin

 **The field of Parkinson disease research continues to be active. Such efforts seek to better understand the disease itself, but also to develop novel therapeutic options. Advances in recent years have led to new pharmacological and non-pharmacological treatments that are now available for use. Nevertheless, the search for better and more effective treatment options continues.**


While it has been nearly 50 years since carbidopa/levodopa was first used to manage the symptoms of Parkinson disease, it remains the mainstay of our treatment. Since that time, however, other drugs with various mechanisms have also been used either alone or in combination with levodopa. These are typically for certain clinical circumstances such as motor fluctuations (ON and OFF time) and dyskinesias (involuntary excessive movement). Since the beginning of 2019, three such medications have been newly FDA-approved. To reduce OFF time, we now have istradefylline (NOURIANZ™) and opicapone (OGENTYS™), each of which are taken once daily and used in conjunction with carbidopa/levodopa. While opicapone is a COMT inhibitor just like the existing drug entacapone, istradefylline works via a different mechanism than any other Parkinson's medications available. Additionally, sublingual apomorphine (KYNMOBI™) has been approved as a "rescue" medication, to be used as needed for sudden or unexpected OFF periods. This is similar to the injectable form of apomorphine (APOKYN) but avoids the need for needles.

Eric Jackowiak, MD

is assistant professor of neurology at Froedtert & the Medical College of Wisconsin. He has no conflicts of interest to disclose.

There also have been advances in surgical/procedural treatments for Parkinson disease. There are now three companies that manufacture deep brain stimulation devices (Medtronic, Abbott, and Boston Scientific). Each product has slightly different technological advances and advantages for use. A separate procedure, MRI-guided focused ultrasound surgery, is also now available for treating tremor related to Parkinson disease.

Other drugs and procedures continue to be evaluated in various stages of the clinical trials process. Some of these are additional symptomatic treatments, including (but not limited to) continuous subcutaneous infusions of levodopa compounds to treat motor fluctuations (ABBV-951, ND0612H), another medication option for dyskinesias (dipraglurant), and gene therapy (VY-AADC02, among others). The search also continues for a disease-modifying treatment, or something that either slows, stops, or reverses progression of the disease. Some of the possibilities being studied include immunization/antibody treatments aimed at alpha-synuclein, the protein that abnormally accumulates in the brain in people with Parkinson disease (BIIB054, RO7046015). Other approaches include testing existing drugs for this new purpose (deferiprone, exenatide).

Of course, the right treatment approach varies among people with Parkinson disease, and individual recommendations regarding the newly available treatments should be discussed with your doctor. Likewise, you may or may not be eligible to participate in ongoing clinical trials. However, your willingness to take part in such research is what makes all these discoveries possible! 

More from the 2020

Parkinson Disease Symposium

Recordings from all of these sessions are available at wiparkinson.org/program-videos/

Early-Onset Parkinson's



Dr. Taylor Finseth from Aurora Neuroscience Innovation Institute covered early-onset Parkinson's and how it impacts people differently from those diagnosed later in life. Dr. Finseth focused on how those diagnosed with PD earlier in life often have a slower progression of the disease, which can impact other areas of their life. Unfortunately,

early-onset PD often takes longer to be diagnosed and can lead to greater loss of income, job and family issues, and greater mental health burden. Dr. Finseth focused on how early-onset PD occurs and may be more linked to hereditary issues. Finally, he discussed how current treatments and exercise can be beneficial for long-term health.

Caregivers: Filling Your Vessel

Ruth Busalacchi, owner of Synergy HomeCare in Milwaukee, focused on how caregivers can maintain their health and energy when providing care and support to their loved one with PD. Through her "vessel exercise," Ruth provided tools to deal with daily stressors, in addition to the stress added from being a caregiver. She encouraged caregivers to seek out resources to assist them and provide them with respite.

Resources may include family and friends, or it may mean seeking help from the broader community, such as a home care agency. Most importantly, Ruth discussed the importance of open communication with your partner to discuss your needs and find a balance in your daily lives.



Moods & PD

Dr. Julie Bobholz, neuropsychologist with Froedtert & the Medical College of Wisconsin and Aurora BayCare Clinic, covered mood symptoms and treatment for PD. With our current pandemic and isolation, Dr. Bobholz hit on a number of ways mood can impact PD and your symptoms. She differentiated

between depression and anxiety and ways to treat both. Dr. Bobholz also provided treatment options for people whose mood is impacted by PD, how this can impact cognitive function, and why addressing mood issues is so important to Parkinson's care.



(More Symposium topics continued on page 13)

Telehealth: Therapy At Home



Patrick Barron, PT
FastBack Physical Therapy

Patrick Barron, PT, owns FastBack Physical Therapy in New Berlin, WI. Visit [FastBackPT.com/telehealth](https://www.fastbackpt.com/telehealth) to learn more.

Most people with Parkinson's have found benefit from physical therapy. PT helps with balance, reducing stiffness, and improving the speed and quality of movement. Receiving access to medical care, however, has become a struggle in the time of COVID-19. As many with Parkinson's have come to know, physical therapy is an essential service not just for feeling better, but also to help prevent the progression of Parkinson's symptoms.

Despite this need, going to a PT clinic multiple times per week may be too much risk to take on right now. Have you noticed your Parkinson's symptoms worsening while being homebound? Fortunately most insurances including Medicare now cover patients to receive PT from the safety of their homes using telehealth.

From the perspective of a physical therapist, telehealth is actually very effective when working with a patient with Parkinson's. We are able to literally see the exact challenges you

and your care partner face with daily home life, and we can offer solutions specifically tailored to those barriers. At the same time we create exercise programs that take into account the unique setup of your home. Little things like what type of surface you lie on while exercising, and how you properly attach exercise bands all make a big difference. As you probably recall from having PT in the past, it is very important to use proper form to ensure the exercises are doing what they are designed to do. Having a PT watch you carry out your program in your actual home goes far better when there is no guessing about how and where to set everything up.

So how does telehealth work? **Step One:** You register and schedule your initial appointment over the phone. **Step Two:** You log on to a quick demo session, by simply clicking a safe and secure link we send by email or text. **Step Three:** Connect for your

scheduled telehealth appointment by using the camera on your smartphone, tablet, or computer. Most of our patients find the process is even easier than ordering something on Amazon. Our patients tell us that the telehealth sessions uncover issues that are too difficult to replicate in the clinic setting. They also say that we find things they would have forgotten to mention and that they appreciate learning how to apply what they learn in PT immediately because they are already home!

Now, not even the winter weather around the corner should get in your way of connecting with your physical therapist who helps to keep you moving and engaged with the activities you can't afford to lose. If your Parkinson's is slowing you down in any way, ask your PT if they offer telehealth. Our Parkinson's specialists are always happy to discuss how we can help, over the phone or with a free virtual video consultation. 🍷

Getting Connected to Stay Connected

By Mary Shannon, SeniorsMeet.org

In this fast-paced world, staying connected can be difficult enough for seniors. Add in a pandemic for which people 65+ are most vulnerable, and you have a situation that can lead to intense feelings of isolation, loneliness, and hopelessness. But through technology, seniors can stay connected in meaningful ways, such as:

Safely Accessing Resources

Whether due to physical limitations, weather, or current events, sometimes it's impossible for seniors to

get out and explore their communities. This makes it important for older adults to be able to access a working home internet connection, both for purposes of socializing and for safety's sake. Ideally, seniors should have access to both a senior-friendly device and a solid internet connection.

Electronics are increasingly senior-friendly, with both smartphones and tablets worth considering. Internet access can be a challenge, though.

For seniors living in more rural areas, Verizon's home internet service can be a practical and affordable option for seniors, connecting them to one of the most reliable networks in the nation. With a powerful connection, seniors can access resources like support groups for Parkinson's, or safely discuss issues with health care providers via telehealth appointments.

Regularly Checking In With Long-Distance Loved Ones

Being geographically separated from family can be especially burdensome for seniors. When travel for families is not an option, seniors can start feeling the effects of isolation and depression, both of which are growing issues within aging populations. Seniors may feel unloved, forgotten, or without a sense of purpose when they are unable to connect with those they care about.


Thankfully, aging family members can reach out to long-distance family members via social media. Social media has become a sort of safe haven for senior mental health, but there may be times when seniors

crave actual face time. As CNBC notes, video chat apps are increasingly useful for maintaining healthy connections.

Staying Safe, Comfortable, and Secure While Aging in Place

When visiting with an aging family member is not possible or practical, aging in place tech can assist with staying abreast of well-being from afar.

For instance, a smart home security system that helps aging family members feel protected at home can double as a monitoring system for long-distance caregivers. Virtual assistants allow caregivers to check in with senior loved ones, plus they provide seniors with a sense of comfort. If a senior has mobility issues that makes moving around difficult or even dangerous, smart home options like automated lighting provide peace of mind.

Tech can be a priceless tool when it comes to protecting seniors and preserving their quality of life. Instead of feeling isolated, seniors can use tech to stay connected to the people they love. 



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**Clinical benefits of brain sensing have not been established.

Medtronic DBS Therapy for Parkinson's is not for everyone. Not everyone will receive the same results. Patients should always discuss the potential risks and benefits of the therapy with a physician. A prescription is required. DBS Therapy requires brain surgery. Risks of brain surgery may include serious complications such as coma, bleeding inside the brain, stroke, seizures, and infection. DBS Therapy may cause worsening of some symptoms. See Important Safety Information www.Medtronic.com/PDSafety or call Medtronic at 800-328-0810.

(continued from page 8)

The Role of Care Partners in Parkinson Disease

Once it is clear as to how much the patient can present and/or understand the purpose of the visit, that's when it's the Care Partner's turn. This gives the advocate the opportunity to verify or augment what the patient has said, as well as to add details from an outside perspective in terms of:

- A. What did they notice in the patient before the patient did?
- B. How fast has this been progressing?
- C. What are they concerned/scared about most?

It also gives them the opportunity to present the patient with a (rare) gift: The gift of support and certainty that the patient will not be going through what's ahead alone, which

can be so instrumental in helping the patient work through both denial and acceptance of the diagnosis. This power also gives the patient reassurance that they do not have to feel ashamed over what is happening, which can lead to more open and specific descriptions of things people would otherwise not want to talk about, including memory/mood changes, hallucinations/delusions, changes in bowel/bladder control, sleep disturbance and dreaming, and sexual dysfunction.

I'll take this point to pause in my words, and again to re-emphasize the need for honesty and open communication with all involved. Remember to hold yourselves and

each other gently, and remember that there is always something that the providers can learn from you, so never hesitate to speak up for yourself/your loved one if you feel something isn't right.

We are all human. We all have our limitations. We all have emotions we are allowed to feel during these difficult times. And we all have the right to support and ask for help.

I wish you all a safe, happy, healthy, and prosperous time until we are together again. Thank you for all that you do, and for all that you teach us.

See you all next time! 🍀

(continued from page 10)

More from the 2020 Parkinson Disease Symposium

Non-Motor Symptoms of PD

Dr. Lisa Kokontis from the Neuroscience Group in Neenah focused on the non-motor symptoms of PD and how they can impact your overall health. Since most discussions on Parkinson disease focus on the main motor symptoms, it's also important to gain insight into these other symptoms that a person with PD experiences. Dr. Kokontis discussed sleep issues, fatigue, depression, and drooling. She discussed how all these symptoms can impact PD and how to best treat each of these symptoms.



Nutrition & Complementary Medications



Dacy Reimer, APNP-C, Neuroscience Group, focused on how proper nutrition can improve PD symptoms and overall health.

Beyond diet, Dacy focused on foods that positively impact health and mood and provided an overview of foods that can improve brain function. She touched on how complementary medications

may impact symptoms and reminded participants to work with their care providers before changing their diet or adding supplements to ensure there are no negative interactions with their current medications.

Support Groups & Exercise Groups: Meeting Online

The COVID-19 pandemic has forced us to redesign how we connect with the important people in our lives. For support and exercise group members, it has been difficult to be disconnected from those in our PD community who share our struggles and successes! We are all frustrated that this is going on much longer than we had hoped, and it will be important to stay open to such communication methods as virtual exercise and support meetings or regular phone calls to reach out and connect together. Exercise is more important than ever in

managing not only Parkinson's symptoms but also for stress management during these trying times. It is imperative to keep moving and find ways to exercise in home or safely outdoors.

Many group facilitators are moving to virtual meetings as a way for members to touch base, see familiar faces, exercise together, and learn how everyone is coping. WPA has found as time goes on that more facilitators are trying this option as a way to be together again. In addition, WPA's virtual exercise classes are easy to access and offer a variety of exercises to provide the movement you need to stay healthy and active. Visit [facebook.com/groups/wpamovementandmusic](https://www.facebook.com/groups/wpamovementandmusic) to participate in these free classes.

For those that are not able to join a virtual meeting or exercise class, options such as telephone trees, letters via regular mail, and teleconferencing can still bring people together and keep them updated on group interests and activities.

WPA staff is still available to help you connect! Reach out to us at mail@wiparkinson.org or 414-312-6990 on how we can help your group stay connected.



We talked with several group facilitators who are meeting virtually to find out how it's going.

- Susanne Carter leads Parkinson's Dance Classes in the Milwaukee area.
- Gail Johnson co-facilitates a support group in Mequon.
- Bruce Piette is a co-facilitator of a support group in Appleton.
- Barb Skutka facilitates a support group in Cedar Grove.
- Mary Wood is WPA's exercise coordinator and leads several Movement & Music classes in southeastern Wisconsin.

How often is your group meeting virtually?

Carter: The Parkinson's Dance Class is meeting once a week on Thursdays.

Johnson: Our support group is meeting monthly at our regular time.

Piette: We had our first virtual group meeting in August. We plan to have a monthly group meeting until we can meet in person again.

Skutka: During the major lockdown March through May, we offered it every Monday evening.

Wood: We offer exercise classes on Facebook Live Mondays, Wednesdays, and Fridays.

How many members usually participate?

Carter: We've had between 5-11. We do have room for a couple more participants.

Johnson: Usually 10-13.

Piette: Our in-person meetings, including spouses and caregivers, are usually 60-70. For our first virtual meeting, we had about 10-15.

Skutka: Usually 8 or so (4 couples). The most we had was 25.

Wood: We have between 10-15 normally.

How have your members responded to this new way of meeting?

Carter: We have lost some of our long-time members but have also gained new students. We have all been so happy to see each other and at the end of class we share ideas and information or concerns that participants may be going through. It has also been exciting to have some NEW students join us and you can join even if you are traveling or live far away.

Johnson: Those who have tried it seem ok with it – but it takes some getting used to!

Piette: A few people liked the virtual meeting, but we've only had one so far, so it's too early to tell!

Skutka: It's better than nothing, but technology can be frustrating sometimes. Some are resistant to trying something new, or just don't have the technology.

Wood: They love it! The Facebook group has broadened to include people across Wisconsin, in other places in the US, and even a few from abroad! We offer Facebook Live and Zoom for more interaction, and some people prefer one over the other.

When we are able to safely meet in-person again, do you plan to keep a virtual component for members?

Carter: Yes!

Johnson: We might consider going virtual during the winter months.

Piette: We haven't talked about it yet, but it might be a good idea during winter months.

Skutka: We'll poll the group and decide from there.

Wood: Absolutely!

Anything else to add?

Carter: I've been able to offer this free of charge, which is exciting! Contact me at carterproductions@sbcglobal.net to sign up!

Johnson: We have had both presentations and open discussion. It's a new format for all of us, but it's great to see everybody!

Piette: People seem to like it, and we'll know more once we have a few more meetings this way.

Skutka: We are all missing the live connections, so I try to contact people who are consistently absent to find out how they are and let them know we miss them.

Wood: I've found that once people join our class on Zoom instead of Facebook Live, they admitted it was much better seeing other classmates. It feels more like an in-person class – and I know we've all missed gathering like that! 🍁

Faces of PD: Donald Randall

Written by Craig Barbian, WPA Board Member



Michael J. Fox has become the face of Parkinson disease. His tireless efforts to raise money for Parkinson's research have made him recognizable to millions for something other than his well-known acting career. The actor, producer, author, and activist has used his talents to prove that while Parkinson's may impact one's body, it cannot dim the flame of creativity.

While Donald Randall is not the face of Parkinson's, he has a different yet just as creative connection with the numerous faces of PD. He draws them.

About 23 years ago Donald, of Cedar Grove, began having some physical issues. Daily walks with his wife became frustrating as he began having trouble keeping up with her. As time went on, his right foot started to slap as he walked and one day his right arm was rigid and his fist was clenched tight. He knew something was wrong and in 2000 his suspicions were confirmed. He had Parkinson's.

Art was always an interest for Donald and back in the mid-nineties he took some art classes. He drew for years with pen and pencil then tried watercolors and other media but returned to drawing with pen and pencil exclusively. His diagnosis led him to another muse for his self-expression – the faces of those with Parkinson's.

These days Donald draws anything, but mainly people with Parkinson's. His subjects are from pictures in magazines, people in nursing homes, or those he has met or knows who have PD.

The disease often robs the person of their ability to smile as the muscles in the face are impacted. Many of Donald's works feature subjects with their hands up to their face, which Donald says reflects the sadness that he sees in the faces of a lot of people with PD. It was this sadness that he wanted to capture on paper.

It's interesting that, as someone with a stutter can sometimes sing with no such impediment being present, Donald has a tremor on his right side that he says goes away when he sits down to draw.

He has enjoyed drawing and meeting the people he drew but had no interest in selling their portraits at trade shows. He tried that once but decided that wasn't something that he wanted to do. He has given some of his works away, retained some, and also thrown some out.

But drawing is not Donald's only interest. He has also collected clocks, made model trucks for family members, and often walks the beaches of Lake Michigan looking for driftwood that he makes into canes or walking sticks with carved tops.

Donald learned of WPA several years ago and has been to a number of neurologists who shared information about WPA. He has taken advantage of the support groups as well as the various materials regarding PD that WPA offers. His neurologist is at Northwestern Medical Group so Donald and his wife Beverly have generally made his quarterly visits into a several day trip to enjoy Chicago.

Donald, like others with Parkinson's, must be more cognizant of things that impact him physically and make sure that he is getting enough sleep and exercise. Donald did yoga for about 15 years but it's too difficult to do any more. Switching to riding an eBike has been a big help as he often tires while out biking. He also does some Wii bowling with his grandkids as well as some walking and gardening.

Like other families impacted by PD, Donald and Beverly have their frustrations. Parkinson's not only impacts the individual but also their family. Beverly says, "being a caregiver limits what you can do. Parkinson's has limited the activities that we can do together and travel or trips to Mexico or the Caribbean have ended." They do have a summer place in Kewaunee, WI where they can go when the mood strikes and bike, fish, or walk some of the trails.

Donald's biggest frustration is "Not being able to do the things I used to do. I don't smile or laugh as much as I used to because of Parkinson's so people aren't as accepting of me because they think I'm a crabby old man. I would love to educate people that we are happy but just can't show it."

In referring to living with Parkinson's, Michael J. Fox said "acceptance doesn't mean resignation."

Donald's advice is similar. "Get a hobby, find something that you enjoy and can still do. Parkinson's is a thief – it slowly steals your life away. It's slow and consistent but it happens and it makes life frustrating. With PD, everything is a struggle but you can't give up. The disease is there but I refuse to quit. Sometimes everything is a struggle but I'm not going to give in."

"That's where the support groups come in," says Beverly. "To know you're not the only one going through it makes you feel you're not alone."

Like many others, Donald and Beverly Randall have had to deal with a situation completely out of their control. But to their credit, they are putting the best face possible on a disease that often does the opposite. 🍷



At-Home Exercises

There are many benefits of stretching for PD: improved mobility, less soreness, reduction of injuries, improved range of motion, better circulation, and improved sleep. Here are some great stretches to try before bed. You'll not only sleep better, but feel better in the morning. It is best to do these stretches after a workout, a walk, or a warm shower or bath at night.

Perform all these stretches slowly, at your own pace; if you feel any pain, stop the stretch and reposition and try again. Stretch to your own comfort. *You can perform each stretch for 2- 5 repetitions.*

Exercises demonstrated by Mary Wood, WPA's exercise coordinator. Mary leads an online "WPA Movement & Music" class LIVE on Facebook several times a week, and past classes are available for viewing or download at wiparkinson.org and our YouTube page.



Hamstring Stretches

Sit in a sturdy chair, place one leg out straight with heel on floor, try not to lock your knee. Place hands on the straight leg. Gently fold forward and push belly button toward the knee of straight leg. Focus on keeping toes towards the ceiling. You should feel this stretch on the back of the straight leg. Hold 10 seconds, repeat on opposite leg.



Upper Back/Lats Stretch

Hold onto a chair or door frame. Bend forward from the waist; walk backwards until you feel a stretch in your upper back. Lower head and line it up with shoulders.

Hold for 10 seconds.



Cross-Body Shoulder Stretch

Sitting or standing, grab one arm with your opposite hand, and pull it across your body toward your chest until you feel a stretch in your shoulder.

Hold for 10 seconds, repeat on the opposite arm.



Chest and Shoulders Stretch:

Seated or standing, reach your arms behind you, if you can, lace fingers together. Straighten the arms and gently lift your hands up a few inches until you feel a stretch in your chest as well as your shoulders. If lifting causes pain, just hold stretch with arms near lower back. Avoid this stretch if you have shoulder problems.

Hold for 10 seconds.

Movers & Shakers: A Celebration of our Parkinson's Community

In late September, we held an online auction and video program to recognize and celebrate some members of our incredible Parkinson's community. The online auction had some unique items made by some people with Parkinson's (pictured below), in addition to some sports memorabilia (like a Hank Aaron autographed baseball!), experiences (like a "Stay & Play" golf package in South Carolina!), health & wellness items (like two kayaks!), and more!

The video program featured Bill & Rita Forrester, Matt & Megan Puthoff, Kristine Johnson, Dr. Katie Spangler from Marshfield Clinic, Rich & Sue Petersohn, Craig & Darlene Barbian, and Samantha & Derek Felder. They each shared a little about their own journey with Parkinson's – either their own or with a loved one, and talked about the impact WPA has had on them.

This event raised over \$100,000 to support local Parkinson's education and resources, and to keep all WPA programs and services FREE to the people who need them!

This was only possible thanks to these generous sponsors and supporters:

- | | |
|--------------------------------|---------------------------|
| HeatTek, Inc. | Ron & Kathleen Mohorek |
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| Ken Foster | The Movers & Shakers |
| Prescott Family Foundation | Planning Committee |
| Bill & Rita Forrester / Anchor | Majic Productions |
| Moving Systems | |



Emcee Dan Pronley joined WPA executive director Gary Garland to host the show.



Special thanks to local Neil Diamond Tribute Artist Eric Diamond for performing before and after the program! Viewers voted for which songs Eric performed at the end of the program.



Rich & Sue Petersohn joined us to share a little about their journey after Sue was diagnosed with Parkinson's.



This birdhouse was created and decorated by Lynn Ettenheim.



Donald Randall created this walking stick from a piece of driftwood he found on the beach by Lake Michigan.



Carved by Patrick Pelkey, this cowboy and these comfort birds were part of the auction.



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.



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