



WISCONSIN PARKINSON

MAGAZINE ISSUE NO. 106 | 2021

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SUPPORT
COMMUNITY
RESOURCES

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TOGETHER

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A PARKINSON'S WARRIOR

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A CAREGIVER



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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,

April is always a special time here at WPA as it is **Parkinson's Awareness Month**. Because Parkinson's affects everybody differently (including caregivers & other family), we always devote a great deal of time and resources to ensuring you are aware of the most beneficial treatments and information to live life fully – **today!** In fact, this past year, WPA was proud to provide you with literally hundreds of hours of new live programs, as well as industry-leading publications like this magazine.

Working to ensure that all who need us know of us has long been our primary goal. In just the past four years, our programs have reached 3,784 **NEW people!** And this year, we are making sure even more who are living with Parkinson's are aware of how to access our programs and receive the great benefits that they offer. Our *Moving Forward Together* campaign – through programs like this month's Recently Diagnosed webinar series (see page 4) will connect us to more people in the Parkinson's community, especially those who are recently diagnosed, rural residents, and persons of color. I hope you will be joining us for some, or all, of these programs April 12-16. You can register at our website at wiparkinson.org.

In this issue of *Wisconsin Parkinson Magazine*, you will find the rare combination of practical daily

living advice from those who, like you, are affected by PD, along with expert guidance from the most knowledgeable Parkinson's professionals. They will cover topics that include caregiving, deep brain stimulation, exercise, and much more!

Finally, I hope you will use the accompanying envelope and consider a special Parkinson's Awareness Month gift to keep WPA's unparalleled programs, including this magazine, FREE and reaching more people than ever!

Thanks,

Gary

Gary Garland



PARKINSON DISEASE: RECENTLY DIAGNOSED

Webinar Series

FREE | APRIL 12-16 | 12:00-1:00 PM EACH DAY

PRESENTED
BY:



WISCONSIN
PARKINSON
ASSOCIATION

(MON 4/12)

Parkinson's Diagnosis

Lisa Kokontis, MD
Neuroscience Group
Neenah

(TUE 4/13)

Treatment Options

Ryan Brennan, DO
Medical College of WI
Milwaukee

(WED 4/14)

Non-Motor Symptoms

Katie Spangler, MD
Marshfield Clinic
Wausau

(THU 4/15)

Mental Health & Cognition

Nichelle Rothong, PhD
Aurora Health Care
Milwaukee

(FRI 4/16)

Activity & Exercise

Mary Wood, WPA
Patrick Barron, DPT
FastBack PT, New Berlin

REGISTER

wiparkinson.org
or 414-312-6990

Programs will be
held on Zoom

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

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Panel Discussion:

Deep Brain Stimulation

Al & Anne Greene and Mick & Ronna Corliss



The West Bend support group recently had a panel discussion over Zoom about deep brain stimulation (DBS). Al Greene and Mick Corliss both have Parkinson's and have had DBS surgery. Together with their wives Anne Greene and Ronna Corliss, they shared their experiences. Here is a summary of their conversation.

Mick Corliss: "I had DBS in December 2019. I was taking different medications, but they seemed to make my Parkinson's worse. I was working as a social worker, and it came to a point at work where I knew I couldn't guarantee the safety of the people I worked with. So something had to change."

Ronna Corliss: "The surgery was definitely needed. He was really struggling with dyskinesia, he had a hernia, and our adult son would have to help me transport him and sit with him in the car. It was so necessary. He has lost some cognitive ability, as well as some short-term memory, which has been challenging for both of us. But what we don't know... is that part of Parkinson's or the DBS? Or dementia? Or normal aging? It probably doesn't matter, because this surgery needed to be done for his physical symptoms. The surgery definitely saved him."

Mick: "I'm not sure if you call it ADHD, but I do have attention-deficit issues now. I might have had that before the surgery, but my ability to focus has definitely decreased. I joke about it as my own way of coping, but I'm acclimating myself to this new life."

Ronna: "That has been hard. We grieve the loss of the life we had before. It's not good, bad, or ugly – it's just different. When he got out of the surgery, we expected everything to be better. But that takes time. We are settling into this life and readjusting to life in a new way."

Al Greene: "I've had Parkinson's for 17 years, and I had DBS about 3 years ago. It's brain surgery, but to me, it wasn't 'brain surgery' because it was really so simple. I never really had any negative side effects from the surgery."

Anne Greene: "It was the type of surgery where you are awake, and that scared him. He might have considered it a few years sooner, but that's scary. He just couldn't imagine being awake for brain surgery."



Al Greene proudly shared his DBS experience with other attendees at WPA's Symposium in 2019.

Al: "But the surgery wasn't that bad! I had met Lisa from Medtronic (a medical device company that provides DBS) at a support group meeting a few years ago, and while I wasn't ready for it at that point, I remembered that meeting."

Anne: "He wasn't ready then, but eventually we knew something had to be done. We talked with Lisa and our doctor and we knew it was time. This is a hard disease, and we were so glad to find DBS and realize that it was something that could help him."

(continued on page 14)



Gloria Gierach, *A Parkinson's Warrior*

Twenty years ago, Tom Gierach bought his wife, Gloria, a Harley Davidson motorcycle for her birthday. When she expressed doubt that she could learn to ride it, he assured her that she could and said that she would be his "wingman."

A Parkinson's diagnosis is often a call to action. Sometimes it's a realization that you now need to care for a loved one or a friend. Sometimes that call means that you become a wingman to more people than you first thought.

Tom Gierach, a military veteran, was diagnosed with PD on December 21, 2018 when he was 72. It's a date that his wife Gloria says she remembers well "because that's the date that our lives were forever changed."

After Tom's diagnosis, they joined a support group in Shawano, Wisconsin that was composed entirely of veterans and several Native Americans like Gloria. The group discussions often veered to whether or not their shared military experiences with various chemicals, such as Agent Orange, was a factor in their Parkinson's.

Gloria and Tom found a support system that they never knew existed and in short order, Gloria became increasingly involved as an assistant to the support group's leader. A few months later, Gloria went to a Parkinson's education program, and one day she went to a PD walk. It was there that she met Kristin Waukau, the Tribal Dementia Care Specialist for the Menomonee Tribal Health Center.

After their conversation, Gloria, a member of the Menomonee tribe, decided to start her own support group in Keshena, Wisconsin. Her goal – to support her community, including the Native American community, in their struggle against Parkinson's.

Waukau was instrumental in helping to find a meeting place on the reservation as well as helping Gloria find speakers and other health care professionals to address

Craig Barbian, WPA Board Member

their group. To spread the word, Gloria began distributing flyers at the grocery store, the library, the laundromat, and even the local McDonald's.

In October of 2019 their group, "The Parkinson's Warriors," had their first meeting. Members of the group come from the Clintonville, Antigo, and Keshena areas and include several other Native American participants.

They invited a pharmacist who spoke about various medications and their interactions with carbidopa levodopa. Their next meeting featured a nutritionist who spoke of Parkinson's-friendly foods.

Their third meeting included a physical therapist who talked about stretching to help with freezing, as well as somebody who discussed dancing and boxing as exercise for Parkinson's patients.

Then COVID-19 hit. Gloria noted that "everything just went kaboom when the pandemic started," forcing them, like the rest of the world, to socially distance. They have not been able to reassemble virtually, but they hope to very soon.

What motivates someone to take on the responsibility for a support group besides the caregiving duties she already has? "My husband is my inspiration, he's one of my biggest heroes. Life is a journey and ours took a different path," says Gloria without a trace of regret.

That path led Gloria to help her husband, as well as others, in their fight to live their best life possible. Parkinson's Warriors – an appropriate name for Gloria, Tom, and all of those involved in the battle against this debilitating disease. 🍷





In my own words...

Bill Forrester

President, Anchor Moving Systems
WPA Board Member

I was diagnosed with Parkinson disease in the middle of 2019, and it has been a whirlwind ever since. I got a quick diagnosis from my family doctor – which shocked us. Since then I have tried to halt the progression of the disease and find capable and quality care.

I was not ready for something like this. But... nobody asked if I wanted Parkinson's. And I'm sure nobody asked you either.

My wife, Rita, and I jumped into action. We started asking doctors what to do. We Googled everything we could. And we scratched our heads a lot. We didn't even know what Parkinson's was, let alone how to fight it.

While asking questions, we were invited to a meeting at Hartford hospital where Jeremy Otte, WPA's director of outreach & education, was speaking – that was my initial introduction to WPA.

I was so impressed by the wealth of information WPA provides. They provided activities, exercises, and many tips related to living with Parkinson's. Rita arrived at that meeting feeling overwhelmed and we left with positive information and tools to move forward in our journey with Parkinson's. We found answers to questions we didn't even know we had.

We started attending WPA's programs right away, and at one meeting, we met two gentlemen who had early-onset Parkinson's. They were very positive and gave us another perspective of living with this disease. Rita and I felt encouraged. Hopeful. Ready to move forward.

WPA has continued to be here for us over the last year and a half. We have attended (in-person and online) education and networking events, and we have learned the value of exercise and how it can help slow the progression of the disease. 🌱

Until we can safely meet together again, I hope to *"see"* you at a WPA program online!



Lucia Francis:

Parkinson's Doesn't Define Me

Lucia Francis has been one of the co-leaders of the Parkinson's support group in Mequon for several years. Lucia was diagnosed with Parkinson's in 2002, the year that she turned 50. It was also the same year her daughter got married, and she started a new job at a large community college.

"I was determined from the start that I was not 'Parkinson's' and I would do all I could to be 'normal' for as long as I could. Being part of a support group helps to strengthen your resolve to control and manage your disease," she said.


Lucia started as a member of the support group, then became a co-leader. Before COVID-19, the group was meeting monthly at Newcastle Place in Mequon and had large attendance. Now the group has been meeting on Zoom each month. They even had the fitness manager from Newcastle Place joining their meetings occasionally to lead the group in some movement and stretching.

For someone who recently received a Parkinson's diagnosis, Lucia has some advice: "Take it seriously, but don't let Parkinson's define you. Stay active. And don't hide your diagnosis. I tell people almost immediately that I have PD."

Lucia's favorite exercises are walking and boxing. Unfortunately, Parkinson's forced her to give up playing tennis, which she loved to do.

After 12 years of living with Parkinson's Lucia decided to retire in 2014. Between her Parkinson's diagnosis in 2002 and retirement, she got promoted twice – from associate dean to dean of a large division, then from dean to vice president at the suburban campus.

"I retired because I was slowing down. I miss the people, but I don't miss the work and the pressure that comes with it!"

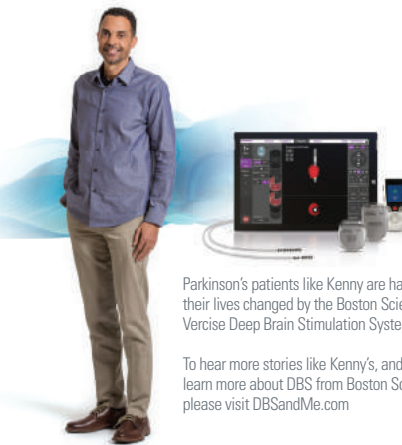
Her other advice? "Parkinson's is manageable. The power of the brain is unbelievable." 

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

Kenny H.
Boston Scientific DBS Patient



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

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

If you're interested in joining the Mequon Support Group's monthly Zoom meeting, contact WPA at mail@wiparkinson.org or 414-312-6990 for the details.

Positive Thinking

Improves Physical Health

Jane Framingham, PhD, PsychCentral

Over the last 12 months, we have been dealing with unprecedented and uncomfortable situations – mentally, physically, and socially. As our worlds start to return to “normal,” we wanted to again share this article that we printed in the Spring 2017 issue of this magazine. Remember that even if you can’t change the circumstances of your life, you can change your attitude. If you are struggling with depression, anxiety, or other mental health issues, please talk to your health care provider, or call WPA’s office for a referral.



No one can avoid all negative feelings in life and it's not realistic to think you can or should. But the happiest people somehow know how to buffer them by keeping life's inevitable tragedies from spoiling the good stuff. And these folks may be the healthiest people as well. There is growing evidence that you may be able to improve your physical health just by changing the way you think and feel about your life.

All the advice to “keep the sunny side up” if you want to be healthy sounds all warm and fuzzy, but almost too good to be true. Actually, though, a load of evidence shows that your attitude about life can improve your health and even speed your recovery from a serious ailment or surgery. The attitudes that seem to help the most are optimism, hope, and, above all, a feeling that you have some impact on the quality of your own life.

Why You Should be Optimistic

No one really understands how or why a positive attitude helps people recover faster from surgery or cope better with serious diseases – diseases as serious as cancer, heart disease, and AIDS. But mounting evidence suggests that these effects may have something to do

with the mind's power over the immune system. One recent study, for example, polled healthy first-year law students at the beginning of the school year to find out how optimistic they felt about the upcoming year. By the middle of the first semester, the students who had been confident that they would do well had more and better functioning immune cells than the worried students.¹

Some researchers think that pessimism may stress you out, too, boosting levels of destructive stress hormones in your bloodstream. Of course, it's also possible that having a positive attitude toward life makes you more likely to take better care of yourself. And you're more likely to attract people into your life (and keep them there) – which in and of itself may boost your health.

How to Become More Positive

We're not saying that you should deny life's darker side or interpret every calamity as a blessing. But when calamity does strike, try not to give in to despair or fatalism. Concluding that you personally have been singled out for suffering, refusing to see any silver lining, and abandoning all hope may not only be a recipe for illness. Such attitudes are also not such great ways to go through life. Try to recognize that your grief and pain, however real and deep, are only part of a larger picture – and that this picture includes many elements of pleasure, success, and meaning.

(continued on page 14)

The Role of Care Partners in Parkinson Disease – *Part Two*

Michael B. Schonberger, DO, MBA



This article is part 2 of the summary of Dr. Schonberger's presentation at the 2020 Parkinson Disease Symposium. To view the recording from his presentation and to read part 1 of this article, which ran in Issue 105, visit wiparkinson.org.

As a "Care Partner" (whether appointed by the patient or by yourself), you are crucial to ensuring appropriate, high-quality care is provided to your loved one. Your role as "historian" can have a big impact on your loved one's care.

Here are some things to consider as you focus on communication:

General Communication:

- ❖ Looking in the mirror: Being honest with yourself
- ❖ Looking at the patient: Being honest with them
- ❖ Looking at the Health Care provider: Being honest with treatment
- ❖ Looking at the support system: Being honest with loved ones

Communicating with Patients:

- ❖ What you have noticed versus what they are aware of themselves
- ❖ Honest and open discussion about changes and concerns
- ❖ Emotional support during both denial and acceptance of symptoms
- ❖ Encouragement to seek medical care, education, resource support

Communicating with Health Care Providers:

- ❖ Allow patient the chance to start the conversation
- ❖ When did symptoms begin? What were the initial symptoms?
 - Collect historical information to present at appointments, as well as previous medical records

- ❖ Have there been any previous attempts to treat?
 - Physical/occupational/speech therapies or medication(s)
- ❖ Clear timeline of symptoms: Non-motor in relation to motor
 - Non-motor symptoms: Things patients may not bring up
 - Memory and/or mood changes/disorders
 - Change in bowel and/or bladder function
 - Change in sleeping (ie. "acting out dreams")
 - Sexual dysfunction
 - Hallucinations/delusions
 - Getting lightheaded when standing/walking or fainting
- ❖ Concerns about patient (and your own) safety
 - Home safety, fall precautions, driving, swallowing difficulties, need for additional/outside help
- ❖ Any other medical history that could contribute to symptoms?
 - Sleep disorders/disruptions, memory, mood, etc.
 - Hydration practices
 - Sexual history
 - Family history of movement disorders or other neurological disorders/conditions, psychiatric conditions, substance use/abuse

A few other things to remember as you fulfill your role as Care Partner:

Parkinson Disease is Progressive – but still manageable

- ❖ “Change” does NOT equal “the end”
- ❖ Don't let the patient “give up”
 - Find counseling, safety resources, social support, and stay active whenever possible
- ❖ Help them stay accountable for their own care as much as possible

Support, Support, Support

- ❖ Help to accept diagnosis and need for intervention, and avoid comparing themselves to others
- ❖ Help patient communicate with family/friends: Identify the support system
- ❖ Be a good patient “advocate”
 - Speak up if you think something is wrong/not going well
 - For nursing home patients, speak up if staff are not following provider's directions

Side-By-Side Learning: “Knowing What You Don't Know”

- ❖ Educate yourself on symptoms and disease progression
 - “What can we expect?”
- ❖ Understand the roles of proper medication administration
 - When doses should be given (time relationship to meals)
 - Drug interactions
 - Potential side effects
- ❖ Roles of non-medication and advanced therapies (i.e. deep brain stimulation)

Some Little “Tricks”

- ❖ Bring all medication bottles to appointments, not just PD medications
 - Don't let patient say “you know, the little round white one”
- ❖ Carry the next dose with you all the time
 - “Oh, I'm due for my next dose soon...it's in the car”

- ❖ Remember your mobility devices (walkers/canes)
 - “Oh, I use my walker all the time... it's in the car”
- ❖ Write down questions/concerns prior to visit
 - “Oh, I forgot to mention...” (as the provider is walking out the door)
- ❖ Don't forget your hearing aids!!!!!!!!!!!!!!!!!!!!!!
 - (“huh, what, say again?”) ... (grumble, grumble)
- ❖ If care partner cannot physically attend, join by speaker phone if possible

Remember:

- ❖ **Start from the beginning:** Honesty, communication, advocacy
- ❖ Learn to adapt together over time
- ❖ Know your available resources
- ❖ Take care of your own health and needs. Recognize when to ask for help.
- ❖ Remember, providers can learn from you too!
- ❖ Always stay in touch no matter what!

I want to re-emphasize the need for honest and open communication with all involved. Remember to keep your loved one's needs front and center, and also remember there is always something 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. 🙏

Michael B. Schonberger, DO, MBA is a neurologist and movement disorder specialist.

Advocacy, Passion, & Art:



Mary Rehwald (left in blue), with her twin sister Sally



Yellow Poplar

People become champions of particular causes for various reasons. Some are proponents for a better life for the disadvantaged. Some crusade for a particular political agenda. Others, like Michael J. Fox, advocate for solutions for a malady like Parkinson disease.

To those who suffer from Parkinson's, like Mary Rehwald, Fox is a man committed to not necessarily solving all the world's problems but making things better for a small, but unfortunately, growing segment of the population.

But like Fox, Mary has long committed her life to advocate on a different scale. Mary has advocated on behalf of future generations and their right to have a sustainable environment long after her generation is gone.

Mary has a long history of social activism and community organizing, working for nonprofits and advocacy organizations. After graduating from the University of Wisconsin-Madison with a degree in French, Mary joined the Peace Corps and spent a year in Tunisia in North Africa teaching English as a second language.

After the Peace Corps, Mary returned to Madison and taught History, French, and English in Sun Prairie and at several Madison high schools before moving to California for seven years.

When Mary returned to Wisconsin in the mid-90's, she helped found The Alliance for Sustainability in Ashland, a grassroots organization whose goal is to

identify and promote ways of meeting the social, cultural, and economic needs of the region without jeopardizing the well-being of future generations or the natural environment.

"I also took several trips to Sweden on behalf of the Ashland and Bayfield city governments and the Native American community in my area to learn more about the Eco-Municipality movement going on in several communities in Sweden at that time," Mary shared.

At one point Mary started keeping journals about the projects that she was working on and started doing little drawings to accompany them. A few years later she started painting watercolors as well as teaching an art class in Washburn, Wisconsin.

Then she began to create greeting cards and calendars that featured her drawings and paintings of local Ashland area landmarks. These items are available through Authentic Superior, a nonprofit organization in Ashland focused on bringing more revenue to the region's artists, craftspeople, and farmers/food producers.

Mary was already retired when diagnosed with Parkinson's about eight years ago. But Mary did what she has always done and decided to fight back the best way that she knew how. She took her skills and used them to advocate for the new community that she had recently become a part of.

Getting to Know Mary Rehwald

Craig Barbian,
WPA Board Member

She joined the Bay Area Parkinson's Support group that brought people together from the Chequamegon Bay area and sponsored the ParkinSong Choir in Bayfield as well as Rhythm and Moves dance classes in Ashland, Washburn, Cable, and Hayward.

In 2017, Mary helped coordinate a Parkinson's Conference in Ashland, "The Mystery and Science of Parkinson's Disease." The conference included a day of panel discussions, physical therapy demonstrations, and discussions about living with Parkinson's, and drew 17 presenters and 120 people from the Parkinson's community.

These days Parkinson's limits Mary's ability to participate in WPA's programs online. But she still goes for walks when the weather permits and has always been involved with the local PD support group in Ashland run by Jeff Obst and his wife.

Unfortunately, Mary is also doing less art these days because of her PD. She can't stand as long and has also started freezing in place occasionally. As Mary says, "All my motor skills are shot to hell." But Mary continues to draw and paint because "it makes me happy." You may have seen Mary's artwork featured on a special "thank you card" from WPA last fall.

When asked for her advice for others with PD, Mary says "That's hard to answer, because sometimes I don't take my own advice. But do at least one thing each day that gets you moving."

Mary also took an opportunity to advocate once again, this time on behalf of a book that she found useful. "I recommend the book 'Goodbye Parkinson's, Hello Life!'" The book combines dance therapy, behavior modification, and martial arts, to prove that there is life beyond the diagnosis of PD.

Not all of us have the platform that Michael J. Fox has. But, thankfully, people like Mary Rehwald continue to advocate on behalf of a better future for all of us. 🍷



Ashland Pointy Skyline from Depot Drive



Hawkins Creek Band Home Concert



St. Peter's Dome

(continued from page 5)

Panel Discussion: *Deep Brain Stimulation*

Al: "I went from 36 pills a day down to 4 or 5 pills a day after the surgery, and a lot less side effects from the pills."

Anne: "One thing to know is that after the surgery, it isn't turned on right away, but Al still had some relief from his tremor. We were glad to discover that. Similar to Mick, Al's cognition has decreased a little too, and we also aren't sure: is that Parkinson's, the surgery, or normal aging? But regardless, for anyone considering this surgery, we want you to know that there are people out there for you to talk to about it. Whether it's other patients like us, or the reps from the company, we are all happy to talk to you. This could be a great change for you, and we encourage you to explore it."

Al: "It's a scary thing, but it's worth it!" 🍷

Laurie Couillard, WPA's director of group engagement shared some final thoughts:

- ❖ DBS can definitely affect the dynamic of the entire family but with some adjustments and teamwork families learn to move forward in new ways!
- ❖ Keep a regular log of your symptoms and any concerns you have, and bring it your next doctor's appointment. Some of the problems you experience may be related to your medications or the DBS device and could be easily adjusted.
- ❖ If you want to learn more about deep brain stimulation and if it might be an option for you, talk to your movement disorder specialist. You can also find several videos about DBS from recent WPA programs at wiparkinson.org.

(continued from page 9)

Positive Thinking Improves Physical Health

Another approach is to try to "use your pain" for good. Many people who have suffered from life-threatening and incapacitating illnesses – including cancer, heart attack, and the like – say that they consider their illness to be "a gift." The illness taught them to value each day, appreciate the moment, and get their priorities straight. Sometimes they discover that they have the power to do things they never knew that they could.

Remember that even if you can't change the circumstances of your life, you can change your attitude! If you need help, talk to a health professional about whether

psychotherapy, support groups, or other structured approaches might help you.

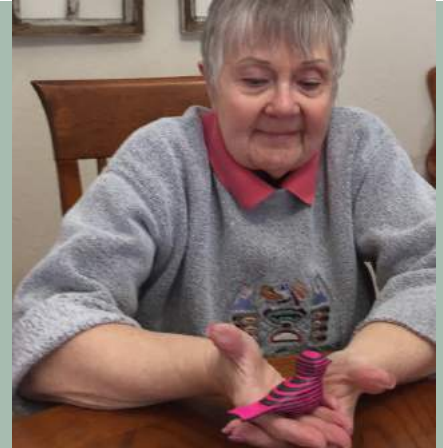
Attitude definitely seems to influence the course of illness. But some people take this link too far and make you feel that your bad attitude caused your disease or is keeping you from healing. Walk the other way if anyone makes you feel guilty for being sick or treats your physical ailments as if they were emotional or mental problems (included are physicians who banish you to a psychiatrist when you have no obvious signs of physical illness). 🍷

1. (See Suzanne C. Segerstrom, Ph.D., et al., "Optimism is Associated With Mood, Coping, and Immune Change in Response to Stress," *Journal of Personality and Social Psychology*, Volume 74, Number 6, June 1998.)

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WPA Happenings

Sandy Dorshak from Rothschild, Wisconsin, shows off her Comfort Bird!
Sandy won a drawing from WPA recently, and the prize was this comfort bird, which was hand-carved by Patrick Pelkey, a woodcarver and support group leader living in New London, Wisconsin.



Paul & Diana Beder are active members of WPA's online **Movement & Music** class, which takes place on Facebook Live and Zoom three times a week. The Beders live in Waupun, Wisconsin, so they really appreciate being able to join WPA online and not having to travel anywhere right now!

In January, in partnership with a group of National Honor Society students at Whitnall High School in Greenfield, Wisconsin, we launched **Game Nights on Zoom**. These events are open to anyone interested in having a little fun and being a little silly sometimes! Attendees start in the same "room," then move into smaller breakout rooms in Zoom to play. Games have included Name that Tune, Bingo, Charades, and more. Register at wiparkinson.org to join us next time!



The Life of a *Caregiver*

Craig Barbian, WPA Board Member

Every person diagnosed with Parkinson disease has their own story. So do the people who love them and are suddenly thrust into a role that most are probably unfamiliar with.

Caregivers are often unprepared to suddenly be the main support lifeline for their loved one. A job description for caregivers would be extensive – cook, driver, financial expert, nurse, gardener, soulmate. How they face those challenges are stories worthy of telling.

Sean

Sean is somewhat an anomaly in the world of Parkinson's caregivers, as it was his wife Barb who, at the age of 50, was diagnosed with Parkinson's (PD is 1.5 times more frequent in men than women and when women do develop PD, the average age of onset is two years later than in men).

"To hear the diagnosis was devastating. Your future plans have been immediately altered and you question what the future will look like. Before the diagnosis I had a 30,000 foot view of Parkinson's, now I wanted to know all about the disease," Sean shared.

Barb started doing some research after her diagnosis and didn't find a support group in the area. So they decided to start their own support group to engage with others with PD and their caregivers. "A support group is key, people need to know they're not the only person going through this."

Caregivers often find themselves torn between their responsibility to their loved one and their need to tend to their own well-being. Sean tries to cycle a couple of times a week when he can, but says he sometimes feels guilty

"There are only four kinds of people in the world. Those who have been caregivers. Those who are currently caregivers. Those who will be caregivers, and those who will need a caregiver."

– Rosalyn Carter

when he leaves home. "It's hard to step away sometimes; you feel like you're letting them down. I didn't realize how emotionally tough it would be. You want to help but you need to get over the guilt and do something for yourself."

Caregivers also need a good support system. His wife has a supportive boss, as does Sean, and that has alleviated their concerns and stress about her condition impacting their jobs. "But be prepared for the emotional toll it takes on you. You experience the same emotions as your partner because her issues affect you. But our strong faith has helped us deal with the reality of the situation."

"My wife didn't want her life to be defined by PD but she came to realize that it is. But this isn't a death sentence. It progresses slowly, so don't give up."

Beverly

What are the hardest things to deal with as a caregiver? "Honestly, I can't narrow things down to the point of being able to name the hardest thing. For me, the difficulties can change from hour to hour, day to day," Beverly explained.

Planning things can be difficult because "we never know what the next hour or day will bring. My whole day can go down the tubes. It's always disappointing to make plans only to have them unravel because of this disease."

"It's important to have your own interests, especially during COVID. But you may need to find things to do close to home so you are available if needed." The time she spends exercising turns her day around because, as she calls it, it's her "me time."

"Parkinson's has definitely narrowed our ability to do a lot of the things our friends are able to do. In a way, COVID has leveled the playing field for us," said Beverly. "We aren't the only ones sitting home on a Friday night! We no longer have friends talking about the wonderful vacations they have planned or the exciting events on their social calendar. To this I say, 'Welcome to the world of Parkinson's!'"

"I have watched as my husband has lost the ability to do many of the things that he once enjoyed. Likewise, 24/7 caregiving has limited my ability to do the things I pictured would be part of my life after retirement." After 24 years as a mental health professional, Beverly was especially hoping to involve herself in a variety of volunteer activities in the community. "But that has pretty much proven to be impossible. Both of us have had to accept the many limitations that Parkinson's has brought into our lives."

Joanne

Joanne dealt with the impact of PD for a number of years until her husband succumbed to the disease five years ago. Though her experiences are in the rearview mirror, they are always in her heart.

"Caregiving is an emotional roller coaster. You've shared years in an equal relationship with a strong competent partner and now your loved one has lost some or much of their essence. This weighs heavily on your heart."

The whole dynamic of marriage often changes with a diagnosis like Parkinson's. What was once an equal partnership has now shifted to one partner's shoulders. "This is a huge responsibility and adds a lot of stress to your life. Even if it is not your nature, you must learn to speak up and advocate for your partner when they cannot do so themselves."

Caregivers need to forgive themselves. "Often there is no right or wrong choice. It is the best choice for the moment. Don't second guess your choices. You are acting out of love. Then forgive yourself and move on. Keep this in mind as you hit a low spot (and you will)."

Don't go it alone. "Spend time with friends and activities that bring you joy. Over the years you will experience anger, frustration, hopelessness. Own your feelings and accept them."

"Lastly – if your loved one needs to be placed in long-term care, don't deny this reality. It's the hardest thing you will do, but delaying this move does neither of you any favors. It may not seem like it now, but caregiving is a blessing. You are pouring out your love for your life partner. Unfortunately, you may not realize this until your partner is gone." 🌻



Virtual Meetings and Classes

In nearly every previous issue of this magazine, we have included a map of support groups and exercise classes in your area. With over 200 listings on our website last year, we were confident you could find a class near you – and if not, we wanted to help you start one!

Obviously, with the COVID-19 pandemic, everything changed and these groups stopped meeting in person. Some groups are now meeting online each week or each month, and many group facilitators and members of the Parkinson's community have both benefited and struggled with connecting to others. We know many support group facilitators are working hard to let their members know they are still supported – even when it's not safe to meet in-person.

While email, regular mail, and phone calls are some of the ways people are staying in touch, virtual meetings have allowed members to stay connected and continue receiving support from facilitators and exercise instructors in a more personal way. Being on the screen isn't the same as being together in-person, but it's a close second! Hearing laughter and seeing one another's faces can bring a sense of comradery and companionship during this time of isolation!

While distance may have previously been a barrier to finding support, with a virtual connection you can join any meeting from anywhere, so location and travel are no

longer a concern in meeting up with others! Members are finding they are connecting with folks from across the state, and sometimes across the world, through virtual exercise classes and support group meetings. Another benefit to virtual connection is that those managing Parkinson's and their caregivers have access to hundreds of expert videos on topics that can help them manage their PD and learn more about topics to discuss with their physicians. (Check out the variety of topics covered on the "Program Videos" page at wiparkinson.org!)

However, connecting virtually is not without its challenges! Many patients and family members do not have the technology to connect even when they would be interested in virtually meeting with others. Yet others have the technology and are willing to try, but it is unfamiliar and can be difficult to understand the process without assistance. Many facilitators are willing to help assist members in joining a class or meeting, but find many members are hesitant to try because it seems overwhelming. On the positive side, once a member has attempted and been successful in accessing a meeting, it is easier to move forward using virtual meetings to stay in touch with others.

Until it's safe to again gather in person, Wisconsin Parkinson Association will continue to search out ways to connect with the members of the Parkinson's community! 🍷

If you would like to be connected to a support group that is currently meeting on Zoom, contact WPA at 414-312-6990. For exercise options, join the WPA Movement & Music Facebook Group at facebook.com/groups/WPAMovementandMusic. You can also find over 100 exercise class recordings on WPA's YouTube Playlist and more at wiparkinson.org/exercise-resources/



At-Home Exercises

Exercise is important for people with Parkinson's to maintain activities of daily living, and focus on balance and mobility while improving strength. Exercise also improves the quality of life and many symptoms of Parkinson's while slowing down the progression of the disease.

These exercises can be done any time of day. Perform 5-10 repetitions of each exercise before moving on to the next one, then repeat the entire set 3 times. Take your time, listen to your body, and remember – any exercise is better than no exercise!



Sit to Stand

Place both feet on the floor shoulder width apart, knees bent to 90 degrees. Cross your arms and slowly rise to a standing position. Once standing, slowly and safely sit back down in a controlled movement. This exercise strengthens the muscles in your thighs and your core to give you stability.



Standing Leg Curl

Stand behind a chair, and if needed hold onto the back for support. Shift your weight on one leg, lift the opposite leg bending it as far back as you can, and hold for three seconds. Lower the leg and switch sides. This exercise helps strengthen the hamstring muscles and improves your balance and posture.



Overhead Press

Seated or standing (feet shoulder width apart) with a weight in each hand, hold them at chest level with your palms forward. Raise both weights straight up at the same time, slowly return to the starting position. This exercise strengthens the shoulder muscles and increases bone strength and improves stability. If you don't have weights, use a can of soup.



Bicep Curls

Seated or standing with a weight in each hand. Rest your elbows at your sides and your forearms should extend out in front of your body. Raise the weights all the way up to your shoulders by bending your elbows. Hold for a moment at the top, slowly lower the weight to the start position. This exercise strengthens the muscles at the front of the upper arm, the bicep and the muscles of the lower arm. These muscles are used anytime you pick something up.

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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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