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CELEBRATING OUR 100th ISSUE

Special Issue
ASK THE DOCTORS
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Board members Cheryl Prescott and Dick Schumann at the Holiday Reception. See more photos from the Holiday Reception on page 19.

Through the years with WISCONSIN PARKSINON MAGAZINE

100th edition

16655 W. Bluemound Road, Suite 330  |  Brookfield, WI 53005  |  414-312-6990  |  wiparkinson.org
Happy New Year, and best wishes for a joy-filled 2019!

As you can see, this is the 100th issue of this magazine! Starting as a small newsletter to share clinical information, advice on managing Parkinson disease, and ways to connect to a community, it has evolved and grown over the years into a nice magazine that still provides clinical information, advice on managing Parkinson disease, and ways to connect to a community! While our look has changed over the years, our commitment to you hasn’t changed over the years – and it won’t change.

One of the things we believe WPA does best is provide you with access to our state’s top Parkinson’s doctors and other health professionals. You’ll see that in this issue with all eight members of our Medical Advisory Committee answering questions that you asked at our 2018 Parkinson Disease Symposium. As well as our Medical Advisory Committee, our friend Danille Parker, PT, DPT, GCS, CEEAA answers a question about the benefits of exercise – something that we know is on your mind, and something to which WPA has invested a lot of program resources!

We’ve also included an update on the great work being done by Dr. Matthew Havrda from Geisel School of Medicine at Dartmouth. Dr. Havrda will be giving an update on the research that is being done with brain tissue donations previously made to WPA through the kindness and compassion of those wanting to advance Parkinson’s research.

You’ll also get a peek into some of the initial results from our first-ever Caregiver Survey. Thank you to all the caregivers who responded to this important survey. Your input will ensure that WPA follows your wishes and helps meet your most pressing needs as we develop our programs. We are so thankful for all that you do, and honored that you help build this organization!

Many of you came out to our annual Holiday Reception in December and we are happy to share some photos from that event. It was a festive night, and we were thrilled to have over 200 of our friends and supporters joining in an evening filled with good friends, good food, celebration, and camaraderie!

Enjoy the magazine, and please send any thoughts on ways WPA can serve you or the Parkinson community better – it is the only reason we exist!

Thanks,

Gary

Gary Garland
Executive Director
garyg@wiparkinson.org
A Parkinson’s diagnosis can be upsetting for you or your loved one. As daunting as the future may seem at times, our Medical Advisory Committee wants you to know the reasons they are optimistic about the future of PD diagnosis and treatment.

**Dr. Rachel Biemiller:**
I am hopeful because there are new frontiers being researched. The new focus on alpha-synuclein may lead us to a potential cure or a way to slow down progression. Fingers crossed!

**Dr. Karen Blindauer:**
So much research is now focused on figuring out what is causing the dopamine nerve cells to fail and die. Along with figuring out the “why,” research is looking at novel therapies to slow down this neuron loss. While much of this research is in very early stages in cell and animal models, it is exciting to see that efforts have moved beyond making medications to simply treat PD symptoms.

**Dr. Ryan Brennan:**
In regard to diagnosis, there is a lot of research being done looking at finding biomarkers (lab tests) that could assist us in making the correct diagnosis sooner. I am also very optimistic about the research that is ongoing in an attempt to find treatments that could slow the progression of the disease. One study was recently completed, and we should have results sometime this year.

**Dr. Taylor Finseth:**
The research is exciting right now. I’m hopeful that recent research strategies of stopping the protein alpha-synuclein and interfering with the immune system’s role in PD will slow the progression of the disease. I think pairing this with our current medication, therapy, and exercise treatments will greatly improve quality of life for patients with PD.
Dr. Kathryn Gaines:
I’m hopeful to see the engineering advances that might produce a closed loop or “self-adjusting” DBS system based on individual patient needs. I’m also looking forward to advances in gene therapy that could produce both symptomatic improvement as well as modify the course of disease progression.

Dr. Lisa Kokontis:
The research for PD is showing incredible promise – both for treatment of symptoms and the cause of the disease. Once the cause is found, a cure will be found.

Dr. Michael Schonberger:
I think the more we come to understand the nature of significantly impairing symptoms that are difficult to treat at present, such as freezing of gait, the more we will be able to devise ways of effectively managing them to the point that everything from basic quality of life to risk of injury will be positively impacted. Once that happens, and patients are able to move with more ease and loved ones are less on-guard, people will realize that there is more hope for their lives than perhaps they do now.

Dr. Katie Spangler:
What makes me hopeful is there is a large group of patients, researchers, and clinicians who are devoted to this disease. They are looking at additional modes of delivery of levodopa, at different neurobiological targets for therapy, and for diagnostic markers.
I am frequently asked this question by my newly diagnosed patients. The most honest answer to this question is “It depends…,” which leads to a good discussion with my patients and their care partners. The medications we currently have available to treat PD are geared toward reducing symptoms. These medications have not been proven to cure PD or to slow the progression of the disease. That being said, if a person with PD chooses to delay starting a medication, he or she has not caused the changes in the brain from PD to get worse. No harm done.

When deciding whether or not to start a medication for PD, we consider many things including, but not limited to, the severity and type of PD symptoms, overall health of the person with PD, type of work or hobbies of the person with PD, and personal values of the PD patient. If the symptoms of PD are mild and not causing any limitations in a person’s job, hobbies, or daily activities, it is reasonable to defer starting a medication. For example, if a person is right handed and the symptoms mainly involve the left hand or if the main symptom is a mild resting tremor of the hand that disappears with using that hand, the PD may not have a real impact on the person’s overall ability to function. On the contrary, there could be a negative consequence of using PD medications that may include possible side effects, possible inconvenience of taking pills, and cost of medications. In this scenario the risk of medication appears to outweigh the possible benefit.

If the PD symptoms have caused a person to have trouble at work, problems with balance or mobility, or a general decline in daily function, then it may not be OK to avoid taking medication. Be honest with yourself and your doctor. Have you given up activities you enjoy because the PD gets in the way? If the answer is “yes,” then I reiterate it is not OK to delay taking medication. If there is a decline in quality of life or concern for safety because balance and mobility are compromised, then the benefit of taking PD medications far outweighs the potential risks. In addition to medication, don’t forget the benefits of exercise, proper diet, education, social support, and physical, speech, and occupational therapies in treating PD.
How is exercise beneficial to my Parkinson’s symptoms? Is there a certain type that will be the most effective?

Danille Parker, PT, DPT, GCS, CEEAA | Marquette Physical Therapy

Exercise plays a crucial role in the medical treatment of people with PD. Exercise or physical activity is medicine and it must be thought of as one of the daily pills we must swallow. Medical professionals contemplate many things before, during, and after prescribing medicine. These same contemplations occur when we envision exercise as medicine:

- Why is it prescribed (benefits and side effects)?
- What medicine will help with the problems the person has?
- What is the most effective dosage?

**Why is this medicine prescribed?**

Studies show that exercise has a significant benefit in both physical and psychological well-being. Exercise is a vital component in symptom management and the positive side effects include improving and maintaining balance, walking, flexibility, strength, coordination, posture, mobility, and activities of daily living. Exercise is also associated with relief of fatigue symptoms, mood, sleep problems, and mental health across stages and severity of the disease.

**What specific medicine will help?**

PD affects many aspects of mobility including walking, coordination, strength, flexibility, and balance. The exercise prescription must target these aspects of mobility in a variety of ways. There are several different types of exercises that can benefit a person with PD, and in general, the exercises should include activities in four categories:

1. **Balance Exercises:** Focus on developing a sense of body awareness, improve postural alignment, and sequencing of body movements, which are all important to reduce the risk of falls.

2. **Strengthening Exercises:** Build muscle mass, strength, and power, which improve the ability to perform all daily activities.

3. **Endurance/Aerobic Exercises:** Raise the heart rate and respiration. This can include activities such as walking, jogging, swimming, and dancing.

4. **Flexibility Exercises:** Focus on stretching and maintaining movement and range of motion critical to performing all required daily activities.

**What is the most effective dosage?**

Dosage of exercise includes intensity of the activity (how hard) and consistency (how long/how often), both important to gain maximal benefit. The Parkinson’s Outcome Project found that people with PD who start exercising early at a minimum of 2.5 hours each week, experience a slowed decline in quality of life as compared to those who start exercising later. Other studies show individuals participating in regular exercise for longer than six months demonstrate significant progress and benefits.

The intensity and consistency of each activity needs to be individualized, however, research indicates that high intensity programs provide greater benefits, including improved walking speed, balance, and ability to climb stairs. General intensity guidelines within all exercise categories include feeling like you are working ‘somewhat hard’ to ‘hard.’

Just like every medication, the prescription for exercise must be individualized. A physical therapist is the best health care professional to provide a tailored program and exercise prescription suited to the needs of the individual. This prescription will include activities that can be done daily that you can safely ‘swallow.’ From now on, think of exercise as daily medicine. Your exercise medicine bottle will read: ‘Take at least once daily, for the rest of your life and refill as often as necessary.’

Danille is the Director of Clinical Education and Clinical Associate Professor for the Physical Therapy Department at Marquette University in Milwaukee, WI, with focused teaching emphasis on clinical education, patient management, geriatric rehabilitation, and exercise prescription. Her clinical practice specializes in management of older adult patients with a variety of medical disorders, impaired strength and balance dysfunction, and development of wellness exercise programs.
What dietary recommendations do you have to help me better manage my disease?

Taylor Finseth, MD  |  Aurora Health Care

There are no proven one-size-fits-all diets for Parkinson disease. That being said, there are some suggestions for managing your diet that may benefit certain individuals with Parkinson disease.

Probably the most important is adequate fluid intake. A goal of about 64 ounces of fluid is suggested to help avoid constipation, lightheadedness, and fatigue that are common in Parkinson disease. This would ideally be fluid intake during the beginning and middle parts of the day to avoid excessive urination during the night.

Second, the amino acids in protein compete for absorption with the medication carbidopa/levodopa, so ideally large amounts of protein would not be eaten in close proximity to the medicine. A 30-60 minute gap between protein and medication is typically recommended. It is still important to continue to eat protein and you could consider yogurt, nuts, or tuna as snacks to supplement this.

Lastly, people who eat healthy often feel better. There is evidence to suggest diets like the Mediterranean diet that are rich in fruit, vegetables, fish, plant-based fats, and whole grains with minimization of red meat and processed sugars are associated with reduced risk of many diseases and are thought to be both good for the heart and brain.

Dr. Finseth is a movement disorder specialist at Aurora Neuroscience Innovation Institute, where he provides management of movement disorders including Parkinson disease, tremor, dystonia, restless legs, and deep brain stimulation programming and performs botox injections for dystonia, chronic migraine, and other conditions. He is a member of Wisconsin Parkinson Association’s Medical Advisory Committee.
Obviously when someone you know and love is diagnosed with Parkinson disease, it does not only affect them, but also their loved ones. Caregiving comes in many ways and roles are very individual. Caregiving styles differ as well. As a caregiver, know there is not always just one way to deal with each situation. Each individual, relationship, and social dynamic are different.

I think it is important to make sure and have all lines of communication open from the beginning with your loved one. Caregiving roles change as the disease changes. In the beginning, it may be just providing emotional support. For some caregivers, it is important to come to doctor appointments and ask the questions they need answering while allowing their loved ones’ continued autonomy to make their own medical decisions. I think that learning about all aspects of Parkinson disease by both the patient and the caregiver helps with coping as times goes on. The more you know, the more powerful you will feel. The more you know, the more you also may be able to “plan” for any needs in the future and the more you as a caregiver, can be an advocate for your loved one.

As each person with the disease progresses (and each person with the disease is very different), more and more may be required of the caregiver. Remember that symptoms can vary daily, hourly, and even minute-to-minute sometimes. Patients that have more falls and psychiatric/cognitive issues can cause more stress and burden for caregivers. If this is the case, it is very important that the caregiver has their own social support network. Included in this should be their health care team. The caregiver needs to be part of the “team.” In some cases, the patient may not be as aware of their symptoms or problems and the caregiver may need to be the person to give some ancillary history about what is “really going on.” Therefore, they need to make sure and develop a good trusting relationship with the health care team. Sometimes it is hard to know from a caregiver standpoint when to step in and when to let their loved one “do it themselves.” I think that in the beginning stages, it is important to urge and guide the patient into doing it themselves (if safe). Of course, in more advanced stages, more oversight needs to occur. Obviously, safety is always a concern and if safety is at risk, then the caregiver should be stepping in. Again, I would encourage that as different scenarios occur, to talk with your health care provider on how to handle those specific scenarios.

Apathy can be a troublesome non-motor symptom in Parkinson disease and for most caregivers, this can be very frustrating. One way I tell my patients to work with this symptom is to have a schedule/calendar that is visibly available for all members in the family. This way it may reduce the “nagging” but things will get done that need to be done. This can pertain to exercise classes, etc. If left up to the patient, they may not have any motivation to exercise on their own at home, but if you have a designated time/place to exercise that is agreed upon by both parties, that can help with follow through and reduce frustration.

As things come up in this journey, ask questions. There are many resources for caregivers and ask your health care provider where you can find them. 😊

So, for you caregivers… communicate with your loved one. Talk about your expectations. Educate yourself about Parkinson disease. Have your own support network. Make sure you have time FOR YOURSELF (which can be very hard depending on the care your loved one needs)... but remember they may need some time away from you too. 😊 It is important to find a balance of caregiving while maintaining autonomy for both you and your loved one. Continue to have your own individual interests while supporting your loved one.
Vision requires a combination of visual perception and the visual system. Visual perception involves the brain interpreting what we see while the visual system includes the optic nerves, a healthy eye, and muscles to move the eye around. The two areas are so strongly interconnected that it can be impossible to determine where one’s function ends and the other begins. Parkinson disease may affect one’s vision in any or all of these areas and to varying degrees.

The eye movements themselves are controlled by a series of muscles called the extraocular muscles. These muscles complete a series of movements to take in the world. A common one is called saccades. Saccades are quick movements towards an object such as looking over at a clock. This is typically done in one quick movement as the eyes dart from a current area of focus to the new one. In PD, this movement may be momentarily delayed or slowed. The eyes may come up short jumping to an area short of its target. This requires the eyes to then make a second saccade to reach their goal.

Pursuits are another movement that essentially pursues an object in motion. As something moves, our eyes follow. Again, PD slows this tracking preventing the eyes from keeping pace with their target. To catch up, the eyes do a quick saccade or dart to where the object is but again may fall behind. This leads to a jerky quality when patients follow an object as the eyes are consistently trying to keep up. The last movement is convergence. Convergence allows the eyes to come inward to focus on a spot can cause light sensitivity. The pupils may even constrict asymmetrically when initially going from dark to light.

The eye itself also changes because of PD. The retina is in the back of the eye and translates what we see into a signal the brain can interpret. PD patients have been found to have retinal thinning. Autopsies have shown Lewy bodies as well as alpha-synuclein, a protein associated with PD, deposited in different layers of the retina. These areas of protein and Lewy body deposition correspond to the thinning retinal segments. The meaning of this is unclear.

Lastly, we do know that color perception, contrast (shading) perception, and acuity (sharpness of vision) all may be diminished and affect visual processing. Loss of contrast perception seems to have a strong correlation to the development of visual hallucinations. Pattern recognition, depth perception, and facial recognition may also be diminished. There seems to be a correlation between vision symptoms and changes in the brain as well including processing speed and white matter changes. Both brain and eye appear to have changes when these complex visual symptoms are involved.

Dr. Biemiller is a Movement Disorders Specialist at Gundersen Health System in La Crosse, WI. She trained in the treatment and diagnosis of movement disorders heavily focusing on Parkinson’s. She is trained in deep brain stimulation, botox injections, and involvement in clinical trials. Dr. Biemiller is a member of Wisconsin Parkinson Association’s Medical Advisory Committee.
CBD oil refers to cannabidiol oil. Cannabidiol (CBD) comes from the Cannabis sativa plant and more specifically, often comes from a strain of plant that is known as hemp. Hemp plants used for the purposes of extracting and compounding CBD do not usually contain significant amounts of the marijuana ingredient tetrahydrocannabinol (THC). THC is the chemical responsible for the marijuana “high” sought by recreational marijuana users. Luckily, CBD does not produce a “high” and is thought to work on many aspects of the human body’s cellular system through a variety of mechanisms.

To provide a little physiology background, the human body produces its own form of cannabinoid and it follows then that the body has cannabinoid receptors; CB1 and CB2 and probably others. CB1 receptors are mostly found within the immune system. The CB1 receptors in the brain deal with movement, coordination, memory, mood, emotion, and pain perception. It’s thought that THC attaches to the CB1 receptors in the brain but CBD attaches to neither receptor. Instead it acts on the body in an indirect way and signals to the body to use more of its own self-produced cannabinoid. There are also plenty of other processes that CBD acts upon, but that discussion is well beyond the scope of this article.

As far as the use of CBD in Parkinson disease, there have not been any recent, large, randomized, controlled studies that convincingly support the use of CBD. And there certainly have not been any convincing long-term studies yet either. Some smaller studies have suggested varying levels of improvement in non-motor symptoms of PD but none have really shown to improve motor symptoms. Anecdotal reports claim that CBD improves tremor, dyskinesia, and rigidity, however the problem is the lack of evidence that supports such claim. Although CBD exists in an FDA approved medication called Epidiolex, this medication is only for the treatment of two childhood forms of epilepsy. There have been no FDA approved CBD based treatments for Parkinson disease. In fact, the production and availability of CBD to the public is not regulated by any agency at the moment and the legalities of CBD in Wisconsin is not straightforward.

At the moment, until further information and more studies are done on CBD, I tell my patients to avoid CBD. Prescription medications are expensive enough and have been extensively tested. CBD from a vendor is often very expensive and it just doesn’t have the reproducible results and quality assurance that I could recommend to a patient.

Dr. Gaines practices general neurology and sub-specialty neurology in the field of Movement Disorders at Aurora Advanced Healthcare in Milwaukee, WI. Her interests include Parkinson disease, Essential Tremor, Huntington’s disease, dystonia, and other movement disorders to include gait disorders and psychogenic disorders. She also provides botox injections for various conditions and deep brain stimulation programming. Dr. Gaines is a member of Wisconsin Parkinson Association’s Medical Advisory Committee.
Hallucinations are a common complication of Parkinson’s. It is part of a symptom complex called psychosis, which is a term used to describe disordered thinking. Psychosis is a frequent complication of PD, and it is characterized mainly by visual hallucinations and delusions. Hallucinations are the most common manifestation, and they affect up to 40 percent of patients with PD, particularly those at an advanced stage of illness. Hallucinations often take the form of people, animals, or insects, or can be incompletely formed, such as seeing patterns on walls or carpet that are not there, or “something out of the corner of my eye that goes away when I look at it.” Delusions often are paranoid, such as spousal infidelity, someone threatening on the property, or financial ruin.

Psychosis may be triggered by infection, medical illness, surgery, advancing dementia, or medications. The adverse effects of antiparkinson medications, the dopamine agonists in particular, are probably the most important cause of psychosis in patients with PD. Patients with PD initially do well on these medications but with advancing impairment, no longer tolerate them.

Management of psychosis in patients with PD involves identifying and treating the underlying causes and contributory factors. Your doctor will review with you what tests to order and medications to change. Once that is achieved, if symptoms are still present, thoughtful consideration as to the burden of psychosis should be done. If the hallucinations are not harmful or do not pose a safety risk, simple redirection or reassurance to the person with hallucinations is all that is needed.

When hallucinations are frightening or pose a risk such as falling to chase out an “intruder,” going outside and getting lost, and redirection and reassurance is not working, medications may be necessary. Options include treatment with quetiapine, pimavanserin, or clozapine, the latter requires frequent monitoring and risk of low white blood cells.

All antipsychotic drugs appear to be associated with a small increased risk of mortality when used to treat behavioral disorders in older adult patients with dementia. In addition, data suggest that antipsychotic use is associated with an increased risk of mortality in adults with PD. However, this risk must be balanced with the high risk and mortality of untreated psychosis.

Your doctor may also choose to try a class of drug initially developed to treat Alzheimer’s dementia (anticholinesterase inhibitors). In some cases this can effectively rid hallucinations.

Talk to your doctor if hallucinations are occurring - often simple strategies can alleviate them.
It goes without saying that getting good, restorative sleep is an essential component to everyone’s health and well-being. This is especially true in many patients with movement disorders, including Parkinson disease, as excess stress of any kind on the body and mind (of which fatigue certainly counts) can seemingly worsen many features of the underlying disease.

PD patients, however, can have a few unique needs when it comes to sleep disturbances. First off, many patients have a history of what we describe as “vivid dreaming,” which can be exacerbated by some PD medications if taken too close to bedtime.

Even more so, some PD patients may experience REM-Sleep Behavior Disorder (RBD), which is known to be associated with many cases of PD and can even herald the onset of motor symptoms, sometimes by several years. This condition is almost universally described as people “acting out their dreams,” which can potentially lead to injuries, both to the patient and the bed partner. It is important to discuss this with your health care provider as this condition can be managed.

One concept that our Sleep Medicine colleagues always like us to communicate to our patients and their loved ones is the idea of practicing “good sleep hygiene.” This generally consists of:

- Going to bed at the same time every night
- Waking up at the same time every morning
- Avoiding daytime napping as much as possible

While this is most definitely easier said than done, the point is that having a dedicated sleep routine/regimen can help minimize excessive daytime fatigue and obtain better quality sleep.

If you do have concerns about your sleep quality and/or excessive daytime fatigue, talk with your health care provider. A referral to a Sleep Clinic should be considered; I always tell my patients not to fall into the trap of thinking that sleep apnea is the only sleep disorder out there, because it is not. Just because you go to speak to someone at a Sleep Clinic does not guarantee you will have a “sleep study” – you may not need one.

When it comes to medicines that can “help people sleep,” it is important to remember that many, if not all, of these medications are much more likely to help people fall asleep rather than stay asleep. Because many of these agents (even the over-the-counter ones) can have potential side effects and/or drug interactions with other medications, it is important to first discuss their use with your provider.

Finally, there are many other reasons for someone to wake during the night. A very common example is nighttime urination, or what we term “nocturia.” This can also be treated to limit the number of times someone gets up to use the bathroom, which can sometimes be quite difficult for people with mobility issues, as in PD.

The bottom line is this: Never underestimate the importance of getting good, restorative sleep, nor the effect of excessive daytime fatigue on PD and overall quality of life. However, many of these sleep disturbances can be managed. It all starts with speaking honestly about your concerns with your provider.

Dr. Schonberger focuses mainly on Clinical Neurology with a sub-specialty in movement disorders. He has reestablished the DBS program, and he also provides botox therapy. Dr. Schonberger is also involved in training medical students and residents, as well as the development of educational programming and seminars for the public. Dr. Schonberger is a member of Wisconsin Parkinson Association’s Medical Advisory Committee.
Dementia is a group of symptoms that causes problems with memory and thinking abilities. It commonly occurs in individuals with Parkinson disease as the disease progresses. People with PD are at a higher risk of developing dementia than the general population. There are many reasons for this. One of the main causes of dementia in people with PD is the progression of changes within the brain to other areas that are responsible for our cognitive (thinking) abilities. These changes are due to abnormal protein clusters (alpha-synuclein) known as Lewy bodies. Early in the disease, these clusters are only found in the deep parts of the brain and brainstem. However, over time these abnormal proteins spread to other parts of the brain where it affects brain cells (neurons) responsible for cognitive functions. It is also important to understand that as we age, other common causes of dementia can occur with PD. This includes Alzheimer’s and other forms of dementia.

As the disease changes and spreads to certain areas of the brain, a variety of symptoms can occur. Cognitive impairment and dementia are common in individuals with PD. There is a wide range in the degree of cognitive impairment experienced by each person. These changes include difficulty with problem solving, difficulty with language, forgetfulness and, in some cases, visual hallucinations, and behavioral changes. These changes are typically very mild at first, but gradually worsen over time. There are medications that can help slow the progression of the cognitive decline and help control symptoms of hallucinations or behavioral changes. Discuss this with a neurologist, or other provider, to identify the best option for you or your loved one.

Dr. Brennan completed his residency in Neurology at the Medical College of Wisconsin, after which he completed a two-year fellowship in Movement Disorders at the University of Nebraska Medical Center. He recently moved back to Milwaukee and is now a member of the Medical College of Wisconsin Department of Neurology. He is a member of Wisconsin Parkinson Association’s Medical Advisory Committee.
Research Update
Matt Havrda, PhD  |  Geisel School of Medicine at Dartmouth

Introduction: The Havrda Laboratory at the Geisel School of Medicine at Dartmouth spearheads an exciting collaboration with WPA analyzing patient samples and developing new tools to understand, detect, monitor, and treat Parkinson disease. The patient samples were collected over the course of several years through the Brain Tissue Repository Wisconsin Parkinson Association previously operated. As you will see, the tissues have allowed them to identify the previously unidentified NLRP3 inflammasome which is now leading to further studies funded by the Michael J. Fox Foundation for Parkinson’s Research.

The Havrda Laboratory is focused on characterizing the molecular basis of neuroinflammation, a pursuit that has identified the “inflammasomes” as key mediators of inflammatory processes in Parkinson’s. Inflammasomes are intracellular protein complexes that respond to cellular damage and stress. During the course of PD, different forms of cellular stress have been well-documented ranging from metabolic and oxidative stress, to proteinaceous insult resulting from the accumulation and propagation of misfolded proteins like alpha-synuclein.

The Havrda Laboratory has characterized the NLRP3 inflammasome in animal models and in tissues obtained from Parkinson’s patients and their generous families in collaboration with Wisconsin Parkinson Association (WPA). Loss of the NLRP3 inflammasome protected mice from neuroinflammation and neurodegeneration in multiple mouse models, as recently reported by the Havrda Laboratory in Toxicological Sciences.

In another recent report appearing in npj Parkinson’s, the lab determined that NLRP3 expression was elevated in brain tissues obtained from PD patients, while analysis of genetic data indicated that an NLRP3 variant that likely inactivated the inflammasome was associated with a significantly reduced risk of developing PD. In exciting new studies supported by the Michael J. Fox Foundation for Parkinson’s Research, the Havrda Laboratory explores the concept that inflammasome proteins might be released from distressed cells in PD during the long process of neurodegeneration.

Newly developed analysis has identified a subset of patients with readily detectable circulating NLRP3. These studies identify a clear trend towards an association between elevated circulating NLRP3 and PD and indicate that NLRP3 levels are suppressed by common anti-inflammatory medications. Taken together, the ongoing studies in the Havrda Laboratory have improved our understanding of inflammation in PD and highlight how important collaborations maintained by the WPA continue to support clinically relevant research unraveling the complex molecular events that underlie the disease.

In November 2018, we conducted a survey for caregivers of people with Parkinson's. The survey was distributed in this magazine as well as through our emails and social media channels. We asked caregivers for input on the support and resources they need, topics they would like to see WPA presentations on, and the value they find in the programs and services currently offered. Caregivers were also asked about their biggest challenges as a caregiver.

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

### Basic Demographics

- **148** survey respondents
- **93%** spouse or partner of a person living with PD
- **77%** female respondents
- **35** counties in Wisconsin, Illinois & Iowa

### When asked about what types of support WPA could provide, caregivers reported the following support needs:

- **42%** Exercise groups or classes in my area
- **39%** Support groups in my area
- **37%** Local resources
- **36%** Education programs
- **35%** Information on PD
- **24%** Respite/relief
- **24%** Caregiver specific opportunities for social interaction
- **22%** Household assistance & maintenance
- **20%** Legal advice
- **20%** Financial advice & planning
- **18%** Literature on PD
- **12%** VA Benefits assistance
- **11%** Webinars
Rate your loved one’s level of caregiving needed in the last 3 months:

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What are your biggest challenges as a caregiver?

Topics respondents are most interested in:

- Physical health and nutrition: 43%
- Anxiety: 37%
- Depression: 37%
- Insomnia or sleeplessness: 36%
- Mindfulness or meditation: 28%
- Isolation: 26%

In Memoriam

We were saddened to learn of the recent passing of a very generous and caring man, Wayne Kreklow. When he was diagnosed with Parkinson disease in 2000, Wayne had a vision to raise awareness of PD, and to raise money to support the search for a cure. For 5 years, Wayne and his wife Nancy spearheaded “All Shook Up for Parkinson’s,” as a fundraiser for Wisconsin Parkinson Association. Their family and the New Glarus community rallied around them, which resulted in over $55,000 for a cause dear to Wayne’s heart. Wayne’s family and friends have continued to support him by designating memorial donations to WPA.

WPA honored the Kreklow family with the Tulip Award in 2012. The award recognizes a worthy individual, couple, or family who have shown dedication and a commitment toward helping people with PD and educating the public about PD. We are grateful to have known Wayne, and for being able to honor his and Nancy’s efforts in the fight against Parkinson’s.
Support Groups & Exercise Groups

WPA works with groups around Wisconsin and in surrounding areas. Groups include support groups, exercise groups, caregiver groups, and young-onset groups. Most groups are run by volunteer facilitators.

For more information on groups in your area, visit wiparkinson.org or call 414-312-6990.
WPA’s Holiday Reception

We had a great turnout at our annual Holiday Reception on December 6 in Brookfield. We honored Dick Schumann for his many years of service on our board of directors, and thanked Dick Cosentino as he ended his term as board president. We also welcomed Jim Cantrell as our incoming board president. Music was provided by Dale Luedtke, a local man who has Parkinson’s and doesn’t let it slow him down!

Thanks to all who attended, and to our sponsors: Cosentino Financial Group, Financial Strategies, Inc., Senior Helpers, and SYNERGY HomeCare.
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.

Upcoming Programs

February 22
Parkinson Disease Program
Appleton

March 15
Parkinson Disease Program
Pewaukee

May 3
Parkinson Disease Program
Rothschild

July 25
Facilitator Retreat
Milwaukee

July 26
Annual Parkinson Disease Symposium
Milwaukee

September 10
WPA Open Against Parkinson Disease
Wales

September 25
Parkinson Disease Program
Green Bay