



WINTER
2024

Parkinson's Perspective

apda AMERICAN
PARKINSON DISEASE
ASSOCIATION
WISCONSIN CHAPTER



EVERY DAY, WE PROVIDE THE SUPPORT,
EDUCATION, AND RESEARCH THAT WILL HELP EVERYONE IMPACTED
BY PARKINSON'S DISEASE LIVE LIFE TO THE FULLEST.



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Want to help APDA WI?

- Join a committee like the Madison Optimism Walk Committee to help plan the event.
- Volunteer at a Walk or other event to help everything run smoothly.
- Become a sponsor. You can help fund our programs and events while getting valuable advertising for your business.

If you're interested in helping, email mramstack@apdaparkinson.org or call 608-345-7938. Thank you so much! Your help keeps us going!

Save the Date!

On Saturday, April 5, 2025 APDA WI will be holding a Parkinson's Conference in Madison, WI at the Warner Park Community Recreation Center. More information will be coming.

If you are interested in joining the planning committee, please call or Megan Ramstack at 608-345-7938 or email her at mramstack@apdaparkinson.org, for more information.

PD DURING THE HOLIDAYS: OUR TOP TIPS

The holiday season is right around the corner. Gift shopping, cooking, cleaning, hosting friends and family, or traveling to see loved ones can feel overwhelming — especially when also navigating life with PD. Here are some tips to make the most of the holidays without creating additional work and stress.

Make gift shopping simple with gift cards or consider a "Secret Santa"-style gift exchange where you purchase a gift for just one person, instead of many.

Consider sending e-cards instead of printed cards and save the time and effort of stuffing envelopes, postage, etc.

If traveling is hard for you, don't miss out completely! Try virtual holiday celebrations instead of in-person. You can visit with friends and family via Zoom, FaceTime, or other video chat technology from the comfort and safety of your own home. You can keep it special and festive with virtual games, storytelling, recipe sharing, and more.

Keep moving. Exercise and movement can help you feel better. There are many online classes you can join from home, or get outside for a walk or a jog.

Take time for yourself. Whether it's to squeeze in your own doctor appointments, a phone call to an old friend, to get some exercise, or just have some quiet alone time to read a book, it is important to find a little time for YOU.

Accept help. Sometimes it takes a village. And that's ok. If friends or family offer help, say "yes" and give them something specific to do.

Find support. You don't have to go it alone. APDA can help you find a support group near you, or you can join an online community like Smart Patients — a discussion forum for people with PD and their loved ones where you can share advice and information.

Did you know?
You can make a donation to APDA WI in honor of someone who is fighting Parkinson's or as a tribute to someone who has passed away. You can donate online today by scanning the QR code below or visiting www.apdaparkinson.org/wi

You can also mail checks to
APDA WI
PO Box 14381
Madison, WI 53708



Deep Brain Stimulation: Is This for Me?

by Chuck Geurink,
APDA Board Member

For about six months, I experienced a slight tremor in my right hand, something I could easily deal with on a daily basis. My health was good, and at age 66, I thought it was a minor issue.

However, my wife convinced me to have the tremor checked by specialist Dr. Harvey Block, a neurologist with SSM Dean Medical Center, Madison, Wisconsin. He diagnosed and confirmed my early-stage Parkinson's disease (PD). I was 66 years old and in good health, so this news was a big surprise to me and my family.

Following this diagnosis, I sought a second opinion and received an extensive evaluation at Struthers Parkinson Center in Minneapolis, Minnesota. Here, my diagnosis was again confirmed.

Suddenly, life was turned on its head. My wife and I were in total shock. What is Parkinson's disease? How do we deal with this progressive disease with no known cure? How will it limit me? How quickly will it advance?

Today, I have lived with Parkinson's disease for



14 years. Fortunately, my years without Parkinson's allowed me to enjoy a 30-year architecture and building construction career with Marshall Erdman and Associates in Madison, Wisconsin. This mid-size design-build firm develops medical facilities nationally.

My career was very enjoyable and included a lot of travel. However, in 2008, after several years in management as a Senior Vice President, it was time to retire. Only two years later, a PD diagnosis interrupted my retirement.

In the early years of my diagnosis, the symptoms included a light tremor in my right hand, and Dr. Block monitored the progression of

symptoms every six months without medication for the first eight years. As my tremor advanced and became more pronounced, I was prescribed a light dose of Carbidopa/Levodopa, a common medication for PD patients.

A critical known treatment for Parkinson's is to be active and exercise (keep moving). My athletic background and active lifestyle helped me to do that. Since being diagnosed, I have been able to regularly complete my daily two-mile walk, golf with my golf group, and bike.

In recent years, I have attended Rock Steady Boxing at Bakke Athletics in Fitchburg, Wisconsin, led by our amazing leader,

Coach Patti Batt. Each participant has PD, and no one person with Parkinson's has symptoms exactly the same. We exercise in aerobics, weight training, balance, flexibility, and boxing movements (no hitting each other). And yes, there is the added benefit of fellowship among our Parkinson's family.

At the end of 2021, Dr. Block retired from practice. After discussing advanced treatment options, Dr. Block referred me to University of Wisconsin Health (UWH) for an assessment of treatment options. After three months, I was assigned to Dr. Baker, a movement specialist in the Department of Neurology Movement Disorders at UWH.

Dr. Baker reported that my current condition had advanced to include tremors on both sides but more significantly on the right side, which also included dystonia (leg cramping) and some of the other typical Parkinson's disorders that settled into my daily life. Dr. Baker prescribed several additional medications known as Carbidopa/Levodopa enhancers.

After a year of testing various PD medications with little relief, Dr. Baker advised that I would be a good candidate to benefit from Deep Brain Stimulation (DBS), which is effective in treating movement disorders for many Parkinson's patients.

DBS is a surgical procedure in which two small electrodes are inserted deep into the brain and connected to a control device placed in the chest. Once activated after the brain has recovered from surgery, the neurologist adjusts the programming device for optimum benefit,



and the settings can be adjusted over time.

I sought information on this procedure, its risks, and potential outcomes. My wife and I have attended American Parkinson's Disease Association (APDA) seminars for many years, and I currently serve on the APDA-Wisconsin Chapter board. I also approached PD patients who had experienced DBS and interviewed them about the procedure and their outcomes.

While each case is unique and must be carefully analyzed, DBS is most effective for

those of us with significant movement disorders. This procedure is not without risks, such as bleeding into the brain, causing a stroke, paralysis, loss of speech, coma, or death. There is less than a one percent chance of a stroke and a five percent chance of less serious complications. My family was incredibly supportive of my decision to move forward with the evaluation process of exploring the benefits of DBS.

With the decision to move forward, UWH did a complete assessment of my condition that included physical therapy, testing my movements off versus being on PD meds, a psychological evaluation, an MRI scan, and a surgical evaluation. In late October, my entire medical team reviewed my results and recommended that I was a very good candidate for DBS surgery.

Suddenly, it was very real. Moving forward toward surgery was not an easy decision. It was a risk, and at age 79, my family's support gave me the confidence that DBS was my best chance to live a somewhat more normal life. We had complete confidence in this seasoned and highly recommended medical staff. Still, was DBS too risky?

Our final decision was much easier when we knew we had the best DBS team in the region to proceed with the surgery. Dr. Lake, a

neurosurgeon with UWH, took the time to communicate the information we needed both before and after the surgery. Dr. Lake specializes in DBS, is highly regarded in the region, and performs approximately 50 cases annually. His career is focused on DBS surgery.

The main risks associated with this type of surgery are physical health and body cleanliness to prevent infection. The pre-op process involved an MRI scan, pre-op physical, medication adjustments, and fasting restrictions. I was also required to have my head shaved and my body cleansed with antibacterial soap.

Approximately three hours after my head was shaved for the first time in my life, Dr. Lake called to inform me that he needed to postpone the surgery due to the surgical team's concern over an inconsistent EKG reading. The surgery dates were rescheduled. Our frustration was immediate, and then we realized waiting three weeks was really not an inconvenience for the outcome we had hoped for. During this three-week delay, I passed my complete stress test and was cleared, and the new surgery dates were confirmed.

The new date arrived for my first surgery, which included an outpatient surgery procedure where markers were set in my skull to attach a surgical device. This was a



simple procedure, and we were home for dinner.

The second surgery was the MAIN EVENT, which lasted nearly six hours. I was kept awake to communicate valuable brain activity to Dr. Lake. The last hour, I was asleep when the control device was implanted in my chest. The surgery was an interesting process; the most difficult requirement was my need to respond to questions throughout the six hours.

Dr. Lake was positioned behind me for an optimal view and access to my head. The surgical team of 10-12 health professionals from surgery, anesthesia, technical, and support staff communicated with me the entire time. I needed to keep talking so that Dr. Lake could be assured that my brain waves were active and that he

could insert the wires accurately.

After being released to my patient room, I was able to see the family. The one-night stay was rough, but I was released to go home the next day. The positive outcome that is our new reality was due to the extreme kindness and leadership of Dr. Lake along with his outstanding medical team.

How did it feel? The brain itself has no feeling. I could only feel the drilling through my skull. It was short-lived, about like getting a tooth pulled.

My recovery back to normal included a six-week waiting period until the device could be activated and tested. During the first two-and-one-half-week period, I needed to stay as calm as (Contd. on pg. 13)

Exploring the Aspects of Dr. Mattioda's Exercise Group

By Gavin Turner

As many have learned, exercise is a significant factor in limiting the symptoms of Parkinson's disease. Exercise groups not only provide symptom relief but also provide a great social setting with other participants in the class.

conducted twice weekly. When walking in for the first time, you can expect to be welcomed by warm-hearted participants and exercise leaders who are there to

between circuit training, balance exercises, and amplitude-based motor retraining. It is almost an hour of exercise, specifically geared toward the most beneficial modes of exercise for individuals with Parkinson's disease."

One of the best ways to get involved in exercise is through Parkinson's disease-specific exercise classes. To learn more about these exercise groups, I reached out to Dr. Melissa Mattioda, a physical therapist at UW Health who is involved with them.

I first wanted to learn what this class intends to provide its participants. Dr. Mattioda mentioned that the class strives to work with the individual and the group as a whole to provide what is seen in all Parkinson's-driven exercise groups: utilizing the association of exercise and Parkinson's disease to benefit anyone who participates.

So, what should someone expect to see in their first exercise class? The classes are an hour long and are

support you and look forward to improving mobility and quality of life.

As Dr. Mattioda describes, "Our class has two components: a treadmill portion in which participants walk forward, backward, and sideways on the treadmill, and a group exercise portion in which we vary the type of exercise from class to class. Those forms of exercise in the group portion can range



Not all exercise classes look like this, though. Individuals can find classes geared towards specific activities, exercises, or sports that they enjoy and still receive the variety of benefits seen in this type of class.

Another great benefit of these classes is the other participants you get to meet and build relationships with. Due to the group aspect of the class, participants in Dr. Mattioda's class are always building new and powerful relationships. This can be exciting for new members to become a part of because they are walking into a positive and supportive atmosphere.

One wonderful thing Dr. Mattioda mentioned was that participants in the class have stuck around for years and built extremely strong bonds with one another. Whether it started on the (Contd. on pg. 13)

Family Fundraising for Parkinson's

By Megan Kelly

Hearing someone close to you has been diagnosed with Parkinson's is different for everyone. Most of you reading this are probably affected by Parkinson's in some way, whether you or your loved one has been diagnosed. For each of us, it is our own uniquely difficult experience.

In my family, when we had a member diagnosed, we all responded differently, but we were all united in wanting to support however we could.

About a year after our family member's diagnosis, we came up with a very Wisconsin idea to have a golf outing to raise money for research. We reached out to our local golf course, Lake Breeze, and asked them how we could host a golf outing. They were very generous in walking us through how they host outings and giving us tips and tricks on running a charity golf outing. We then invited our family and friends and said we were going to golf, have raffle prizes, and have a good time raising money for Parkinson's!

We contacted the WI Chapter of APDA to let them know what we were thinking, and they quickly provided a resource to help support us in the event. Our first year was great, and by the end of the event, everyone was asking



what the date was for next year!

Our event grew the second year when another member of our community who had also been diagnosed with Parkinson's and his group joined it. We created a website to move participant sign-ups online and provide resources about Parkinson's.

We just completed our 3rd Annual Fox Cities Parkinson's Golf Outing, and I'm proud to say that we have donated over \$20,000 to the WI Chapter of APDA! This money will help fund research and support families in Wisconsin facing the financial burden of

Parkinson's treatment.

All our donations for this event come from the folks participating and local businesses in our community. There is no way to say a big enough thank you to them for their support over the last three years. They golf, donate raffle baskets, buy tickets, and show up and make the event awesome!

If you are trying to get an event up and running in your area and want to hear more about how we started a friends and family event that is sold out every year, feel free to email foxcitiesparkinsonresearch@gmail.com.

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-Megan Kelly



Pictured above are Eric Kelly, Megan Kelly & Cathy Van Eperen, organizers of the Winneconne fundraising event at Lake Breeze Country Club.

Punch Out Parkinson's: Community Comes Together to Fight PD

Evan Riley, a schoolteacher from Janesville, turned his connection to Parkinson's disease into a powerful community event with POP, or Punch Out Parkinson's.

Inspired by his father, who has Parkinson's and loves golf and music, Evan created this annual fundraiser to make a difference for those affected by the disease. Held each year in Middleton, WI, POP features a golf outing in the morning followed by a lively gathering at Capitol Brewery. Guests enjoy live music, plenty of raffle baskets, and the camaraderie of a community coming together to support a common cause.

Evan's event has become a meaningful way to connect with his dad and support the PD community. The funds raised benefit APDA WI. If you want to start your own APDA WI fundraiser, email apdawwi@apdaparkinson.org or call 608-345-7938 for more information.



Taking Change into Our Own Hands: Scott Rider on Being the Change We Want to See

By Megan Ramstack

You might not know who Scott Rider is yet, but you will. Scott, a former Big Ten track star and young-onset Parkinson's patient, inspires communities to take fundraising into their own hands, helping people see they can make a meaningful difference.

In a recent talk in Janesville, I witnessed his energy firsthand. Scott opened with humor and relatability, but his message quickly became urgent and passionate: "Change will not happen if we wait for some other person or some other time. We're the ones we've been waiting for. We are the change we see."

Scott explained why raising funds for Parkinson's is crucial. "Over a million Americans have Parkinson's



Pictured above are Connie Udell who coaches the Janesville Rock Steady Boxing Program and organized Scott's visit, Megan Ramstack, Chapter Coordinator of APDA WI & Scott Rider, a Parkinson's advocate.

disease. Every six minutes, someone in the United States is diagnosed. Think about it—every six minutes! That's staggering."

He emphasized that

donations are not just about funding research; they provide essential support for programs that improve the daily lives of people with Parkinson's. Programs like Rock

Steady Boxing, which help those living with Parkinson's maintain their quality of life, require consistent funding to



continue offering their services.

Scott reminded us that people often shy away from asking for money. "People say, 'I feel like I'm begging.' I say, if you're passionate, you're not begging. You're asking people to be involved in something important."

Scott shared a powerful example from his life: He led a project to build an adaptive house for Parkinson's patients. This wasn't just a charity project; it brought the community together. He encouraged everyone to think beyond financial donations—consider volunteering time, offering expertise, or mobilizing others to contribute.

Scott has carried this idea of

being resourceful and making connections into other events, too. For example, he organizes a neighborhood street fair, where the community donates items for auction, and tables are sold to raise funds. He also took to the road in a documentary project, sharing stories from across the country to raise awareness about life with Parkinson's.

In each endeavor, Scott's philosophy remains clear: take charge and don't be afraid to ask others to help in a way that suits them.

Scott underscored a powerful lesson from his conversations with advocates from other health communities. He noted how the HIV and breast cancer communities made strides by aggressively advocating for support. These groups secured essential funding and drove significant progress by uniting and bringing their voices to policymakers.

Scott believes that those of us in the Parkinson's community can learn from this approach. "It does take money," he says, "but it also takes determination and people willing to step up."

So why does Scott give? "I get back so much more than I give," he said. "The more you're involved, the more knowledgeable you become, the more relationships you build. You can choose to be a consumer or a contributor. I decided to be a creator, not just a taker. Contributing feels really, really, really good!"

Scott Rider's challenge is simple: don't wait for change—be the change. Ask yourself how you can give:

- Financially
- Through your expertise
- By volunteering
- Encouraging others to get involved

In the end, making a difference is about taking action. As Scott says, "Decide to be a contributor, not just a consumer. Together, we can accomplish so much more."



Lucky Number 7: My Journey With Parkinson's Disease

By Sandy Schwartz

Since my twenties, I always sensed that Parkinson's disease (PD) was in my future. My father, his mother, and his sister had it. I even joined my dad at his doctor's appointment once to ask if Parkinson's was genetic, but the doctor brushed it off, saying it was "maybe just familial." I moved on with life, never expecting how soon it would catch up with me.

In 2008, I began experiencing issues with my feet. After a ruptured tibial tendon, my foot had to be fused, throwing off my balance. Years later, I endured injuries that shattered my elbow, shoulder, and hip, leading me to blame my odd gait on these accidents. A tremor started in my pinkie, which I brushed off as nerve damage. I even attributed my declining sense of smell to allergy treatments. Yet, I couldn't shake the feeling that Parkinson's was behind it all.

Finally, I noticed my arm no longer swinging when I walked, a hallmark of PD. Armed with this, I pushed to see a Movement Disorders Specialist. My diagnosis came in December 2023, a moment I thought I was



prepared for, but still, it brought me to tears. Unlike others who face the shock and uncertainty of Parkinson's, I knew too well what to expect. I was scared. The disease had already touched my life through family, and now, I would be the seventh to bear it.

Lucky number 7.

Eager to learn more, I dove into research. I joined the PDGeneration study at the University of Indiana, where I was tested for seven PD-related genes. Despite my family history, my tests came back negative. Stumped, I continued researching and found another potential link: exposure to TCE, a solvent and dry-cleaning chemical common in Milwaukee, where my family lived. My father, a dry cleaner himself, may have unknowingly exposed us all.

Ultimately, I realized that only 10-15% of PD cases are genetic, with the rest likely triggered by environmental factors. I felt a mix of relief and frustration; the mystery of Parkinson's felt bigger than ever. But through it all, I found hope.

My doctor recommended the LSVT BIG program, a four-week physical therapy regimen designed for people with PD. Thanks to this program, I felt empowered to take control of my future through exercise, the one proven method to slow the progression of PD.

Today, there's even more reason for hope. In July 2024, President Biden signed the National Plan to End Parkinson's, a bipartisan bill aimed at advancing research and improving lives for those with PD. (Contd. on pg. 13)



Deep Brain Stimulation (Contd.)

possible, maintain the activity restrictions, and rest, rest, rest.

My wife had a hard time keeping me inactive. However, I could tell that my brain was tired, and it was hard to focus on anything useful. The remainder of the recovery went very well and focused mainly on strength and endurance.

After six weeks, my neurologist activated the device. It was a two-hour process of setting and adjusting the device to a baseline setting. From this baseline, I am able, with my own control unit, to adjust and refine it until I can hopefully reach a sweet spot.

Glory Hallelujah, it is working and helping reduce and control tremors. It is not perfect and will not cure my advancing Parkinson's Disease, but I do now have the help of a proven, useful tool while living a somewhat more normal life.

Finally, every single day is one of thankfulness and gratitude for the mentoring I received from other DBS users, my entire neurological team, and Dr. Lake, who created an environment of positive direction toward what life with Parkinson's can be. With my tremors under control, I am more engaged, positive, and active once again.

Exercise Group (Contd.)

treadmill or with a simple conversation before or after the class, it blossomed into a beautiful friendship lasting many years.

From what I have learned, I could not recommend more than looking out for and joining some of these classes. Utilizing exercise groups is one of the best ways to improve quality of life, movement, and health while learning and building new relationships with others.

To find an exercise group near you, visit apdaparkinson.org/wi or talk to your physical therapist. You can contact Dr. Mattioda's office by calling 608-316-9744 to join.

Lucky #7 (Contd.)

I am grateful to be living in a time when people are advocating for change. Organizations like the APDA are working tirelessly, and we now have programs, resources, and support that my relatives never had. While my future might not look the way I once imagined, I know that positive change is coming for those of us with Parkinson's. We have new paths to explore, tools to slow our symptoms, and a community of dedicated advocates supporting us. And that is something worth believing in.

Check out these fun pictures from the positive local PD community.

Theses Rock Steady Boxers in Fitchburg got into the Halloween spirit!

Thanks to Patti Batt for sharing these images and leading such a great group!





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Disclaimer: The information and references contained herein concerning research being done in the field of Parkinson's disease and related disorders are solely for the informational use of the reader. It should not be used for treatment purposes, either for it or in conjunction with the patient's physician.



Project support provided by Wispact, Inc.

Don't forget to check out www.apdaparkinson.org/events for a calendar of virtual events that you can access from your computer. These include educational webinars, exercise classes, Sing Loud, and much more!

Do you want to submit an article for the next newsletter? We'd love to hear your story. Please email us for more details.

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