



**MICHIGAN
PARKINSON
FOUNDATION**
Helping Families Since 1983

MESSENGER



SUMMER
2023

Hello MPF Community!

I hope everyone is well and enjoying the Michigan summer! It's been a busy one here at the Michigan Parkinson Foundation. In addition to the programming we've had all around the state, Social Worker, Stephanie Woznak, delivered presentations throughout the Upper Peninsula over more than a week's time, the newest member of our team, Angee Ludwa, and I attended the World Parkinson Congress in Spain, we hosted a wonderful Support Group Facilitator Summit in Mount Pleasant welcoming more than 70 facilitators and guests, and we've just kicked off our first Walk of the season on August 12 in Traverse City.

In addition to all of this exciting work, I'm happy to announce that we have finalized our new Michigan Parkinson Foundation logo and have redesigned and updated our website. In this new logo, we aimed to give a geographical representation of the state that we serve, while also showing helping hands reaching for one another.



**Michigan
Parkinson
Foundation**



The colors give a further nod to the blues in Michigan's Great Lakes. As you can see, these themes flowed into the Walk logo, which brought back to its original form of two feet making a heart, but adding a new name. Our Walks will now be known as the *Parkinson Hero Walks* to honor all those that are courageously fighting PD each and every day—from individuals with the disease, to care partners, to the health care community and beyond.

Just after Labor Day, I encourage you to visit our new website—same web address, same great information, but with a new look: www.parkinsonsmi.org. Our goal was to keep the website bright, the information easily accessible, and the opportunity to connect with us ever-present. Once it launches, you'll see a "contact us" form at the bottom of each of the main

pages. We want to give everyone the opportunity to reach out and engage with us. We know, however, that change can be difficult and we want to make sure that you can find the information that you need. I will be doing a tutorial on September 5 showing the ins and outs of the website which will be recorded on our YouTube channel along with all of our other education and exercise programs.

Please feel free to reach out to us at any time with any questions regarding the website—we want to make sure it's serving YOU effectively!

I am so grateful for this wonderful community and I hope to see you at one of our many fall events!

Sincerely,

Kristin Don

My Deep Brain Stimulation Journey

By Stevel Lonsbury

Follow Steve Lonsbury's individual journey with Deep Brain Stimulation (DBS). This experience was so life-changing for Steve and his family, they wanted to share in hopes that others might consider if the procedure is right for them. Steve has also recently become one of the first mentors in our mentorship program and will be happy to talk to mentees more in-depth about his experience.

My Deep Brain Stimulator (DBS) story began in June 2020: June 9, 19 and 29. On those dates, I underwent three surgeries to have a DBS implanted into my body. It is similar to a cardiac pacemaker, except it sends electrical shocks to my brain, not my heart.

The benefits of said stimulator are relief from some symptoms of Parkinson's Disease (PD) with which I was diagnosed in September 2009 — tremors, bradykinesia (slowness of movement), and rigidity/stiffness. Also, if successful, I would be able to reduce my medication. However, I suffered horribly from a freezing gait issue, and the DBS system doesn't address gait issues necessarily.

The best description was that the DBS system would act like an electric Sinemet generator. Sinemet (levodopa and carbidopa) is the man-made, pharmacological form of dopamine (chemically healthy brains generate sufficiently, but people with PD don't).

My journey began on June 9 with, what I call, the building of Frankenstein. The first step in the process was to insert screws into my skull and to take a picture of it with an MRI so they could be sure that I looked exactly like Frankenstein...in ten days. After the outpatient surgery, I found the recovery to be most painful, yet I only took an NSAID.

Next, June 19, was the open brain, insert electrical circuitry part of the journey. Once the screws healed, I had another MRI to ensure I looked like you-know-who. Then my surgeon placed two leads, essentially coated wires with openings cut in predetermined locations, in the right and the left sides of my brain, to improve the function of the opposite sides of my body. My experienced surgeon deftly located the correct spots for the leads right away. The last step was to connect the wiring to the leads, and tuck the wiring under my skin behind my ear for the future connection to the brains (pun intended) of the system, the neurogenerator. Then the incision was sutured. I returned home to recover the next day and prepare for the final surgery in (you guessed it) 10 days.

Finally, on June 29, the system was connected. Now with my Halloween costume complete, the final surgery was to place the neurogenerator under the skin in my chest and attach the pieces of my three-piece-brain puzzle. Beware the 'boring' tool.. they don't call it that because it is named after my 7th grade English teacher (honest, that was her name). A subcutaneous tunnel was bored from behind my ear down the neck to the neurogenerator to complete the circuit.

Phew, with the surgeries complete, I had to wait roughly two weeks to turn it on.

Currently, they are offering a single surgery of a longer duration instead of the three I experienced. This all-in, one-time surgery still includes the option of being awake during the equivalent of the second procedure. If you completely trust your neurologist and surgeon (as I did, do, and always will) and think you can stomach being awake while they are actively electrifying your brain, I promise you won't regret it. I found it to be the most fascinating experience in my life! But then, I find doing my taxes exciting. Anyway, I wasn't in pain and was able to communicate with my neurologist as I watched him 'tune in' the system after locating the electrical leads by testing my arms and legs for rigidity (again, no pain) and listening as I endlessly repeated a key phrase about 6,000 times ..."today is a sunny day." And oh, what a sunny day it was!

During the surgery, I didn't want to miss an opportunity to make another request of my team, so I asked if they could fix the slice in my golf game. Of course, of all the neurosurgeons, mine didn't play golf.

Then came mid-July — turning the system on. The big moment arrived; my neurologist turned it all on (via Bluetooth), and voila! Frankenstein lives! My wife and I watched as he adjusted the frequency, amplitude, and other electrical settings, and within minutes, we watched as the tremors slowly melted away! Tears welled up in my eyes as I rose from my chair and walked—without freezing once—right out the door.



From left to right: Steve Lonsbury, wife Heather, son Gabriel and daughter Grace.

My story doesn't end here, though. With the DBS implanted, my doctor told me the battery life in my neurogenerator would last some 3-5 years. My good friends, Garth Toddner and Toni Nunnabot, confirmed this as each had similar systems before mine, and their batteries each lasted three years. My neurologist, however, estimated that mine would probably need replacing sooner as it had been set to "plaid" speed, not just "ludicrous" speed!²

On the day before Thanksgiving, November 23, 2022 (less than 2 1/2 years later), the iPod I used to monitor my neurogenerator indicated in yellow (and with an exclamation point, no less) that I should replace the battery. So, I diligently called and scheduled my replacement surgery for December 23. That turned out to be a huge mistake as that became the morning after 'the blizzard of the generation,' and we had a 75-mile drive to the hospital. After speaking with my favorite surgery scheduler and against my wise wife's advice, I asked to delay it for a week until December 30. Of course, my wife was correct in her concerns as my neurogenerator went completely kaput the next day, Christmas Eve. I knew this because my iPod wouldn't even connect with the neurogenerator yet put forth the image of a robot stating, "Danger Will Robinson, Danger!"³ The neurology offices were closed for the Christmas holiday on Monday, December 26, so I was on the phone with my favorite surgery scheduler again on Tuesday morning. Miracle of miracles, they had an opening the following day, so we jumped at it.

Let me attempt to paint a picture of the four days between Christmas Eve and the thrice-rescheduled day of surgery. My neurogenerator had failed entirely, and subsequently, my condition worsened steadily as my brain wasn't cranking out enough dopamine. No matter how many Sinemet pills I gobbled, the tremors, bradykinesia, and rigidity were taking over. The only relief I found was when I slept because, for some reason, PD symptoms disappear when I sleep, praise God. Then, of course, finding sleep became very difficult. I found peaceful slumber only after constant petting and stroking from my endlessly patient wife. Finally, in the early morning hours on the day of surgery, my wife's alarm went off, but alas, I couldn't get out of bed as the "dastardly three" had overwhelmed my body. I felt the genuine impact of PD for the first time since my diagnosis some 13 years earlier. I knew PD was capable of all of this, but until that moment, I suppose I didn't think it would happen to me. I cannot describe the despair and anger I felt lying there, hopelessly unable to move. Were it not for my wife (you know, the one I love beyond words), I would still be lying there; I wouldn't have been able to dress, feed, medicate, or toilet myself.

Then the doubts began to creep in. What if my neurosurgeon couldn't turn on the new neurogenerator right away? On a scarier level, what if the DBS didn't function as well as I had previously experienced? After all, my symptoms had progressed over the last 2.5 years. Would the DBS be able to keep up? The previous four days had been unbearable, and I wondered how many more of them I could endure. A lot was riding on the new neurogenerator's success, and it delivered!

After returning home later after surgery, we stopped at a breakfast restaurant because after fasting for 12 hours, what sounds better than runny eggs, bland coffee, and stale toast? A friend told me that I would experience dyskinesias (uncontrolled body movements) immediately following DBS surgery. Dyskinesias are caused by an overabundance of dopamine in my system resulting from my newly installed DBS unit and all of the Sinemet I had ingested leading up to the surgery. I recalled experiencing this phenomenon after the original implantation, and lo and behold, I was fortunate to feel it again.

Steve's Journey (continued)

Upon returning to our home and following instructions from my utopian wife, I went to bed to nap. But a nap was not in my future as an epiphany hit. I could only lay there, dog at my side, sobbing like I had never done before. I suddenly understood the wave of emotions that Ebenezer Scrooge experienced as he gleefully repeated, "I don't deserve to be this happy." I had been given not one but TWO opportunities for redemption in my life! The significance of the first I had minimized and attributed to the marvels of modern science. But the second has stricken me so powerfully that I feel compelled to share my story in hopes that I may encourage someone to consider the contemporary miracle of DBS!

I know the decision to have DBS surgery is very serious to those of us with PD, and I hope you don't think I have trivialized the life-altering DBS process through my trite attempts at humor. Keeping a sense of humor is necessary when you have PD (even if brain surgery is involved). I am ever thankful for my good health, strong family support, and the opportunity to live in an era where DBS exists — how I define my Hand of God. It is also my tribute to those who are truly doing God's work; all of the neurosurgeons, neurologists, PAs, nurses, anesthesiologists, support staff personnel, and all I have personally encountered throughout my journey. Finally, I cannot express how grateful I am to my wife and soulmate, whom I so wisely married 35 years ago, for she is truly my Hand of God!

References

2. *Spaceballz* (Movie), Mel Brooks, director, 1987.
3. *Lost in Space* (TV series), CBS, 1965-1968



New MPF Program: Mentorship

At MPF, we focus on 4 pillars of support: Community, Exercise, Education and Respite. These four pillars guide us in our programming and ensure that we're providing the support every age and stage of Parkinson's disease. The community pillar is broad reaching and is mostly aimed at socialization—making sure that no one feels isolated and alone in the shadows of Parkinson's disease. We support this pillar in many ways; through our 70 support groups throughout the state, in our outreach initiatives in the community, but we have been looking for a streamlined way to connect individuals based on their experiences with Parkinson's disease.

We are proud to announce that we will be launching a new program to address this need for individual connection in our new mentorship program. Starting in September, we will be launching

this program available through our website here under the Community pillar.

The program is set up so that anyone seeking a Parkinson's mentor, can visit our site to see a photo and bio of all of our mentees and fill out a form to connect with them directly. All communication will happen between mentors and mentees. We'll have the following categories available for people (with more to unfold!)

- Individuals with Parkinson's
- Newly Diagnosed Individuals
- Care Partners
- Those who have had Deep Brain Stimulation (DBS)
- Veterans

We are very excited for our community to find one on one connections with one another! If you would like to sign up as a mentor, please contact Volunteer Coordinator, Rita at rdachs@Parkinsonsmi.org.

Pain in Parkinson's Disease: Prevalent Yet Poorly Understood

By Michael D. Staudt, MD, MSc

Defining Pain in Parkinson's Disease

Parkinson's disease (PD) is generally thought of as a disorder of movement, characterized by tremor, slowness or bradykinesia, and stiffness or rigidity. Perhaps equally as important are the non-motor symptoms, which are diverse and can include sleep and mood disturbances, fatigue, difficulties with attention and memory, and pain, among others. Pain in PD is frequently overlooked and poorly understood but is present in up to 80% of patients with PD (Beiske et al., 2009). In his landmark monograph, James Parkinson described pain as an early sign of disease, and a symptom that was prevalent in numerous cases (Parkinson, 1817).

One of the main challenges in diagnosing and treating pain in PD is to recognize that there are many different causes or "pain generators" (Valkovic et al., 2015). It is common to classify pain as:

- Musculoskeletal: cramping and aching sensations in the joints and muscles; exacerbated by postural changes, stiffness, and immobility
- Dystonic: pain generated contractions and twisting movements or postures; tends to be closely related to medication use as drug dosages wear off
- Radicular/neuropathic: "nerve-related" pain, typically caused by nerve compression and causing pain, numbness and/or weakness in a predictable distribution
- Central: burning and tingling pain that don't conform to a nerve root distribution; can occur independent of musculoskeletal or dystonic pain, and is presumed to be part of the PD disease process itself; can be associated with temperature changes and unusual pain in different organs
- Other: headaches, non-radicular low back pain, oral pain, genital pain

Treating Pain with Conventional Therapies

Painful symptoms tend to worsen in patients who are off medication and vary with motor fluctuations. Unsurprisingly, the first line of therapy is with dopamine



replacement drugs such as levodopa, although pain may not be adequately treated by these medications alone as the disease progresses. Deep brain stimulation (DBS) targeting either the subthalamic nucleus or globus pallidus has been demonstrated to improve pain in a variety of studies (Dellapina et al., 2012). It seems that the majority of improvement following DBS is seen in musculoskeletal and dystonic pain; as such, a major challenge is in understanding which types of pain are treated by DBS.

Because pain in PD is so diverse in both cause and presentation, it is difficult to assess it based on traditional measurements of pain (e.g., "rate your pain as a score between 1 and 10"). The King's Parkinson's Disease Pain Scale (KPDPS) was recently developed as a method of evaluating pain symptoms and the overall burden of pain in PD (Chaudhuri et al., 2015). As the causes and description of pain in PD tend to be derived from a clinical description, having a validated assessment measure will help improve both the diagnosis and study of pain in the future.

Interestingly, there also appears to be a sex-related difference in the non-motor symptoms of PD, with pain being more prevalent and more severe in women (Martinez-Martin et al., 2012). Furthermore, one recent study showed that, following DBS surgery, men reported greater improvements in musculoskeletal and chronic pain compared to women (Khazen et al., 2020). Such studies will help us consider what variables may have important implications for DBS in pain treatment moving forward.

What About Other Medications?

Overall, most patients with PD will treat pain with standard over-the-counter medications such as acetaminophen or nonsteroidal anti-inflammatory drugs (mostly ibuprofen), and with good effect (Buhmann et al., 2017). Anticonvulsants (gabapentin and pregabalin) and antidepressants (tricyclic antidepressants

Support Group Facilitator Spotlight

and serotonin (norepinephrine reuptake inhibitors) are commonly prescribed for nerve-related pain. Even opioid use is somewhat common; however, it is of the utmost concern to emphasize the risks of opioid therapy – short or long-term abuse can potentially lead to heart or lung damage or death. Any opioid use should be prescribed and monitored by an experienced practitioner.

Few studies have evaluated the use of specific drugs in the treatment of pain associated with PD. What are lacking are robust studies that provide “level I evidence”, which refer to studies that compare investigational drugs to placebo, randomize participants to receiving one drug or the other, and “blind” both participants and investigators to which drug is being received. Two recent studies met such criteria, looking at the effects of an extended-release opioid (Trenkwalder et al., 2015) or a transdermal dopamine patch (Rascol et al., 2016). Although neither study was able to demonstrate definitive success for the use of their respective drugs in the treatment of pain, some promising responses were seen that warrant further research in larger trials.

A Multimodal Approach

Ultimately, the approach to pain treatment in PD should be multimodal, meaning therapy should be approached from different angles and sometimes with multiple specialists. The importance of exercise and physical activity cannot be overemphasized. The judicious use of medications, both PD-related and others, can enhance pain control and work synergistically with routine physical activity. In some cases, a referral to a surgical specialist may be necessary. Work with your primary care physician or neurologist to come up with the best individualized treatment plan for your needs.

- Musculoskeletal: physical and occupational therapy, exercise, acetaminophen or nonsteroidal anti-inflammatory drugs, referral to rheumatologist and orthopedic surgery, if necessary, deep brain stimulation
- Dystonic: optimize dopamine medications, consider Botox injections, deep brain stimulation
- Radicular/neuropathic: physical and occupational therapy, exercise, neuropathic pain medications (anticonvulsants, antidepressants), spine surgery, if necessary, consideration for spinal cord stimulation
- Central: optimize dopamine medications, neuropathic pain medications (anticonvulsants, antidepressants), deep brain stimulation

The Michigan Parkinson Foundation would like to recognize one of our most dedicated and longest standing Support Group Facilitators, Hettie Molvang. A nurse by training (first trained during World War II in England), a natural teacher, and a care partner for her late husband for many years, Hettie has been an unwavering beacon of help and hope for the Parkinson’s community in Northern Michigan for several decades. As a leader of the non-profit, Parkinson’s Network North, Hettie has helped thousands of people through their Parkinson’s journey.



Hettie singing at her coronation

This year, we honor Hettie’s incredible service through the aforementioned “coronation” at the facilitator summit—a surprise that the facilitators and MPF staff came up with. It was wonderful to watch Hettie walk into the room filled with more than 70 of her peers applauding her efforts while Marilyn Bernthal, Virginia Buggia and Kathy Freeland lead us in “God Save the Queen” followed by one of Hettie’s favorites; “Yankee Doodle.” This was only fitting as Hettie loves music and incorporates song into vocalization exercises for people with Parkinson’s—something that truly brings joy into every room Hettie steps into.

We at MPF also started the Hettie Molvang Educational Fund for Northern Michigan Programming. This will ensure Hettie’s name, vision, and support will live on in perpetuity.

Hettie, you have been a wonderful partner, collaborator and friend over many years. We thank you and we commend your storied and continued vocation to the PD community.

MPF Support Group Facilitator Summit: A Royally Good Time!

Our more than 70 facilitators throughout the state of Michigan work so hard for their communities all year round. MPF is proud to be able to honor these wonderful leaders each year at our Support Group Facilitator Summit in Mt. Pleasant, MI. In our two days together, our goal at this event is threefold: celebration, appreciation, and shared knowledge.

Celebration was in the air from the royal 'coronation' honoring long-time leader (and native Brit), Hettie Molvang (Traverse City Support Group), to the dancing on day two lead by MPF exercise instructor



Honoring Legacy Leader, Carole Briggs



Tai Chi fun on the final day of the summit

and support group leader, Jamie Haines (Mt. Pleasant Support Group). Appreciation was our main goal in honoring our new and legacy leaders throughout the summit, and we hope our gratitude was felt far and wide. We were able to award Hettie and Carole Briggs (Jackson Support Group) as two of our legacy support group facilitators, and some of our newest leaders like Shelby Budzeak (Chesterfield Support Group). The shared knowledge of this group of leaders is



The Coronation of Hettie Molvang



Support Group Summit Gathering

abundant. It was wonderful to see the reuniting of friends, resources shared across the state and late-night bonfire conversations on struggles and victories. We already can't wait for next year's event on July 17 and 18 in Mt. Pleasant!

If you're interested in joining a support group, or becoming a support group leader in your area, please contact Stephanie Woznak at stephaniew@parkinsonsmi.org or 248-419-7170.

Michigan on the Move! Parkinson Hero Walks Commence



Top Team Joliff at last year's Metro Detroit Walk



The Parkinson's community is special to say the least, and we recognize that it can take an entire team to manage this disease. In honor of all who are part of that team valiantly fighting Parkinson's every day, we are thrilled to announce that the

walks will now be referred to as the...Parkinson Hero Walks!

For individuals with Parkinson's, to care partners, healthcare professionals, family, friends, and loved ones: you are all our heroes. We will work to recognize you and honor your courage in facing this disease every day.

If you haven't already, start a team and encourage friends and family to join! This will be a special, fun time for the whole family and together we can make a real difference for the 35,000 individuals (heroes!) with Parkinson's in Michigan and their families. Funds we raise will support Michigan Parkinson Foundation's critical programs and services like respite care assistance, daily exercise classes, education, and more!

Special shout-out to the top teams as of August 2. We encourage friendly competition—feel free to catch up with these amazing team leaders! YOU could be next!

Traverse City Walk August 12, 2023

at Civic Center in Traverse City, MI

First Place – Leelanau County

Parkinson's Warriors **\$9,010**

Team Captain: *Torrey Davenport*

Metro Detroit Walk September 23, 2023

at Jimmy Johns Field in Utica, MI

First Place – Team Joliff **\$20,678**

Team Captain: *Nate Joliff*

Lansing Walk September 30, 2023

at People's Park (MSU Campus)
in East Lansing, MI

First Place – Team TNT Dynamite . . **\$2,325**

Team Captain: *Toni Talbot*

Grand Rapids Walk October 14, 2023

at Frederik Meijer Gardens & Sculpture Park

First Place – Rock Steady Fighters

. **\$4,930**

Team Captain: *Amy Hooyer* who had a very successful Garage Sale fundraiser event

raising **\$1,917**



A special shout out to our Parkinson Hero Honorees! These are individuals who truly exemplify what it means to be a hero, courageously fighting Parkinson's every day and working to lift others up while they do!



Traverse City:
Gary Dennis,
Parkinson Hero Honoree



Metro Detroit:
Tim Dougan,
Parkinson Hero Honoree



Metro Detroit:
Dr. Aaron Ellenbogen,
Medical Hero Honoree



Grand Rapids:
Dr. Danette Taylor
Medical Hero Honoree



Grand Rapids:
Renee Orr,
Parkinson Hero Honoree



Lansing:
Carla Morggenborg,
Parkinson Hero Honoree



Lansing:
Kelli Brumbaugh,
Community Advocate Honoree



Virtual Education Series

Monday, September 11, 1 pm.,

Veterans and Parkinson's Disease Disability
Laura Rios, MSgt, USAF (Ret)
Chief Veteran Services Officer,
Macomb County Veteran Services

Tuesday, September 19, 7:00 p.m.,

Get Back to More Green Lights: What to Do When Levodopa Stops Providing Consistent Symptom Benefit. Aaron Ellenbogen, DO, MP. Sponsored by Supernus Pharmaceuticals

Tuesday, October 17, 7:00 pm

Moving Forward: Discovering a Treatment Option for Advanced Parkinson's Disease. Presented by Julie A. Burnham, DO, Michigan Neurology PLLC, Mr. Clemens, MI Sponsored by Abbvie.

Tuesday, November 14, 7:00 p.m.,

Amneal Pharmaceuticals (TBD)

Tuesday, November 21, 7:00 p.m.

Adaptive Wear. Patrick Hoag, LMSW
University of Michigan

Tuesday, December 19, 7:00 p.m.,

Holiday Coping. Laurie Boore-Clor, MD
Henry Ford Health.

Welcome new staff member: Angee Ludwa

I am very excited to join the team at the Michigan Parkinson's Foundation as the new Director of Exercise. Many of you know me as the Tuesday exercise instructor on Zoom, which I love and have been doing for 3 years! Prior to this new role, I worked in an outpatient neuro clinic and treated people who had PD one on one. I met so many amazing people throughout the years and felt like I had a real impact on their lives. I know in this new role I will continue to meet even more amazing people and have an even bigger impact on those living with PD in Michigan.

Our goal is to continue to provide free exercise classes and hopefully expand those class offerings to in-person classes throughout the state, with special concentration on communities with less access to exercise.

Many people have asked me how I became involved with the Parkinson's community. It started about 20 years ago when I was working at Beaumont hospital as a physical therapist and had a wonderful mentor who pulled me under her wing and introduced me to working with people with Parkinson's. I never looked back and knew this was my passion. Then, 3 years ago, it became even more personal when my mom was diagnosed with PD. I went from health care provider to care partner which is a very different role. Having a loved one with Parkinson's has given me a new perspective and level of understanding of what it takes to provide the best care possible.



I look forward to helping the Michigan Parkinson Foundation grow and expand our exercise programs which will directly impact the lives of those living with Parkinson's.

All About Angee

Angee Ludwa has been practicing as a physical therapist for 25 years and has spent the past 16 years following her passion: helping people with Parkinson's disease live every day to their fullest. She teaches exercise classes for people with Parkinson's at Ascension Genesys Health Club. Angee is the person who brought the idea of virtual exercise classes to the Michigan Parkinson Foundation during the pandemic. Out of her concern that people with Parkinson's would become more isolated and sedentary during lockdown, these enriching classes were born. She has been actively involved in Michigan Parkinson foundation programs and events for many years and serves as an ambassador for the Davis Phinney Foundation. Angee is incredibly active in the local community supporting fundraisers and speaking at events to help grow awareness about Parkinson's disease. She loves teaching the virtual exercise classes for the MPF and has met many wonderful people across the state.

Angee also has a very personal connection to Parkinson's in her mother. When she's not teaching or working with patients, Angee likes to stay active with her husband and three boys.

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World Parkinson Congress Barcelona 2023

Michigan Parkinson Foundation CEO, Kristin Rossi, and Director of Exercise, Angee Ludwa were the lucky representatives for the World Parkinson's Congress in Barcelona, Spain in July. This conference happens only every three years and had been previously delayed due to Covid-19. Both representatives found themselves reeling by the end of the conference—there was so much information shared and connections made across the globe. Here are each of their three takeaways from the conference, but check out the Virtual Education Series program they did on July 25 along with representatives from Parkinson's Association of West Michigan here: <https://www.youtube.com/watch?v=hr3SnG1BgzA&t=2s>

Angee

1. Dr. Bastiaan Bloem and his talk about the importance of tracking symptoms and why it will help over time was really interesting to me. He was such a dynamic speaker, and the message was great!
2. Exercise, of course! Currently exercise is the only medicine that can slow the disease. Which exercise is the best investment is always a topic of conversation. The best takeaway is to find something you love to do and keep it up—whether that's PWR! Moves, Boxing, Yoga or Ping Pong.
3. I felt an incredible amount of hope for the future from this World Parkinson Congress. In particular with regards to current research and highlighting a few lectures from Dr. Georgina Aldrige and Dr. Ashley Harris—check out our talk on YouTube to learn more!



Members of the Independent Parkinson Network Meet at Congress



Kristin Rossi, Ben Rossi from InMotion, and Angee Ludwa

Kristin

1. I loved the session on the environmental contributions to Parkinson's disease. The presenters, in particular Ray Dorsey co-author of *Ending Parkinson's Disease*, did an amazing job outlining the environmental toxins putting us at greatest risk for Parkinson's disease and motivating everyone in the room to advocate for better, safer handling of these toxins.
2. Cutting edge technology was really interesting as well. There was so much here on wearables and virtual reality used for clinical trials, but I found the presentation from the founder of Emerald Innovations/Dina Katabi to be very interesting: <https://emeraldinno.com/science/> and am eager to hear more about this technology.
3. Parkinson's as a multi-system disorder by Iracema Leroi from Ireland was really insightful. She talked a lot about the importance of addressing some of the Parkinson's symptoms that often fly under the radar such as apathy, depression, anxiety, and disordered sleeping. She talked a lot about treating them with the same level of care that we do many of the more outwardly obvious motor symptoms. This talk alone has spurred so many ideas for future education programs and discussions, some of which are already in the works!



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MPF provides the following services to those with Parkinson's and their families:

- More than 73 Affiliated Support Groups • Medication Assistance • Information Literature • Exercise Programs
- Subsidized Respite Care • Neurologist & Community Referral • Education Programs • Advocacy

Consult your medical providers before acting on information in newsletter articles. This MPF publication offers information intended to be useful to people with Parkinson's, their caregivers and families, and the professionals who assist them, but they are not a substitute for qualified medical advice.

YOUR GENEROSITY IS GREATLY APPRECIATED. PLEASE HELP US NOW! No matter how large or how small, every donation helps. Return to MPF, 30400 Telegraph Road, Suite 150, Bingham Farms, MI 48025, or donate on-line at www.parkinsonsmi.org



Yes I want to help!



PLEASE SEND INFORMATION ON:

- How I can become an exclusive member of the Michigan Parkinson Foundations **CLUB 500**
- Parkinson's Disease

Enclosed is my gift of \$ _____

Visa Mastercard Discover Amex

Account # _____ exp. _____

Card Security Code: _____

Last 3 digits on back of card (4-digits on front of AMEX)

In Memory of _____

In Honor of _____

Special Occasion of _____

Please notify the following person of my gift:

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- How I might make a gift to MPF in my will, life insurance or other special means which may have tax advantages.

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