

Community for the Journey -- June 2025

#### PANC SUPPORT GROUPS HERE

Welcome to new PANC Affiliated Support Groups in Penn Valley and two Veterans groups. If you would like to facilitate a group in your area, PANC can help. Contact Jen Westoby here if interested.

"Summer afternoon, summer afternoon; to me those have always been the two most beautiful words in the English language." – *Henry James* 

### **Unexpected Joy**

by Kat Hill

I was diagnosed with Young Onset Parkinson's Disease (YOPD) at the age of 48. I was at the pinnacle of my career, the Director of a Midwifery group practicing in a large inner-city hospital in Portland, Oregon. I had cared for thousands of families and had delivered nearly 800 babies. I felt blindsided and run off course. With the help of my husband, Ken, and my



health care team, I decided that leaving my high stress, long and unpredictable hours job was the best choice for our family and my patients.

After several months of regular sleep, exercise and clean eating, I found that I was feeling better. I still had tremor and fatigue but was learning tools to manage my new normal. I mourned the loss of my career and identity as a health care provider, and I also knew that to optimize feeling well and not focus on disease I must continue to manage stress. It was a scary and uncertain time with two children in college and one at home in high school. Ken and I had to rethink our plans for the future and spent months brainstorming how to navigate our new and unexpected reality. True to our value of open dialogue, during one of our many conversations about next steps we remembered our shared dream about traveling across the US in a travel trailer. Kindly, Ken chuckled and said, "I don't think we can do that, can we?" I said, "I think we can."

It was 2020 and the world was shifting with the COVID pandemic. Everyone was working from home and our youngest had graduated high school. Everyone was having to get creative about how to live which helped us lean into our dream. We decided to make the leap of faith. We started to sell and give away our belongings and ready our family home of 17 years for sale. It took us over a year to sell the house and whittle our belonging down to 22 boxes, a guitar and a saxophone. Our adult children cheered us on as we celebrated our last family Christmas in our house. Many friends and family thought we were crazy, others offered words of encouragement. We trusted ourselves, however, and with my diagnosis, knew that the window of time to act on our dream may be closing sooner rather than later. We did not know how long we would choose to live and travel, and it was part of the adventure to be open to all the possibilities.

We moved into our home on wheels in May of 2022 and spent the following 22 months traveling coast to coast with a truck and trailer. Planning our travel to follow the moderate temperatures whenever possible. We visited National Parks, swam in the Pacific and Atlantic oceans, dodged two tornadoes and an unexpected hailstorm. We visited family and friends, learned about boondocking, Hip Camp and Harvest Hosts. We camped on two Alpaca Farms, several wineries and beautiful lakes. We visited farmer's markets and found the best local ice cream shops.

We learned more than we expected about ourselves, our marriage and about LIVING with Parkinson's disease. We cherished feeling free and realized the work of tending to the inventory of a house. We learned how few "things" we needed to live and thrive. We learned about finding reliable internet while traveling and about access to services in under resourced areas. We learned that people everywhere have more in common than not.

We also learned about how we wanted to live after life on the road. After a while, we started to miss the cadence and comfort of knowing a local market, having our own laundry

facilities and having the predictability of a single address. As year two approached I was ready for the privacy of a bedroom door and missed living near our children. We learned that life on the road takes a lot of careful planning and a great deal of flexibility to adapt to changes in weather and road conditions. It was a huge, unexpected gift to learn gratitude for many things that we had taken for granted living in a house.

We returned to our roots in the Portland Oregon area after our travels and bought a singlestory home. We have our beloved spud parked on land we share with friends about a ninety-minute drive away in the Columbia Gorge. We split our time between the two.

I am grateful we are still happily married and continue to learn about limits and adaptations as we age. We continue to nurture the values learned on the road -communication, flexibility and mindful consumption. I am, forever grateful that we took the leap of faith and fulfilled our dream. The catalyst for the leap of faith was a direct result of my unexpected diagnosis.

I look forward to speaking and meeting you at the PANC conference in October and sharing my experience in living my best life with Parkinson's. See you there!



### PANC Conference Registration begins July 15 In-person (includes lunch) Farly-bird rate is \$40

In-person (includes lunch) Early-bird rate is \$40 Zoom Early-bird rate is \$25

Sponsor and Exhibitor Opportunities Here



### Vision Challenges with Parkinson's

by Alyson K Chew, OTD/S '25

When people think of Parkinson's disease (PD) one of the first things that may come to mind are physical motor symptoms such

as tremors, freezing gait, and decreased range of motion. However, there is less awareness of the potential visual impairments as PD progresses. Vision is perhaps one of the most acute senses that impacts every aspect of your daily life. Visual deficits associated with PD may include dry eyes, blurriness, double vision, abnormal saccades (rapid, jerky eye movements), difficulties with perception and identifying contrasts.

Impaired vision can increase your risk of falling because you may not visually see things clearly or accurately and your depth perception may be affected. An example of this could involve stepping up/down a street curb or climbing stairs. Misgauging the depth or height of a stair or curb can lead to stumbling and result in bad falls. Some home adaptations to address these barriers can be as easy as adding floor stripes to mark steps and using sensor nightlights to ensure the room has sufficient light to navigate safely.

The combination of Parkinson's motor impairments along with visual deficits can limit one's ability to participate in meaningful and productive daily activities. This can often feel limiting and isolating when an individual loses their sense of independence, thus relying on others to accomplish tasks. This can vary significantly between basic self-care tasks to impacting hobbies such as gardening, cooking, and painting. Self-care tasks like going to the bathroom, taking a shower, and cooking your own meals can be affected when vision becomes impaired. This can lead to decreased independence and increased reliance on others.

It's important that caregivers and people with PD understand the symptoms and impacts that can occur and are encouraged to be proactive and schedule routine eye exams with an ophthalmologist. Optometrists focus on primary eye care, while ophthalmologists have specialized training in diagnosing and treating various eye diseases. With early intervention

these potential challenges can be mitigated by being proactive instead of reactive, leading to a more autonomous life.

# Last one is this week! ParkinsonWISE® for Care Partners

### Register and for Information Click Here Flyer Click Here

Citrus Heights on June 19



It's the last one! If you'd like to join in this no-cost class with tips to help your loved one live well with Parkinson's, this week is your chance. Click here for the flyer and registration information.



### Comedy in the Barn Benefits PANC

The Comedy in the Barn event was hosted at the barn/theater of Kevin and Morgan McDonald of McDonald Real estate and raised just about \$5,000 for PANC. A good time was had by all!

The featured comedian, Joseph "JoeyC" Crespillo, is a person with Parkinson's and found his voice and a freedom by laughing at his imperfections and all things absurdly PD. Laughter really is the best medicine.

A sincere thank you to Joey (pictured) and all of the talented comedians who donated their time along with sponsors Tri Counties Bank, McDonald Real Estate (Kevin pictured above), Chim Chimney's (Jerry pictured above), Cal Pro, and Auburn Moving. Your support of PANC's constituents and services is very much appreciated!





## Potential Benefits of Acupuncture for PD

At a recent Lincoln Support Group meeting, member Mark Hyjek mentioned that acupuncture has been a wonderful complimentary healing modality for him and his Parkinson's symptoms. While conventional treatments like medication and physical therapy remain the cornerstone of management for Parkinson's disease (PD), many patients like Mark are turning

to complementary therapies such as acupuncture to support their overall well-being.

Acupuncture, a traditional Chinese medicine practice, involves inserting thin needles into specific points on the body to restore balance and promote natural healing. In the context of PD, acupuncture may offer several potential benefits:

- 1. Improved Motor Symptoms: Some studies suggest acupuncture may help reduce tremors and improve muscle stiffness by modulating the central nervous system and enhancing dopamine release—the neurotransmitter that is deficient in PD patients.
- 2. Reduction in Non-Motor Symptoms: PD is often accompanied by symptoms like insomnia, depression, fatigue, and constipation. Acupuncture may help regulate mood, improve sleep quality, and support digestive function, contributing to a better quality of life.
- 3. Neuroprotective Effects: Preliminary research indicates that acupuncture might offer neuroprotective benefits, potentially slowing the progression of neuronal damage. While more research is needed, animal studies have shown promising results in reducing oxidative stress and inflammation in the brain.
- 4. Enhanced Medication Efficacy: Acupuncture may complement traditional medications by improving their effectiveness or reducing side effects like nausea and dry mouth, especially in patients taking levodopa.

Mark shared the following about his journey with acupuncture. "Myfirst experience with acupuncture was very enjoyable and therapeutic. I am not sure what my expectations were exactly, but I was very pleasantly surprised. The primary symptoms I was experiencing were lack of balance, freezing of motion, rigidity, awkward gait, and slowness of movement. The central portion of my body was the primary location of the feelings (or lack thereof); it felt like I had a weight belt around my midsection and my legs were lacking power."

He included, "I will tell you, without exaggeration, that the very next day after my first acupuncture session, my gait improved ever so slightly and my rigidity was lessened, again, ever so slightly, but still noticeable. Within a few weeks, I had follow-up treatments and with each one, the symptoms gradually and steadily decreased. Since the start of my treatments, I felt confident to begin medications to also address my symptoms and continue to be treated by an acupuncturist and that combined with the medication has resulted in my symptoms becoming very controlled and barely noticeable. I intend to continue doing both and am very thankful for each."

While acupuncture is not a cure for PD, it can be a valuable complementary therapy. By addressing both motor and non-motor symptoms, it offers a holistic approach to improving quality of life. Patients interested in acupuncture should consult their healthcare provider and seek treatment from a licensed acupuncture practitioner experienced in treating neurological disorders.

### Parkinson's Study Opportunity

What happens to muscle function in individuals with Parkinson's after exercise

This volunteer study opportunity looks at measuring leg (thigh) muscle function before and after an episode of exercise. This is not an exercise training study. Requires three visits over the course of 1 to 2 weeks with visits 2 and 3 scheduled 24-48 hours apart.

The tool utilized is simple neuromuscular electrical stimulation (nonpainful). Conducted at the University of the Pacific campuses in both Sacramento and Stockon. Contact study investigator Joy Williams, PT, DPT for more information and to schedule a brief call to see if you qualify at (209) 946-2397 or by email here.

Basic eligibility: PD at any stage or are a caregiver of a loved one with Parkinsons (we are looking to compare PD vs those without PD) or interested community members. Process: If you can straighten your knee from a seated position without help, no chronic heart, lung, or thyroid conditions, no DBS or other implanted metal, and you are willing to hold off on your regular exercise routine between testing days (1-2 weeks). Thank you!

#### **June Free Webinars**

Tuesday, June 17 at noon

Managing Stress with a Movement Disorder with PMD Alliance

Acute vs. chronic stress, how people with PD might be particularly affected by stress, how care partners are affected by stress, and techniques and strategies for dealing with it.

Info and Register Here

Tuesday, June 17 at 4pm

Adaptive Equipment: Meeting Your Needs to Maximize Your Independencewith the Maryland Association for Parkinson Support Info and Register Here

Wednesday, June 18 at 10am

**Tips for Daily Living: Easing Movement Challenges** with the Parkinson's Foundation Practical tools and strategies that can help you address the movement challenges that are common in PD.

Info and Register Here

Wednesday, June 18 at 11am

**Dr. Google, and How to Spot Parkinson's Misinformation** from Parkinson Canada Tips to help us sort through the myriad of PD information coming our way every day and separate fact from fiction.

Info and Register Here

Wednesday, June 18 at 11am

**Traveling with Parkinson's Disease** with the Parkinson Association of the Carolinas **Info and Register** 

Tuesday, June 24 at 11am

**Managing Driving with Parkinson's** with the American Parkinson Disease Association The importance of driving assessments – what they are, how they work, and where to find qualified providers. How PD can affect driving ability over time and the signs that it may be time to modify driving habits, as well as practical guidance for family members and loved ones on how to approach this delicate conversation with care, empathy, and respect.

Info and Register

Thursday, June 26 at 9am

**Building Your Best Parkinson's Care Team** with the Michael J Fox Foundation Hear from people living with Parkinson's, a care partner, a movement disorder specialist, a physical therapist and a speech language pathologist, to learn how each of them can contribute to a robust care team.

Info and Register

Friday, June 27 at 2:30pm

**Staying Upright: Fall Prevention Strategies** with the Parkinson Society of British Columbia Why individuals with PD are at increased risk of falling and share practical, evidence-based strategies to reduce that risk.

Info and Register

Thank you to Stanford Parkinson's Community Outreach for providing information in this section.

\* Contact Jan Whitney **here** if you are interested in placing a sponsor article in the *Update*.

www.panctoday.org
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