

Community for the Journey -- July 2025

## PANC SUPPORT GROUPS HERE

If you would like to facilitate a group in your area, PANC will help. Contact Jen Westoby here if interested.

"Deep summer is when laziness finds respectability." — Sam Keen



# PANC Conference Registration begins TODAY!

Saturday, October 18 from 8 to 3 pm Roebbelen Center, Roseville In-person (includes lunch) Early-bird -- \$40 Zoom Early-bird rate -- \$25



It's that time of year! PANC's popular annual education conference is coming soon! The theme this year is, "Attitude is Everything: Strategies for Success."

The cost to attend is just \$40 for in-person attendees (includes lunch) and \$25 for virtual attendees through September 30. The prices increase by \$10 on October 1. Tables near the stage can also be reserved for up to 8 people. Check out the website here for

#### additional information and to register. Share the event flyer here.

Learn from experts on strategies for optimal health and attitude when living with PD. Network with PD community friends and learn about products, services, and medications to support moving forward with courage and hope. The agenda for this year's event is:

- Approaches to Care Partnering
- Keynote Speaker Kat Hill
- Tailoring Speech & Swallow Techniques
- Movement Breaks
- GI/GU & Pelvic Health Strategies
- Psychology of Parkinson's: Living Well Today & Tomorrow
- Lunch & Vendor Tables
- Revisiting Dopamine
- Panel Discussion: Technology Advancements that Help
- Panel Discussion: Movement Disorder Neurologists Q&A

Sponsor and Exhibitor Opportunities Here

### Conference Register and Information Here

### **Dolores Weighs In**

by Robert J. Smith

Stop the presses! Yesterday, Dolores, our almost 4-yearold granddaughter took a good look at my mouth and the way I was uttering words. She then felt compelled to say, "You don't talk like that."

Sensing I needed support with her innocent comment, Patty, my wife and care provider, told Dolores, "That's grandpa's Parkinson's voice."



Leave it to Dodo (Dolores' current nickname) to depict an aspect of my progressive PD. My speech therapist gave me mouth exercises to help with enunciating words, but sometimes my PD voice just takes over. Goodbye to grandpa's "usual" voice and hello to drooling (when I really exert myself). Plus, sometimes I have long pauses before I can respond to the simplest question.

The good news is, I am in that sweet spot where I can empathize with Dolores' transition to becoming a fluent talker while I'm becoming LESS fluent. Yes, the same guy who nicknamed those two steps down to our sunroom as "Niagara Falls," is now being challenged by the same potentially hazardous steps just as Dodo is becoming a confident runner. Furthermore, my wife is WAY tired after a weekday spent communicating with, cleaning up after, and feeding Dodo. There's a simple reason for that, Patty and Dodo work much harder than I do. It now occurs to me that my hand tremors are the one part of me that just keeps humming right along (until my DBS neurosurgeon solves that problem later this year).

More good news, I feel like I'm getting better at sleeping during the night. I may have the cannabis industry and CBD gummies to thank for that. While we still need scientific proof of their efficacy, it's difficult for me not to like their business model which gives senior citizens a "wisdom discount" at the register. Score!

Today I bumped into another PD wall as I tried to make my famous potato salad, and I needed to take a break from cooking. When the alarm sounded to take my dose of Carbidopa-Levodopa, I was emboldened to try another idea from my speech therapist which is swallow the pills with a spoon of apple sauce. I'm happy to report her suggestion worked! Later on, I'll see how the potato salad tastes. For now, I'm enjoying the apple sauce!

### **New PANC Website Pages**

Thank you to Alyson (Aly) Chew, from the University of the Pacific who spent the summer doing her Occupational Therapy (OT) Capstone project with PANC. Aly was able to visit a number of PANC support groups with a presentation on fall prevention and about OT. She also added three new pages to the PANC website including her wonderful presentation, a plethora of adaptive equipment options, and about the various clinical and alternative medicine providers available for people with Parkinson's. Click below to see the new resources. All the best to Aly in her career as an OT!

- Occupational Therapy and Fall Prevention
- Adaptive Equipment
- About Clinical Providers



# The Importance of Networking with Others with Parkinson's

Living with Parkinson's disease can be challenging, but connecting with others who share the same journey can make a powerful difference. Networking with fellow

people with Parkinson's offers emotional support, practical advice, and a sense of community that is hard to find elsewhere.

One of the biggest benefits is emotional validation. Talking to someone who truly understands the ups and downs of the condition can ease feelings of isolation and anxiety. These connections remind individuals that they are not alone and that others face —and overcome—similar struggles every day.

Networking also opens the door to shared experiences and helpful tips. Whether it's managing symptoms, navigating medications, or finding the right healthcare providers, fellow patients often provide valuable insights that doctors may not always offer.

Support groups, online forums, and PANC conference attendance can also boost motivation and mental well-being. Seeing how others cope and thrive can inspire hope and encourage proactive self-care. Ultimately, networking with others who have Parkinson's builds a sense of solidarity, offering strength, empathy, and empowerment in the face of a complex condition.

# Finding Resilience When Care Partnering is Hard

by Lisa Mooney MSW, LCSW, UC Davis Health PANC Conference Speaker

Assisting and caring for a loved one with Parkinson's Disease can be HARD. The World Health Organization points to neurological conditions as one of the greatest threats to public health and the symptoms and disabilities associated with neurological conditions have a major impact on individuals, their families and caregivers and health care service use. These impacts can often lead to



emotional, physical, and financial distress for the entire family, especially care partners.

Changes and challenges of care partnering can include loss of self-identity, lower levels of self-esteem, anxiety, depression, isolation, stress, worry, not feeling in control of your life, financial strain, loss of employment and feelings of overwhelm. These feelings are normal, valid, and understood by other care partners.

A current concept in care partner communities is **resilience**. Resilience is a process and practice of utilizing positive thoughts, behaviors, and actions to adapt, adjust, and recover or heal in the face of adversity, trauma or stress in life.

How do you find resilience? Building resilience is the practice of learning coping strategies and effective stress management techniques to move forward from life stressors and/or life struggles. Practice involves self-reflection, personal growth and improvement, effort, and intentionality. Most importantly, resilience can be learned and developed overtime, by anyone!

Practicing resilience can benefit and improve various areas of life including:

- An ability to adapt and adjust to changes, new symptoms, etc.
- Managing stressful situations and helping others get through challenging times without adversely impacting you
- Communication with family, friends, medical team, and an ability to ask for help when needed
- Adjust and adapt to stress, disease progression, and challenges
- Minimize the feeling of frequent "crisis", feeling stuck or paralyzed by stressors
- Interpersonal connection with family, friends and a social connection with your support community
- Feeling a sense of control or empowerment even when things are hard knowing you will overcome and bounce back from the situation

The good news is that by reading this publication you are engaging in a positive and high resilience practice, so keep it up!

The comparison chart below shows what can be considered positive resilience practices and low resilience practices.

#### **High Resilience**

- Maintaining Social Connectedness
- Finding Joy and Gratitude
- · Positive Attitude
- Ability to relax and unwind
- Good quality sleep, feels rested, ready to take on day.
- · Energized for things to come
- Feel accomplished, confident

#### Low Resilience

- Withdrawing from family or friends, avoiding social settings
- Overwhelmed by everything
- Increasing sadness, crying, feelings of depression, anxiety or irritability out of your normal.
- Feeling stuck or paralyzed, not able to make decisions
- Scared to make "wrong" decision or do "wrong" thing
- Constant worry or self doubt
- · Fatigue, lack of motivation

Read part 2 of this article for resilience recommendations in the August Update

# We Need You! Tell Congress to Fund Scientific Breakthroughs

The Michael J. Fox Foundation for Parkinson's Research is calling on Congress to ensure that a robustly funded, collaborative National Institutes of Health (NIH) — the essential engine of medical progress and hope for millions of Americans — is a cornerstone of the nation's budget today and in the future.



**Your voice is essential!** Members of Congress will be debating the federal budget this summer. Now is the time to raise your voice and be heard. We need them to keep the Parkinson's research going!

Take action today by clicking here! Urge your lawmakers to protect and expand NIH funding for vital Parkinson's and brain disease research. You can also amplify your voice by attending a local town hall or event hosted by your members of Congress during the August congressional recess. Visit your members' websites or call their local offices for information about upcoming events.

Your voice does make a difference! Please visit MJFF's Action Center here to find more information, as well as advocacy tools and resources, or email the MJFF Public Policy team here at policy@michaeljfox.org with any questions.



# Participants Wanted Study to Reduce Motor Symptoms of PD

The ARISE study is evaluating a new oral medication called solengepras (CVN424) for

people with Parkinson's disease experiencing motor symptoms that aren't well-controlled. Solengepras is designed to target a different part of the brain than current solutions and minimize side effects caused by other dopamine therapies.

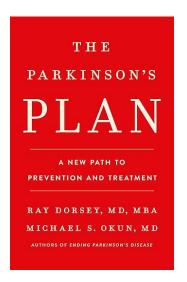
Sponsored by Cerevance, the study aims to assess whether solengepras can reduce "off" time (the time during the day when patients experience symptoms of slowness and difficulty moving) and improve "on" time without dyskinesia.

Lasting about 12 weeks, the Phase 3 study is enrolling individuals age 30+ who have been diagnosed with Parkinson's disease, experience at least three hours of daily "off" time, and are on stable Parkinson's medications. To learn about participation in the study, visit the ARISE trial website here.

#### The Parkinson's Plan Book

In *The Parkinson's Plan: A New Path to Prevention and Treatment,* Dr. Ray Dorsey and Dr. Micheal S. Okun report their findings on the cutting edge of Parkinson's research and detail the steps necessary to prevent, slow, and treat the condition.

They introduce the "Parkinson's 25," a detailed checklist to prevent and slow the progression of Parkinson's along with interviewing the world's top scientists, clinicians, and thought leaders in the field and offer a detailed plan for treatment and the latest technological and medical advances. Click here to learn more.



## **July Free Webinars**

Wednesday, July 16 at 10am

**Exploring the Possibility of Disease-Modifying Therapies** with the Parkinson Foundation There are no disease-modifying therapies available at this time, but researchers are excited about the potential of current studies to improve, slow or someday stop PD. **Info and Register Here** 

Wednesday, July 16 at 11am

The Silent Symptom: Apathy and Parkinson's with Parkinson's Canada

The causes and physical, social and mental health impacts of apathy on a person living with Parkinson's and the people who care about them. Includes management techniques, and when and how to seek professional help. A person with PD will also share his experience with apathy and management strategies that have worked for him.

Info and Register Here

Thursday, July 17 at 9am

**Finding the Right Tech Tools for Your Parkinson's Journey** with the Michael J Fox Foundation

Experts will discuss the kinds of tech options available for different Parkinson's needs and offer advice for picking the best tools to fit your life.

Info and Register Here

Friday, July 18 at 10am

**Live Fitness Friday - Gait Practice & Moving with Confidence** with the Parkinson's Foundation

Focuses on safe and mindful walking, with options for slow, quick, turning, and pivoting steps. Learn how to align your body and walk with greater ease across the floor. Have two folding chairs, a tennis ball, and a small object like a tissue box or water bottle. For all

levels; seated modifications available.

Info and Register Here

Monday, July 21 at noon

Nutritional Strategies in PD, Part I: Timing Is Everything - Protein Distribution & Parkinson's Meds with APDA Northwest

(This is part one of a four-part series (four Mondays in July and August, at 12pm). Please attend all four sessions. This is not meant to be a drop-in program as info in each class will build upon the other.)

Getting enough protein is important, but when you eat it matters, too. In this class, we'll look at how protein timing and spacing can impact the effectiveness of medications like levodopa. You'll learn how to adjust your meals to get the most out of your medication while still meeting your nutrition goals.

Info and Registration Here

Monday, July 28 at 10am

Cultivating Patience in Uncertainty with the Parkinson's Foundation

Develop tools to practice patience and accept what is beyond control. A session to nurture inner peace amidst the uncertainties of life with Parkinson's.

Info and Registration Here

Monday, July 28 at 4pm

**PD Caregivers: Unique Challenges and Approaches to Support** with the Maryland Association for Parkinson's Support

How and why caring for someone with Parkinson's Disease or Lewy Body Dementia is so different and challenging, compared to other conditions as well as recent studies that offer hope and what support is available now to help PD and LBD caregivers gain practical information and support.

Info and Registration Here

Tuesday, July 29 at noon

Parkinson's Dementia vs. Typical Age-Related Decline with PMD Alliance

A neurologist will explain the hallmarks of PD dementia and how to distinguish them from signs of typical age-related cognitive decline.

Info and Registration Here

Wednesday, July 30 at 11am

Climate, Weather, & Parkinson's Disease with the American Parkinson Disease Association The connection between climate and PD, including how geographic and climate-related factors might impact PD symptoms, why people with PD are more sensitive to temperature variability, and practical steps to effectively manage heat or cold sensitivity. Info and Registration Here

Wednesday, July 30 at noon

Late-Stage Lessons from PD to LBD with PMD Alliance

The stages of Parkinson's Disease (PD), including who the staging system misses, with particular attention to the needs of care partners and people who are homebound. The speaker will also share lessons that apply across the Parkinson's and Lewy Body Dementia (LBD) journey and discuss the care partner support study she's leading and how to participate.

Info and Register Here

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

Ways to Support

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