Building Community for the Journey -- May 2025

### PANC SUPPORT GROUPS HERE

"You cannot swim for new horizons until you have courage to lose sight of the shore." — William Faulkner

## THANK YOU PANC COMMUNITY!

A heartfelt thank you to all of our incredible donors. PANC received just over \$45,000 on this year's Big Day of Giving which included a \$20,000 match donation from the Hart Family of the Sacramento Region Community Fund and a \$5,000 gift from an anonymous angel.

Your generosity will translate directly into enhanced programs, respite grants, and other services for the NorCal Parkinson's community. Thank you, thank you! Your kindness will help many to have an improved tomorrow.



PANC Conference Registration begins July 15 In-person (includes lunch) Early-bird rate is \$40 Zoom Early-bird rate is \$25

# This DBS Candidate Has Been Cleared for Surgery!

by Robert J. Smith

The fact that DBS surgery is officially in my future, means two things. First, I got to meet both my neurosurgeon and a psychologist. Second, the healthcare acronyms in my vocabulary continue to grow! However, if DBS surgery can stop my hand tremors, I'm willing to learn as many acronyms as I need. By the way, the latest two include DBS (deep brain



stimulation) and MCI (mild cognitive impairment).

Speaking of MCI, what would you do if you took a series of mental health assessments and it is determined that you have "mild" cognitive impairment? For me, "mild" is a comforting word, so I thoroughly enjoyed hearing some positives from that visit. Here's how I described my Parkinson's disease memory gaps to her. "I have difficulty randomly accessing information from my brain. If questioners want answers from me, all they need to do is provide me with an answer list of four options. As long as the correct answer is amongst those four options, I'm very likely to find the correct one."

At the neurosurgeon's appointment for the DBS, we were reminded that the DBS device will not cure PD but should relieve my hand tremors. There are 25 people in line before me, but I hope to have my surgery by the end of the year. Some other great news from my neurosurgeon at Kaiser, in the 19 years that he's been working, he said that all DBS patients survived the surgery. The news just keeps getting better!

When I told friends that I wanted to become a candidate for DBS surgery, everyone seems to know SOMEBODY who has gone through that life changing experience. The only story that elicited a hearty laugh from me happened after my sister sent me a text about a friend of her husbands who felt so good after his DBS surgery that he decided to "divorce his wife." Normally, I'm not someone who laughs about divorce. However, here I am making light of someone else's post-surgery revelation. Could it be that I'm suddenly more open to finding a random chuckle since I finally discovered a way to take a poke back at Parkinson's disease for all the poking it has done to me?

I've seemed to discover that my laughs are arising from unusual places and to be honest, it feels darn good to not take life so seriously. As I close here, just a reminder that laughing truly is one of the best medicines and no co-pay is needed; so, do so long, loud, jovially, and as often as you can. Poke Parkinson's where it deserves to be poked the most -- in the comedy aisle of your own brain!



### ParkinsonWISE® for Care Partners

# Register and for Information Click Here Flyer Click Here

Citrus Heights, Davis, Folsom, Redding, Sacramento, Santa Rosa & Zoom

There are still quite a few opportunities to attend a PANC developed 2-hour training specifically for care partners. There is no cost to attend. You'll learn tips and empowering information to help your loved one live well with Parkinson's while also easing your conscience for this sometimes difficult yet rewarding season in life. For experienced to new care partners. Topics include:

- Pathology of PD
- Motor symptoms
- Non-motor symptoms (including psychology)
- Deep brain stimulation
- Medications
- Safety and fall prevention
- Exercise
- Transfers
- Q&A
- Resources



# AB 829 Supports CA Parkinson's Research and Services

CA Assemblymember LaShea Sharp Collins authored AB 829 which will allow donations to be made to benefit Parkinson's research and services (such as PANC) in California through the creation of the California Parkinson's Disease Research Fund and Voluntary Tax Contribution Fund. This voluntary tax contribution fund has been a successful fundraising tool for other disease research including Alzheimer's and cancer.

Incoming PANC President Harry Starkey (photograph -- on the right) testified before the CA Assembly's Revenue and Taxation committee in support of the Bill late last month, which was passed by unanimous support. It heads to the Assembly Appropriations Committee next. Watch Harry's testimony in support of AB 829 here.

Over 1 million Americans and 120,000 Californians live with Parkinson's disease which costs the state over \$5 billion annually in direct and indirect costs. Even though Parkinson's disease is the second most common, and fastest growing, neurological disease, research for Parkinson's treatments and cures is underfunded compared to other diseases. While other neurodegenerative diseases receive billions from the federal government each year,

Parkinson's only receives a couple hundred million.

It's critical that a system be established allowing donated revenue to be used to support research and services benefitting Parkinson's patients in the state.

The bill adds Parkinson's disease to the existing list of items on the California tax return where people can voluntarily contribute to their issue of choice. It also creates the California Parkinson's Disease Research Fund to receive public and private donations which will fund research and services benefitting Parkinson's patients in the state.









# Meet the Newly Elected 2025-2026 PANC Board Members and Officers

The PANC family continues to evolve! Welcome to the following individuals who were voted onto the Board of Directors at the April meeting. Each has committed to helping grow the organization as we continue to provide services and benefits to the NorCal Parkinson's community.

**Anders Bostrom** is a corporate attorney for Weintraub Tobin. He counsels businesses, nonprofits and healthcare organizations across California and has a close relative with Parkinson's disease (PD).

**Tom Cadman** is a semi-retired fence contractor. He is the care partner for his wife Lynda who has had PD for over 20 years. Tom has been active in the PANC community for years and currently serves at our outreach coordinator. If you know of an event that PANC should be at to present or have an exhibit table, let Tom know!

**William "Gray" Medlin** is a graduate of the Warton School of Business and ran his own investment banking firm until retirement. In 2023, Gray was diagnosed with Parkinson's and is on a mission to support and inspire others on their PD journeys.

**Edna Ochoa** serves as a community liaison for Advanced Hospice in Sacramento. She is passionate about education, encouragement and connection and will be facilitating two PANC-affiliated Support Groups for veterans.

Additionally, Harry Starkey was elected as PANC's first-ever President serving with a Parkinson's diagnosis and Jennifer (Jen) Westoby was elected Vice President, also serving with a Parkinson's diagnosis.

PANC is in good hands moving forward! Please join in welcoming these incredible individuals who have stepped up to serve this community.

### **Dizziness and Parkinson's**

Dizziness is a common symptom for people with Parkinson's disease, and can cause feelings of faintness, dizziness, unsteadiness or vertigo. Possible causes can include side effects of medications, orthostatic hypotension, and deep brain stimulation.



Click here for an article about this topic from Ignite Neuro
Fitness in Sacramento and talk to your doctor about managing these symptoms.



### **Exercises for Parkinson's**

For people with Parkinson's, engaging in specific types of exercises can lead to improvements in gait, balance, tremors, and motor coordination and constitute a fundamental component of treatment, paving the way for a better, more mobile future.

Whether it's through stretching, movements, and strengthening routines, people with Parkinson's can experience substantial benefits by having a regular exercise routine. Research underscores the vital role of exercise, revealing that it can induce positive changes in the brain and affect progression of the disease. A solid exercise plan, which can include the LSVT BIG program that focuses on large amplitude whole-body movements, is infinitely

helpful to wellbeing.

Check with your doctor and/or meet with your physical therapist before starting new exercise activities. Look for Parkinson's-specific exercise programs in your community and online live and video courses. Here are some options for people with Parkinson's (and everyone!):

#### Aerobic Exercises for Physical and Cognitive Improvement

Engaging in aerobic activities can significantly enhance brain function and impart measurable protections and improvements for those with PD, both physically and cognitively.

#### Strength Training for Muscle Strength and Stability

Strength training extends beyond just muscle building; it focuses on constructing your body's support system. By focusing on exercises that increase muscle strength, individuals with Parkinson's can improve stability and ease in performing daily tasks.

#### **Balance and Agility Exercises**

Balance and agility exercises serve as the tightrope act of Parkinson's management, ensuring steadiness and fall prevention. Engaging in balance training can fortify stability, making it less likely to experience falls – a common and dangerous symptom for those with Parkinson's.

#### Stretching to Relieve Stiffness

Stretching acts like a soothing melody, ensuring the body's range of movement stays in harmony. Muscle stiffness can be a struggle, but stretching exercises can offer relief. Incorporating stretches into your daily routine can help maintain flexibility and moving comfortably.

#### Coordination Exercises to Enhance Motor Skills

Coordination exercises act as conductors, orchestrating smoother movements and enhancing motor skills. Simple activities like rotating Chinese medicine balls in a palm or using clothespins to pick up objects can significantly improve hand coordination and dexterity.

#### Breathing Exercises for Better Respiratory Function

Breathing exercises play an unheralded yet vital role in managing Parkinson's disease. Chest wall stiffness and weakened muscles can make breathing difficult for those with Parkinson's, but breathing exercises, particularly those that engage the diaphragm, can enhance respiratory efficiency.

#### Cognitive Challenges and Brain-Boosting Exercises

Cognitive challenges and brain-boosting exercises serve as the catalysts that kindle mental agility in people with Parkinson's. Engaging in activities like word association games or playing strategic games like chess can greatly enhance memory and cognitive abilities.

#### Working with a Physical Therapist

Physical therapists are an important part of your Parkinson's team. They provide assistance tailored to the individual movement needs of each unique person and help restore functionality that make movements easier.

#### Tai Chi from Mindfulness to Mobility

Tai Chi embodies a blend of mindfulness and movement, providing people with Parkinson's with a gentle option to improved balance, coordination, and overall well-being. Experts say that practicing Tai Chi for as little as six months can significantly improve walking ability and posture and reduce falls.

#### Unleashing Creativity through Art Therapy

Art therapy allows people with Parkinson's to harness their creativity, becoming a potent tool for improving cognitive function and emotional well-being. Engaging in art-making activities can reorganize the brain's visual networks, enhancing visual-cognitive skills and general motor function.

## **PANC** at the Capitol

On April 21, PANC staff and constituents joined the Michael J Fox Foundation and other Parkinson's advocates from across the state to celebrate the Parkinson's community and witness both the California Assembly and Senate recognize April as Parkinson's month in the state.

We're looking forward to an all-community Parkinson's Advocacy Day at the Capitol sometime in future.





## **Volunteers Needs for New Safety Product**

Dot Boyd, Senior Safety Specialist is looking for a few volunteer testers of Addison Aware Activity

Monitoring, a simple system for your home that notices movement and non-movement that can keep you or your loved ones monitored and safe.

A Wi-Fi signal from the plug-in unit picks up on patterns, like walking to the kitchen or getting out of bed, <u>without cameras or microphones</u>. An app for your phone or your care partner's phone taps into this info with the help of AI, which determines what is normal activity in the home then alerts you or your care partner(s) if something is off, such as no movement for too long. It's like a gentle, invisible helper keeping an eye on things. View the product flyer here.

Testers will be shipped four Wi-Fi-enabled outlet plugs for the kitchen, family room, bedroom, and bathroom that transform your home into a connected care hub. There is no cost to be a tester. Please contact Dot Boyd **here** or at 916-799-1660 for details. With your feedback, you're helping shape new innovations to improve your life and the lives of others.

## Parkinson's Study Opportunity

Exploring Perceptions and Predictors of Shared Decision-Making in the Pharmacological Management of Parkinson's Disease: Insights from Patients and Providers

The purpose of this University of Jamestown (Nebraska) research is to understand how individuals with Parkinson's Disease and their healthcare providers make decisions about medications including how personal and clinical factors may influence the decision-making process.

#### Who can participate?

 Adults (18–80) diagnosed with Parkinson's Disease currently taking medications (excluding those undergoing surgical interventions like deep brain stimulation or ultrasound treatments).

#### What does participation involve?

- Complete a short, anonymous online survey that takes about 10–15 minutes.
- Answer questions about how you make decisions with your healthcare provider and your understanding of health information.

Responses are completely anonymous and confidential. No identifying information will be collected. There is no payment for participating, but your help is very important and appreciated.

If you meet the criteria and are interested in participating, please clickhere to start the survey.

If you have any questions, please feel free to contact Paula by emailhere. Thank you for your help!

## **May Free Webinars**

Sunday, May 18 from 7am to noon

Parkinson's Symposium with the Mid-Atlantic Chapter of the Parkinson's Foundation Current and upcoming treatments, ongoing research, and resources available in your community to help you live your best life with Parkinson's.

Info and register here

Wednesday, May 21 at 10am

Taking Charge: Strategies for Meaningful Healthcare Visits with the Parkinson's Foundation Encourages individuals living with PD to take charge of their care by providing strategies for effective communication and self-advocacy before, during and after healthcare visits. Additionally, learn about tools and resources from the Parkinson's Foundation to support their journey. Info and register here

Wednesday, May 21 at 12:30pm

**Finding our Footing Again: The Changing Roles of [PD] Care Partners** with Parkinson's Canada The changing roles of care partners and the emotional and practical implications of these changes. Practical take-away tools for navigating change will be provided. **Info and Register Here** 

Thursday, May 22 from 11:30am to 1pm

Staying Active as a Veteran with Parkinson's with the Parkinson's Foundation How staying active can positively impact physical symptoms, mood, and overall health. Participants will learn about the benefits of exercise, discover strategies to stay active beyond traditional workouts, and explore meaningful activities that bring joy and purpose.

Info and Register Here

Thursday, May 22 at noon

Does Parkinson's Begin in the Gut? Rethinking the Origins of the Disease with the Parkinson Society of British Columbia

How early signs of Parkinson's may originate in the gastrointestinal system and spread to the brain via the vagus nerve. He'll also discuss the implications for earlier detection, preventative strategies, and more personalized treatments.

Info and Register Here

Monday, May 26 at 1pm

Our Environment and Parkinson's – Uncovering Hidden Risk Factors with the Parkinson Society of British Columbia

The evidence linking pesticides, air pollution, and occupational toxins to increased Parkinson's risk and how these factors may interact with genetic susceptibility, and what this means for prevention, advocacy, and public health policy.

Info and Register Here

Wednesday, May 28 at 11am

PD's Impact on Other Medical Problems with the American Parkinson Disease Association How a concurrent diagnosis of another medical illness may impact your PD symptoms, how to evaluate if a change in PD symptoms is due to worsening of PD or a new medical problem, and essential tips for preparing for a hospital stay if you have PD.

Info and Register Here

Thursday, May 29 at 1pm

**Nutrition and Parkinson's – Feeding the Brain, Fueling Wellness** with the Parkinson Society of British Columbia

Common challenges like appetite changes, digestive issues, and meal timing with medication, offering practical tips you can apply right away.

Info and Register Here

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

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

www.panctoday.org

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