

Building Community for the Journey -- October 2024

## PANC SUPPORT GROUPS HERE

"It's the first day of autumn! A time of hot chocolatey mornings, and toasty marshmallow evenings, and, best of all, leaping into leaves!" — Winnie The Pooh

# 2nd Annual TOPGOLF Fundraiser in 2 Weeks!

No golf experience required! But Fun Is!

Sunday, October 27 from 10am-2pm REGISTER HERE FLYER HERE



Hosted by Mark S. Allen

Hurry! Register soon -- Golf Ticket: \$75 / Social Ticket: \$50

Price increase 10/22 to 10/24 -- Golf Ticket: \$85 / Social Ticket: \$60

A great late morning event of socializing and swinging clubs with PANC friends. Much like mini golf + bowling + music + food/drink + scoreboards = FUN!

For the golf-shy, enjoy brunch buffet and camaraderie of community. Let's celebrate!

Register for the Swing for Parkinson's Event Here



### Silent Auction Bidding Begins this Sunday!

Help support the PANC community and its services

Details to participate emailed soon!

Easily bid from your computer/phone or in-person at TopGolf

event

Auction Items to Date...

Entertainment -- G&L Tribute Guitar/Nutcracker Ballet Tix//Rescue Experience Flight/Smart Axe

Health & Wellness -- 60 Min. Bodywork/Varimax Personal Training/Theracycle/FitGolf 3D Swing Eval

Art & Stuff-- David Garibaldi Einstein Prints/Large Deep Purple Amethyst/Hand-made Quilt

Wine & Bubbles -- Justin Isosceles Red Wine/William Hill 2021 Cabernet Sauvignon

Practical Things -- LED Light Bulbs/Picnic Set

**Visit the Auction Here** 



# Report from the 2024 PANC Education Conference

The 2024 PANC Education Conference was another success! Over 800 individuals attended the event both in-person and online. Comments from event surveys on some of the important things learned that day:

- We are not alone
- All the hopeful new breakthroughs in treatment and research
- PD is not a crisis, but a process
- Keep going!
- How much PANC contributes to our community and well-being
- I need to give permission to my caregiver to take care of me which takes trust
- Encouraging updates about PD and what the future holds
- The importance of vigorous aerobic exercise & weight training
- Tips on communication with spouse
- The Q&A panel gave very practical answers and were a highlight

Thank you to Supernus Pharmaceuticals, Boston Scientific, Medtronic and all of PANC's incredible industry sponsors and supporters. We couldn't host this event without their support. Accolades to Community Event Co. for their impeccable event assistance and guidance, the Loveridge family for heading up the volunteer champs, Edwin Garcia for beautiful photography year-after-year, our phenomenal speaker's panel, and Celia Coughlin-Surridge and Danielle Hand for their insightful Roving Reporter spots. Finally, thank you to the many individuals who paid-it-forward and made donations to help PANC continue on.

If you weren't able to attend and would like a recording of the full event, please make a \$20 donation below. Includes video link, conference program, speaker slides, and vendor roster. See you in 2025...the planning begins!

**Purchase the Conference Recording Here** 



Υ



# ParkinsonWISE Training in Davis November 9th!

Calling all exercise professionals!
Learn to work most effectively with those affected by Parkinson's disease.
Receive a certificate of completion and your contact information will be included on the ParkinsonWISE resource website. Registration Flyer



### Hoisting the Oar of Parkinsons: My Caregiver Story

By Michael Wrisley

When you get married you join. You build a boat. A brand new, shiny boat with all the possibilities in the world, ready to cross the Ocean of Life .... Together. I'll call it the 'SS Possibility' and you begin writing in the "Logbook of Life."

Sometimes, somewhere in the vast ocean crossing you experience stormy weather. Rain, wind and waves that seem to never subside. Yet eventually they do...and life goes on. You share the burden, equals in every task, basking in the embrace.

The journey of life has the two of you, constantly rowing, each with an oar, communicating to try and stay in sync with each other and keep the boat headed in the right direction -- despite the constant distractions of life and occasionally turbulent conditions.

Then the PD (Parkinson's) wave hits your boat, and it gets a new name: 'SS PD'. The two of you don't really know what to make of it, yet you know somehow it means rougher waters ahead. At first, the two of you continue to row as before, maybe even a little bit faster. The water seems to be going by as it always has, but you notice your partner seems to be catching their oar or missing a stroke/getting out of sync, more often. Communications seem to be harder, but you figure it's just a temporary thing.

As the waters of life brush quickly by the hull, you find yourself bailing more and navigating a lot less. You realize that your partner is out of sync and that you are the only one rowing. After a while you realize that with only one oar in the water you are rowing in circles, so you make course corrections with only one oar and almost never get up on deck to do any navigation. In fact, at some point you realize the 'current' of life is pulling your little boat along quite fast.... despite the fact that you generally only have little more than one oar in the water.

At some point you ponder your direction and course, yet the horizon seems cloudier and the waters more turbulent. You begin to realize that you don't even need to row anymore....in fact in retrospect you begin to wonder why you ever did!

The seas are mostly baren of other vessels, say for an unexpected Mercy ship that bumps into yours.... offering understanding, compassion and unsolicited warmth. It can be as simple as holding a door open, an employee or patron rushing up to help your partner walk out of a store or restaurant before you can. These unexpected acts of kindness, instead of unfriendly stares, bring a swelling of your heart that can't be imagined.

At some point, the Tsunami hits and your boat capsizes completely. You find yourself floundering in the cold water with little more than a life jacket...the one your spouse made you put on. Wait, your spouse...where are they? Then it starts to sink in.... you are all alone, a long way across the journey of life and your spouse/boat is almost over. You look at your lifeline. Thankfully it's still there. Family and friends are trying desperately to pull you in.... but you're not responding...you're not sure you want to be rescued.

Many years of marriage, companionship and love is dissolving around you. You reach out, try to hold on to them...find solace, find peace in the raging storm. You realize you miss the bailing, the caring, the companionship of a dear one-- the things at times you resented. The SS PD is back in the Harbor and the Logbook states as such. The Logbook is part of an up-and-coming rebuilt boat...an integral part.

The next chapter of this journey will be written into the Logbook. You promise yourself to be better in the next one. Promise to take a more caring, less assuming and broader view on your next expedition. To make yourself a better person and do all that you can to enrich the worlds of those around you and continue making headway, regardless of their course or the condition of their boat.

# People with Parkinson's Disease to Live Fully

by Natalie Perkins, Chair/Program Director & Associate Clinical Professor -- University of the Pacific

Living with Parkinson's disease can present daily challenges, but with the right support, individuals can continue to lead fulfilling, purposeful lives and

engaging in activities that bring joy. Occupational therapy (OT) is a key part of the healthcare team that provides practical solutions to help people with Parkinson's maintain independence and quality of life.



#### What Is Occupational Therapy?

At its core, occupational therapy focuses on helping people engage in the activities that matter most to them. This can be anything from getting dressed in the morning to engaging in hobbies or socializing with friends. Occupational therapists (OTs) work closely with individuals and their caregivers to understand their specific challenges and tailor interventions to meet their personal goals. For those living with Parkinson's, OT offers customized strategies that address movement difficulties, fatigue, medication management, and the cognitive changes that often come with the disease.

#### **Supporting Daily Activities**

Parkinson's can make simple tasks feel overwhelming, but OT's can help to ease that burden. An OT can teach techniques to conserve energy, simplify routines, and use assistive devices to make tasks like bathing, dressing, and eating easier. For instance, something as basic as buttoning a shirt or opening a jar can be challenging due to tremors or reduced grip strength. Occupational therapists can recommend adaptive tools such as button hooks or jar openers, making everyday tasks more achievable.

#### **Improving Safety at Home**

Fall prevention is a major concern for individuals with Parkinson's disease. An occupational therapist will assess your home environment and suggest modifications to enhance safety. They may recommend installing grab bars in the bathroom, removing loose rugs, or adding better lighting to prevent falls. These changes create a safer, more accessible space where you can move about with greater ease and confidence. OTs can also guide individuals through exercises that improve overall strength, dexterity, and movement.

#### Managing Cognitive Changes

Parkinson's doesn't just affect movement; it can also impact thinking and memory. Occupational therapists can help with strategies for managing cognitive challenges by teaching skills such as using reminders, calendars, or alarms to stay on track with medications or appointments. They can also help create routines that reduce mental strain and enhance focus.

#### **Supporting Caregivers**

OT isn't just for people with Parkinson's—it also offers support to caregivers. An occupational therapist can provide training on safe ways to assist loved ones, offer advice on managing caregiver stress, and suggest resources that lighten the caregiving load. They can also teach techniques that ensure caregivers protect their own physical health while helping with transfers or assisting in other ways.

#### Living Well with Parkinson's

Occupational therapy is about more than adapting to changes—it's about thriving in the face of them. By addressing the physical, emotional, and cognitive challenges that come

with Parkinson's disease, OT empowers individuals to maintain their independence and pursue the activities that bring them joy and meaning. Through personalized support, people with Parkinson's and their caregivers can find new ways to engage in meaningful activities, one day at a time.

#### Dear Sharon and PANC Board

Jon and I want to thank you for the respite care grant you have awarded us. It is such a relief to have this help. The respite time is what is keeping me going as a caregiver, and Jon is happier when I am happier!!! Your help is much appreciated.

Many thanks, Jon and Carol Glicker



### October Free PD Education & Webinars

Wednesday, October 16 at 10 am

<u>Parkinson's 101: What You and Your Family Should Know</u> with the Parkinson Foundation Basic overview of Parkinson's disease. Discover its causes, common symptoms and available treatments. Learn practical daily living tips to empower you to take charge of your health and to navigate the challenges of living with PD.

Info and Register Here

Wednesday, October 16 at 10:30am

Navigating Anxiety with the Parkinson Society of British Columbia

Identify how anxiety commonly manifests in people with Parkinson's *and* caregivers, the disease-related factors that can influence anxiety levels and mental health, and learn lifestyle changes, therapeutic techniques, and medication options to manage anxiety and improve quality of life.

Info and Register Here

Thursday, October 17 at 9am

<u>Hitting Stride: Research Advances on Walking with Parkinson's</u> with the Michael J Fox Foundation

Replay of a past webinar on gait, with updates on the latest research advances.

Info and Register Here

Saturday, October 19 from 8-11am

<u>Parkinson's Disease Patient and Family Symposium 2024</u> with the Parkinson Foundation This program will feature tips from a movement disorder specialist, and other experts on advances in Parkinson's research, and the benefits of the creative arts for people with PD. Q&A will follow each presentation.

Info and Register Here

Tuesday, October 22 at 9am

<u>Cardiac Manifestations of Parkinson's Disease</u> with the Parkinson Social Network of Northern Virginia

The speaker will discuss the effect of PD on the heart.

Info and Register Here

Tuesday, October 22 at 10am

<u>Navigating Long-Term Care with Parkinson's</u> with the Parkinson's Foundation Highlights the importance of planning for long-term care and the role of elder law in protecting your assets and securing quality care. Participants will learn about different care options, their costs, and payment sources like Medicare and Medicaid. Also covers eligibility for these programs, helping attendees make informed decisions about their long-term care and financial security.

Info and Register Here

Wednesday, October 23 at 10am

Is it Still Safe to Drive [With PD]? with Neuro Challenge

The speaker will discuss medical driving evaluation - what it is and who it is for.

Info and Register Here

Friday, October 25 at 10:30am

<u>Interdisciplinary Perspectives on Atypical Parkinsonism: Multiple System Atrophy and Lewy Body Dementia</u> with the UC San Diego Parkinson and Other Movement Disorders Center

The speakers will discuss current perspectives on care for multiple system atrophy (MSA) and Lewy body dementia (LBD).

Info and Register Here

Wednesday, October 30 at 10am

<u>Gene and Cell-based Therapies in Parkinson's</u> with the Parkinson's Foundation While still in the developmental stage, genetic and cell-based therapies hold some promise for people with PD. This webinar will review the basics of gene and cell-based therapies. The speaker will discuss what these therapies may or may not accomplish for the person with Parkinson's as well as what to expect in terms of the treatment process.

Info and Register Here

Wednesday, October 30 at 11am

Medicare Advantage Plan hosted by the Stockton Support Group

Discover the benefits about Medicare Advantage Plans and In Home Care options

For more information or to register for Zoom, email lou@ageinplacesacramento.com

Thursday, October 31 at 11am

<u>Vision Changes and Parkinson's Disease</u> with the American Parkinson Disease Association An expert on the eye problems of neurologic disorders and will provide a helpful overview and answer your questions live. Attendees will learn the common vision changes that can accompany Parkinson's disease, why these vision changes occur, which doctors can help navigate these symptoms, and the steps you can take to help improve your vision.

Info and Register Here

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

placing a sponsor article in the *Update*.

### www.panctoday.org

### Ways to Support

Parkinson Association of Northern California | 1024 Iron Point Rd., Ste 1046 | Folsom, CA 95630 US

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