



# PANC

Parkinson Association of Northern California

# UPDATE

*"Building Community for the Journey"*

July 2023

**Find A Support Group  
Here**

*"I am not what happened to me. I am what I choose to become." -- Carl Jung*

## Multidisciplinary Care for Parkinson's Disease

by **Norika Malhado-Chang, MD, Associate Professor of Neurology, UC Davis School of Medicine**



One important aspect of Parkinson's Disease (PD) that sets it apart from other conditions is its complexity.

Twenty years ago, PD was purely considered a "movement disorder," resulting in symptoms affecting mobility, such as stiffness, slowness, and difficulty walking. Now, we know that only scratches the surface! In addition to motor symptoms, PD involves an array of non-motor symptoms like constipation, sleep disturbance, depression, anxiety, cognitive impairment, and trouble with speech and swallowing to name a few. Therefore, it really makes sense to approach this from a multidisciplinary care perspective.

What does multidisciplinary care entail? It is a model of healthcare that harnesses the expertise of a variety of specialists to provide truly comprehensive care for the whole person. Fifty years ago, a patient would have all their medical issues managed by their primary care physician. As the medical field has evolved, we have subspecialists trained in a variety of diseases to provide expert care in a certain area. Within the realm of Parkinson's, we should capitalize on the talents and skills of others in the healthcare field by employing a "team" approach. If I were to recruit an all-star team for PD, it would include:

1. Parkinson's Neurologist (may include a Movement Disorders Fellow and a Nurse Practitioner)
2. Neuro Physical Therapist (unlike most PT's who are orthopedics-focused, Neuro PT's have special training in neurologic conditions, like PD. They may even have certification in LSVT BIG or PWR-Parkinson's Wellness Recovery)
3. Speech/Swallow Therapist (some specialize in PD, with certification in LSVT LOUD to help with both voice and swallowing)
4. Psychiatrist or Geri-psychiatrist (doctors who are experts in depression, anxiety, and psychosis)
5. Psychologist or counselor (both for the person with PD and the spouse)

6. Social Worker (An MSW provides valuable information about community resources, caregiver assistance, medication financial assistance programs, etc.)
7. Occupational therapist (OT's help with hand and finger dexterity, specialized utensils, and assistive devices for getting around)
8. Personal Trainer
9. Gastroenterologist and/or urologist (constipation and bladder dysfunction can become challenging and require a specialized approach)
10. Dietician or Nutritionist (maintaining proper nutrition while optimizing the effect of one's medications can be a tough balancing act, and nutritionists can be quite helpful in this regard)
11. Palliative care specialist
12. Financial planner

This may look like a fantasy sports team line-up, but this is the future of Parkinson's care. The days when you saw a neurologist alone will be gone, and the "clinic of the future" will have all these specialists in one place to help you from all different angles. For the time being, getting all these specialists in the same place, at the same time, is a challenge (but we're working on it!).

So, for now, each person should assume the role of Team Manager and look to recruit these specialists to work in their corner. With a condition as complex as Parkinson's, enlisting the help of professionals across this spectrum ensures a holistic and comprehensive approach that, in all likelihood, might slow the complications of PD or even slow progression of the disease. This, in turn, will help you stay proactive and live your best life with Parkinson's. (*Parkinson Path, 2019*)



## NorCal Representatives at the World Parkinson's Congress

PANC's Sacramento Area Young Onset PD (YOPD) group members Brenda Bess, Susan Lopez-Payan, Danielle Hand-Nicholls, PANC board member Jennifer Westoby, Kaiser's Dr. Suketu Khandar & Jennifer Liu, and Sutter's Dr. Nick Thakur, are amongst the many attendees at the [World Parkinson's Conference \(WPC\)](#) in Barcelona Spain this week!

The triennial World Parkinson Congress is an international forum for scientists, clinical researchers, health care professionals, people with Parkinson's, and others to come together under one roof to discuss, learn, and engage in debate around the latest scientific discoveries and medical and comprehensive care practices related to Parkinson's disease.

The YOPD group will be sharing their conference experience, including the trip and traveling with Parkinson's at their August 1st Sacramento [YOPD support group](#) meeting in Carmichael from 6:30 - 8:00 pm for those interested in attending.

Unlike other scientific congresses, the WPC brings together all members of the Parkinson's community. The WPC was founded on the belief that getting world leaders out of their professional silos and forcing a cross pollination of the scientific, clinical, rehabilitation, and advocacy communities would expedite the discovery of a cure and cultivate best treatment practices for this disease.



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## Official PANC Education Conference Schedule!

Registration Opens August 1

Register by September 15

In-person: \$30

Reserved Table for 8: \$400

Virtual: \$20



Just a reminder that PANC Annual Education Conference is scheduled for **Saturday, September 30** at the Roebelen Center in Roseville. Here's the official event agenda:

- 8:00 Registration & Exhibits Open
- 9:00 Welcome



- 9:10 Dr. Michel Medina -- Apathy, Depression, & Anxiety
- 9:40 Dr. Indu Subramaniam -- Wellness in PD
- 10:25 Exhibits Open/Morning Break
- 10:50 Movement Break
- 11:05 Dave Iverson -- A Personal Caregiving Story (book signing in-person)
- 11:55 Exhibits Open/Lunch provided by Hannibal's Catering (in-person)
- 12:45 Dr. David Brandman -- Updates on DBS & Neurosurgery
- 1:15 Panel Discussion with local movement disorder neurologists
- 2:00 Movement Break
- 2:15 Panel discussion & attendee Q&A session
- 2:45 Closing Remarks
- 3:00 Exhibits closed

Please forward the conference flyer [here](#) to friends, family, and colleagues who may be interested in attending. The event recording will be provided to all registered attendees. PANC is thrilled to be adding Spanish-translation services this year for our online registrants and a new caterer has been selected for the in-person lunch attendees.

Much gratitude to the following companies whose sponsorship\* helps to keep the costs low so many can attend this incredible event of education and fellowship!

**Presenting Sponsor: Supernus Pharmaceuticals**

**Platinum Sponsors: Abbott DBS; AbbVie; Boston Scientific; Medtronic DBS**

**Gold Sponsors: Avion; Sutter Health Valley Area; UC Davis Medical Center**

**Silver Sponsors: Acorda Therapeutics; Amneal Pharmaceuticals; Dignity Health Medical Foundation, Kaiser Permanente; Kyowa Kirin**

Sponsor or exhibitor opportunities -- Email Jan [here](#)

*\* As of July 7, 2023*

## PD Research Studies: How You Can Help

- **New!** Motor Control Experiment. (\$25/hour) UC Davis Motor Lab -- Click [here](#) for flyer.
- The Effects of Exercise on Parkinson's and Related Disorders . CA Sacramento State University -- Click [here](#) for flyer.
- PPMI Data -- Looking for people with and without PD including those recently diagnosed. Michael J Fox Foundation -- Click [here](#) for website.



**Swing for Parkinson's**  
**1st Annual PANC TopGolf Social**  
**& Silent Auction**  
**Sunday, October 29 from 1-4 pm**

[Register by October 7](#)

Golf Ticket: \$80 | Social Ticket: \$50

Event flyer [here](#)

Bring your family, friends, and colleagues to swing clubs, smack a few balls, socialize, and

have fun raising funds for PANC! Join for an afternoon of unique golf, friendly competition, fajita buffet lunch, 50/50 raffle, silent auction, and more! All skill levels welcome. Registration opens August 15th.

A limited number of social tickets are available for spectator fun and lunch buffet for those who don't want to golf. Seating is plentiful. Limited tickets so register early! We can't wait to have fun with you at this new event benefitting the services of PANC. **Sponsorship opportunities [here](#)**

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*Sponsor Article by Supernus Pharmaceuticals*

## Medication Notification

According to the Sunovion Pharmaceuticals website, Kynmobi, their therapy for those with PD has been discontinued in the U.S. as of June 30 due to "limited utilization of the product." Patients who currently use Kynmobi are advised to consult with their healthcare provider about alternative treatments. When doing so, please consider inquiring about **APOKYN** (apomorphine hydrochloride injection) from Supernus Pharmaceuticals as an alternative option for acute, intermittent treatment of hypomobility ("OFF" episodes). **APOKYN** has been shown to be a reliable, rapid, robust on-demand therapy that can provide greater control of OFF episodes.

In a placebo-controlled trial, **APOKYN** demonstrated a robust 24.2-point reduction in mean Unified Parkinson's Disease Rating Scale and helped patients walk, talk, and move more easily.

**APOKYN** may be used adjunctively with most PD treatment regimens by rapidly entering systemic circulation providing an onset of benefit that is not affected by gastroparesis or intestinal absorption. The pen device uses a very fine gauge needle for subcutaneous administration that is like those used for insulin injections in patients with diabetes.

If you have questions about or are considering **APOKYN** as a treatment option and would like additional information, talk with your PD clinician at your next appointment, click [here](#) for the website, or email **Alison Miller** [here](#).



## Alaska Cartoonist's Experience with Parkinson's

Peter Dunlap-Shohl was living his lifelong dream, as an editorial cartoonist for the Anchorage Daily News. In 2002, when he was diagnosed with Parkinson's disease, he asked himself: What would he be losing besides his craft as an artist with PD? His

identity? What else?

Peter soon discovered new and exhilarating possibilities for expression by using computers for his drawings in both color and animation. This inspired him to publish his book “**My Degeneration**”, a graphic novel documenting his time with Parkinson’s disease as an inspiration for others and included tools and optimism for those who are just as scared as he was. Click the arrow in the graphic above and start the video from the beginning. Enjoy!

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## Help US Grow PANC

PANC is seeking candidates to serve on our Board of Directors. Board service with PANC is a unique opportunity to help develop the organization into an even stronger and more effective non-profit. Monthly meetings are conducted via Zoom. Please email PANC nominating committee member Ralph [here](#) by Friday, July 29 if you are interested and would like additional information.

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PANC's Benicia Support Group was represented at their local 4th of July parade. A giant shoutout to this group and their wonderful float in support of the Parkinson's community!

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## July PD Webinars

- July 1 at 5:30 pm --**Building Your Parkinson's Care Team** (PD Active) Register [here](#)
  - July 12 at Noon --**Sleep Issues in PD** (PMD Alliance) Register [here](#)
  - July 15 at 10:30 am --**All About PD Research, Why It Matters & How You Can Join One** (UCSD Parkinson & Other Movement Disorders Center) Register [here](#)
  - July 17 at 1:00 pm --**Mindfulness of Emotions** (Parkinson Foundation) Register [here](#)
  - July 20 at 9 am --**Genetics and Parkinson's: Understanding the Role of Gene Therapy in a Cure** (Michael J Fox Foundation) Register [here](#)
  - July 25 at Noon --**Tacking Tough Symptoms** (Brown University) Register [here](#)
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Community Partner:

PMD Alliance

The Parkinson & Movement Disorder Alliance (PMD Alliance) is an independent, national nonprofit dedicated to providing opportunities for people to learn, live more fully, and spark meaningful connections around them.

Whether it's those living with a diagnosis, their care partners, adult children or support group leaders, PMD Alliance helps to meet the needs of those they serve by providing solutions that inform and incite change in the PD industry. For additional information, click [here](#).

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[www.panctoday.org](http://www.panctoday.org)

[Ways to Support](#)

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