



Building Community for the Journey -- August 2024

**PANC SUPPORT GROUPS
HERE**

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

A poster for the 2024 Annual Education Conference. It features a circular logo on the left with the PANC logo and the text "Annual Education Conference EMPOWERED MINDS WANT TO KNOW • 2024 •". Below the logo is a circular portrait of Sharon Krischer, a woman with blonde hair, smiling. To the right of the portrait, the text reads "2024 ANNUAL EDUCATION CONFERENCE Saturday, Sept. 28". Below this, it says "Featuring SHARON KRISCHER AKA 'Twitchy Woman' and other authors, experts, care partners, and more". At the bottom, it says "Register Today In-person or Virtual options www.panctoday.org".

Register Now with the Conference Early-Bird Discount!

In-person Ticket (by 9/14/24) -- \$40* (includes lunch)

Virtual Ticket (by 9/14/24 till noon) -- \$20*

Student Virtual Ticket (by 9/26/24) -- \$10

Reserved Seating for 6 -- \$300

Reserved Seating for 8 -- \$400

**Prices increase on individual tickets by \$10 on 9/15/23*

GET TICKETS HERE

We are looking forward to seeing our Parkinson's community friends and family in just 7 weeks! Table reservations are going fast so if you want a table near the stage, register

10 Reasons to Attend the PANC Conference

by Dr. Suketu Khandar

1. This is one of the largest (if not the largest) PD educational events in the country
2. Hear from exceptional local and national specialists
3. Created in collaboration with our local medical institutions
4. Topics chosen from attendee requests
5. Hear from an inspiring keynote speaker and empowered caregiver
6. Receive a recording after the event so you can watch it again or for the first time
7. Meet with exhibitors and medical community experts to learn about new and exciting treatments, services, developments, and products
8. Connect with other patients with PD and their care partners
9. Attend in-person or online from the comfort of your home
10. Become a part of this dedicated and loving community and know that you are not alone on your PD journey



The Day I Was Diagnosed

by Terri Van Bibber

On a cold early January morning in 2015, I walked into a neurology office for what I thought would be a quick appointment on my way to work. My family doctor had referred me for weakness in my left hand/arm because I was noticing an intermittent but increasing tremor and sense of weakness in my left hand over the previous two years. I thought it was related to my thyroid, an isolated nerve issue or stress. There was a lot of stress over the past year.

The office staff led me to the exam room where I was quickly greeted by the neurologist. She listened as I explained my concerns and asked a few questions and had me stretch my arms out. She then checked my joints to see how easily they moved. I have always been very flexible, in part due to the private Pilates training I had attended for the last 8 years. I knew I passed that test! The doctor asked me to follow her into the hall and had me walk to the end of it then turn around and come back. Walking quickly and always with a purpose supported my desire to be efficient. We returned to the exam room where I took my seat and waited while she returned to her chair. She then sat across the room from me writing notes then looked up and said, "This is not what I expected to be saying this morning, but you have Parkinson's disease."

Tears rolled down my face and she said, "It's not what you may be thinking; people with Parkinson's can have long and full lives." I didn't even know what she was talking about. My only frame of reference was Michael J. Fox. She was communicating with me and all I heard was that weird "wha wha wha" when adults talk in the Charlie Brown cartoons.

I got back to my car and sat there for a long time not knowing what to do but pray. How would I tell my husband, friends, kids, and work? I buried my head in my hands and cried with my whole-body convulsing for a very brief minute or two. Then I sat up in my seat and gave all my concerns to God. He knows everything and I reminded myself that he had a good plan for my life whether I had Parkinson's disease or not. I was going to choose to focus on what was right in front of me including driving and attending to a full day at work. I turned on my Christian worship music, sang as loud as I could, put the key in the ignition, and drove. I gave myself a lot of grace that day and focused on one thing at a time rather than 10. I needed to get through the day, get home, and figure out how to tell my husband.

That evening, Jim sat in his usual recliner watching the nightly news. I took a seat on the couch across the room from him and said, "I went to the doctor today and I was diagnosed with Parkinson's disease." He was quiet and then said (what most would think is a cold and callous comment, but it was the perfect response for me!), "Well, you're not dead." Nope, I wasn't dead! As a matter of fact, I had a whole lotta life left to live!

Next, I called and told my daughter and asked her how she was feeling about it. She said she was not worried at all and reminded me that her biological dad's grandmother has been living well with Parkinson's for 20 years. I had completely forgotten that. I saw my ex-mother-in law several times over the last 20 years, and she looked remarkable. This was very encouraging!

Today, I am strong, living well with Parkinson's, and doing everything I can to lead a productive and loving life that I may not have had without the diagnosis. In fact, in a lot of ways, I'm an improved version of the woman that showed up in that neurologist's office that day and still have so much to look forward to.

The PANC conference is coming up next month and I'll be on the podium sharing a little more of my story. I hope you can attend and join me in celebrating all the good things that this change in life has provided for me. My diagnosis does not define me and it sure isn't holding me back!



PANC is Growing! Welcome Julie

We are thrilled to announce that the PANC staff is growing!

To accommodate the expanding need for services in the NorCal Parkinson's community, the PANC Board of Directors is pleased to announce that we have added Julie Donohue as our part-time bookkeeping and marketing manager.

Julie comes to PANC with a robust background in building and serving non-profit entities including her family's long-running organization that provides rowing education and experiences to disadvantaged youth in Delaware. Julie has quickly become an integral member of the organization, and we are excited to see what we accomplish with her added participation. Julie is excited to be a part of the team and will be working hard at the conference -- please stop by the PANC table and introduce yourself!

In other staff news, Sharon D'Nelly-Warady, our steadfast office manager, has been promoted to programs manager. Thank you, Sharon, for your many years of incredible service to PANC and we look forward to all the more that you will achieve for the Parkinson's community ahead.

Registration NOW Open for the 2nd Annual Topgolf Fundraiser!

Sunday, October 27 from 10am-2pm

For the 2nd year, PANC will be hosting the "Swing for Parkinson's" Fundraiser at Topgolf in Roseville to help raise revenue to fund PANC's many programs and services. This is a super fun event! No talent for golf needed or required. Both golf and non-golf tickets are available and include a full breakfast buffet. **Space is limited.** Early-bird rates are available through October 9 and ticket purchasing ends on October 22.



Get Tickets for the Swing for Parkinson's Event Here

Theracycle 300



Silent Auction Bidding Begins October 20

The 2nd Annual PANC Silent Auction will take place from October 20 to October 27 with proceeds from the event benefitting the services of PANC including support groups, respite grants, conference production, program development, and so much more. Participate from your computer and/or by attending the "Swing for Parkinson's" event (see above). A few of the items you will have an opportunity to win:

- Victorian vacation apartment in Glasgow, UK
- Theracycle300
- Paso Robles vacation home
- Case of Justin red wine
- Truckee/Soda Springs mountain vacation cabin
- Limousine services
- Airplane flight over Folsom Lake and region
- Park City, Utah vacation home
- Gift cards for restaurants and services

Watch for coming details on all of the opportunities and how to participate/bid to help PANC.

If you have an item of value that you'd like to donate to PANC for the auction, [please email Danielle here](#). THANK YOU!

Conference Volunteers Needed

It takes a village to successfully host our annual conference and ensure that all of the needs of our attendees are accommodated.

If you are a Parkinson's family or community member available to help or a student needing service hours, we need you on September 27 and 28! [Please click here to view the volunteer opportunities](#) or [email Julie and let her know you are interested in helping](#).





THANK YOU TO OUR 2024 CONFERENCE SPONSORS

As of August 9, 2024



Sponsorship & Exhibitor details at www.panc today.org

Featured Service

Go Go Grandparent: Rides, Groceries, Meals and More for Older Adults and People with Disabilities



Go Go Grandparent provides screened & monitored services from Uber, DoorDash, Instacart and more, with or without a smartphone, and is available 24 hours a day/7 days a week! Millions of requests are fulfilled for hundreds of thousands of people living independently at home. This service is available in all 50 states, Canada, and Australia.

How does it work? Order rides for seniors, groceries, prescription medications, meals, home chores and more with a simple phone call to (855) 464-6872. Their "GoGoGuardian" technology improves the reliability and usability of partners like Uber, DoorDash, Instacart and others for people who want to live independently in their home for as long as possible. Various membership plans are available. [Click here to learn more](#) or call (855) 464-6872 extension 16.

Focused Ultrasound Therapy for PD -- Learn More at the PANC Conference!

Focused ultrasound is a noninvasive,



therapeutic technology with the potential to improve the quality of life and decrease the cost of care for patients with symptoms secondary to Parkinson's disease (PD). This novel technology focuses beams of ultrasonic energy precisely and accurately on targets deep in the brain without damaging surrounding normal tissue.

Currently, focused ultrasound is only approved for tremor in PD, but when additional clinical trial data is available, it is anticipated that focused ultrasound may be used to treat the same set of symptoms as DBS including wearing off, motor fluctuations and dyskinesias

For certain patients, focused ultrasound could provide a noninvasive alternative to surgery and has the potential to treat the underlying disease pathology and prevent progression and/or restore function.

Focused ultrasound has the potential to achieve symptomatic relief by making thermal lesions deep in the brain to interrupt circuits involved with tremor and dyskinesia.

Symptoms and targets being assessed for treatment using focused ultrasound include:

- Parkinsonian tremor – target in the thalamus (thalamotomy)
- Parkinsonian dyskinesia – target in the globus pallidus (pallidotomy) or subthalamic nucleus
- Parkinsonian tremor, akinesia or dyskinesia – target in the pallidothalamic tract

At this time, focused ultrasound is only being assessed to treat one side of the brain, so it will affect tremor or dyskinesia unilaterally. Studies are being organized to assess the possibility of treating patients bilaterally.

Dr. Lary Bodden from Kaiser Permanente will be speaking on this topic at the PANC Conference in Roseville next month. To hear his presentation and others, purchase your [online or in-person tickets here](#).

August Free PD Education & Webinars

Thursday, August 15 at 2pm

Exercise for Fewer PD Symptoms and Better Balance with the Northwest Parkinson's Foundation

Strengthening exercises to help reduce PD symptoms and better maintain balance.

[Info and registration here](#)

Sunday, August 18 at 10am

Managing Your [PD] Meds (for women) with Twitchy Woman

Sort out the cocktail of meds and supplements most people with Parkinson's take throughout the day, including interactions between any of the drugs and/or supplements, should some be taken before or after a meal, how to manage meds while traveling, and more.

[Info and registration here](#)

Wednesday, August 21 at 9am

Update on New Potential Treatments for Parkinson's with Neuro Challenge

[Info and registration here](#)

Wednesday, August 21 at 10am

Speech & Swallowing in Parkinson's with the Parkinson's Foundation

Most people with Parkinson's disease will experience changes in speech, voice and swallowing at some point during the course of the disease. Learn tools and exercises to help you better understand and manage speech, swallowing and communication problems in PD.

[Info and registration here](#)

Thursday, August 22 at 1pm

Deep Brain Stimulation with the Stockton Parkinson's Wellness Circle

Learn what Deep Brain Stimulation (DBS) is, if you are a candidate, and expectations before and after the procedure with Laura Sperry, NP, the UC Davis Medical Center's DBS program director. Also learn about current research and the future of DBS.

Attend in-person at 3400 Wagner Heights in Stockton. Call Lou at 916-382-3754 for info.

Friday, August 23 at 10:30am

Perspectives on Care for PSP and CBS with UC San Diego

A movement disorder specialist will discuss current perspectives on care for progressive supranuclear palsy (PSP) and corticobasal syndrome (CBS).

[Info and registration here](#)

Monday, August 26 at noon

Benefits of Rock Climbing for Parkinson's Disease with the Northwest Parkinson's Foundation

Learn how rock climbing provides multiple health benefits to people living with Parkinson's. Hear from people with PD who rock climb and how they have improved their physical strength, balance, mental acuity...and have a whole lot of FUN!

[Info and registration here](#)

Thursday, August 29 at noon

Deep-Dive into Multiple System Atrophy (MSA) with PMD Alliance

Multiple System Atrophy (MSA) affects balance, movement, and the autonomic nervous system, and, as an atypical parkinsonian neurodegenerative disease, it can be confused for Parkinson's and related conditions. Learn how MSA is diagnosed, symptoms of MSA, current treatment options and those on the horizon.

[Info and registration 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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