



PANC

Parkinson Association of Northern California

UPDATE

Building Community for the Journey -- September 2024

PANC SUPPORT GROUPS HERE

"Heroes didn't leap tall buildings or stop bullets with an outstretched hand; they didn't wear boots and capes. They bled, and they bruised, and their superpowers were as simple as listening, or loving. Heroes were ordinary people who knew that even if their own lives were impossibly knotted, they could untangle someone else's. And maybe that one act could lead someone to rescue you right back." – *Jodi Picoult*

**"Empowered Minds Want to Know" in 2 Weeks!
September 28 at the Roebelen Center in Roseville**



PANC Conference Early-Bird Discount Ends Tomorrow!

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

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

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

Reserved Seating for 6 -- \$300/Reserved Seating for 8 -- \$400 (by 9/20)

**Prices increase on individual tickets this Sunday by \$10*

Don't miss the resources, information, and camaraderie!
There will be many volunteers to assist in the parking lot
and getting to/from the Conference Center

**The video recording will be provided to all registrants
within a few days after the event**

Establishing Social Connection

It is incredibly important that people with Parkinson's disease and their family care partners remain connected with friends and family and form new relationships. You may find yourself isolating from others due to ongoing and unpredictable Parkinson's symptoms. Your challenges may feel like a burden or may come with feelings of embarrassment and frustration leading to loneliness, isolation, sadness and anxiety being around others. You may also find it difficult to talk about feelings and about your Parkinson's journey, but it is important to find an environment where it is safe to talk about what you are experiencing and share and celebrate "small and big victories."



Research has shown that engaging in any form of social or leisure activity can improve your quality of life and slow down the disease progression. **Positive mental health is key to quality of life.** Adopting a healthy outlook and attitude can encourage increased participation in activities, which in turn may lead to the development of new friendships. Life does not stop after a diagnosis of Parkinson's; it can open new doors to different experiences and opportunities.

Ways to ease into being social with PD

Attend the PANC Conference and learn as much as you can about resources in the community, exercise programs, and new/different treatment options. Get to know others with PD and share how you are approaching the journey that is PD.

Join a Parkinson's support group and if you are able, get involved with the planning, communication, and social activities of the group. Join a Parkinson's specific exercise program such as Rock Steady Boxing, Dance for PD, tai chi, ping pong, yoga classes for PD, etc.

A PANC support group attendee recently said, "I always enjoy engaging with my local Parkinson's community. I'm fascinated by watching other people move like me. It's a kindred spirit kind of thing that gives me comfort that I'm not alone. I also have friends who are constantly asking how I am doing. As opposed to sharing how I am, I enjoy much more educating them about this mysterious journey, as opposed to my ups and downs with PD."



THANK YOU!

Supernus Pharmaceuticals has been a longtime Presenting Sponsor for the Annual PANC Conference. We are incredibly appreciative for their ongoing support and that of all the sponsoring companies who make the annual conference possible. We wouldn't be able to gather without you. Thank you!

The Magical Power of Music for Parkinson's disease



As anyone who has ever heard “their song” can attest, the right music has the power to make you move. Healthcare providers are harnessing this power to help patients with Parkinson’s disease (PD) including Terrell Liedstrand, MA, MT-BC from McConnell Music Therapy Services and Sutter Health who will be leading a music therapy movement break at the September 28 PANC conference.

Over the past several decades, researchers have begun to uncover the neural basis of music’s effect on the brain with an eye toward treating diseases like PD. A growing body of research reveals that the influence of music is far-reaching—shaping connections in the brain, improving the senses and movement, and enhancing mood.

The brain is not a static object. It's malleable and plastic, able to change its connections and activity based on a person’s experience. Engaging with music requires a multifaceted set of skills—keeping a rhythm, hitting the correct notes, or coordinating specific body parts, for example—and may make it particularly effective in activating and reshaping many parts of the brain affected by PD.

In a series of studies, researchers provided a rhythmic beat to PD patients and instructed them to walk. Typically, PD makes it difficult to produce and maintain the rhythmic movement required for walking. But the rhythmic beats in these studies provided a metronome to help patients sync their steps, leading to improvements in gait speed and cadence.

Music is more than just a beat: it can also stir up powerful feelings, which can help PD patients. Listening to and producing music is associated with increased activity in brain areas involved with reward and emotion and increased release of dopamine. By naturally increasing the brain’s dopamine levels, music may partially counteract the loss of dopamine neurons from the progression of PD. As an added benefit, music is intrinsically motivating, which means music therapy is more effective and easier to keep up with compared to other training regimens, like conventional physical therapy.

Group music sessions also provide a social benefit, establishing a community for PD patients who may otherwise find themselves isolated and lonely. Allowing PD patients to experience camaraderie and develop social bonds likely benefits their mood and quality of life.

There are still many questions about how music affects the brain and PD and there are relatively few studies involving large numbers of research subjects that investigate the systematic changes music can have on PD. As a result, scientists do not have a clear idea about what kinds of music therapy work best for particular subgroups of the PD population. However, when looking at music and arts-based interventions, the overall level of evidence for helping those with diseases like PD is rising. With a growing body of evidence, music may help bring harmony to the brain and life of patients with Parkinson’s disease.

To learn more and experience the benefits of music therapy, register for the annual conference [here](#).



2nd Annual Topgolf Fundraiser!

Sunday, October 27 from 10am-2pm

[Get Tickets for the Swing for Parkinson's Event Here](#)

Silent Auction Bidding Begins October 20

Watch for coming details on all of the opportunities and how to participate/bid to help PANC build and provide services to our growing Parkinson's community. If you have an item of value that you'd like to donate to PANC for the auction, [please email Danielle here](#). THANK YOU!

Rally with Thousands of Parkinson's Advocates for the 2024 National Day of Action

Every year on September 17th, the Parkinson's National Day of Action, thousands of advocates across the country unite to encourage policymakers and elected officials to support the 1 million Americans living with Parkinson's disease.

This year, all are asked to join in advocating for the federal government to take steps to better understand and address environmental risk factors for Parkinson's disease. Led by the Unified Parkinson's Advocacy Council (which PANC is a member of), the National Day of Action is entirely online, so you can participate from wherever you are. It only takes a minute and every message you send gets us closer to a future free from Parkinson's disease.



How can I participate in the Day of Action?

1. [Sign a petition to the White House here](#) to urge a ban on paraquat, a harmful herbicide thought to increase Parkinson's risk by as much as 500 percent. [Here is additional information.](#)
2. [Send a \(pre-written\) email to Congress here](#) to ask them to cosponsor the HEALTHY BRAINS Act, a new bill that would direct the federal government to research the connection between the environment and neurodegenerative diseases.

No one understands Parkinson's disease better than those who live with it every day. Sharing your story with your elected officials can help them understand how their policy choices affect Parkinson's patients, families and care partners.

On National Day of Action, we invite you join in celebrating these historic advancements while urging policymakers to level up their support of the Parkinson's community and get us even closer to a cure!

Is Your Service Club Looking for Speakers?

PANC is seeking opportunities to educate local community members about Parkinson's disease and the mission, services and benefits of our organization. If you are a member of a NorCal service club (Lions, Rotary, SIRS, etc.) or know of one who may be interested in having a PANC presentation in 2025, [please contact Jan here](#).



UC San Francisco Research Study Opportunity

A new research study is available if you would like to participate. The topic of study is, "Attitudes and Beliefs Regarding Medical Research and Genetic Screening for Parkinson's Disease."

This study will help researchers learn more about people's knowledge about Parkinson's disease, as well as their attitudes and beliefs about genetic and risk factor screening and taking part in medical research. It is funded by the Michael J. Fox Foundation for Parkinson's Research.

If you choose to take part in this study, you will complete a questionnaire that asks about your thoughts on research studies and screening for genetic and other risk factors for Parkinson's disease. The questionnaire will take about 30-60 minutes to complete. You can choose how and where you complete the questionnaire either online, at your doctor's office, on paper using a printed copy and postage paid envelope, or by talking with a member of their research team in person or by telephone or computer video call.

This study is being led by Dr. Caroline Tanner and other neurology researchers at the University of California, San Francisco. If you would like to participate and/or have questions, contact the research team at (415) 353-4031.



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September Free PD Education & Webinars

Monday, September 16 at 11:30am

The importance of the gut-brain axis in Parkinson's with No Silver Bullet 4 PD

A researcher who investigates the relationship between gastrointestinal symptoms and the microbiome in Parkinson's disease will share what is known.

[Info and Registration Here](#)

Wednesday, September 18 at 9am

Exoband: What is it and How Can it Help Me [with PD]?with Young Onset PD

The creators of the ExoBand talk about this exoskeleton that leads to functional improvement in walking for the PD community. A study demonstrating the effectiveness of Exoband was published in the Journal of Neuromuscular Diseases in 2024.

[Info and Registration Here](#)

Wednesday, September 18 at 10am

Teamwork in Action: Maximizing Movement & Function in Parkinson'swith the Parkinson's Foundation

Understand how rehabilitation professionals, including physical therapists, occupational therapists, speech-language pathologists and others work together to maximize functional abilities and quality of life for individuals with Parkinson's, including managing symptoms, utilizing assistive devices, and coping with the physical impact of PD.

[Info and Registration Here](#)

Thursday, September 19 at 9am

A Conversation on Parkinson's-Related Hallucinations and Delusionswith the Michael J Fox Foundation

An expert panel will discuss what hallucinations and delusions can look like in Parkinson's, how to talk about them with loved ones and doctors, and what medication and non-medication strategies may help you and your care partners ease these symptoms.

[Info and Registration Here](#)

Thursday, September 19 at 11:30 am

Resources for Veterans with Parkinson's Diseasewith the Parkinson's Foundation

The speakers will explore the extensive resources and dedicated support services that veterans with PD have access to through the VA and the Parkinson's Foundation.

[Info and Registration Here](#)

Tuesday, September 24 at 9:30am

Why is it So Hard to Get a Good Night's Sleep with Parkinson's Disease?with the Parkinson's Social Network

The speaker will share his knowledge and expertise helping those living with Parkinson's disease to find a better night's sleep.

[Info and Registration Here](#)

Wednesday, September 25 at 8:30am

The Benefits of Urban Poling for Parkinson'swith Neuro Challenge

Learn the benefits of Nordic walking if you have Parkinson's.

[Info and Registration Here](#)

Wednesday, September 25 at 10am

Diagnosing Parkinson's Diseasewith APDA

The clinical method of diagnosing PD, progress that has been made in diagnosing PD, lab tests that can shed light on whether or not you have PD, how to get a test if your doctor hasn't ordered one, the limitations of these tests, and more.

[Info and Registration Here](#)

Wednesday, September 25 at noon

Demystifying Access to Treatments [for PD]with PMD Alliance

There are several advanced therapies available for PD beyond carbidopa/levodopa, but getting insurance authorization can be challenging. A pharmacy specialist will review roadblocks of medication access and tips for overcoming them, including prior authorizations, navigating multiple pharmacies, and overcoming hurdles for your medical team.

[Info and Registration Here](#)

Wednesday, September 25 at 1pm

Understanding Parkinson's Disease and the Impact of Home Carewith Neuro Challenge

Hiring in-home care can provide a sense of independence and dignity to Parkinson's patients, while also offering respite and education for caregivers. The speaker will discuss these impacts of in-home care and whether it is right for your PD caregiving situation.

[Info and Registration Here](#)

Thursday, September 26 at 1pm

Parkinson's Wellness Recovery (PWR) with the Parkinson's Wellness Circle of Stockton
Local Parkinson's Wellness Recovery (PWR) therapist, Laura Sifuentes, PT, will demonstrate PD
specific exercise programs for posture, alignment, weight shifting, transitions, balance and
movement.

E-mail [here for the Zoom link](#) or info or attend live at 3400 Wagner Heights in Stockton

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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