



# PANC

## UPDATE

Parkinson Association of Northern California

*Building Community for the Journey -- January 2025*

### PANC SUPPORT GROUPS HERE

*"Celebrate endings — for they precede new beginnings."*  
Jonathan Lockwood Huie



## Finding My Purpose through Parkinson's

*by Joe Staub*

*Did you know that one of the biggest reasons that getting new Parkinson's drugs approved is slow due to the lack of patient volunteers that participate in clinical trials? I'm a huge proponent of participating in trials and this is my story.*

For a long time, I knew something was wrong. Deep down, I just knew. My handwriting was getting bad, I had a tremor in my hand, my arms no longer swung when I walked, and I had trouble standing and walking because of my balance. I didn't want it to be true and prayed that it was not.

The first 10 years of my marriage were spent helping my dad. He had Parkinson's. My wife's mother was also diagnosed with Parkinson's, so I witnessed firsthand the impact and demands of being a primary caregiver and didn't want that for my wife or family.

Eventually, I found the courage to stop ignoring my symptoms and hiding it from others and shared that I had PD. There, I said it! As it turned out, this was not surprising news for those who knew me best.

The diagnosis was devastating, expected, but none the less devastating. I accepted it, after all, I had been preparing myself for a while. I was surprised at that time that the basic treatment of Parkinson's had not changed much since my dad's diagnosis in the late 1980's. I learned that the single most important thing to do is keep moving to slow the progression. My wife (a librarian) also jumped into research mode and found the right doctor and together we explored emerging treatments and therapies which gave me information about clinical trials.

I knew nothing about them, how to find the right ones, what was involved, what was expected, how long they lasted, the commitment, potential risks, the potential benefits and if they would adversely affect my health.

When I first contacted a clinical research representative, I learned about the screening

process, eligibility, how/where the trial was conducted, the goals of the study, and disclosure documentation.

A few research related links we found at that time were: [www.clinicaltrials.gov](http://www.clinicaltrials.gov), [www.michaeljfox.org/trial-finder](http://www.michaeljfox.org/trial-finder) and <http://www.questri.com/>. Many are also conducted in local towns, at medical institutions, and at universities.

Since that first one, I have participated in quite a few including simple trials that required just a single office visit, drug studies that lasted from 1 to 3 months and required several overnight stays and even completed a long trial that required a 30-day inpatient stay.

My experience participating in trials has always been positive. Some of the benefits include...

- Receiving early access to the newest drugs and therapies
- Access to expert medical care by physicians focused on advancing the treatment of Parkinson's
- Care by compassionate medical professionals who understand the ups and downs of Parkinson's and have my best interests at heart
- Meeting other people with Parkinson's on a similar journey and comparing notes, creating new friendships, and realizing that I'm not alone.

Participating in clinical trials, I have overcome many fears and anxieties plus contribute to the advancement of a cure. Next to marrying my wife and fathering my children, participating in trials is the single most rewarding accomplishment of my life. I never expected to do something like this, but I don't want others to have to endure this same journey either. This has become my sole purpose – to help others.

I ask of you, whether you are a person with Parkinson's, a caregiver, a relative or a friend, please consider volunteering for a clinical research trial. We are on the verge of a cure and trials are available for those with and without Parkinson's. With your help, progress towards the goal of curing Parkinson's is closer to a reality than we may realize!



## GRATITUDE ABOUNDS!

Thank you to the **MANY** generous individuals who donated to PANC through our 2024 year-end giving campaign. We exceeded our fundraising goal by \$10,000! Your financial gifts have direct impact on the services and benefits that greatly help those impacted by Parkinson's disease in Northern California. Thank you!



## TCE Ban is Big News for the Parkinson's Community

In December, the U.S. Environmental Protection Agency (EPA) finalized a rule banning the use of trichloroethylene (TCE), a chemical long associated with serious health and environmental risks. This ban marks a significant step towards protecting public health.

TCE, a powerful solvent, has been widely used for industrial applications such as metal degreasing, paint stripping, dry cleaning, spot removers, adhesive glues, cleaning equipment and more. Some dangers of TCE include:

- Health Risks: TCE is linked to cancer, including kidney and liver cancer, Parkinson's disease and other central nervous system disorders, liver disease,

and immune system problems.

- **Environmental Impact:** TCE can contaminate groundwater and persists in the environment, posing long-term risks to ecosystems and communities. Federal and State surveys indicate that 9 to 34 percent of the water supply sources in the U.S. may be contaminated to some degree with TCE. It is also commonly found as a contaminant at Superfund sites.

With the ban, most businesses must phase out TCE in most applications within a year and switch to safer alternatives, but for industrial applications the phase-out may take slightly longer.

**In other news, the EPA is currently evaluating Paraquat** an herbicide used for agricultural purposes, known to harm U.S. citizens, and studies have shown to be a leading cause of Parkinson's disease. **The agency has until January 17 to make a decision** on Paraquat's future availability in the U.S.

The Michael J Fox Foundation, PANC and our constituents, and many other Parkinson's organizations have been lobbying government and EPA officials to ban Paraquat which is STILL legal in the United States while most other countries have banned it's use! Stay tuned for an update in next month's *Update*.

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## Expressing Emotions on A Parkinson's Journey



Enjoy the above video from PANC constituent Terri Van Bibber entitled, "Inside Out," which was originally performed at the 2024 PANC conference. In this creative production, Terri shares her emotional and psychosocial journey regarding living with Parkinson's disease.

How do you express your emotions? Do you have an outlet to release thoughts and feelings that might be burdening you? As Terri says, "It's OK to feel ALL of your feelings."

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## APDA's Free Annual Virtual Conference

The third annual American Parkinson Disease Association's Virtual Parkinson's Conference is now open for registration. Taking place on February 19-20 from 9am to 1pm PST daily, attendees will hear PD updates, get expert advice, learn real-life perspectives, and have some fun with music and exercise classes. Attend 15 sessions from the comfort of your home.



Information, agenda, and [register here!](#) For questions or problems with registration, contact ADPA at [apda@apdaparkinson.org](mailto:apda@apdaparkinson.org) or 800.223.2732.

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## Rebuilding Sacramento's Accepting Safe at Home Applications

Now is the perfect time to focus on safety and independence at home. Rebuilding Together Sacramento's *Safe at Home Program* helps qualified residents -- especially older adults -- live securely with free home safety modifications. Their services are designed to reduce risks, prevent falls, and make home a safer place.

To participate, recipients must reside in Sacramento, El Dorado, and North San Joaquin Counties, plus the city of West Sacramento. [Click here](#) to verify if you fall within their service region.

Key features of the program:

- Bathroom Safety: Grab bars, shower stools, and handheld shower hoses for easier and safer bathing.
- Mobility Support: Handrails and transition ramps to help you move confidently throughout your home.
- Fall Prevention: Toilet support frames and in-home fall risk assessments.

If you or someone you know could benefit from these free services, spread the word and get access to tools needed to stay safe and independent.

## Seeking Members for the PANC Board of Directors

Are you someone that raises your hand to help? Do you want to give back to the Parkinson's community? Now is your opportunity!



PANC is searching for individuals to help grow the services and reach of our expanding and hands-on organization. Individuals are welcome from all career backgrounds including but not limited to financial, senior care, legal, fundraising, media relations, government, and retirees! PANC is committed to building a board of directors that represents the broad diversity of our NorCal Parkinson's constituency. It's fun, directors learn a lot, plus they get connected to a community of incredible individuals like no other.

[Click here to learn more and for the application](#) which is due **March 21**. To discuss the opportunity, please email Jan Whitney [here](#) or call her at 707-582-3624. We can't wait to hear from you!

**Changes to Medicare Part D:  
Out-of-pocket Costs  
Capped at \$2,000**



Beginning this month, patients can benefit from a new \$2,000 cap on out-of-pocket expenses within the Medicare Part D program. Patients can also opt into a "smoothing" measure that will allow you to spread out-of-pocket costs evenly throughout the

year. Seniors must choose to opt-in to the "smoothing" period; however, the out-of-pocket cap is automatic.

Review the resources below provided by the Movement Disorders Policy Coalition (PANC is a member).

- [One-pager](#)
- [Video](#)
- [FAQ document](#)

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## Michael J Fox Honored with the Presidential Medal of Freedom

Actor, author and advocate Michael J. Fox has been awarded the nation's highest civilian honor. On Jan. 4, Fox received the Presidential Medal of Freedom in recognition of his efforts in Parkinson's disease research with The Michael J. Fox Foundation for Parkinson's research (MJFF).



President Biden presented the medal in a White House ceremony, which honors individuals who have made exemplary contributions to the prosperity, values or security of the United States, world peace, or other significant societal, public or private endeavors.

"Receiving the Presidential Medal of Freedom is humbling, an honor I could never have anticipated," Fox said in a press release statement from MJFF. "I'm grateful for this recognition, which I share with the patients, families and researchers who have brought us closer than ever to ending Parkinson's disease once and for all."

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## January Free Webinars

*Thursday, January 16 at 9am*

**Managing the Hidden Symptoms: Mood and Motivation Changes in Parkinson's** with the Michael J. Fox Foundation

How mood changes can impact life with the disease, tips and treatments to manage them, and the latest research on these non-motor symptoms.

[Info and register here](#)

*Monday, January 20 at 1pm*

**Nutrition and Parkinson's Disease: Enhancing Well-Being through Diet** with the Parkinson Society of British Columbia

How food choices impact the body's detoxification system, a key process in the progression of PD, as well as the role of essential organs, such as the gut and liver, in maintaining health, and how disruptions in the gut microbiome may contribute to the development and progression of Parkinson's.

[Info and register here](#)

*Wednesday, January 22 at 9am*

**Benefits of Speech Vive [for PD]** with Neuro Challenge

SpeechVive is a wearable speech device allowing you to speak louder and more clearly, every time you talk. The speaker will explain how to use this new device.

[Info and register here](#)

*Thursday, January 23 at 11am*

**Practical Tips to Maintain Independence and Make Life Easier** with the Parkinson's Community of Los Angeles

Practical tips for leisure and recreation including exercise, car arrangement, travel, socialization, and adaptations for hobbies such as gardening and painting.

[Info and register here](#)

*Wednesday, January 29 at 8am*

**The Power of Food: Supporting Parkinson's Wellness Through Nutrition** with Neuro Challenge

[Info and register here](#)

*Wednesday, January 29 at 10am*

**A Deep Dive into Deep Brain Stimulation** with the Parkinson's Foundation

An in-depth look at what DBS involves, how it works, and who may benefit from the procedure. Participants will also hear from individuals who have undergone DBS who will share their experience of the preparation, procedure, and outcomes.

[Info and register here](#)

*Wednesday, January 29 at 10am*

**Focused Ultrasound for PD & ET** with PMD Alliance

How focused ultrasound technology is used to treat Parkinson's Disease (PD) and essential tremor (ET) and hear testimony from a focused ultrasound patient with PD who will share his treatment experience.

[Info and register here](#)

*Friday, January 31 from 8-11am*

**Learn More. Live Better. Parkinson's Symposium** with the Parkinson's Foundation

Expert speakers will provide information to help you find the balance between a proactive approach to living with PD and wondering what lies ahead.

[Info and register here](#)

*Friday, January 31 at 11am*

**Psilocybin Therapy for Depression in PD** with the Parkinson's Community Los Angeles

How oral psilocybin can be used for depression, anxiety, and motor symptoms in people with Parkinson's.

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

[Ways to Support](#)

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