



PANCC

UPDATE

Parkinson Association of Northern California

Building Community for the Journey -- June 2024

PANCC SUPPORT GROUPS

"There are three stages of a man's life: he believes in Santa Claus, he doesn't believe in Santa Claus, he is Santa Claus."

Anonymous

Registration Opens July 15th **Annual Education Conference** **September 28 in Roseville** **"Empowered Minds Want to Know"**

2024 Conference Topics:

- Sharon Krischer (aka "Twitchy Woman") -- See photo
- A Care Partner's Story
- Cognition Issues
- Focus Ultrasound
- Orthostatic Hypotension
- Research Updates & Panel Discussions
- Movement Breaks
- Audience Q&A
- Lunch and Exhibit Hall of Resources
- View the conference flyer [here](#)



Photo courtesy of Sharon Krischer

Interested in conference sponsor and exhibitor opportunities? E-mail Jan [here](#)



My Mom's Parkinson's

by Danielle Hand-Nicholls

They say it takes a village. For my family, it takes a village to help support my mom who has Parkinson's disease. Our village includes me, my brother, my teenage son, my aunt, and now a 24-hour live-in who all help to ensure she has the care that she needs and deserves.

Helping mom manage her care can be a lot and include things such as: schedule/take her to medical and other appointments; convince other family members to pull their share of the care; ensure she has food and medicines; help

her with home maintenance and repairs; and monitor all the miscellaneous components of running a household. As an adult child of a person with Parkinson's, I must juggle Mom's needs all while also doing my best to maintain my own family, household, and my Parkinson's disease.

One of the hardest parts for me is to experience mom feeling helpless and dependent upon us. She really hates it, and she doesn't like to 'bother' us either. You see, she has always been the family/friend care giver when someone was ill. Today, she can't even bathe or make her own meals. She detests how the disease is progressing and is continually searching for the right concoction of meds that will reduce her symptoms.

As her daughter, watching mom go from Superwoman to not that is super frustrating. I feel helpless in not being able to fix the situation and it's scary witnessing what she goes through each day. My future could be the same. On the flipside, sharing this disease with my mom has given us the opportunity to fight it together and bond in a way that we probably wouldn't have otherwise.

Being with mom and others with PD has given me a new perspective on aging. First, I have more empathy, patience, and protectiveness than I ever have. Going through this with my mom has allowed me to slow down and appreciate interactions with people more than ever before. Going through this, I realize that folks can fight hard and do the work to maintain a better quality of life or choose not to and have a very different experience with this disease. It's been super important to my own well-being and hers to make connections, do research, exercise, listen, rest, love her the best that I can, and have fun!

One of the greatest discoveries that I've had on this journey is how fortunate we are in Northern California to be part of such a vibrant and robust Parkinson's community to lean on for support. Our medical systems work together to share and provide best practices. There are several Rock Steady Boxing (RSB) locations and multiple other exercise opportunities specifically for those with PD to participate in throughout Northern California.

Organizations like PANC work behind the scenes to provide services for people with PD and their care partners (including us kids). It's been a pleasure to serve as a PANC director for the past two years and put effort into making things better for my mom, me, and the community. I recommend that all children who have parents with Parkinson's disease learn from, get involved with, and donate to organizations like PANC and make this world a better place for those who gave the world to us.

NorCal's Real Estate Community Supporting Parkinson's

Last week, Kevin McDonald from McDonald Group Real Estate and comedian Joe Crespillo from Realty 1st, who has Parkinson's, presented PANC's Executive Director Jan Whitney with a check for \$5,167.51 raised at their spectacular *Comedy in the Barn* event in April.

Attendees, sponsors, and comics all came together to celebrate our Parkinson's heroes and contribute to the well-being and services for those affected.



The NorCal Real Estate community has been incredibly supportive of PANC, and we are so

appreciative of the many industry leaders who are truly contributing to the health and welfare of our constituency.

According to McDonald, "We are happy to have fun while donating to a great cause. The real estate industry can be competitive, but we really are like a small family and enjoy helping one another and great organizations like PANC that provide needed assistance for those in our community. Seeing Joe and others fight Parkinson's disease can be tough, but we all support one another. Talking about Parkinson's and its effects can be a little shaky, but Joe has fun with his situation and his comedy helps him and others to cope with it. I'm so pleased to be a part of this event."

Webinar on National Plan to End Parkinson's Act Don't Miss It -- This Coming Monday

At noon PST on Monday, June 17, the American Parkinson's disease Association President and CEO, Leslie A. Chambers will answer questions and interview Ted Thompson, the Senior Vice President of Public Policy at the Michael J. Fox Foundation who led the advocacy team that was instrumental in getting the bill passed (see below).

[Reserve your spot by clicking here](#) and join for a compelling conversation to learn more about how this new law will impact people with PD today, and in the future.



Big Parkinson's Policy Updates!

National Plan to End Parkinson's Act

WE DID IT! In late May, the U.S. Senate passed the National Plan to End Parkinson's Act! For those that helped and contacted your legislators in favor of this Bill, thank you!

Now that the bill has passed through the Congress and Senate, it is sitting on the president's desk where it is expected to be signed into law. This piece of legislation is the first of its kind dedicated to ending Parkinson's disease.

"When we started the Foundation, we could only dream of the breakthroughs the Parkinson's community has experienced over the last year, from the [discovery of a biomarker](#) to the federal government advancing a plan to end Parkinson's," Michael J. Fox said in a [press release](#). "A National Plan to End Parkinson's is a historic opportunity to accelerate our search for cures, and now is the time."

The legislation (H.R.2365/S.1064) brings public and private sector specialists — Parkinson's patients, their care partners, researchers, clinicians, and members of federal agencies — together in a federal advisory council. It is to regularly report on its progress to the U.S. Congress and the secretary of the Department of Health and Human Services.

It intends to work to increase federal research funding, create standards and measures to promote Parkinson's prevention, improve ways of diagnosing the disease earlier, develop more effective pathways to Parkinson's treatments, and find new or better patient care models. Addressing health disparities in diagnosis, treatment, and clinical trial participation, as well as enhancing public awareness of the disease, are other potential outcomes.

None of this would have happened without your impassioned advocacy and partnership. Thank you for your voices and leading the charge for change!

Paraquat Ban Passes Through California Assembly

In what was a complete surprise, legislation to ban the use of the highly toxic herbicide paraquat in California was passed last week by the California state Assembly. Paraquat has been linked to Parkinson's disease for decades.

Assembly Bill 1963, authored by Assemblymember Laura Friedman (D-Burbank) and sponsored by the Environmental Working Group, now moves to the CA Senate. If approved by the full legislature and signed into law by Gov. Gavin Newsom by the end of September, A.B. 1963 would ban the use of paraquat on California fields and orchards starting January 1, 2026.

"Paraquat's dangers to health and the environment are undeniable," Friedman said. "With many countries already banning it, California must act to safeguard its residents, particularly those in rural areas, from this toxic weedkiller. The mounting evidence linking paraquat to serious diseases like Parkinson's, non-Hodgkin lymphoma and childhood leukemia cannot be ignored."

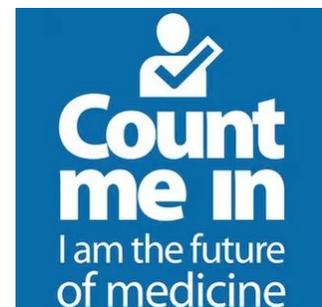
"Farmworkers, their families, and nearby communities in California face serious risks from toxic pesticides like paraquat," said **Dolores Huerta**, renowned labor leader and civil rights activist, at a press conference in support of AB 1963 alongside Friedman and EWG. "This dangerous weedkiller has been used since the 1960s, endangering millions of essential agricultural workers, their families and local residents. It's time for action. California must ban paraquat now to protect future generations from harm."

Although more than 60 countries have banned paraquat, the EPA continues to permit its use on crop fields, disregarding mounting evidence of harm – even though the agency does not allow the pesticide to be used on golf courses due to risks to groundskeepers and the public.

PANC will let you know how you can help to get this Bill passed and set the standard for the rest of the country.

Parkinson's Clinical Study at Sacramento State University

Sac State's neurophysiology and exercise physiology labs are hosting a clinical study on the effects of acute intermittent hypoxia and transcranial static magnetic stimulation on people with Parkinson's disease and looking for volunteer participants for the study.

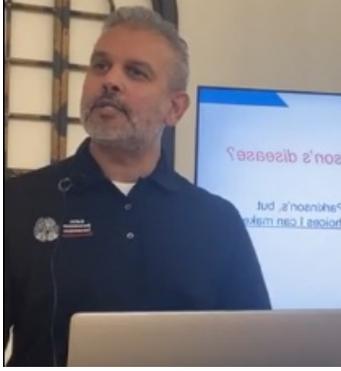


There is a growing body of research that supports acute intermittent hypoxia as beneficial for the brain and may even be able to improve movement behaviors and cognition. Using this type of hypoxia in combination with transcranial static magnetic stimulation may be able to boost the effects on the brain.

If you are interested in participating and want to learn more, [click here for the study flyer](#) or [send an email here](#) with a request for additional information.

PD Hacks -- Things We Don't Get Around to at the Appointment

On May 23, Dr. Suketu Khandhar from Kaiser Permanente



made a presentation to the Arden Arcade Parkinson's Support group entitled, "PD Hacks -- Things We Don't Get Around to at the Appointment." This was an exceptionally helpful and information-packed presentation of suggestions and tips for all those affected by PD.

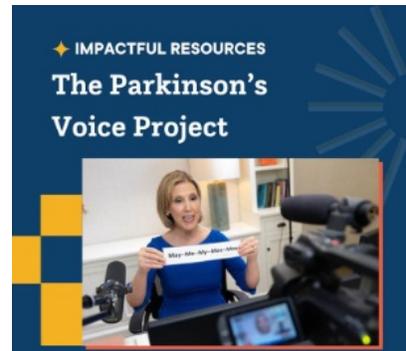
You can view [Dr. Khandhar's slide deck by clicking here](#) and watch the presentation on PANC's Facebook page for the next 15 days here. (Heads up that Dr. Khandhar appears about 10 minutes into the video). Thank you to Dr. Khandhar and the many other exceptional regional professionals who donate so

much time to educating and supporting our Parkinson's community.

The Parkinson's Voice Project

The Parkinson Voice Project is a 501(c)(3) nonprofit organization dedicated to preserving the speech and communication of individuals with Parkinson's and related neurological disorders through continuous speech therapy, follow-up support, research, education, and community awareness.

90% of people with Parkinson's are at risk of developing a weak voice that can lead to serious speech and swallowing difficulties. Parkinson Voice Project has developed an effective program that combines education and individual speech therapy (Speak OUT!). They conduct daily "Speak OUT" voice practices, weekly sing-a-longs, and provide resources for speech-language pathologists. [Click here to locate your nearest Parkinson's Voice Project provider.](#)



Experience Parkinson's Differently Through Storytelling and Improvisation

Dr. Robert Cochrane, a local visual storyteller, motivational speaker/coach and Parkinson's care partner, has a couple of outstanding programs coming up if you are interested. Contact Dr. Cochrane directly to register or for additional information. He's hosting, "Fielding Your Dreams" starting June 18 and "The Parkinson's Prison and the Hero's Journey to Escape" course in August. [Click here for additional information.](#)

Worksheets, Checklists, and Assessments

The Davis Phinney Foundation has free worksheets, checklists, and assessments that are a great way to help you become more aware of the timing and characteristics of your symptoms, document those symptoms, note changes, and discuss them with your doctor. You can also log progress toward achieving your wellness goals, such as exercise, and see how far you've come and where you need to go.

They are designed so you can fill them out right from your computer or tablet and you can then print it out and take it to your next appointment, conversation, or treatment session. [Click here for more information.](#)

Monday, June 18 at 11 am

Parkinson's Medications Explained with Banner Health

Explore the medications used to treat Parkinson's and how they work in the body

[Info and registration here](#)

Wednesday, June 19 at 1 pm

Palliative Care with the Michigan Parkinson's Foundation

At meeting time, [click here to login and join](#)

Wednesday, June 19 at 1 pm

Newly Diagnosed with Parkinson's with the Neuro Challenge Foundation for Parkinson's

If you or your loved one have been recently diagnosed with Parkinson's, chances are you are looking beyond your doctor for answers to your questions and for support on how to live well on this new journey. Tune in here for information and help.

[Info and register here](#)

Thursday, June 20 at 9am

You Want to Volunteer for Parkinson's Research: Now What? with the Michael J Fox Foundation
Panelists will discuss the experience and impact of participating in research studies, how to find the right study for you, what to expect as a participant, and how you can help shape what and how research is done.

[Info and register here](#)

Thursday, June 20 from 10am-Noon

Debriefing the Caregiver Role with the Parkinson Society of British Columbia

For PD caregivers who lost their loved one in the past 2 years. This is an online group session dedicated to sharing experiences and coping with loss and grief.

[Info and register here](#)

Friday, June 21 at 11am

Parkinson's Dystonia: Symptoms, Manifestations & Treatments with the Parkinson's Community of Los Angeles

A movement disorders neurologist will discuss how to recognize and treat the symptoms of dystonia in Parkinson's.

[Info and register here](#)

Thursday, June 27 at 11am

Overcoming Exercise Barriers in Parkinson's with the Parkinson Association of the Rockies

Strategies to overcome common obstacles to exercise and establish a routine that is both enjoyable and beneficial.

[Info and register here](#)

* 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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