

Building Community for the Journey -- February 2025

PANC SUPPORT GROUPS HERE

"In the coldest February, as in every other month in every other year, the best thing to hold on to in this world is each other." — *Linda Ellerbee*



8th Annual Walk to Cancel Out Parkinsons

Saturday, April 5 from 9 to 11:45 am Maidu Park, Roseville

Information and Registration Here Event Flyer Here

The joint regional Lions Clubs are thrilled to announce they are hosting the 8 th Annual Robert G. Smith Walk to Cancel Out Parkinson's to benefit PANC on Saturday April 5. Registration is now open!

To register, form and join teams, order early registration t-shirts, create and donate to individual fundraising pages, and even volunteer, check it out here! Early bird walk registration for \$40 runs through March 7. COP Walk t-shirts are provided to those who register through March 22. Lunch is included with registration.

Bring your friends and family to join for this wonderful day of inspiration, vendors fair, fellowship, and exercise. This is a fun and family-friendly event and a terrific way to help PANC provide services to people with Parkinson's and the care partners throughout Northern California.

Thank you to Amneal Pharmaceuticals, Auburn 49ers Lions Club, Boston Scientific, Embarcadero Lions Club, Higgins Diggins Lions Club, McGinnis Solutions, Supernus Pharmaceuticals, and Weintraub Tobin Law Firm for sponsoring this inspirational event to date. For sponsor and exhibitor opportunities, click here or call 707-582-3624. See you in April!



SATURDAY, APRIL 5 MAIDU REGIONAL PARK, ROSEVILLE

Registration from \$40 -\$45

Registration/Resource Fair @ 9:00 am * Walk @10:00 am * Lunch/Awards @11:00 am







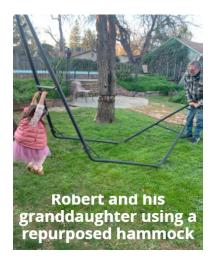
Join for a special day of celebration, determination, and friendship! All funds raised support local services for people with Parkinson's disease and their care partners.

Celebrate the heroes amongst us!

- Short and ADA friendly course
 Can't participate? Donate to
- Lunch and resource fair Register as a team or individually
- New! Participate as virtual walker! Fundraising prizes
 - Early registration includes official COP walk t-shirt

Sponsored by Lions District 4-C5 & an endorsed project of CA Lions MD4 Proceeds benefit the services of the Parkinson Association of Northern California, a 501(c)(3) nonprofit

Register online at panctoday.org (or) rgsmith.raceroster.com



Nearly Random Reflections of a Person with PD

By Robert J. Smith, Jr.

Act 1: Mortality and An Important Day to Remember

"I'm playing the back nine." That's what Tom Hanks told a Saturday Night Live Show alumni during their Youtube chat/hike. He added, "That's a more poetic version of 'my days are numbered."

Since I was given my Parkinson's disease diagnosis, I've given myself permission to be more direct with people. I surely don't want you to get the impression that I binge-watch celebrities. But the fact that Harrison Ford, Mr. Han Solo himself, has taken on the role of an aging therapist struggling to tell his daughter he has PD (a wonderful series called "Shrinking,") it's time to give Michael J. Fox another grateful nod for spreading the word and making Parkinson's as important as it is.

I spend a lot of time pondering the significance of occasional "coincidences" that pop up. Take yesterday for example. It was a call to schedule an evaluative process to see if I qualify for DBS (Deep Brain Stimulation) surgery. The date of that important meeting is

February 19th which is also the day American Marines stormed the beaches on Iwo Jima in World War II. I happen to remember that detail because in 1995, this was the date of our deadline to finish a 90-minute "Iwo Jima: Red Blood, Black Sand" documentary which aired on many PBS stations.

Over 6,000 Marine soldiers perished at Iwo Jima. The documentary was a huge success and touched many brave survivors of that battle and helped them to process long held grief. To me, February 19th is a hopeful coincidence.

Writing about this topic gives me the opportunity to thank Norm Sahmaunt for his service to our country during that difficult battle. I met Norm, a Kiowa Indian, after I finished working on the documentary -- I would have LOVED having Norm in that film. We became fast friends, and I also became great friends with his progeny. We have stayed in touch ever since. By the way, Norm was the first person I met who had Parkinson's Disease.

Act 2: Poor Mr. Parkinson. He Gets Blamed for Everything!

"Don't blame poor Mr. (James) Parkinson for your angry outburst!" That was the gist of my wife's recent discord. The one thing we PD patients have in common is that no two of us manifest the disease in the same way. I also happen to believe we are a tad too familiar with our unique symptoms. Mine are that both hands tremor so typing can be a slog. Even my mouth is now involved in the movement business. I drool, which serves no useful purpose that I can discern. And, as hinted above, I have a shorter fuse than I used to BPD (before PD). Finally, I get stressed out by things that shouldn't bother me that much (i.e. anxiety).

What do I do about this? Well, even though I have not yet taken a PD boxing or dance class, most weekdays my wife and I have our granddaughter Dolores on site who scripts her own movement therapy classes for us. On the mornings she goes to preschool, my wife and I go walking. The "Shrinking" show reminds me to eat well and hydrate.

I'll close this part of my PD reflection on a positive note because I just received a call from the radiologist. My second evaluative appointment (a brain scan) is now scheduled!

Act 3: The Power of Positivity for PD Patients and their Caregivers

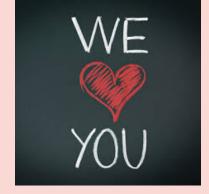
Today, as we finished our morning walk, Patty and I saw our neighbor for the first time in a long while. He recently spent a month in the hospital and was treated for complications from surgery. He confided that his wife (and caregiver) was struggling. Slowly, the jovial banter between the three of us brought out this fine gentleman's feisty and funny side. It felt so good to have played a role in lifting all our spirits.

Too often negativity becomes the lower hanging fruit, which is never nourishing for our complex yet gentle souls. So, I hereby absolve ANYONE with PD for feeling guilty about not being good enough to our very demanding bodies. Who knows? You, too, may be prone to anxiety -- so take a deep breath or two. And smile. The real purpose of our being here is to help each other out. As my dad used to say: "It's pretty basic."

PANC LOVES OUR CONSTITUENTS!

It's an honor to be part of an incredible community of heroic individuals!

Thank you



2024 PANC Conference Recording Now Available

Click Here for the Link and Check Out All the Resources

Experience it all over! You are invited to view the 2024 PANC Education Conference recording.

Enjoy sessions from "Twitchy Woman," Terri Pease and her



The 2025 Conference is scheduled for **Saturday, October 18th**. Attend in person or virtually. Save it on your calendar and watch for registration opening soon.





Brian Anthony's Road to Singing with "Martha and the Muffins" and Advocating for Parkinson's

While downsizing his home, a chance introduction connected Brian Anthony with Martha and the Muffins lead singer, Martha Johnson, who was looking for voices from the Parkinson's community for her new song about PD called Slow Emotion.

Soon, Brian found himself in a state-of-the-art studio, rehearsing with four other singers—none of whom had ever performed together. Their shared experience with Parkinson's

gave Slow Emotion its heart. What started as a song became a movement, inspiring a documentary that captures the creative process and the resilience of the human spirit.

Slow Emotion was co-written by Martha Johnson, Mark Gane, and songwriter Fabio Dwyer. They all have Parkinson's disease. The idea for the song was suggested by Martha's neurologist as a means to raise awareness of the disease and to show that life and creativity don't end with a diagnosis.

You're invited to watch this powerful journey firsthand. Join on February 26, 2025, at 11am for a virtual screening of Slow Emotion and the behind-the-scenes documentary. Stay after for a live discussion with Brian, Martha, and the team behind the project. Reserve your spot here.



Spark the Night for Parkinson's

Spark The Night marks a profound evolution in advocacy efforts for PD. While April 11, World Parkinson's Day, remains crucial, focusing on the night draws attention to the hidden struggles of Parkinson's—when isolation, anxiety, and loneliness often feel most overwhelming. But within this darkness, we find a guiding light: the enduring hope that promises a brighter tomorrow.

This moment is an invitation for global solidarity, an opportunity to spark collective change. "Spark the Night" represents a mission to illuminate cities worldwide in unity and support for the 11.8 million people living with Parkinson's. On April 11, 2025, each blue light will shine as a symbol of a story, a voice, and an unwavering commitment to a better future for those affected by the disease.

If you want to volunteer to help contact buildings, bridges and iconic landmarks OR if you have a building to illuminate and want to tell him about it - email Larry Gifford from PD Avengers here and let him know the building, location, and any contact information you may have.



Parkinson's Wellness Recovery Program

PWR!Moves are the core of the Parkinson's Wellness Recovery Program's PD-specific functional exercise and physical therapy programs. The Basic 4 PWR!Moves are designed to each target a skill known to deteriorate in

people with Parkinson disease, which often lead to loss of mobility and function.

The PWR!Moves can be practiced in multiple positions, made progressively more physically and cognitively challenging, and used differently to target each person's unique symptoms.

PWR!Moves can mitigate symptoms and rebuild functionality, no matter how you incorporate them into your life. They're beneficial in stand-alone group exercise classes, integrated into your daily activities and routines (such as activities of daily living,

recreation, sports, and hobbies), in physical and exercise therapy settings. Click here for information about the program and here for virtual opportunities to participate.

The EPA's Decision on Paraquat

As mentioned in recent *Update* articles, the EPA had a January 17, 2025, deadline to complete their review of paraquat's registration in the U.S. Paraquat dichloride, commonly referred to as "paraquat," is one of the most widely used herbicides in the United States. It is also often referred to as Gramoxone (a popular end-use product) which is a tool used for the control of weeds in



many agricultural and non-agricultural settings. Unfortunately, the agency instead asked for a delay on making a determination to continue or discontinue its use and filed a motion to withdraw its 2021 interim decision so it can complete a new assessment, which they estimate could take up to four years.

PANC and numerous other Parkinson's organizations are incredibly disappointed by the EPA's decision to delay action. This is a dangerous chemical that threatens the health of American people, especially agricultural workers and those living in rural communities. Nearly 70 countries have banned its use and it's illegal to utilize on golf courses in the U.S.

The Michael J Fox Foundation, the Unified Parkinson's Advisory Council (PANC is a member), the Environmental Working Group, and many others will continue to work towards a nationwide ban. Stay tuned. We may need your voices to amplify this message to Federal and California legislators and EPA officials. Parkinson's disease doesn't wait for bans to occur, and neither should we.



707-582-3624.

Applications Open for PANC Board of Directors

PANC is committed to building a Board of Directors that represents the broad diversity of our NorCal Parkinson's constituency, and we'd love to have you on board!

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

Parkinson's Studies

1) The Department of Neurology at Stanford is looking for people with Parkinson's disease and healthy volunteers, between the ages of 50 and 80. Click here for the flyer.



The goal of this research is to learn more about changes in cognition and motor function with aging. Study participation includes:

• 2 days of testing at baseline, and again after 2 years

- MRI brain scan
- Cognitive and motor exams
- Remote sleep assessment (via Oura ring)
- Participants will be compensated for their time

2) The Neurophysiology and Exercise Labs at the California State University of Sacramento is looking for any person living with Parkinson's disease that meets eligibility requirements (determined after screening visit). Click here for the flyer.

The goal of this research study is to evaluate the effects of acute intermittent hypoxia and transcranial static magnetic stimulation on people with Parkinson's disease. Study participation includes:

- Answer physical activity questionnaires
- Wear a fitness tracker for one week
- Undergo blood draws for biomarker analysis
- Perform fitness tests including a supervised maximal aerobic exercise test and 6-minute walk test.
- Be evaluated for motor and non-motor symptoms
- Measure brain activity using non-invasive brain stimulation using transcranial magnetic stimulation.

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. E-mail khs-sacneurophyslab@csus.edu for additional information and to register.



Plan Your Giving and Help Our Parkinson's Community Friends

The Parkinson Association of Northern California Fund, established at the Sacramento Region Community Foundation, supports the mission of PANC now and into the future. Until there's a cure, the many families affected by Parkinson's disease will need support and services for some time to come.

As you plan your estate and legacy giving, please consider a gift to benefit PANC. For information on the various planning options, please contact the Sacramento Region Community Foundation's planned giving team at legacy@sacergcf.org.

What I Didn't Say: A Journey Through Parkinson's

Hosted by the Parkinson's Support Group

of Sonoma County Sunday, April 13 from 3-4:30 pm Sebastopol Community Cultural Center

Tickets available here -- \$20

Written and performed by Matthew Moore, this powerful 50-minute play is a journey through Parkinson's spoken loudly, fervently and with unfettered compassion. It gives a voice to not only those affected by Parkinson's, but its caregivers as well.



The production, void of props or scenery save for two stools and a curtain behind which the sole two actors playing husband and wife can switch to their roles as spouses, educates the audience in an entertaining and informative fashion plus showcases the progression of PD, especially its many psychosocial issues. Followed by a O&A session with Matthew.

February Free Webinars

Tuesday, February 18 at 2pm

Overcoming Hurdles to Exercise with the Davis Phinney Foundation

Ways to overcome some of the common hurdles to exercise possibly encountered while living with PD.

Info and register here

Tuesday, February 18 at 5pm

Managing Neuropsychiatric and Other Non-Motor Symptoms with the University of Kansas **Medical Center**

Non-motor symptoms that can occur even before a PD diagnosis, as well as the various symptoms that may occur throughout the disease course. Plus, treatment options for non-motor symptoms, particularly drooling, orthostatic hypotension, hallucinations, delusions, memory impairment, depression, and anxiety.

Info and register here

Wednesday-Thursday, February 19-20 from 9am-1pm each day

Virtual Parkinson's Conference with the American Parkinson Disease Association.

Topics include new PD treatments on the horizon, emergency preparedness and Parkinson's, the power of connection and care, voices of Parkinson's, pain management in PD, how to avoid falling, how palliative care can help people with PD, and fun, interactive activities including drumming, journaling, improv, and fitness. Agenda here

Info and register here

Wednesday, February 19 at 10am

Impulse Control Disorders: Understanding and Managing the Challenges [in PD] with the Parkinson's Foundation

What causes impulse control disorders (ICDs), how to manage them, and practical tools to support those impacted. Part of the "Wellness Wednesday" webinar series. Info and register here

Wednesday, February 19 at 10am

Medications, Alternative and Advanced PD Therapies for Newly Diagnosed with the Parkinson Society of British Columbia

An overview of treatment options for individuals living with Parkinson's, addressing when treatment or medications should begin, whether there is a benefit to delaying the start of medications, and when to start advanced treatments, as well as viable alternative forms of therapy such as cannabis.

Info and register here

Thursday, February 20 at 9am

How Government Policies Impact Parkinson's Research: Wins and Next Steps with the Michael J

Fox Foundation

How Parkinson's policies make a real difference in the lives of people living with the disease or at risk for developing PD.

Info and register here

Thursday, February 20 at 9am

World Parkinson's Coalition Partner Highlight for Veterans with PD and their caregivers with the World Parkinson Coalition

Learn about the National VA PD network, specialized care provided, benefits available through the VA, and the relationship between PD and toxin exposure for US veterans. Info and register here

Tuesday, February 25 at 10am

Living Well with Parkinson's for Newly Diagnosed with the Parkinson Society of British Columbia Practical tips and strategies designed to help slow the progression of Parkinson's symptoms, and stay motivated, active, and in control of your health. Info and register here

Tuesday, February 25 at 5pm

Living Your Best with Parkinson's Disease & Treatments on the Horizonwith the University of Kansas Medical Center

The importance of seeing a PD specialist, having a multidisciplinary care team, getting the most from a clinic visit, questions to ask, information to provide to the doctor, and resources available for those with PD, caregivers, and loved ones. Plus, treatments currently under investigation for PD including those designed to delay or potentially reverse disease progression, as well as investigational symptomatic treatments.

Info and register here

Thursday, February 27 from 11:30am-1pm

Veterans and Parkinson's: Mental Wellness with the Parkinson's Foundation

The real impact of loneliness and isolation, offer strategies for managing post-traumatic stress disorder, provide guidance on overcoming fears associated with symptoms, and share resources and support options designed to relieve isolation and nurture meaningful connections.

Info and register here

Thursday, February 27 at noon

Proactive Brain Health: Evaluating Environmental and Chemical Exposure with Ray Dorsey, MD from the University of Rochester and PMD Alliance

Learn about the recent banning of trichloroethylene (TCE), an extremely toxic chemical with a known link to movement disorders. Dr. Dorsey will discuss the role pesticides, dry cleaning chemicals, and air pollution have on our health, as well as what we can do to lower our risk of exposure.

Info and register here

Thank you to Stanford Parkinson's Community Outreach for providing information in this section.

How did you like this email?







* Contact Jan Whitney here if you are interested in placing a sponsor article in the *Update*.

www.panctoday.org

Ways to Support

Parkinson Association of Northern California | 1024 Iron Point Rd., Ste 1046 | Folsom, CA 95630 US

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