



"Building Community for the Journey" ----- January 2024

PANC SUPPORT GROUPS

"Be at war with your vices, at peace with your neighbors, and let every new year find you a better man." — *Benjamin Franklin*

Seeing the Possibility with Parkinson's

by Melissa Tafoya,
Owner & fitness trainer at *Hope in Your Corner*
a *Rock Steady Boxing Sacramento* affiliate

While I don't have Parkinson's, I know what it is like to navigate life differently both physically and cognitively. As a toddler, I remember seeing my dad's severely deformed feet, his crutches, cane, and permanent limp all due to his rheumatoid arthritis. His flareups were always a dark time, but he persevered. Crutches, orthotics, prescription medication, icepacks, heating pads, and Ace bandages lying around the house were all normal to me.

Like my dad, experiencing several auto immune diseases myself has taught me how to work through and live with chronic pain. Plus, I grew up as an undiagnosed woman with autism spectrum disorder. I understand that I have non-conventional learning patterns, difficult emotions, elevated pain, and an especially soft heart. These unique traits have given me the strength and fortitude to experience life differently and to see possibility in the seemingly impossible.

At our facility, *Hope in Your Corner*, my clients with Parkinson's disease (PD) are not only my "Champs", but they're also like my kids -- I love them so much. I want to equip my Champs with the skills and confidence that my dad taught me through his perseverance. Too often I hear people refer to Parkinson's as a debilitating disease. I don't see it that way. I've realized that a sedentary lifestyle is the biggest source of debilitating disease. If we live long enough, we will all have something significant to challenge us. It's exciting to report that most of my Champs have overall health and fitness levels far superior to their peers who are not living with PD. Parkinson's has the potential to be a motivator to move more, eat better, learn new skills, and have a social life. It really is about embracing life, ALL of it.

Living in Northern California and specifically Sacramento, my Champs are fortunate to have access to an overwhelming number of resources and healthcare for Parkinson's. (See the article below for online options for PD activity.) Most recently, two of my Champs began neuro music therapy through their healthcare provider. This technique uses metronomes and favorite songs to improve gait function.

My client "Go-Big" Greg now uses a metronome app on his phone to navigate through challenging spaces whether at home or running errands. This not only reduces his freezing episodes, but also keeps him better acquainted with his smartphone technology. When Greg doesn't have access to his phone, he actively seeks songs on store speakers to match his stride to the beat. "Go-Big" also applies his metronome app when walking to and from our exercise stations in the gym. This Champ is developing new skills, sharpening his senses, and taking pride and ownership of his own wellbeing then shares his successes with his comrades to then help them. Greg's confidence navigating public spaces has soared and he has embraced the possibility of something better. It is incredibly inspiring to watch him and so many others in our fight family flourish with PD.

Embrace the possibilities, practice gratitude, and love the entire journey. Learn to love the whole you.

P.S. If you have a story of perseverance and hope you'd like to share with our Parkinson's family, please email Jan [here](#).

Your Help Is Needed!

US House Passed the National Plan to End Parkinson's Act: The Senate is Up Next

In late December, the U.S. House of Representatives passed the National Plan to End Parkinson's Act! Now we need the Senate to follow their House colleagues' lead and advance this critical bill. This first of its kind of legislation is aimed at preventing, treating, and curing Parkinson's disease and unites the federal government and private enterprise to create an advisory panel to look at:

- Increasing federal research funding.
- Developing more effective pathways for treatments and cures.
- Improving early diagnosis.
- Sparking new and improved models for patient care.
- Creating standards and measures to prevent Parkinson's disease.
- Enhancing public awareness of the disease.

Click [here](#) to learn more about easily contacting your state senator to vote yes on this bill that will help so many.

Save the date!

**Walk to Cancel Out Parkinson's
Maidu Park in Roseville**



The Lions Club is excited to once again host this fun annual event that benefits PANC. Add **April 6**, during Parkinson's Awareness month, to your calendar and watch for additional details coming soon. We look forward to walking with all of our Parkinson's friends and family in the warmth of Spring!

Year-End Donations Were Remarkable. Thank you!

Thank you to ALL of the gracious individuals who made the 2023 giving season a huge success! PANC will be able to continue with our mission, support groups, respite grants, annual conference, and sustain and build new services into the coming year thanks to your generosity.



There is SO much work to be done and so many more people to help. Until there is a cure, we believe in hope and healing every day. The entire community of PANC is AMAZING and we are so incredibly grateful for each one of you who participates as a donor, volunteer, support group member, sponsor, medical community partner, friend, and more. Gratitude abounds for what we are accomplishing together, and more help is always welcome.

It's Time to Move! Comprehensive List of Live Online PD Exercise Classes

Do you have a 2024 resolution to move more? For those with Parkinson's disease (PD), exercise is as important as medications and essential to managing the disease and can help reduce its symptoms. PD frequently affects movement, balance, and coordination and it can be improved with regular physical activity. Additionally, it can support the preservation of muscle endurance, flexibility, and strength. Apart from its physical advantages, exercise can also positively affect mood and cognitive performance, which can be advantageous considering the mood swings and cognitive difficulties that may be associated with PD.

For those who are unable to leave home or may not have access to local PD appropriate exercise options, Stanford Parkinson's Community Outreach has developed an incredible **list of creative in-home online exercise opportunities** that can work for most individuals. These live virtual programs allow you to move in your home with the added benefit of some social interaction (albeit virtual). The many classes provide a great opportunity to try something exhilarating and new and make friends at the same time. Enlist your care partner or family members to join to double the joy!

It is recommended for individuals with PD to engage in exercise routines tailored to their specific abilities and needs and to consult with healthcare providers, such as physical therapists who specialize in Parkinson's disease, for personalized exercise recommendations.

Stanford Parkinson's Community Outreach Exercise Class List

Industry Partner

Inspirational Program to Aid in Your Parkinson's Journey

**Day One: The Parkinson's Prison and the Hero's Journey to Escape
Begins January 16* for 16 weeks via Zoom**

**New students accepted until January 23*

Instructor: Robert Cochrane, PhD

Click here for additional information about Day One

Hurry! Only a couple of spots left!

Day One refers to the date of one's Parkinson's disease (PD) diagnosis. This new evidence-based class is for everyone in the PD community, including care partners and medical/wellness experts, to discover, craft and share their stories.

Dr. Ray Dorsey, author of *Ending Parkinson's Disease*, says the Parkinson's community must tell their stories to gain the attention, understanding, and funding we need to end PD. Our mission is urgent. PD is the fastest growing neurological disease in the world. Together, by discovering and sharing our stories, we can fix this.

According to a recent graduate, "This course surpassed the benefits of therapy. Within a secure environment, we could express our reflections and emotions regarding the challenge of facing Parkinson's disease and navigate through the spectrum of feelings from day one (the day of diagnosis) to the present."

Click here to register for the Parkinson Foundation endorsed program! The sessions are 90 minutes and recorded for your convenience. Questions? Contact Robert by **email here** and listen to **testimonials here**.

"I guess it comes down to a simple choice: get busy living or get busy dying."

- Andy Dufresne



Adaptive Living "Gadgets" for Parkinson's disease

Last year PMD Alliance partnered with University Hospitals Cleveland and a person with Parkinson's (PWP) to survey PWPs about which gadgets and devices they find most useful. The researchers found that only about 15% of PWP take advantage of occupational therapy, which is where they are most likely to learn about assistive devices.

Numerous devices are available that could make your life or that of your loved one more comfortable or even easier. Check out the following webinars for information on what might be a good fit for your situation. (There may be a very short commercial before the video begins).

- [PMD Alliance Gadget Webinar](#)
- [Stanford Parkinson's and Brain Support Network Gadget Sharing Webinar 2023](#)
- [Stanford Parkinson's and Brain Support Network Gadget Sharing Webinar 2021](#)

2024 Sponsorship & Marketing Opportunities for Affiliated Companies

Remove
'shoulds' from
your vocabulary
this year. Start
your journey of
self-love now!
Kelly Martin

January Free PD Webinars

Tuesday, January 16 at 10am

Understanding Sleep Issues in Parkinson's Disease *by the APDA Virginia Chapter*
[Register and info here](#)

Thursday, January 18 at 9am

Explore Exercise for Life with Parkinson's *by Michael J Fox Foundation*

The best exercise for Parkinson's is the one you'll do. But it's not always that easy and you have questions, like how many times a week to exercise, how to work out with symptoms, as disease progresses, or as you get older and have more aches and pains, and how to motivate a loved one with PD to move more.

[Register and info here](#)

Thursday, January 18 at 11am

Yoga Workshop *by the Parkinson's Community of Los Angeles*

A demo of how the ancient art of yoga has been shown to improve both motor symptoms (i.e. tremors or rigidity) and non-motor symptoms (stress and mood regulation) for people living with PD.

[Register and info here](#)

Thursday, January 18 at noon

Treating the Person, Not the Patient by *PMD Alliance*

Managing PD often means taking pills and utilizing treatments, but rest, physical exercise, and mental healthcare, along with a balanced diet, are also extremely important. The speaker will discuss developing a personalized plan suited to your lifestyle to achieve successful treatment.

[Register and info here](#)

Sunday, January 21 at 9am

Balance and What You Can Do About It by *Twitchy Woman*

[Register and info here](#)

Friday, January 26 at 11am

DBS vs Focused Ultrasound: Which is the Right Option for You? by *Parkinson's Community Los Angeles*

The speaker discusses the benefits of deep brain stimulation (DBS) and focused ultrasound.

[Register and info here](#)

Tuesday, January 30 at noon

Staying on Your Feet at Home and in the Community by *PMD Alliance*

Webinar discusses the challenges to staying on your feet and remaining active when you have PD, including motor and non-motor symptoms, emotional and psychological symptoms, and other barriers like stigma, access to PD specialized therapy and group exercise, transportation, and financial burden. The speaker will share ways to manage some of these challenges and creatively problem-solve how to stay on your feet and live fully!

[Register and info here](#)

* Contact Jan Whitney [here](#) if you are interested in placing a sponsor article in the *Update*.

www.panctoday.org [aaaaaaaaaaaaa](#) **Ways to Support**

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