

Building Community for the Journey

April 2024

PANC SUPPORT GROUPS

"The only thing you should feel entitled to is gratitude" -- J.S. Mason



SAVE THE DATE!

Big Day of Giving is Thursday, May 2 Donate starting April 18

TOGETHER WE ARE BETTER. WON'T YOU HELP?

Mark your calendars for another 24 hours of fun and philanthropy!

As valued community supporters of PANC, we are relying on you to help us reach our goal of raising \$45,000 so we can continue providing much needed support groups, educational opportunities, respite grants, newsletters, and so much more to people with Parkinson's and their family members.

To join the giving team, between April 18 and May 2, please visit PANC's Big Day of Giving webpage here to make a financial gift. All proceeds stay within our local NorCal community!

Thank you in advance for your participation and for making life better for so many affected by Parkinson's disease. We truly couldn't do this work without our supportive community.

One Way to Deal with a PD Diagnosis: Continue Doing What You LOVE For As Long as You Can

by Robert Smith

The best advice I've received in the 3 years since I've been diagnosed with PD came when I read an article in the March PANC e-newsletter. Thank you, Tom Turkington, for being a deputy sheriff for 34 years AND for urging me as a fellow PD

person to continue doing what I love. For me, that means writing, so here it goes!

Sometimes my shaky PD hands don't cooperate, but, for now, I'm able to type on my computer's keyboard so I'm writing this article to remind my Parkinson's peers (and others) about the importance of gratitude and remembering the wonderful people who

have tried to teach us life's most valuable lessons.

For me, I'm starting this list with my *first* teacher, my mom. While she modeled hundreds of life skills for her children, one that stands out is that she was an enthusiastic letter writer herself. Mom was an *early morning* letter writer, often at her LC Smith manual typewriter at the crack of dawn. Just like mom, here I am, at 2:00 a.m., beginning to type this article.

Mr. Class is the next valuable teacher in my life. He taught high school English and always wore a sport coat and tie. He taught me that wearing a tie could be a life-saving uniform and I followed suit much later in life when I also became a teacher at the ripe age of 60.

Then there is Mrs. Alexander who had the honor of trying to teach me for the second half of 4th grade. This was after my dad's employer uprooted our family from Studio City (near Hollywood) to Stockton and I was now in a brand-new school. I quickly learned it was a little different there -- some of my fellow 4th grade students had graduate degrees in the use of the f-word! So much so that I made the tactical error of trying to impress my new schoolmates by handwriting the f-word on Raymond Hench's binder.

When Raymond showed Mrs. Alexander my work, she said, "I don't know what they taught in your last school, but that's not a word we use at Lincoln Elementary!" Fortunately, Mrs. Alexander's real teaching skills went far beyond the public shame she presided over when I wrote on Raymond's binder. In fact, as the year went on, she taught me about the fine art of a guided missile called "encouragement."

A non-credentialed teacher I want to thank is Garland Mines, a World War II veteran who I interviewed for a documentary called *Iwo Jima: Red Blood, Black Sand*. Not only was Garland the only Black American to be interviewed in our film, but he was also the only interviewee to cry on screen. The rest of his co-stars had experienced the searing pain inflicted by mortal combat, but Garland was the only one who shed tears publicly. He told of his personal shame for having left his surviving friends behind on Iwo Jima, and without taking that difficult extra step of saying, "goodbye" to them. For Garland to express that heartfelt regret in such a public manner took profound courage. His humility was a lesson I will take to my grave.

My second non-credentialed teacher is Michael J. Fox, the star of *Back to the Future*, one of my favorite films. I have bonded with Mr. Fox for lots of reasons besides our shared Parkinson's Disease diagnosis. I loved reading his memoirs and watching the *Still* Documentary about Fox's PD journey. The most impactful thing I've learned from this celebrity teacher is his ability to make fun at his own expense and as he jokes about his experience with this challenging disease.

My final non-credentialed teacher for whom I'm so grateful is my granddaughter Dolores Garcia-Smith. Thanks to the magical energy that happens when you are in the company of a two-year-old, I recently fell in love with the city of San Francisco again. On a recent trip there, Dolo (her current nickname) carried a baton of bread to help lead an orchestra of ducks with a new park buddy and found sheer delight in a pink balloon. Everyone would endorse the joy this kid was dispensing that day.

I'll conclude my article with a question: "Where do all these lessons come from?" My current vantage point tells me to venture out into the world with hope in my heart. And, sometimes it really helps to be in the company of an engaging 2-year-old.

About the writer: Robert Smith is a retired teacher. He taught at a number of schools in Sacramento County. It was during his last year of teaching that Mr. Smith's right hand began to shake. His students taught him how to accept his disability with grace and humor.

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.



Cancel Out Parkinsons Walk Was a Success!

Thank you to the joint Lions Clubs and all of the walkers, cheerers, many volunteers, sponsors, and exhibitors for making the 7th Annual Robert G. Smith Walk to Cancel Out Parkinson's a complete success! The crisp spring morning air made for a perfect celebratory stroll and the joy and heroism exhibited by attendees was palpable.

With the generosity of donors and participants, just over \$30,000 was raised, which will help PANC continue to provide valuable support groups, respite grants, and other services. Thank you!

Save April 5, 2025, on your calendar for next year's walk!

Congratulations to the Sacramento Young Onset Support Group/Hope in Your Corner Team for their success as the top fundraising team and Terri Van Bibber for her incredible efforts as the top individual fundraiser! Kay Griffin and Karen Switzer were also honorable donation earners.

Much gratitude to the following companies who supported the event as sponsors:

Captain -- Supernus & the Embarcadero Lions Club

Sergeant -- Acorda Therapeutics, Higgins Diggins Lions Club, McGinness Solutions, & Rock Steady Boxing/Quinn's Gym

Deputy -- Auburn 49ers Lions Club, Boston Scientific, Kyowa Kirin, NuMotion Mobility, Sacramento Rehabilitation Hospital, & Weintraub Tobin

These companies and non-profits also shared their resources with attendees: Amevian Home Care, Auburn Senior Center & Matter of Balance, Brightstar Care, Canine Companions, Northern California Care Planning Council, Oasis Senior Advisors, Parkinson's Foundation, Placer Independent Resources, Placer Protect, Silver Wishes, and UC Davis Department of Neurosurgery.

A special debt of gratitude to members of the Lions Club who make it happen including Dave

and Dana Johnson, Richard Decuir, Vickie Smith, and Steve Straton who comes all the way from **Bakersfield** each year to supply and cook the terrific hot dog lunch.

See you next year!

Donate to Big Day of Giving by Clicking Here Starting April 18



Sleep Advice from Dr. Hadi

by Dr. Ehsan Hadi, Dignity Health

Parkinson's disease (PD) has traditionally been known as a motor condition. A significant aspect of PD is also recognized as a non- motor component. To provide the best care and quality of life in PD, both motor and nonmotor

components of PD should be considered.

One of the notable non-motor symptoms of PD includes sleep disorders, which people can begin experiencing years before an actual PD diagnosis is made. Sleep disorders can vary from dream acting out behaviors (REM behavior), sleep apnea, difficulty falling/ staying asleep, excessive daytime sleepiness (EDS), fatigue and more.

EDS has been reported as inappropriate or undesirable sleepiness during waking hours, whereas fatigue has been defined as a sense of physical tiredness or lack of energy. These symptoms can have a big impact on quality of life, affecting physical functionality/accidents, socialization, mood, thinking process etc., which makes it essential to regularly screen, monitor, and manage these symptoms.

Treatment should be multimodality and it is important to address both non-pharmacologic and pharmacologic solutions. Non-pharmacologic approaches can include identifying underlying triggers, making lifestyle modifications, using light therapy, participating in cognitive behavioral therapy, using mental stimulating activities, modifying socialization practices, avoiding drops in blood pressure, and utilizing natural supplements.

Pharmacologic management can include discontinuing/minimizing daytime sleep-inducing medications, optimizing PD medications to improve nighttime sleep, and considering wakefulness promoting agents such as caffeine, modafinil etc.

Talk with your doctor or members of your PD team about sleeplessness that you are experiencing to come up with a plan that will be most successful for you.

Order Dave Iverson's *Winter Stars* book, the Kindle version, For a Discounted Rate This Month

During the month of April and to celebrate Parkinson's Awareness month, the Kindle version of Dave Iverson's caregiving story, *Winter Stars*, is available to purchase for just \$0.99.



Dave spoke at the 2023 conference and read excerpts from this book which shares his beautiful caregiving journey with his beloved mother. Click here to learn more and order.



2nd Annual Comedy in the Barn Event Benefitting PANC Tickets Here

Featuring the incomparable Parkinson's comic, Joey C and other comedians

Friday, April 12 from 7 - 9 pm

Join for a fun evening. This is an open barn, and the comedy is adult!

Watch "Matter of Mind: Parkinson's" Documentary

If you missed the April 8 PBS broadcast of the new documentary, *Matter of Mind: Parkinson's*, it is now available to watch here.

In this film, three people navigate their lives with resourcefulness and determination in the face of a degenerative illness, Parkinson's disease. An optician pursues deep brain stimulation surgery, a mother raising a pre-teen daughter becomes a boxing coach and advocate for exercise, and a cartoonist contemplates how he will continue to draw as his motor control declines.

Research Study Looking for Participants

The University of Rochester Computer science department is running a one-time, online, observational study about a PD screening tool they are developing. The research team is looking for participants with and without PD to complete the online study. Participation takes about 30 minutes and involves completing speech and motor tasks in front of a web camera, and then answering some questions to provide feedback about the tool.

Participants are compensated with a \$15 Amazon gift card. Those who are interested in the study can complete **this form here** and a study team member will follow-up.

Click Here If You're Interested in Serving On PANC's Board of Directors

April Free PD Webinars

Tuesday, April 16 at 11 am

What is Occupational Therapy & What Can it Do for Me? by the Parkinson's Association of the Rockies

About occupational therapy (OT) services and how it can help people diagnosed with PD maintain independence and navigate their lives with more efficiency and in meaningful

ways.

Register and Info Here

Tuesday, April 16 from 7 to 9pm

<u>Intimacy with Parkinson's</u> with the Parkinson Society of British Columbia A discussion on intimacy and sexual functioning in PD. Delve into the challenges and explore strategies to address emotional and physical barriers. Couples are encouraged to participate together, as the webinar focuses on relationship dynamics and communication. Participants have the option of remaining anonymous during the presentation.

Register and Info Here

Wednesday, April 17 at 10am

Exploring Longevity and Progression by the Parkinson's Foundation Explore why people with Parkinson's progress differently, how to live well in the marathon of PD, and how treatment and care needs may change over time.

Info and Register Here

Wednesday, April 17 from12:30-2pm

<u>Mind and Body Program: Less Stress, More Nutrition!</u> by the American Parkinson Disease Association

Share your favorite recipes in a friendly environment with nutrition tips and tricks, simple recipes, and ways to manage your stress.

Click here at the time of the webinar to join

Thursday, April 18 at 9am

<u>Let's Talk Taboos: Hard-To-Discuss Parkinson's Symptoms</u> with the Michael J Fox Foundation

Expert panelists will get frank about some of the more difficult-to-discuss realities of living with Parkinson's from drooling to bladder issues to memory problems to sexual dysfunction. They'll cover research, treatment and practical tips for dealing with hard conversations, embarrassment and uncomfortable moments.

Info and Register Here

Thursday, April 18 at 2pm

<u>Lips Sealed: What You're Not Telling Your Doctor</u> with PMD Alliance
Are there things you aren't telling your healthcare provider about living with
Parkinson's? Whether it is a symptom, relationship issue, or outlook on life, the webinar
host wants to understand what things you aren't disclosing and why. <u>Share your</u>
anonymous experience by completing this form and then join the webinar for a discussion
on common challenges, why people aren't sharing these with their providers, and why
communicating all experiences can improve quality of life.

Register and Info Here

Monday, April 22 at noon

Parkinson's Doesn't Discriminate: A Panel Discussion with PMD Alliance

A panel of experts will discuss disparities in care for those who identify as members of the global majority (people of African, Asian, Latin American, or indigenous descent) and/or the LGBTQ+ community. They will share challenges, countermeasures, and why this is important to everyone, even if you're not a member of one of these groups.

Info and Register Here

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Thursday, April 25 at 11am

<u>Strategies for Successful Fall Prevention in Parkinson's</u> with the Parkinson's Association of the Rockies.

Strategies to manage concerns regarding falling and how to avoid injuries.

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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