



PANC

Parkinson Association of Northern California

UPDATE

"Building Community for the Journey"

February 2024

PANC SUPPORT GROUPS

"To love and be loved is to feel the sun from both sides."

David Viscott



The Blessings We Found Along the Way

by Rick Newman

On Valentine's Day, my wife Dawn and I were discussing our Parkinson's journey over the years and how so many things have fallen into place, making the road far more promising than when we first received the life-altering news. Our chat continued with how thankful we are for the progress that research has made since that time, all the support that is now available, and the hope and supportive community of friends that we have gained since diagnosis.

This summer, it will be 31 years since Dawn at the age of 42, received her diagnosis of Parkinson's disease. It was 1993 and we were raising 3 young children in Fairfield. She came home from her neurology appointment and said the doctor diagnosed her with Parkinson's. I asked, "What's that?" Her answer was, "some kind of nerve/brain disease" that is causing her trembling hand, dragging left leg, and stumbling. We had no idea what Parkinson's was, and the neurologist was not very informative or helpful. We searched Solano County for help or any information on the disease and came up pretty much empty handed. There were no support groups, no movement disorder specialists in her medical group, and no real recommendations on what to do next except take a medication called Carbidopa Levodopa.

Soon after Dawn's diagnosis, we were burdened with additional challenging news when we both lost our jobs when Mare Island closed. However, fortune came right back! I am a Navy veteran and at this time was in the Naval Reserves and earned a position at the San Francisco VA Hospital (SFVA) in the engineering department and soon learned that I'd be working on a Parkinson's movement disorder clinic that would bring in nationally known Parkinson's movement disorder doctors. This stroke of luck gave us the opportunity to learn more about PD from them as I was building their clinic. This became incredibly helpful since my wife was unable to receive treatment at the VA because she's a non-vet and was receiving minimal care through her health system. Within 3 years of her diagnosis, she was unemployed, disabled, and the disease was progressing. I'm incredibly

grateful for all that I was able to learn at that job and helped her as much as I was able during this time.

In another stroke of luck, after the 911 attack, many reservists were activated to active-duty Navy, so we both now received our treatment at Travis Air Force base. We spoke with the physicians about Dawn's condition and how it had been progressing and negatively affecting her daily life. They indicated that they had not treated Parkinson's patients, so I told them about the wonderful Parkinson's clinic where I was working, about their research on PD, and deep brain stimulation (DBS). So, the Travis team signed an authorization for Dawn to visit the SFVA hospital's PD clinic and was admitted to a research study and then in 2005 received an early version of DBS.

This procedure was an immediate game-changer for her. After that, the visible symptoms mitigated for quite some time and this fortunate treatment gave her many good years of a full life by relieving tremors, pain, and stiffness. We were blessed to have our lives changed and benefit from a medical arena that had previously provided very little for PD patients to one of some of the best in the country. By this time, Michael J Fox had been diagnosed and was also moving the needle of research and information forward.

After Dawn's fortune of receiving DBS, we agreed to become further involved in the Parkinson's world and do our best to spread the word about PD and help others. The SFVA was now providing us with guidance and started support groups plus we became involved with the Michael J. Fox organization. We also found PANC and got involved because they provide much help and resources on the local level. We are now PANC Support Group facilitators where we get to share with others on what's available and everything that is changing for the better.

I have learned through our PD journey how incredibly strong my wife is in not giving up, especially during really difficult times. She has Parkinson's, but Parkinson's DOES NOT have her. She continues to be an incredible wife and mother and exists in a life as normal as possible, even as the disease advances causing her additional pain and immobility.

Our lives have been forever changed by PD, but we are so thankful for the good that has come and hopeful for further advances in treatment and disease mitigation. Dawn receiving that initial devastating diagnosis, losing and change jobs, my activation to active duty and changing medical treatment, and the incredible folks at organizations like MJFF and PANC all ended up as blessings in disguise. I hope everyone on this path also becomes energized about new treatments coming forward and finds hope and encouragement to get involved and make a difference as we collectively fight this battle called Parkinson's disease.

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](#).



7th Annual Walk to Cancel Out Parkinsons

Saturday, April 6 from 9 to 11:45 am

Maidu Park, Roseville

[Registration and Event Website Here](#)

[Event Flyer Here](#)

The joint Lions Clubs are thrilled to announce they are hosting the 7th Annual Robert J Smith Walk to Cancel Out Parkinson's to benefit PANC on Saturday April 6. Registration is now open!

A new website makes it seamless 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. Popular local band, The Vino Banditos, and Mike and Sherry will provide entertainment for the event.

Bring your friends and family to join for this wonderful day of inspiration, vendors, 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. We look forward to seeing you in April!

World Parkinson Coalition Research Spotlight

The World Parkinson Coalition (WPC) Research Spotlight series highlights six expert scientists chosen from the work they have published (or will publish) about Parkinson's disease over the past year. The monthly topics include:

- The rise of 5-HT: How serotonin could change PD therapy
- Does α -synuclein contribute to cognitive and psychiatric symptoms of Parkinson's?
- Pre-clinical models of levodopa-induced dyskinesia
- What is the key pathology to Parkinson's?
- Update on prodromal Parkinson's
- Inflammation in Parkinson's

[Click here to register](#) for one or any of the five left of the six-part series and to learn more. Each webinar will be recorded and available for viewing.

Please Help a Local College Student

and Take a Short Survey

Ms. Julia Dang is a senior design student at UC Davis. Her eventual goal is to design clothing to aid people with dexterity challenges from neurological disorders including those with Parkinson's disease.

Julia is working on her senior thesis and could use some input on what might work best for people affected by Parkinson's. Can you please help her by answering a few questions so she can develop clothing prototypes that could best assist you or others in the future? [The short survey is here](#). Thank you in advance for your help!



Tell the EPA to Ban Parkinson's-Linked Pesticide

The EPA recently announced it intends to let the agricultural industry continue to utilize paraquat, a herbicide linked to Parkinson's disease and banned in more than 50 countries. Syngenta, paraquat's primary manufacturer, has been indicating to the EPA to ignore scientific studies on paraquat's health risks. Cases of Parkinson's disease have more than doubled since 1990 and thousands are now suing Syngenta, alleging paraquat exposure led to their Parkinson's.

It will take a tidal wave of grassroots support to get the EPA to accept the science. Please join the Environmental Working group in Washington DC to get this accomplished by adding your name to their petition. Since 1993, the Environmental Working Group (EWG) has spotlighted outdated legislation, harmful agricultural practices and industry loopholes that pose a risk to our health and the health of the environment. [Click here to join EWG on a Paraquat ban in the U.S.](#)

The logo for eBay FOR CHARITY. The word "eBay" is in its signature multi-colored font, followed by "FOR CHARITY" in a bold, black, sans-serif font. To the right of the text is a blue and yellow awareness ribbon.

eBay > eBay for Charity > Parkinson Association of Northern California

eBay for PANC!

Did you know that you can buy or sell on eBay and benefit PANC services at the same time?

"eBay for Charity" empowers community members to support the causes they care about when they buy and sell on the popular platform. This means you can repurpose your treasures and sell through eBay on behalf of PANC, determine what portion of the sale goes to PANC, and receive a donation receipt upon sale. Using eBay for Charity also reduces seller fees and provides increased tax savings. [Learn how you can sell for PANC here](#).

You can also purchase items listed for the benefit of PANC [here](#).

Statistics show that items tagged on eBay that benefit charity may sell faster and even at an additional premium price. Donate 10% or more of your item's proceeds, and it will be featured on an attention-grabbing charity ribbon that helps the sale too!



Santa Rosa ParkinsonWISE Graduates

Congratulations to the latest group of individuals who received certificates for their participation in the January ParkinsonWISE training in Santa Rosa. This group of passionate individuals dedicated a day to learning about best practices in working with people with Parkinson's disease in their respective exercise-related professions. Thank you to instructor Jennifer Park from Sacramento State for the wonderful instruction.

If you're interested in attending a ParkinsonWISE training, you can learn more [here](#) and email Sharon [here](#). To find ParkinsonWISE trained professionals in your neighborhood, click [here](#)!

Parkinson Support Center of Northern Nevada's Music & Motion Event

Thursday, April 18 at the National Automobile Museum in Reno, NV

The Parkinson Support Center of Northern Nevada is hosting an inaugural event of Music & Motion™ that features prominent cars owned by performing artists as well as those driven by legendary racers who were challenged by Parkinson's.

Actress Vanessa Williams will be moderating the event and joined by Rasheda Ali, known for her acting and as the daughter of Muhammad Ali, who lived with Parkinson's for over 20 years. Shelby Hall will also speak. Shelby is from a family with a history in the world of off-road racing and proud multi-time Baja 1000 class champion, Rebelle Rally X-Cross winner, business owner, and athlete. Her grandfather, Rod Hall, was a pioneer in off road motorsports and set many records and diagnosed with Parkinsonian disease in 2014 with his final race in 2017 at age 80 before his passing. [Click here for additional information and to purchase tickets.](#)

CEU Training Course for Mental Health Professionals on PD

Dr. Eric Egli, a retired psychologist, Parkinson's expert, and immediate past PANC Board member helped the San Diego Parkinson's Association develop a continuing education course entitled, "Working with People with Parkinson's and Their Families: A Guide for Mental Health Professionals." This course was developed with the Zur Institute to train mental health professionals on the behavioral and mental health needs and best practices

for working with this population.

There is a great need for professionals to whom referrals can be made for assessments and care for patients, care givers, and families affected by PD. The goal of this course is to get more individuals trained and additional help out there for many who need it. [Click here for information](#) and please forward to those who may be interested.

February Free PD Webinars

Sunday, February 18 at 10am

Tremble Clefs for Women with PD with Twitchy Woman

Audience: Women with PD

Learn about Tremble Clefs, a therapeutic singing group for people with Parkinson's. (This talk was postponed in December 2023.)

[Registration and Info Here](#)

Tuesday, February 20 at 11:30am

New PD Diagnosis (last 3 years): Living Well for Newly Diagnosed by the Parkinson Society British Columbia

Insight on the crucial role of exercise in managing the progression of Parkinson's symptoms and advice on tailored exercises and proactive measures to help individuals stay active and potentially slow down the impact of PD on daily life.

[Registration and Info Here](#)

Wednesday, February 21 at 11am

Dizziness with PD by the Parkinson Association of the Carolinas

[Register Here](#)

Thursday, February 22 at 12pm

Managing Changes in Communication & Voice with PD with the Parkinson Association of the Rockies

Tools and techniques to improve verbal and non-verbal communication at home, in public settings, and at the workplace.

[Registration and Info Here](#)

Wednesday, February 28 at 10am

New to Parkinson's: Care Partner Basics by the Parkinson's Foundation

It takes time to learn the best ways to help a spouse, partner, or loved one living with PD. This program will offer tips on how to make a positive impact in the life of your loved one living with Parkinson's while also supporting yourself.

[Registration and Info Here](#)

Wednesday, February 28 at 10am

Preparing for Care Needs in PD with the Parkinson Association of the Rockies

The care challenges you may encounter as a person living with PD, or as a care partner and options and resources to stay at home, including care management services, in-home care services, and when it may be time to consider a senior living community. Learn what steps you can take now to prepare for the potential care needs of the future.

[Registration and Info Here](#)

Thursday, February 29 at 11am

Dystonia symptoms, manifestations, & treatments by the Parkinson's Community of Los Angeles

Recognizing and treating symptoms of PD dystonia.

[Register and Info Here](#)

* 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

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