

NORTH COUNTY PARKINSON'S SUPPORT GROUP

September 2019



NEWSLETTER for La Costa-Carlsbad, Fallbrook, Oceanside, and Rancho Bernardo Support Groups

Wow! One Social Opportunity After Another!

Fall Potluck - September 16 Monday 11:30 - 2:00 Gracious hosts of the village of Fallbrook Chapter of NCPSPG will prepare the main course, and you are asked to bring a side dish or dessert. Come and enjoy the relaxed country life and warm hospitality. Please RSVP and let Sam know that you're coming and what you're bringing. **Sam Cooper**, Social Chair, scprphd@gmail.com or call/text **520-820-0339**.

Parkinson's Association of San Diego's **Sunset Soiree "Knock Parkinson's Out of the Park" - Saturday October 5** This is the major fundraising and educational gathering at Del Mar Plaza that helps pay for PASD's significant support activities across the County. Your NCPSPG Board is participating with a display table exhibiting our activities. Details on the event are outlined in the flyer that's attached to this newsletter.

Empowerment Day - Mission Bay - Friday November 15. This comprehensive all-day event has more than 15 speakers, each expert in their field. A catered lunch offers time to socialize, meet over 30 vendors, and compare notes on important updates. (Social AND educational event)

Cruise the Mexican Riviera November 30- December 7 - a cruise hosted by UCSD Support Group Network sailing on the Holland America ship *Oosterdam* from San Diego with ports of call of Cabo San Lucas, Mazatlán, and Puerto Vallarta. Reservations are being handled by AAA Travel representative Liliana Almeida at 619-397-6434 or almeida.liliana@aaa-calif.com

Our Annual Holiday Luncheon - Saturday December 7 - A festive meal held at Vista's Shadowridge Country Club where we welcome the holidays with fun and song - a great way to wrap up a very successful year.

Pictures worth a thousand words



What could be more fun than *S'mores*? More and more *S'mores*! Maybe finding old friends in videos of previous NCPSPG gatherings. Or just sharing good conversation.

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Support Group Meetings

RANCHO BERNARDO - TUESDAY - note day change September 3rd 10am - noon (NCPGS Sponsored) (usually meets first Monday of each month) **San Rafael Catholic Church**, 17252 Bernardo Center Drive, RB (San Diego) **Speaker:** Kindra French, 101 Mobility Center **Topic:** **Mobility and Safety Solutions**, helping PwP Gain Freedom and Independence. Call **Carol Maher 760 749-8234**

LA COSTA CARLSBAD – Wednesday September 4th 1pm - 3 pm (NCPGS Sponsored) (first Wednesday of each month) **Christ Presbyterian Church**, 7807 Centella St, Carlsbad, CA 92009 **Speaker:** **Jonathon Simon**, San Diego Sheriff's Department Crime Prevention unit. **Topic:** - **Safety and Crime Prevention**, emphasis on County programs for seniors, including the *Take Me Home* program. Breakout groups follow. Call **Rex McCoy 760-519-9588**.

OCEANSIDE - Wednesday, September 11th (NCPGS Sponsored) 1pm - 3pm (second Wednesday of each month) at **Oceanside First Presbyterian Church 2001 S. El Camino Real , Oceanside.** **Speaker:** **Stacy Rivera, MSW**, social worker **Topic:** **Advanced Directives**, including **Power of Attorney for Healthcare**, the **POLST** form, the **Five Wishes** form, **Hospice care**, **Palliative care**. Breakout groups follow. Call **Paul Dawson 760-497-1200**.

FALLBROOK Monday, September 16th (NCPGS Sponsored) (normally meets fourth Friday of each month) **Christ The King Lutheran Church**, 1620 S. Stage Coach Lane, Fallbrook. ***This month we host the Fall Parkinson's Potluck on September 16. See the front page.*** Call **Irene Miller 760-731-0171**

ATYPICAL Parkinson's (Caregivers only) Wednesday, September 4th 11am - 1pm (first Wednesday of every other month) at Tri-City Wellness Center, 6250 El Camino Real, Carlsbad. Contact **Darlene Gerow 619-806-9649** darlene.gerow@gmail.com

ATYPICAL Parkinson's (PwP & Caregivers) Monday, September 16th 1pm - 3pm (third Monday of the month) at UCSD, East Campus, 9423 Health Science Drive, Medical Center Modular 1, Room 140, La Jolla. Contact **Darlene Gerow 619-806-9649** darlene.gerow@gmail.com

NCPGS Board of Directors

Wednesday September 18th 1pm - 3pm

Tri-City Wellness Fitness Center, conference room, 6250 El Camino Real, Carlsbad. Call 760 497-1200

Physical Exercise

CARDIFF LOCATION - Tuesdays & Thursdays 11am - noon (NCPGS Sponsored) Encinitas Elks Lodge, 1393 Windsor Rd., Cardiff. Take I-5 to Santa Fe exit east to Windsor Rd. and turn right. (Fee charged). Call **Betty Byrd 760-635-1144**.

OCEANSIDE LOCATION - Fridays 11am - Noon Tri-City Hospital, 4002 Vista Way, Oceanside, Lower level Assembly Room. Confirm room location at lobby info desk. Class and Valet parking are free. Call **Tracy Park, PT, 760-940-3617**.

MEDICAL INTEGRATED PROGRAM – Mondays through Saturdays - a variety of Parkinson's related individual and group exercises, including *Dance for Parkinson's*. Tri-City Wellness & Fitness Center, 6250 El Camino Real, Carlsbad. Parkinson's exercise classes (Fee charged.) Call **Susan Webster 760-931-3171**.

PERSONALLY FIT - Tuesdays & Thursdays 2pm - 3pm Parkinson's exercise classes at Personally Fit in Rancho Bernardo. (Fee charged.) Call **858-485-6706**

ROCK STEADY BOXING - various North County sites and days Check their national website for a location near you, along with contact information. <https://www.rocksteadyboxing.org/>

Vocal Exercise

Tremble Clefs -Therapeutic Singing North Coastal Chapter Encinitas Tuesdays 1pm - 2:30pm - St. Andrews Episcopal Church, 890 Balour Dr., Encinitas.

North Inland Chapter Rancho Bernardo Wednesdays 10 am - noon - San Rafael Catholic Church, 17252 Bernardo Center Drive, San Diego (RB) - Parish Center. (Free) Call **Deanna Hastings at 619-363-0814** or check website: www.trembleclefs.com/san-diego

AudAbility - Music therapy program offering numerous music related activities for People with Parkinson's. (Fee charged) Call **Lindsay Zehren 858-457-2201** or email lzhren@musicworxinc.com.

Big and Small Social Groups

Fallbrook Potluck! Our small social groups gather in rotating private homes in months that we don't have a large group activity. This month we'll enjoy getting together in Fallbrook. Our hosts are providing the main course, and you bring a side or dessert. Please RSVP to **Sam Cooper**, Social Chair, scprphd@gmail.com or call/text **520-820-0339**.

Christ Presbyterian Church La Costa, Oceanside First Presbyterian Church, Christ the King Lutheran Church Fallbrook, and San Rafael Catholic Church, RB provide their facilities at no charge. Thank You!

In Focus: Pat Kenney

By Sam Cooper



Pat Kenney was born in Billings, Montana, in 1954 and lived there until age 14 when he moved to Ft. Collins, Colorado, with his mother and brother. After earning an Associate Degree in photography from Colorado Mountain College in Glenwood Springs, he moved to Montana working as a photographer for Preview Magazine. When his mother was diagnosed with cancer, he moved back to Ft. Collins to be near her where he studied wastewater technology. He then embarked on a 36 year career in water treatment; 29 years of which he was the chief water plant operator for the City of Arvada, Colorado.

Pat cared for his mother the last 12 years of her life. "It was very important to me to do this for my mother. I learned a great deal about compassion and what it means to be a family caregiver. I have nothing but praise for those of you caring for a loved one." Diagnosed with Parkinson's in 2012, he received a medical disability retirement from the City of Arvada in 2015 and moved to Oceanside to be near his sister, Sally Sporrer, and her family. "I can't imagine having any better care and support than I get from my sister and her husband, Bob. Family is everything."

"I don't have any major tremor issues, but I do have freezing, balance, falling, swallowing, fatigue, body pain, and scoliosis difficulties. Sialorrhea is also a concern, but is controlled for the most part with Myobloc injections. My biggest challenge right now is walking without falling. As much as my Upwalker helps, I recently purchased a power chair." Even with his physical limitations now, Pat encourages everyone to "keep moving" and attends PT three times a week in addition to daily exercise classes. "These things help me keep up my physical strength and also gives me a reason to get up and out the door."

Pat attends our Oceanside and La Costa support group meetings. "I look forward to the meetings each month. Not only is the speaker information excellent, I particularly enjoy the breakout sessions. We are very lucky to have such dedicated people running our North County Parkinson's Support Group and who are so involved with supporting all of us." Over the last seven years I have met many wonderful people in our Parkinson's community. People with Parkinson's have bigger hearts!"

He reminds us about the importance of outreach. "Whenever I meet someone who has been recently diagnosed with PD or has a family member or friend who has been diagnosed, I strongly urge them to join their local support group. Being with other people that not only understand but are so supportive is just priceless. If you have to have Parkinson's, you couldn't have it in a better place than right here in North County."

"Though I have been dealt a tough hand of cards, I know people who are holding a tougher hand. I don't feel sorry for myself. I try to remain positive and make the best of everyday. It really is true. We are not on our PD journey alone."

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NCPSPG Notices

We take photos and videos at our meetings and events and may use them in our Newsletter, website and other promotional materials. Please let the Support Group leader know at the start of every meeting or event if you do not want your image to appear.

We provide information in our newsletter and chapter meetings on a broad array of Parkinson's-related topics and perspectives. Please recognize that a presentation should not be interpreted as our endorsement. Do your own research, and talk with your neurologist before taking action.

Parkinson's database - Dept of Health information-gathering for your protection

Our discussions of *Driving with Parkinson's* at several Support Group chapters also touched on the separate issue of a California Department of Public Health program created by Assembly Bill 715 that requires that medical professionals report the names of persons diagnosed with Parkinson's to CDPH's secure database.

This raised concerns for some of our members. Those concerns are shared by the Department of Public Health. Confidentiality and privacy is of utmost importance to CDPH.

The information gathered helps document the extent of Parkinson's in California and the state's need for treating PD's impact as a priority.

123,000 records have been submitted to CDPH; there are some duplications. It is estimated that there are more than 100,000 people with PD in California.

These are links to the CDPH website about the registry.

<https://www.cdph.ca.gov/Programs/CCDPHP/DCDIC/CDSRB/Pages/CPDR-FAQs.aspx>

<https://legiscan.com/CA/bill/AB715/2017>

Our Thanks to UpWalker/ LifeWalker

UpWalker is a unique mobility device which helps its users stand up straight as they walk, take longer steps and improve posture as they exercise. It was developed locally, and the company has improved the product through several updated "editions". As newer versions were brought into production, older versions were less likely to be purchased.

While revamping their warehouse in Clairemont Mesa, they decided to dispose of their oldest model, making about twenty units available to people with Parkinson's through support groups around the County. NCPSPG was able to place several in the hands of our members.

We thank **LifeWalker's** regional sales manager **Shelley Federhart** for thinking of our Parkinson's community. Your generosity is greatly appreciated.

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for our Newsletter postage.



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