

SD CENTRAL COUNTY PARKINSON'S SUPPORT GROUP

January 2019



NEWSLETTER for • DUOPA • Flying Solo • Pt. Loma • Pacific Beach • Support Groups

Edition 1

Welcome to the First Edition of our SDCCPSG Newsletter!

Thanks to the mentoring of the North County Parkinson's Support Group and the efforts of our Board, the first edition of our monthly Newsletter is here!!! Available by both email and US mail, the Newsletter provides information regarding activities at the county and local levels, as well as resources to help us live well with Parkinson's. Monthly articles include *In Focus*, featuring an in-depth interview with a support group participant, as well as *Parkinson's Hacks*, where participants share helpful ideas for improving life with Parkinson's. Enjoy!

Our 501(c)(3) is Up and Running...

Tony Jeske, our Board Treasurer, worked tirelessly this past year to ensure we obtained our 501(c)(3) status. As a result, we are now a non-profit foundation, the **San Diego Central County Parkinson's Support Group (SDCCPSG)**, comprised of several separate support groups, each providing specific services to our Central County Parkinson's community.

There are several easy ways to support our foundation, including: selecting us as your charity of choice at AmazonSmile and Ralphs or by making a direct donation. Our annual **Registration Drive** starts this month. For your convenience, a Registration form can be found attached, at any of our support group meetings, and online at www.sdccpsg.org.



Holiday Potluck & "Ugly" Sweater Contest

Our annual Holiday Potluck was a hit from start to finish! Family, friends and newcomers alike gathered at the County of San Diego Health & Human Services Agency where we were greeted by our youth Sidekick, Kagen Yates, and then treated to a wonderful musical medley by the Tremble Clefs who put everyone in the holiday spirit. The food was delicious, the company delightful, and the setting beautifully decorated by our Social Director, Debbie Stubbe and her able team. The gently used LifeWalker, graciously donated by Bruce Lowe, was raffled off and won by Grant and Carol Gooch. "Festive" sweaters abounded, with participants putting their name on a "sweater tag" that best described theirs (Most Festive, Most Beautifully Tacky, Most Colorful, Ugliest). Kagen pulled submitted tags out of a hat and the winners were rewarded with a table decoration of their choice. As the evening drew to a close, it was clear a very festive time was had by one and all!



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Support Group Meetings

(SDCCPSG Sponsored)

Contact: Nancy Floodberg 619.857.6638

DO YOU DUOPA? **NEW**

Saturday, January 5TH 4pm (future meetings TBD)

Berta's Latin Cuisine

3928 Twiggs St., San Diego, 92110

For People with Parkinson's (PwP), receiving Duopa Therapy, and their caregivers.

SPEAKERS' SERIES

Wednesday, January 9TH 6pm – 8:30pm

Second Wednesday of each month

County of SD Health & Human Services Agency

3851 Rosecrans St, San Diego 92110

San Diego Room

Research Opportunity: **Pete Fronte**, President/CEO Altura, will present on the **Fox Insight Study**, an online research study where People with Parkinson's and their loved ones share information that could improve the understanding of the disease and transform the search for better treatments.

Speaker: **Bruce Lowe**

Topic: **Navigating our Support Group Websites** –

Learn firsthand, from our very own webmaster, how to access and get the most out of our two websites.

Bring your laptop! Refreshments.

PACIFIC BEACH

Wednesday, January 16th 1 pm – 3pm

Third Wednesday of each month

Oakmont of Pacific Beach

955 Grand Ave, San Diego 92109

Speaker: **Nancy Floodberg**

Topic: At home vocal exercise options.

Breakout will follow where People with Parkinson's and care partners meet together to discuss challenges, strategies and successes. Refreshments.

FLYING SOLO (time change this month only)

Monday, January 28th 11:30am – noon

Fourth Monday of each month

County of SD Health & Human Services Agency

3851 Rosecrans St, San Diego 92110

San Diego Room

People with Parkinson's living without a care partner gather to discuss issues specific to "Flying Solo".

PT. LOMA (time change this month only)

Monday, January 28th noon – 1:45PM

Fourth Monday of each month

County of SD Health & Human Services Agency

3851 Rosecrans St, San Diego 92110

San Diego Room

People with Parkinson's and care partners meet together to discuss issues and successes.

Refreshments.

Physical Exercise

PARKINSON'S EXERCISE CLASS

Wednesdays 11:40am – 12:35pm

YMCA Mission Valley, 5505 Friars Rd, San Diego 92110

Contact Instructor: **Jeff 619.298.3576**

www.ymca.org Fee charged

PARKINSON'S NETWORK

Wednesdays noon – 1:15pm

1371 Sunset Cliffs Blvd, San Diego 92107

Contact Instructor: **Lisbeth Garces 619.971.3904**

Lisbeth.garces@jccorg.org Free

ROCK STEADY BOXING (for PwP)

Monday - Friday 10:30am – noon, 12:30 – 2:00pm

Box Fit, 4101 30th St, San Diego 92104

Contact Coach: **Mike Reeder 310.923.5535**

www.boxfitsd.com Fee charged

SDSU ADAPTIVE FITNESS CLINIC

Monday - Friday (several sessions/day)

SDSU – Peterson Gym, 5400 55th St, San Diego 92115

Contact Director: **Matt Soto 619.594.2017**

www.ens.sdsu.edu Fee charged

Vocal Exercise

AUDABILITY - Music Therapy

Numerous weekly classes for People with Parkinson's, including singing/drumming, piano and harmonica.

10455 Sorrento Valley Rd #202, San Diego 92121

Contact Music Therapist: **Lindsay Zehren 858.457.2201**

www.musicworxinc.com Fee charged

LOUD MAINTENANCE - Vocal Exercise Program

2nd & 4th Thursdays of each month 11am – noon

Scripps Center for Voice & Swallowing

9800 Genessee Ave, La Jolla 92037

Contact Speech Therapist: **Cedar Smith 858.626.7456**

Free

TREMBLE CLEFS -Therapeutic Singing

Thursdays 1 - 3pm

Palisades Presbyterian Church

6301 Birchwood St, San Diego

Contact: **Deanna Hastings 619.363.0814**

www.trembleclefs.com/san-diego Free

SDCCPSG Board of Directors

Monday, January 14th 10am - 12pm

Second Monday of each month

County of SD Health & Human Services Agency

3851 Rosecrans St, San Diego, CA 92110

San Diego Room

Contact **President Nancy Floodberg 619.857.6638**

president@sdccpsg.org

The County of San Diego Health & Human Services Agency and Oakmont of Pacific Beach provide their facilities for our meetings at no charge. We thank you!!!

In Focus: Donne Willett

By Dolores Cohenour



Those of you who have met Donne Willett probably know she is one free-spirited, independent woman, but you might not know she grew up a “Navy brat”, frequently on the move, and that’s been a theme throughout her life.

In 1959, Donne entered UCLA, then left college and moved to Subic Bay. Returning to LA, she attended Los Angeles State College where she majored in Special Education, completing her master’s degree.

Back in San Diego, Donne took advantage of the State’s offer to write off student debt by teaching at a minority school. After working at seven schools,

she took a 3-year sabbatical to attend Mesa College and “learn something new”. She studied building technology, and used the knowledge gained to work on a friend’s house. She returned to education as a Resource Specialist, assessing students’ special needs, augmenting their instruction, and recommending adaptive technology.

During her last year of teaching, tremors manifested themselves, making her handwriting illegible. When the school districts began down-sizing Special Ed classes, Donne decided it was time to retire. “In 2002, I got the ‘Golden Handshake’ and a month later was diagnosed with Parkinson’s. I left the doctor’s office, sat down and cried, and then decided I needed to develop a plan. I knew that you cannot [easily] gain power over things that are a problem. By action, speaking that action, and by doing something, instead of moaning and groaning, you gain power over your situation. I decided that I would do things with other people diagnosed with Parkinson’s and perhaps get everyone busy doing something.”

Donne met Lester Cohen and together they started the Pt. Loma Parkinson’s Support Group. “I had been involved in other support groups and thought that I could lead a support group.” As more and more people began to attend their meetings, they needed to find a larger space and moved to the County of San Diego Health & Human Services Agency where the group still meets, 17 years later!

In addition to developing a very successful support group, which she led until 2016, Donne (along with AnnD Canavan) was instrumental in bringing Rock Steady Boxing to central San Diego and, in doing so, has truly gotten everyone “busy doing something”. “I found a coach one day while I was wandering through Balboa Park. I asked the Parkinson’s Association to pay for his training in Indianapolis. The response was, ‘Next year.’ My response was, ‘I may not have next year. I want it now!’ ” And she got it! She also got Deep Brain Stimulation (DBS), something she hadn’t planned on.

“I was always someone who said to the neurologist, ‘Don’t ever bring up DBS, because I am not going to do it!’ Then my dyskinesia became really significant, so I felt that I did not have much of a choice.” Before her surgery, Donne fell and broke her wrist and, the summer after, tripped and broke her hip, resulting in her move to Oakmont of Pacific Beach, a residential community. “I didn’t really want to come here; I thought it would really be awful. But once you are here, it’s family, like the family you have in Parkinson’s. Now I am getting to the point that I have something new I want to do. I am thinking about being a senior person with Parkinson’s that people here at Oakmont can go to.” Here’s to you, Donne!!!

“In 2002, I got the ‘Golden Handshake’, and, a month later, was diagnosed with Parkinson’s. I left the doctor’s office, sat down and cried, and then I decided that I needed to develop a plan.

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In addition to developing a very successful support group, ...Donne was instrumental in bringing Rock Steady Boxing to central San Diego and, in doing so, has truly gotten everyone “busy doing something”!

Please visit our website: www.SDCCPSG.org. There you will find an overview of our Board and support groups, as well as both local and national resources. In addition, the site features video and PowerPoint archives from our Speakers’ Series, as well as previous Newsletters. We update it often and welcome your feedback.

PARKINSON'S LIFE HACKS

Life Hacks: /'lif,haks/ • Tools or techniques that make some aspect of one's life easier or more efficient.



Aware in Care Kit: to be taken with you any time you go to ER or are admitted to the hospital. The kit includes a Medication Bag, Hospital Action Plan, PD ID Bracelet, Medical Alert Card, Medication Form, PD Fact Sheet, I Have PD Reminder Slips, Meds On Time Magnet, and *your PD meds*. Whenever new PD meds arrive, put one bottle of each in your Aware in Care Kit, removing the older bottles to start using. Available at www.parkinson.org or 800.473.4636. **Free**

To submit a Parkinson's Life Hack, send an email to: president@sdccpsg.org

PARKINSON'S COMMUNITY RESOURCES

Parkinson's Association of San Diego

Executive Director:
Chris Buscher – 858.205.2802
info@parkinsonsassociation.org
www.parkinsonsassociation.org

FACT Transportation: 888.924.3228
Monday - Friday 7:30am – 8:00pm, 8:30pm pick up for SDCCPSG Speakers' Series. Call 72 hrs ahead to schedule transportation to or from a PD-related event. Mobility chairs and service animals accommodated. Care partners ride for free. Cost: \$15 each way or whatever you can pay.

East County Parkinson's Support Group

Support Group Leader:
Lorenzo Higley – 619.447.2855
EastCountyPSG@cox.net

North County Parkinson's Support Group

Board President, Support Group Leader:
Paul Dawson – 760.497.1200
paul@video-fire.com www.ncpsg.org

UCSD Parkinson's Network

Group Manager:
David Higgins – 619.565.0411
info@Support4PD.org www.Support4PD.org

SDCCPSG CONTACTS

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SDCCPSG provides information to keep you informed of the latest findings in research, new treatments and living well with Parkinson's. Although we have speakers on a variety of topics, we do not endorse any of them. Our motto is "maintain close communication with your neurologist/movement disorder specialist and exercise, **exercise, exercise!!!**"