NORTH COUNTY Www.NCPSG.org PARKINSON'S SUPPORT GROUP

- MAPE CAMPE -

A NEWSLETTER FOR EVERYONE AFFECTED BY PARKINSON'S IN NORTH SAN DIEGO COUNTY

Take Advantage of Every Learning Opportunity

Parkinson's is a very complex disease. [Tell me something I don't know!] No two individuals experience it in the same way. Although there are some commonalities, treatment of symptoms vary person to person, and change for the individual as the disease progresses.

So what can we do? We could follow the old "head in the sand" approach, and ignore as much of it as we can for as long as we can. Or, we could learn about current thinking of what causes PD, how our meds work, new concepts being developed, exciting research, and so much more. And we can talk face-to-face with amazing, dedicated experts.

Empowerment Day

Here is one great opportunity to learn more from subject experts about our very complex disease: Parkinson's Association of San Diego's EMPOWERMENT DAY on December 4 at a new location, Four Points by Sheraton, San Diego. Registration information link:

https://raceroster.com/events/2024/93779/parkinsons-association-of-san-diegos-7th-annual-empowerment-day

There will be about 20 speakers, experts in their fields, and about 60 representatives who provide services for the Parkinson's community. A \$25 fee covers a light breakfast and very nice lunch. It is an important conference to attend, and if the fee is an obstacle, contact Paul Dawson, who also serves on the PASD Board.

Parkinson's IQ + YOU

We hope you were able to attend the Michael J Fox Foundation's "Parkinson's IQ + YOU" on September 21 at Omni Resort Carlsbad. Over 750 attended from around Southern California, including a number of NCPSG members! Among the panel discussions were "Building your Healthcare Team", "Advances in PD Research", "Turning Education into Action". This link has information on the MJFF's "Parkinson's Progression Markers Initiative" (PPMI). https://www.michaelifox.org/ppmi MJFF may later publish information from the PD IQ event.

Social Events

Our annual NCPSG Fall Potluck was hosted by Rancho Bernardo and was attended by members from all four of our chapters. Entertainment was provided by the Tremble Clefs.





Winter Social

Our special Winter Social will be held at the Shadowridge Golf Club in Vista on **Saturday**, **December 7**. The Reservation form is on Page 5.



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Support Group Meetings

RANCHO BERNARDO

Monday, October 7, 10:00 AM to Noon

Speaker: Doris Flood, DPT, Personally fit

Topic: Chair Exercise - Discussion & demonstration

San Rafael Catholic Church 17252 Bernardo

Center Road, San Diego, 92128

Host: Brigit King bkicedancer@gmail.com.

or 858-354-2498

LA COSTA CARLSBAD

Wednesday, October 2, 1:00 PM to 3:00 PM

Speaker: Chris Buscher

Topic: "An Overview Of The PASD Website"

Christ Presbyterian Church

7807 Centella St. Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

OCEANSIDE

Wednesday, October 9, 1:00 PM to 3 PM

Speaker:

Topic:

Oceanside First Presbyterian Church 2001 S. El Camino Real, Oceanside 92054, at Fire Mountain Rd *Host*: Paul Dawson paul@video-fire.com or 760-497-1200

FALLBROOK

Friday, October 25, 10 AM to Noon

Speaker: Leslie Salmon E-RYT500, YACEP, CIYAT

Topic: Yoga as a tool for PwP & CPs
Fallbrook Regional Wellness Center

1636 E. Mission Rd, Fallbrook 92028

Host: Irene Miller NCPSGF@gmail.com

or 760-731-0171

Social Gatherings

We hope you join in our NCPSG large and small socials, where no one blinks an eye at a spilled drink or tremoring hand, or soft voice.

If you are interested in joining our small groups, please contact Sam Cooper at scprphd@gmail.com or 520-820-0339.

Passings

- Ken Schultz
- Dick Ridley

Our thoughts & prayers go out to family & friends

NCPSG Board of Directors

Wednesday, September 16, 1-3 PM. The Board meets online on the third Wednesday of the month.

Contact Sam Cooper NCPSGLC@gmail.com

or 520-820-0339.

Physical Exercise

In-person or On-line Options. Fees May Be Charged. For more information on Scholarships see NCPSG.org

Personally Fit (NCPSG Scholarships Available)
In-person and Zoom classes for Parkinson's.
Personallyfitonline.com or contact Doris Flood, PT at dflood@personallyfitonline.com

LifeSpan Health (*NCPSG Scholarships Available*) Drug-free program to enhance a healthy life span. https://lifespanhealth.me/

NeuroLab 360 (*NCPSG Scholarships Available*) Neurologic physical and occupational therapy, and wellness sessions. <u>www.neurolab360.com</u>

Rock Steady Boxing (NCPSG Scholarships available for some affiliates) Improve Parkinson's quality of life through non-contact boxing-based fitness curriculum. In-gym and online classes available. https://www.rocksteadyboxing.org/

Rx Ballroom Dance - Dance therapy, the best therapy for mitigating and reversing symptoms of brain deterioration. Classes in Oceanside, Fallbrook, Rancho Bernardo. (no charge) Details at https://www.rxballroomdance.com/ or call Erin Angelo 310-938-1620

Tai Chi - Temecula - (*NCPSG Scholarships Available*) Physical exercise & wellness. www.oyd-ca.com

Parkinson's Exercise - Tri-City Hospital - Led by Physical Therapist and Occupational Therapist. Every Thursday, 3 - 4 pm. (no charge) Check in at main desk.

Vocal Exercise

Tremble Clefs -Therapeutic Singing & Socializing *Inland Chapter (Rancho Bernardo)*Wednesdays at 10:00 AM (no charge)

San Rafael Catholic Church in the Parish Hall, 17252 Bernardo Center Road, San Diego 92128

North Coastal Chapter (Encinitas)

Tuesdays at 1:00 PM (no charge)

Bethlehem Lutheran Church, 925 Balour Dr,

Encinitas, CA 92024

In-person participants should be fully vaccinated, or attend via Zoom. Contact Matt Ignacio for details.

Email: matt.sdtrembleclefs@gmail.com Website: https://www.trembleclefs.com/

Parkinson Voice Project - Speak Out home practice exercise Monday - Friday 8 AM PST online at www.parkinsonvoiceproject.org

MusicWorx for Parkinson's (Formerly AudAbility)

Music therapy is the use of clinical, evidence-based interventions to achieve clients' non-musical goals. See MusicWorx.com. Cassandra Richtsmeier 858-457-2201 or crichtsmeier musicworxinc.com

In Focus: Karen Guevara

By Sam Cooper



"I am a first generation San Diegan born at Mercy Hospital. I married Daniel Luis Guevara 42 years ago. We have a son from his previous marriage and a granddaughter. I attended San Diego State University and graduated from California State University San Marcos with a B.S. in Business Administration. I spent 25 years in law firm management and was a member of the International Association Of Legal Administrators. Sports, travel, and music have been integral parts of my life. As there is no snow in San Diego, I took a gap year and moved to Jackson Hole, Wyoming, and learned to ski. In the senior phase of my life I have entered the frenzied world of pickleball. Another passion of mine is Hawaiian music and dance. Dan and I learned to play the ukulele before we retired to have a hobby to share. We belong to a Hawaiian cultural organization, Hui O Hawaii of San Diego. I served on its Board for several years.

"Dan was diagnosed with Parkinson's in 2012. Understanding the benefits of support groups we joined the North County Parkinson's Support Group and attend the Rancho Bernardo group regularly. I am one of the "snack ladies" for our monthly meetings. The informational speakers are always valuable. I particularly value the Care Partner breakout group. It provides a safe haven to exchange information and advice. It is a place where I can share my thoughts and feelings with others who are experiencing similar challenges. The suggestions and referrals to professional services help empower me to better manage my circumstances. I have gleaned invaluable tips and advice from these sessions and am very grateful for the support system.

"...I particularly value the Care Partner breakout group. It provides a safe haven to exchange information and advice..."

"Caring for a partner with Parkinson's is challenging. I know I can only do a good job if I am healthy mentally and physically. My number one priority is keeping us both exercising and having as much fun each day as possible. Fortunately Dan has an excellent sense of humor and we laugh a lot. I am blessed that my family and friends continue to be so incredibly supportive. I can't imagine this Journey without their love, support, and kindness. I suggest Care Partners ask for help when feeling stressed before you become too overwhelmed. I am a strong independent woman, but I can't do this alone. Don't isolate yourself. Exercise and laugh each day. Remember, you are not on your Parkinson's Journey alone."

Considering Deep Brain Stimulation?

The San Diego Parkinson's Association is continually adding to its Resources pages and has moved the most current information about Deep Brain Stimulation (DBS) to a new position. Information on DBS and MR-Guided Focused Ultrasound has moved to our "DBS/HIFU Corner" on the drop down menu under "Living with Parkinson's"

Click here: DBS / HIFU Corner

NCPSG Notices

We provide information in our newsletter and chapter meetings on a broad array of Parkinson's-related topics and perspectives.

A presentation should not be interpreted as our endorsement. Do your own research, and talk with your neurologist before taking action.

We take photos and videos at our meetings and events and may use them in our newsletter and promotional materials. Please tell the event leader if you do not want your image to appear.

You may **click the links** in this newsletter to be taken directly to the referenced resource. If you find a broken link, contact the editor at ncpsgNL@gmail.com.

New Long Acting Drug

The Michael J. Fox Foundation (MJFF) is monitoring 151 priority treatments in clinical testing for Parkinson's disease according to its website: https://www.michaeljfox.org/news/crexont

The U.S. Food and Drug Administration (FDA) has approved a new, long-acting oral formulation for the treatment of Parkinson's disease. Developed by Amneal Pharmaceuticals, **Crexont** aims to offer patients improved symptom control through fewer doses of medication. Crexont includes both immediate- and extended-release levodopa plus carbidopa in one pill. The medication aims to alleviate symptoms for longer with fewer doses.

Levodopa/carbidopa is commonly used to treat the motor symptoms (tremor, slowness, stiffness) of Parkinson's disease (PD). Parkinson's disrupts dopamine production in the brain, leading to the motor symptoms of PD. Levodopa helps temporarily replace some of the lost dopamine; carbidopa helps improve uptake of levodopa. The potential promise of the new drug is more "on" time where symptoms are controlled by medication.

PASD's New Medical Safety Program

This new **Medical Safety Program** consists of an introductory letter from Brent Wright, MD, PASD Medical Advisory Director, describing many of the issues with Parkinson's and treatment in medical care facilities, including hospitals. A series of forms, including your medication list and schedule, medical and personal contacts, and much more are available for download here: https://parkinsonsassociation.org/medical-safety-program/

Our mailing address:

NCPSG PO Box 230566

Encinitas, CA. 92023

Our Website: (Donations accepted)

NCPSG.org

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Our monthly NCPSG Newsletter is available on our website NCPSG.org. It is posted about one week before the end of the month. Archived editions are also available there. Challenged by computers? Lack online access? Speak with your Support Group leader or Micheline Allen.

To update or remove your contact info, please let **Micheline Allen** know. 760-631-0649 ncpsqCS@gmail.com

We are a 501(c)3 non-profit organization, dedicated to serving the Parkinson's community. Your donation of funds and of volunteer service are truly appreciated! Thank You!



Saturday, December 7, 2024, 11:30 A.M Check-in 11:00 Shadowridge Golf Club 1980 Gateway Drive, Vista

All choices include water, iced tea, or coffee, rolls with butter, salad, and dessert.

1. Honey Glazed Salmon with mashed potatoes and vegetables

We must receive your reservation by Monday, December 2, 2024

- Lemon Roasted Chicken with mashed potatoes and vegetables
- 3. Butternut Squash (vegetarian)

\$32.00 per ticket. Number Of Tickets ____

Name Menu Choice

Your phone number _____

Make your check payable to "NCPSG" and mail this form and your check to:

NCPSG PO Box 230566 Encinitas, CA. 92023