

NORTH COUNTY PARKINSON'S SUPPORT GROUP

July 2024
www.NCPSG.org



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

Golden Age Gala

Rx Ballroom Dance students showcased their "continuing journey through dance" at a fundraiser. Nine dancers with Parkinson's and their teachers performed on June 1, 2024; three are from the North County.

Rx Ballroom Dance enhances the quality of life in people who are coping with neurological conditions, such as Parkinson's and Alzheimer's, and their care givers. A professional ballroom dancer leads the class through a curriculum specifically designed to engage the mind, body, and spirit. Classes are free thanks to generous donations from individual and corporate sponsors.

Dance is not only physical exercise. In a number of studies, dance is shown to alleviate symptoms and increase functioning in depression, anxiety, attention and memory. In a limited survey conducted by Rx Ballroom, participants report growth in their coordination and balance, as well as their emotional well-being. The social aspect and fun are important factors.



For more information about a class near you and Golden Age Gala pictures and videos:

www.rxballroomdance.com

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National Plan to End Parkinson's Act Pending Presidential Signature

On May 23, 2024, the U.S. Senate unanimously passed the [National Plan to End Parkinson's Act](#) (H.R. 2365), the first-ever federal legislation dedicated to ending Parkinson's disease, sending the bill to President Biden's desk to be signed into law. The bill passed with overwhelming bipartisan support in the U.S. House of Representatives last December.

The National Plan to End Parkinson's Act, which passed unanimously in the Senate, and by a strong bi-partisan vote in the House, demonstrated Congress' ability to work across the aisle on significant issues. The Bill now goes to President Biden for signature.

Moving testimony supported The National Plan, testimony from PwP representing national Parkinson's organizations, and from Congressional members themselves. Senator Schumer, in calling for a "unanimous consent" vote, thanked many who championed the bill, and stated "Parkinson's is truly a terrible illness. It has taken an awful toll on my own family. My mom suffers from this disease. It is very hard on us."

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Support Group Meetings

RANCHO BERNARDO

Due to Vacation Bible School for children, we will not be having a meeting in July. We will be back in action in August.

San Rafael Catholic Church 17252 Bernardo Center Road, San Diego, 92128
Host: Brigit King bkicedancer@gmail.com
858-354-2498

LA COSTA CARLSBAD

Wednesday, July 3, 1:00 PM to 3:00 PM

Speaker: Jeff Seckendorf

Topic: "The Parkinson's Association Of San Diego Mentor Program"

Christ Presbyterian Church

7807 Centella St. Carlsbad 92009
Host: Sam Cooper NCPSGLC@gmail.com
or 520-820-0339

OCEANSIDE

Wednesday, July 10, 1:00 PM to 3 PM

Topic: Constipation with Parkinson's— a Different Challenge— video

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, July 26, 10 AM to Noon

Speaker: Perla Hurtado, Foundation for Senior Care, Executive Director

Topic: "Local Resources for Extending Independent Living "

Fallbrook Wellness Center 1636 E. Mission Rd, Fallbrook 92028
Host: Irene Miller NCPSGF@gmail.com
or 760-731-0171

Social Groups

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

Fall Social Potluck Monday, September 16

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

NCPSP Board of Directors

Wednesday, July 17, 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 NCPSP.org*

Personally Fit (NCPSP Scholarships Available)

In-person and Zoom classes for Parkinson's. Personallyfitonline.com or contact Doris Flood, PT at dflood@personallyfitonline.com

LifeSpan Health (NCPSP Scholarships Available)

Drug-free program to enhance a healthy life span. <https://lifespanhealth.me/>

NeuroLab 360 (NCPSP Scholarships Available)

Neurologic physical therapy & wellness. www.neurolab360.com

Rock Steady Boxing (NCPSP 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.rxbalroomdance.com/> or call Erin Angelo 310-938-1620

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
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

Passings

- **Andrea Johnston**

Our thoughts & prayers go out to family & friends



"I was born in 1951 and raised in Los Angeles County. I earned three Associate of Arts degrees from East Los Angeles College and Cuesta College in San Luis Obispo. I was a police officer for 30 years from the age of 21. I was with the Alhambra Police Department for 8 years then 22 years with the San Luis Obispo Police Department. My wife, Rita, and I have been married for 50 years. We have three adult sons. My greatest accomplishment has been my marriage and my best life memory is being present at the birth of each of our sons. I have been very blessed.

I love reading and birding.

"After I was diagnosed with Parkinson's in 2018 in Orange County, I began private pilates classes, daily walking, and physical therapy exercises. When we moved to San Marcos, I started going to NeuroLab 360 doing exercises that focus on heart rate and movement. My physical therapist recommended a neurologist who was very interested in my symptoms and overall well being. I have some tremoring and overall slowing of movement, particularly in the last hour of my medication.

"Rita got us involved with the North County Parkinson's Support Group. The social activities are very helpful and lets us participate with people that understand. We typically attend the La Costa chapter support group which has provided a wealth of information. The breakout group is particularly helpful as it offers different kinds of information and support at the personal level. I have come to understand that while we all share commonalities, our Parkinson's Journey is unique to us. It is not the same as anyone else's. The biggest realization for me has been reinforcing the knowledge that my wife, Rita, is the best thing that has ever happened to me. I could not do this without her. I would encourage anybody with Parkinson's to join our North County Parkinson's Support Group. Get active and stay active. You are not alone."

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Skin Test Accurately Detects Neurodegenerative Disorders

A simple skin biopsy test is able to detect an abnormal form of alpha-synuclein with high accuracy in individuals with neurodegenerative disorders such as Parkinson's disease (PD) according to *Medscape Medical News*. The test identified phosphorylated alpha-synuclein (P-SYN) with 95.5% accuracy in the blinded, multicenter trial.

Syn-One is not approved by the US Food and Drug Administration as a diagnostic test for PD but is available as a pathologic assay that determines whether a tissue sample contains phosphorylated alpha-synuclein and can be billed through Medicare.

NCPGS 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.

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

Call For Articles

Our North County Parkinson's Support Group is all about supporting each other on our Parkinson's Journey. We do this through our four support group chapters, sponsored activities, and social opportunities communicating through our website, ncpsg.org and our monthly newsletter.

We are inviting you to write an article for our newsletter sharing some aspect of your Parkinson's Journey. Tell us about your experience traveling with Parkinson's, flying, driving, or taking a cruise. Maybe you could share how Parkinson's is impacting your daily life and what strategies you are using to cope. How has Parkinson's impacted relationships in your life with family, friends, or co-workers? Maybe you are no longer able to do something like you could before. What are you doing instead? How are you exercising? Share your experience with becoming part of a research project. What is something you would like to share with our North County community?

Articles should be about 450 words long. Don't worry about trying to make it perfect. Please send a draft and a portrait style cell phone picture to our Publisher, Paul Dawson, paul@video-fire.com

NCPSPG "Business Cards" for You to Give

We have prepared simple card handouts the size of business cards which you could carry and hand to someone you know or meet who is dealing with Parkinson's: as a person with the disease, a care partner, or others affected by PD. It includes a list of our NCPSPG services and the date, time and address of each of our chapter meetings. It's a low-key way to let them know that there are resources that they would find valuable – as we "*Fight Parkinson's Together!*" Contact your group leader to get your cards.

Our mailing address :

**NCPSPG
PO Box 230566
Encinitas CA 92023**

Our Website: (Donations accepted)

NCPSPG.org

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Newsletter Published Online

Our monthly NCPSPG Newsletter is available on our website www.NCPSPG.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

ncpsgCS@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!**

2024 Summer Social



Continued from page 1 **National Plan to End Parkinson's Act**

The Senator also thanked in particular Representative Jennifer Wexton (D-Va) who spent months championing this bill even after being diagnosed with a particularly rare form of Parkinson's, identified as Progressive Supra-nuclear Palsy, type-p (PSP-P), a form of Atypical Parkinsonism.

Representative Gus Bilirakis (R-FI) recently lost his brother, Dr. Emmanuel Bilirakis, a physician, and his mother-in-law to Parkinson's. A number of other Representatives and Senators have close family members dealing with PD.

The United Parkinson's Advocacy Council (UPAC), a collection of nearly 30 Parkinson's organizations came together to help shape federal and state public policy in ways that support the Parkinson's community.

George Manahan, a small business owner and PwP, spoke before a House committee and said, "In my testimony, I spoke about what it's like living with Parkinson's disease and the impact it has on my family and my work. It was important for me to share what the National Plan bill really means for those of us living with Parkinson's. It means hope. It means progress. It means that all federal agencies who have anything to do with Parkinson's are going to be able to come together for the first time in a strategic way to ensure there is a laser focus on preventing and curing Parkinson's.

This monumental bill has the potential to shape the lives of the one million Americans living with PD. It is designed to:

- ◆ Dramatically increase federal research funding
- ◆ Develop more effective pathways for treatments and cures
- ◆ Improve early diagnosis
- ◆ Spark new and improved models for patient care
- ◆ Create standards and measures to prevent Parkinson's disease
- ◆ Address health disparities in diagnosis, treatment and clinical trial participation

Tens of thousands of advocates published op-eds, signed our petition, wrote letters and called members of Congress to get the bill this far. You might consider writing to President Biden to encourage to sign the bill into law. The Michael J. Fox Foundation has a PARKINSON'S ADVOCACY TOOLKIT which simplifies constructing an effective letter. Visit <https://www.michaeljfox.org/form/advocacy-toolkit>

Watch the recording and slides of PASD's Good Start Program on June 13:

<https://player.vimeo.com/video/961217377>



Rx Ballroom Dance by Anne Lee

As a PWP and avid Rx Ballroom student, I can testify that Rx Ballroom has improved my balance, gait, and confidence. It enriches my life in so many ways; I look forward to dance days when I can meet with friends and have fun. I participated in the Golden Age Gala, dancing the waltz with my professional partner and teacher Matyus Pragar, fulfilling a childhood dream of dancing on stage. The support of teachers, Rx Ballroom dancers from Fallbrook, family and friends was overwhelming.

Parkinson's is a journey of acceptance, another chapter in my long and varied life. The Rx Ballroom Dance program opened up an unexpected opportunity, enhancing my life in so many ways.

Founded in 2018 by Erin Angelo, Rx Ballroom Dance provides an effective way to promote health. Dance and music have remarkable effects on our well-being both physically and mentally. The dance program consists of twice weekly dance classes, two ballroom dances are learned each month. Rhythmic dancing and choreography stimulate the brain and create new neural pathways. A professional ballroom dancer leads the class through a curriculum specifically designed to engage the mind, body, and spirit. In Fallbrook we have Tricia Bowman an energetic and supportive teacher.

Parkinson's is a journey of acceptance, another chapter in my long and varied life. The Rx Ballroom Dance program opened up an unexpected opportunity, enhancing my life in so many ways.



The Fallbrook Rx Ballroom Dance group, their family and friends, enthusiastically supported dancers.



NORTH COUNTY PARKINSON'S SUPPORT GROUP

POTLUCK LUNCH

Main Dishes provided by NCPSPG Rancho Bernardo

- Oceanside Members (Salads)-*
- La Costa Members (Side Dishes)-*
- Fallbrook Members (Desserts)-*



WHEN: Monday, September 16th, 2024
Starts at 11:30 AM

WHERE: San Rafael Church (Parish Hall)
17252 Bernardo Center Dr.
San Diego, CA 92128

MORE INFORMATION: Please visit www.NCPSG.org
or call 858-354-2498 or 760-749-8234

NCPSG serves the North San Diego County Parkinson's community...providing Parkinson's disease education, patient and family support, exercise and social opportunities and encouraging research.