

NORTH COUNTY PARKINSON'S SUPPORT GROUP

April 2025

www.NCPSG.org



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

Young Onset Parkinson's Support Group Formed

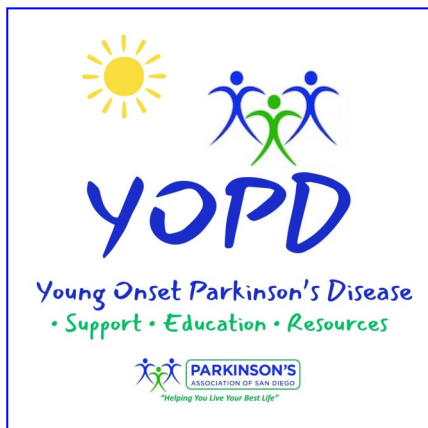
YOPD - Young Onset Parkinson's Disease is different. Not only does it affect people at a younger age, it also varies in the way symptoms present, how it progresses, and its genetic factors. Roughly 10% of the total Parkinson's population is considered "Young Onset". The exciting news is that there is a **new support group** (SG) forming that takes these and other factors into consideration. But more about that new group in a minute.

Typical Parkinson's disease is diagnosed at 60 years or older. "Young Onset" strikes most often while the patient is under fifty - sometimes as young as nineteen! People with Young Onset are usually family bread-winners, competing in the job market, parenting children, and are active in social circles - all areas where a movement disorder can present real challenges. Those challenges also apply to participation in a Support Group. YOPDs have to juggle family and employment schedules and so much more, making it difficult to join daytime support groups. Because Young Onset is distinctly different from typical PD, a different SG is planned.

Most of you who are active in support groups know of SG's value in learning about the variety of symptoms and treatments - although we know that no two Parkinson's journeys are alike. SGs expand our knowledge of this very complex disease, new developments towards an eventual cure, new medications and treatments. But without a doubt, the greatest value of a SG is realizing that we are not alone! New friendships grow from meeting amazing people who just happen to share the PD journey, and are fighting the same foe.

Now for the **good news for YOPD** here in San Diego County! A new support group is forming to deal with these distinctive issues, especially issues around work, socializing and family. It is open to anyone diagnosed with Parkinson's prior to age 50. The group meetings will focus on these unique issues, as well as general challenges people with PD face. Besides offering support for those with YOPD, there will also be an educational component with presentations by various service providers and other resources for the community.

Beginning April 15, 2025, meetings will be held the **third Tuesday of each month at 6 pm**. For more information or to receive the Zoom link to the first meeting, contact Steve Steinberg (951) 719-9195 or at steve@whatsshakingman.com.



PASD 5K Walk April 5, 2025 - Liberty Station

Hurry Up! We're almost at the Starting Line! **Great Exercise, Great Fun, Excellent Information.** The Health Fair offers amazing resources! Registration at <https://parkinsonsassociation.org> For event questions or to register by phone, please call (858) 215-2570. More information on Page 5.

Register under team names: *Fallbrook Walkers, Ocean Hills Walkers, RB Walkers - or make up your own team.*
Adults 18 and older \$50 – Youth 12-17 years \$10; Children under 12 are FREE. Dogs are FREE too! (Most cats probably aren't interested.)

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Support Group Meetings

RANCHO BERNARDO

Monday, April 7, 10:00 AM to Noon

Speaker: Dan Sweiger, BrightCare

Topic: "Services BrightCare offers to PD community"

San Rafael Catholic Church 17252 Bernardo

Center Road, San Diego, 92128

Hosts: Brigit King bkicedancer@gmail.com

858-354-2498 & Carol Maher hcmaher@cox.net

760-518-1963

LA COSTA CARLSBAD

Wednesday, April 2, 10:00 AM to Noon

Speaker: Melanie Harris

Topic: "Hybrid Assistive Limb Exoskeleton and Physical Therapy for Parkinson's"

Christ Presbyterian Church

7807 Centella St. Carlsbad 92009

Host: Sam Cooper NCPISGLC@gmail.com

or 520-820-0339

OCEANSIDE

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

Speaker: Dr. SanDeep Thakkar, Hoag Hospital

Topic: "GoCovri - Apokvn for "OFF" episodes"

Oceanside First Presbyterian Church

2001 S. El Camino Real, at Fire Mountain Rd

Oceanside 92054

Host: Paul Dawson paul@video-fire.com

or 760-497-1200

FALLBROOK

Friday, April 25, 10 AM to Noon

Speaker: Louis Ciampi, Acadia Pharma

Topic: "Non- Motor Challenges (Dementia / Hallucinations)"

Contact Irene at email NCPISGF@gmail.com

Fallbrook Regional Wellness Center

1636 E. Mission Rd, Fallbrook 92028

Host: Irene Miller NCPISGF@gmail.com

Social Gatherings

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

Save the Date

Summer Social, Saturday, June 14, Ed Brown Center, Rancho Bernardo.

NCPISG Board of Directors

Wednesday, April 23, 1-3 PM. The Board meets online on the third Wednesday of the month.

Contact Sam Cooper NCPISGLC@gmail.com or 520-820-0339.

Physical Exercise

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

Tri-City Hospital - Parkinson's Exercise

Led by a Physical Therapist and an Occupational Therapist. Every Thursday, 3 - 4 pm. (no charge) Check in at hospital main desk.

Personally Fit (NCPISG Scholarships Available)

In-person and Zoom classes for Parkinson's.

personallyfitonline.com or contact Doris Flood, PT at dflood@personallyfitonline.com

LifeSpan Health (NCPISG Scholarships Available)

Drug-free program to enhance a healthy life span.

<https://lifespanhealth.me/>

NeuroLab 360 (NCPISG Scholarships Available)

Neurologic physical and occupational therapy, and wellness sessions. www.neurolab360.com

Rock Steady Boxing (NCPISG 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

Tai Chi - Temecula - (NCPISG Scholarships Available)

Physical exercise & wellness.

www.oysd-ca.com

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



"I was born in Cuba and immigrated to the United States in 1967. I met my husband, Jay, while we were working at the same place and have been together since 1984. We married in Kauai in 1992. We have a daughter and four adult grandchildren. I am a realtor and enjoy bowling, traveling, and getting massages.

"Jay was diagnosed with Parkinson's in July of 2023 after months of misdiagnosis. He was in shock and seriously depressed and experienced several anxiety attacks. I began researching Parkinson's and advocating for him with health insurance providers trying to get support and resources.

"The first thing I learned was movement is critical, so we started attending Rock Steady Boxing. At this time I convinced him to retire so we could focus on his treatment. On initial visit to the gym, we ran into our friends Tony and Leslie LoPiccolo. At the time, we didn't know Leslie had been diagnosed with Parkinson's also. They are the ones that told us about the Fallbrook support group which we started attending right away.

"We now have new insurance coverage, a new doctor whom Jay really likes, a movement disorder specialist at UCSD, our Fallbrook support group, Rock Steady Boxing, and are attending such events as Empowerment Day. We have settled into this new normal.

"The support group is very helpful. We always learn from the informational speaker and the breakout sessions for Care Partners is just what I need. They allow me to ask other spouses questions about the process and allow me to vent if there's something I'm struggling with. The group helps me focus on the positive while being realistic about the future.

"Parkinson's has forced us to focus on the important things in life. We have been traveling more while we still can and checking things off our bucket list. We have learned to enjoy each day. Family and friends have been supportive which is very helpful.

**"...the Breakout sessions
for Care Partners
is just what I need.**

**They allow me to ask
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"Here's what I would say to someone caring for a loved one with Parkinson's. Stay active. Stay involved in life. Exercise. Socialize. Join a support group. Find yourself a community. You do not have to do this alone."

Parkinson's Awareness Month - Giving to Help Now and into the Future

April is **Parkinson's Awareness Month**. Our annual "ask" is that you consider making a donation to NCPSPG in the form of a yearly gift or by including NCPSPG in your Will or Trust (see last month's Newsletter). Your gift will allow us to continue to offer services that are important to you and to the Parkinson's community here in North County. Thank you.

NCPSPG 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!

Parkinson's Infusions Research

The Federal Drug Administration has approved the first infusion-based apomorphine therapy approved in the U.S. for Parkinson's disease according to a report from the Michael J. Fox Foundation on February 4.

The drug is **Onapgo**, apomorphine hydrochloride, a dopamine agonist. It provides a constant supply throughout the day via an under-the-skin device for the treatment of "off" time and motor fluctuations throughout the day in people with progressing Parkinson's. This is the second drug the FDA has approved within the last four months for managing Parkinson's motor fluctuations. The first, **Vyaley**, delivers a continuous infusion of levodopa and cabidopa.

"This approval represents another step forward in the treatment of people with Parkinson's who experience motor fluctuations," says **Rachel Dolhun, MD**, DipABLM, principal medical advisor at The Michael J. Fox Foundation. "The more options we have for easing motor fluctuations, the better our chances of improving the daily lives of all people and families with Parkinson's."

Drop By and Say Hi!

We have an *Outreach Team* that brings Parkinson's Awareness to public events. We're going to be at **PASD Walk**, Point Loma Liberty Station on April 5, and **Fallbrook Avocado Fair** April 13. Look for our blue tent. Stop by, say hi and encourage others to join NCPsG!

If you learn of other community events, let us know. Maybe we can reach out there too!

Please consider Legacy Giving and helping those who are now on the Parkinson's journey and those who will be following us.
Our mailing address:

NCPsG
PO Box 230566
Encinitas, CA. 92023

Our Website: (Donations accepted)
NCPsG.org

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!

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Newsletter Published Online

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
ncpsgCS@gmail.com

STEP by STEP 5K

April 5 2025

Join us to Fight Parkinson's
Our 23rd annual 5K STEP BY STEP WALK
in support of the
Parkinson's Association of San Diego

Saturday, April 5, 2025 • 7:30am Check In • 9am WALK, Dog Friendly
LIBERTY STATION, SAN DIEGO

Your support of Step by Step enables PASD to offer critical resources to thousands of individuals with Parkinson's here in San Diego County.

All contributions remain in the County and provide services, assistance, and education to people with Parkinson's, their care partners, and families.

Meet over 50 exhibitors.



PARKINSON'S
ASSOCIATION OF SAN DIEGO

"Helping You Live Your Best Life"

REGISTER AS:

An Individual
A Team or
Sponsor a Walker

REGISTER AT:

parkinsonsassociation.org
(858) 215-2570

After February 1
Youth 12-17
Under 12

\$50
\$10
Free

