NORTH COUNTY April 2024 www.NCPSG.org PARKINSON'S SUPPORT GROUP



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



April is Parkinson's Awareness Month

Unless touched by it, most people are unaware of what a challenge Parkinson's disease (PD) can be, not only for people with Parkinson's (PwP), but for their families, friends, and even employers. Most people think it's just a tremor that maybe gets worse over time, and they hope that they'll never have to deal with it.

Parkinson's Awareness Month represents a way that we can help others gain an understanding of Parkinson's impact on those of us battling the disease, and those around us as well. It also offers an opportunity for us to focus on what we, those of us battling PD, can do to further the fight.

Talk about it. Let others know how PD affects us, and how we gain strength from their understanding and certainly NOT from their sympathy.

Get involved. Of course we're balancing medical appointments, exercise, timing of medications. But go deeper. Learn all you can about PD. Look for research that you can take part in, moving forward early detection, new treatments and procedures, and eventually, a cure.

Support your support group by taking a more active role in helping with group activities, like greeting newcomers, registering first-timers, helping with check-in, assisting with refreshments, facilitating breakout groups, and just by making others feel welcome.

Stay active physically, mentally, socially. Whether we practice it or not, we know that physical exercise is key to slowing Parkinson's progression. But the same is true for mental exercise – finding ways to keep mentally sharp through challenging our brain to try new things like a musical instrument, a hobby, even learning a new language. Social contact tends to decline after diagnosis. However, our NCPSG large and small social gatherings give you a chance to relax and visit, maybe never mentioning PD.

The Parkinson's Association of San Diego's annual **Step-by-Step Walk** at Liberty Station, Point Loma, on **April 6** combines exercise, social, and contact with experts, all in one really fun, morning. Join us!

And yes, all that we do takes funds. Our NCPSG all-volunteer non-profit has ongoing expenses, the cost of services we provide. You can help with an annual donation, a monthly sustaining donation or a legacy gift. Please thoughtfully consider our request which is on page 5 of this newsletter and take action this Awareness month.

Mark your Calendar

ANNUAL WALK- Parkinson's Association San Diego Saturday, April 6, Liberty Station, Point Loma, San Diego.

Summer Social is Saturday, June 15. RSVP in May Newsletter.

Inside This Issue

Monthly Meetings	page 2
In Focus Eva Zamora	page 3
Contacts	page 4
Fundraising	page 5
Spring Social photos	page 6

Support Group Meetings

RANCHO BERNARDO

NOTE: Meeting on Tuesday, not usual Monday

Tuesday, April 2, 10:00 AM to noon

Speaker: Marty Acevedo

Topic: "Nutrition" Update on VA study

San Rafael Catholic Church 17252 Bernardo

Center Road, San Diego, 92128

Host: Brigit King bkicedancer@gmail.com.

858-354-2498

LA COSTA CARLSBAD

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

Speaker: Samantha Banta Topic: "Hospice Care 101" **Christ Presbyterian Church** 7807 Centella St. Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

OCEANSIDE

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

Speaker: Lindsey Unger, Parkinson Voice Project

Topic: "Speak Out!"

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, April 26, 10 AM to Noon

Speakers: Dr. Ana Maleki, MDS, and Shawn

McMenamin Abbott

Topic: Technology Advancements in Treating

Parkinson's Disease

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.

"Save The Date" the Summer Social is Saturday, June 15.

NCPSG Board of Directors

Wednesday, April 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 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 therapy & wellness.

www.neurolab360.com

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

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

Claire Schlegel

Our thoughts & prayers go out to family & friends

In Focus: Eva Zamora

By Sam Cooper



"20 years ago I read a book about walking on a spiritual journey through Spain. Each year thousands of people do a pilgrimage to the tomb of the Apostle St. James in Santiago. The route originated in medieval times. I walked El Camino Primitivo, the original way where there is a 1000 year-old monastery pilgrims can

stay. I chose the most difficult route and I chose to walk alone, but at the end of the day I would meet up with other hikers at the same accommodations, usually quaint hostels, creating my camino family of people from all over the world. As I walked I could hear my footsteps. It became a meditation to breathe and to hear my hiking sticks knock on the earth as if announcing myself to the gates of this sacred land. I averaged about 13 miles a day. I lost 3

Diagnosed with Parkinson's 10 years ago, Eva was our "In Focus" for February, 2019, with a photo of her skydiving. Here is her latest...

toenails and had blisters every day. But on the day of my arrival at the cathedral, I had no blisters. Nobody noticed my tremors, not even me. I did it! I completed 327 kilometers in 18 days arriving at the Cathedral of Santiago to the sounds of bagpipes taking me into the plaza. As Mohammad Ali noted, "You don't know how strong you are until strong is the only choice you have."





Volunteer!

All Board members, officers, support group leaders are volunteers as are our greeters, refreshment team, sound folks, and breakout facilitators. Is there a way you could help? Volunteering benefits our members; it's a fun and rewarding way to contribute. to our Parkinson's community.

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 ncpsqNL@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!

Medical News: National Institute of Health

Breakthrough Results of NIH-Sponsored Study of Syn-One Test® as a Skin-Based Diagnostic Tool for Parkinson's Disease and Related Disorders Published in the Journal of the American Medical Association.

"This blinded, 30-site, 428-patient study has the potential to unlock a new era in diagnostic testing and address urgent unmet needs by reducing common misdiagnoses while enhancing clinical drug development efforts.

"The primary goal of this study was to define the positivity rate of skin biopsies to detect P-SYN deposition in clinically confirmed cases of PD", and related diseases.

https://finance.yahoo.com/news/breakthroughresults-nih-sponsored-study-152000704.html



Step-by-Step 5K Walk April 6, 2024



In memory of **Madonna Bingham**, your NCPSG Board of Directors suggests that you register under the team name "Bingham Bunch," the team that she created. Her wish was **Bing-**

ham Bunch would be the biggest and highest fundraising team this year! Register online at https://raceroster.com/events/2024/82261/fighting-parkinsonsstep-by-step-5k

Our mailing address:

NCPSG PO Box 230566 **Encinitas CA 92023**

Our Website: (Donations accepted)

NCPSG.org

NCPSG OFFICERS, DIRECTORS, LEADERS

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Our monthly NCPSG Newsletter is available on our website www.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

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!



April is Parkinson's Awareness Month. We wanted to take a moment and focus on the work that NCPSG, North County Parkinson's Support Group does. But this isn't a story about what we do. This is a story about what you allow us to do.

NCPSG is a 501c3 nonprofit. As dedicated volunteers, the main goal of our work is to support People with Parkinson's (PwP), and their families in North County San Diego with the resources and know-how you need to live your best life. When you request resources through NCPSG.org, you access resources free of charge. The contributions we receive help us support our programs. This support — along with support from individual donors, legacy donors, and participants — allows us to do the work we do.

By choosing to use NCPSG resources and website, you're helping us spread the word to others in our county that might have need to access the technology, skills, and support we have to carry out our purpose. That's money going back into the nonprofit community. That's something that doesn't happen when you get your services through a for-profit provider.

This makes you a stakeholder in the success of NCPSG — and the success of the world of PwP's & their families. So, we wanted to provide you with a snapshot of some of the work we've done.

NCPSG Year in Review

What We've Done Together

Here are just a few ways you've helped us support PwP's and their families.

Over 7,000 PwP served: During our 2023 fiscal year, NCPSG connected approximately 7,000 individuals with services they need to live their best lives. This included information and resources through our monthly newsletter, website resources and scholarship programs offered through *NCPSG.org* and social events. Together, this represents \$23,000 worth of value delivered to PwP's in North County.

Over \$12,000 delivered to PwP's for Scholarship funding: NCPSG Scholarship Program, the brainchild of our Past President, Paul Dawson, provides "opportunities to participate in a number of therapies and programs specifically for PwP's, encouraging individuals to step out and take control of their journey, to not allow the disease to define them." This includes Rock Steady Boxing, Voice therapy, Physical therapy, and Respite care. In the fiscal year 2023, we received more than 40 requests from PwP's and their families for scholarship opportunities.

Support for Education: In fiscal year 2023, NCPSG distributed over 9,500 newsletters with education, resources, and *In Focus* articles highlighting participants from our Support Groups. We supported four local NCPSG chapters throughout the North County in Oceanside, Rancho Bernardo, La Costa and Fallbrook - a monthly safe meeting place provided with refreshments; a current topic educational speaker secured and a time of sharing their challenges and successes in coping with Parkinson's.

Support for Social Gatherings: The brainchild of our current President, Sam Cooper; otherwise known as "Everything Social", we provided the opportunity to participate in four large group socials – Spring (March), Summer (June), Fall (September) and Winter (December). Monthly Small Group Socials meet in homes for a more intimate setting and social conversation.

Thank You!

For over 40 years, NCPSG, together with donors, generous individuals from our nonprofit community, have worked to support the continuation of our purpose, to support individuals affected by Parkinson's Disease. None of it happens without you. Thank you for partnering with NCPSG. Thank you for trusting us. And thank you for helping us make the world of those living with Parkinson's Disease thrive stronger.

SUPPORT OUR WORK

We are grateful for any and all donations which will go a long way to help your loved one affected by Parkinson, a care partner, or friend. Please consider a one-time donation, re-occurring donation or legacy contribution.

Checks payable to North County Parkinson's Group may be mailed to: NCPSG PO Box 230566 Encinitas. CA 92023

You may also donate on our website: www.NCP\$G.org or through PayPal: www.paypalme/ncpsg

Thank you on behalf of those whose life you touched this past year and for your support of North County Parkinson's Support Group.

42 attend the Spring Social at Broken Yolk Oceanside









