NORTH COUNTY February 2025 www.NCPSG.org PARKINSON'S SUPPORT GROUP



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

Your Parkinson's Legacy

If you are reading this, you and your family are impacted by Parkinson's. Parkinson's can affect people in a variety of ways from occasional annoyances and inconveniences to impacting virtually every aspect of life, physical and mental. None of us like to contemplate increasing challenges, but we've learned to find ways to deal with those challenges, and to find the joy in life.

Members of our support groups work very hard to help us understand the disease and to find ways to cope with it. Beyond information and coping skills, we point you towards exercise opportunities and emphasize the importance of physical activity. Mental "fitness" is another of our goals because like the body, the mind stays healthy and "fit" through activity and challenges. We know that for some, this disease causes us to withdraw from friends and even family, whether its because of our physical difficulties or our speech. NCPSG has developed ways for us to interact with others in a supportive, enjoyable atmosphere at our Small Group and Large Group Socials. There we learn so much about each other, our families, our careers, our hobbies and so much more. We realize that there are fascinating people all around us—who also are dealing with Parkinson's.

We encourage you to participate in our activities, to volunteer at our gatherings. But have you thought about leaving a legacy for others on this journey? In this way, you can reach out to those who follow, helping them lead their best life. Several such gifts have made our Scholarship program possible, through which you can sample fee-based services that you may decide to continue at your own expense. In the next few months we'll offer information on initiating a legacy gift - and how you can honor NCPSG's work and "pay it forward".

"Ya got Progress Right Here in River City!"

Paraphrasing (and modifying) Meridith Willson's 1957 "Music Man" "Ya Got Trouble" lyric, we are fortunate to live in the San Diego region. With all its outstanding research, development and Parkinson's treatment facilities, we're in a special place. We've mentioned the research formerly conducted at Scripps Research Institute, La Jolla, in which a small skin sample from an individual is converted through intricate procedures into dopamine-producing cells to be implanted in that same_individual. The potential is for replacement of dying cells with new cells, potentially provide that individual with a new source of dopamine with cells that the body recognizes as it's own, thereby avoiding cell rejection. As we recently mentioned, they are embarking in limited human patient testing, to confirm it is tolerated and effective, before expanding to larger scale testing. "Aspen", the corporation that expanded the research is based right here!

We intend to bring other local promising research programs to you - research that may provide that elusive "cure" to PD.

Our Spring Social - Just Around the Corner

As the seasons change, we move to our next exciting LARGE social event: the **Spring Social**. It will be held at Oceanside's **Broken Yolk** restaurant on Vista Way, near Hwy 78. An informal gathering for food and engaging conversation where you can make new friends and meet old ones (*old* as known for a long time, not **old** old). Parkinson's can be isolating, so grab this chance to fight back over good food! Yes, call it a *food fight*!

Details and reservation form is on the last page of this newsletter.

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Support Group Meetings

RANCHO BERNARDO

Monday, February 3, 10:00 AM to Noon

Speaker: Ed Hunter

Topic: "A new method of receiving medications"

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, February 5, 1:00 PM to 3 PM

Speaker: Ed Hunter

Topic: "Vyalev: A Different Approach With

Continuous Delivery"

Christ Presbyterian Church

7807 Centella St. Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

OCEANSIDE

Wednesday, February 12, 1:00 PM to 3 PM

Speaker: Sherrie Gould, NP and Lou Ciampi, Acadia

Topic: "Hallucinations and Delusions"

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, February 28, 10 AM to Noon

Speaker: Ed Hunter - Abbott Pharmaceutical

Topic: "PD Therapy Update" - Vyalev
Contact Irene at email ncpsgF@gmail.com

Fallbrook Regional Wellness Center

Social Gatherings

Our next large group event is the **Spring Social**, **Monday, March 17**, in the Oceanside Room at the Oceanside Broken Yolk. The ticket form is on page 5 and must be returned by Monday, March 10.

Passings

- Carolyn Kelly
- Bill Sproul

Our thoughts & prayers go out to family & friends

NCPSG Board of Directors

Wednesday, February 29, 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)

<u>Tuesdays at 1:00 PM</u> (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: Steve Frisina By Sam Cooper



Steve Frisina worked for over 30 years in the automobile insurance industry. He led product management organizations for companies such as Progressive, AAA, and The General. An avid sports enthusiast, Steve grew up a Chicago sports fan, pulling for his teams win, lose, or tie. While his teams have come up short in championships, they have never been at a loss for his support.

"My career moves brought me to San Diego where I was diagnosed with Parkinson's in 2015. My symptoms are numerous. Initially it was only tremors, but now include hallucinations, agitation, and drooling.

I play ping pong and attend Rock Steady Boxing for exercise. I really enjoy the boxing class. It is a real outlet physically and emotionally and feeling exhausted after class just feels good. I met my wife, Pam, at Rock Steady Boxing after the passing of my first wife. Pam also has Parkinson's. A few of us in the class started an informal support group that has been meeting monthly for about 6 years. I also met Howard Maher and his wife, Carol, in Rock Steady Boxing. They are the ones that founded the Rancho Bernardo support group which is part of the North County Parkinson's Support Group. [Editor's note: See below* for more details of RB chapter creation.]

"Pam and I started attending the Rancho Bernardo group about 3 years ago. We volunteer at the New Member table each month. We find the group very helpful. The monthly speaker is always informative and the Parkinson's breakout group allows us to share current concerns and solutions with folks who understand. We have met many new friends through these two groups and enjoy the company of others in a similar situation.

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"Pam keeps me active and engaged. She is my greatest supporter and my biggest help. I love her so very much and am so very lucky to have met her. She drives me to be a better man and makes life and Parkison's an adventure. Her symptoms are different from mine. We have come to understand those differences and are able to help each other. My advice to others with Parkinson's is to engage with others at every opportunity. Share the gift that is uniquely you."

*Our NCPSG Rancho Bernardo chapter was created as a result of a study by Board members a few years ago. Then-President Paul Dawson challenged the Board to evaluate our services in north county and identify where we could better serve the Parkinson's community. A committee lead by then-Vice President Rex McCoy, consisting of Rick & Linda Ankrom, Ken & Brigit King, Howard & Carol Maher, Bill and Willa Burns and Peter Fusselman, identified the need for a new support group in the RB/ Escondido area, found a venue, and publicized locally. Their first meeting had close to 100 participants!

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.

ncpsgRB@gmail.com

Parkinson's Research in Imaging

According to Jen Fisher Wilson reporting in *Fox Focus* least six alpha-synuclein tracers used in PET scanning recently advanced to testing in human trials according to the head of research resources and imaging lead at The Michael J. Fox Foundation Jamie Eberling, PhD. The hope is the imaging tool will allow scientists to see the clumping proteins inside the brains of people living with Parkinson's disease by using a tracer during a PET scan. Currently those clumps can only be seen at autopsy.

Dr. Eberling says such imaging holds "game changing" potential for expanding disease understanding and drug development. She anticipates that it will be applied almost immediately to help with early diagnosis, shed light on disease progression and monitor treatment response.

Wilson reported the use of PET imaging in Alzheimer's research offers perspective on how much value it could hold for PD pointing to the 2004 development of a tracer for amyloid, a brain clumping protein linked to Alzheimer's disease. Scientists then applied the tracer to anti-amyloid drug trials. Data from those trials helped lead the way for two new drug therapies approved in 2024.

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.

Our mailing address:

NCPSG

PO Box 230566

Encinitas, CA. 92023

Our Website: (Donations accepted)

NCPSG.org

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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 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!

North County Parkinson's Support Group



Monday, March 17, 2025, Oceanside Room, 11:30 A.M. at the Oceanside Broken Yolk 2434 Vista Way, Oceanside

Ticket price: \$17.50

- -Hamburger with choice of cheese, French fries, onion rings, or side salad
- -Club Sandwich on sourdough with choice of French fries, onion rings, or side salad
- -Grilled Chicken Caesar Salad
- -Veggie Wrap with choice of French fries, onion rings, or side salad Menu Choice includes hot/cold tea, coffee, soft drink, lemonade, or Arnold Palmer

| Number of tickets ordered: | |
|----------------------------|-------------|
| Name | Menu Choice |
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Reservations must be received by Monday, March 10

Mail ticket form and check to:

NCPSG

PO Box 230566

Encinitas, CA. 92023