NORTH COUNTY May 2022 www.NCPSG.org PARKINSON'S SUPPORT GROUP

E HOPE

UP

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

We Sprang Into Spring!

On Monday March 21st we held our very first annual large group Spring Social. Over 40 folks arrived at Bobby's Hideaway Café hungry and ready to socialize. The food was great and the company better.



We Met Outdoors...



Paul Dawson, NCPSG Board President is a loyal supporter of all our events.



And Indoors.



Social Chair Sam Cooper and past Treasurer Betty Byrd

PASD Walk Success



PASD Board President Marty Acevedo & Madonna Bingham

A beautiful day for a walk in the park! April 9 was the Parkinson's Association of San Diego's annual 5K "Fighting Parkinson's Step-by-Step" Walk at Liberty Station. NCPSG was well represented with over 100 of the thousand or so participants this year. NCPSG and the other three support group organizations around the county had displays, and lots of visitors.

Madonna Bingham was the second top fundraiser collecting just under \$13,000. Carlo Cecchetto, CBS 8 news anchor, was MC, and asked Madonna what her secret was. "Stamps" was her answer. She writes to every potential donor, and includes a self-addressed stamped envelope -

for a little added pressure. The Bingham Bunch was second largest group with 59 walkers (Madonna,captain), and the Rancho

Bernardo Walkers (Jan Semerad, captain) were fourth with 32 walkers!

Funds raised stay in SD County, and underwrite the most comprehensive website you'll find, the outstanding new "Mentor program" with one-on-one advice and support, and "Empowerment Day" with 20+ subject-expert speakers and dozens of resource displays and vendors. Many thanks to all who helped support these important services.

Inside This Issue

- Events Calendar
- Page 2
- IN FOCUS: Marty Acevedo
 - Page 3
- Significant Parkinson's Research Page 4

Support Group Meetings

Attendance at NCPSG in-person events requires full vaccination or natural immunity (recovered from infection) against COVID-19. Attendance at an in-person event constitutes your certification of full vaccination or natural immunity.

Chapter Meetings

RANCHO BERNARDO

Monday May 2, 10:00 AM

Speaker: Susan Neese, Speech Pathologist

Topic: "Speech and Parkinson's"

San Rafael Catholic Church 17252 Bernardo

Center Road, San Diego, 92128 Hosts: Brigit King & Carol Maher hcmaher@cox.net or 760-749-8234

LA COSTA CARLSBAD

Wednesday May 4, 1:00 PM

Speaker: Leslie Salmon

Topic: "Yoga Therapy For Persons With

Parkinson's"

Christ Presbyterian Church

7807 Centella St Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

OCEANSIDE

Wednesday May 11, 1:00 PM

Speaker: Cheryl Kyinn Certified Physician Assistant Topic: "Duopa - delivery of Levodopa, a dopamine replacement, directly into the intestinal track."

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 May 27, 10:00 AM

Speaker: Rex McCoy, NCPSG Board

Topic: "Emergency Readiness/Aware in Care"

Fallbrook Wellness Center

1636 E. Mission Rd, Fallbrook 92028 Host: Irene Miller NCPSGF@gmail.com

or 760-731-0171

Social Groups

Small Group No Host lunch, Monday, May 16, 11:30. If you are interested in joining us, contact Social Chair Sam Cooper at scprphd@gmail.com or 520.820.0339

NCPSG Board of Directors

Wednesday May 18,1 - 3 PM Board meets online on the third Wednesday of the month. Paul Dawson 760-497-1200

Physical Exercise

(Contact Provider for In-person or On-line Options. Fees May Be Charged)

ROCK STEADY BOXING - Improve Parkinson's quality of life through non-contact boxing-based fitness curriculum. In-gym and online classes available. Find a class at:

https://www.rocksteadvboxing.org/

PERSONALLY FIT ONLINE - Zoom classes for PD. Personallyfitonline.com or contact Doris Flood, PT at dflood@personallyfitonline.com

CEREBRAL MOTION Specialized personal training for PD. Cerebralmotion.com or contact Mickey Burke MS at mickey@cerebralmotion.com

COACH ME STRONG A one-on-one exercise coaching program. Email Coachmestrong.com

SmartXPD Online Exercise with Patrick

An online/video exercise community. See SmartXPD.com or contact patrick@smartxpd.com

Don Skaggs Total Healthworks: Evidence based online fitness program. Email totalhealthworks.com

Vocal Exercise

Tremble Clefs -Therapeutic Singing and Socializing. North Inland Chapter (Rancho Bernardo)

Wednesdays at 10:00 AM

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, in the Youth Multi Use Center, 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/ Facebook: https://www.facebook.com/TrembleClefsSD

AudAbility - Professional music therapy program for People with Parkinson's.

Check the website to see if you are eligible for special subsidies for North County residents for this program. MusicWorx.com. Or Cassandra Richtsmeier 858-457 -2201 or crichtsmeier@musicworxinc.com.



Marty Acevedo grew up in Bristol, Tennessee and completed her BS in Nutrition And Dietetics at the University of Tennessee and a MS in Biology at the University of Bridgeport. She married her husband, Ace, in 2000 and has two stepchildren and a grandson. "I love to travel. Ace and I have visited 41 states and 21 national parks so far. I also am a passionate fan of the

University of Tennessee and San Diego State athletics." During her 32 year career she was the Director of Food and Nutrition, Environmental Services, and Patient Transportation at TriCity Hospital in Oceanside managing

190 employees and a nine million dollar budget and implementing numerous new programs.

"My first noticeable symptom was on March 3, 2002, the day my father passed away, when I developed a tremor in my left hand. After seeing other doctors over the next several years due to balance and falling issues, no arm swing, and altered gait, I was diagnosed by a Movement Disorder Specialist in 2010 who told me I had Parkinson's and would be bedridden in ten years. Determined to prove her wrong, I immediately began an exercise program. I had DBS in 2016. Current symptoms include morning rigidity, some bradykinesia, and dystonia."

"My Parkinson's Journey has been challenging, rewarding, empowering, and humbling. I have become more mindful of each hour and each day."

"We find purpose by staying positive, exercising, socializing, and practicing mindfulness. Most of all we find purpose by remembering to support each other. We are all in this together."

Her involvement in the Parkinson's community runs deep. She is the Board President of the Parkinson's Association Of San Diego, an Ambassador for the Davis Phinney Foundation, an Ambassador for the Aware In Care initiative for the Parkinson's Foundation, and an Advocacy Ambassador for the Michael J. Fox Foundation. She assisted with the development of the exercise program at TriCity Wellness Center, cofounded Coach Me Strong, and has presented at several of our North County support group chapter meetings. Marty has also participated in clinical studies including the MJFF S-4 and PPMI 2 biomarker studies. "I learned through GENEration that I have two autosomal recessive variants of PARKIN, meaning I likely inherited from both parents."

"My Parkinson's Journey has been challenging, rewarding, empowering, and humbling. I have become more mindful of each hour and each day. I am very grateful that my husband is so supportive and urges me to continue my daily exercise and busy life as a volunteer. My mother always said that everything happens for a reason. My Parkinson's diagnosis has enabled me to find a way to live my best life and to help others find a way to live their best life."

"We find purpose by staying positive, exercising, socializing, and practicing mindfulness. Most of all we find purpose by remembering to support each other. We are all in this together."

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 promotional materials. Please tell the event leader if you do not want your image to appear.

Did you know?

If you are receiving this newsletter electronically you can click on the links and be taken directly to the resource. To switch to electronic delivery contact Micheline at micheline.allen@cox.net or Caryl at carylparrish@gmail.com. If you find a broken link, contact Rex at ncpsqnl@gmail.com.

Critical Advance Announced in Imaging the Living Parkinson's Brain

A team funded by the Michael J Fox Foundation announced significant progress in the pursuit of detecting alpha-synuclein in the brain. The ability to detect alpha-synuclein activity in the brain would be a step towards the ever-elusive biological marker for Parkisonianism, and would also allow for the testing of new drug therapies to address the protein's activity.

Alpha-synuclein is a protein found in everyone. But the misfolding of the protein is a pathological hallmark of Parkinson's. (See our March 2021 newsletter for a discussion of protein folding.)

PET (positron emission tomography) images of alphasynuclein in the human brain were presented to the International Congress on Alzheimer's and Parkinson's Diseases in Barcelona Spain this year.

More good news: In February MJFF announced the award of a grant to the AC Immune team to commence human clinical trials for a specific PET tracer to detect misfolded alpha-synuclein. The ability to detect alpha-synuclein would allow researchers to determine if a particular drug therapy was impacting the disease.

For further information see the MJFF website article at https://www.michaeljfox.org/news/breaking-news-critical-advance-announced-imaging-living-parkinsons-brain.

Passings

Elaine Weiler

Our thoughts & prayers go out to family & friends

To update or remove your contact info, please let **Micheline Allen** know. 760-631-0649 micheline.allen@cox.net

Our mailing address:

NCPSG

PO Box 230566 Encinitas CA 92023

Our Website: (Donations accepted)

NCPSG.org

Our Facebook page: (Donations accepted, no fees)

https://m.facebook.com/NorthCountyParkinsonsSupportGroup/

THE NEUROLOGY
CENTER
OF SOUTHERN CALIFORNIA

CONTACTS

Rancho Bernardo Support Group Leaders

Carol Maher <u>hcmaher@cox.net</u>

760-749-8234

info@ncpsq.org

Brigit King <u>bkicedancer@gmail.com</u>

858-354-2498

La Costa Support Group Leader

Sam Cooper <u>NCPSGLC@gmail.com</u>

520-820-0339

La Costa Co-leaders

General Email Contact

Art Braun <u>artjbraun@hotmail.com</u>

760-550-0508

Bill Farrington <u>billfarr48@gmail.com</u>

760-815-5234

Oceanside Support Group Leader

Paul Dawson <u>paul@video-fire.com</u> NCPSG Board President 760-497-1200

Oceanside Co-Leader, Library

Madonna Bingham granny6mb@gmail.com

760-757-7564

Fallbrook Support Group Leader

Irene Miller <u>NCPSGF@gmail.com</u>

760-731-0171

Fallbrook Support Group Co-Leader

Open

Treasurer, Recording Secretary & Webmaster

Caryl Parrish <u>carylparrish@gmail.com</u>

760-753-5004

Corresponding Secretary <u>micheline.allen@cox.net</u>

Micheline Allen 760-631-0649

Social Director <u>scprphd@gmail.com</u>

Sam Cooper 520-820-0339

Video Documentation Google: Arthur Bierle on Vimeo

Arthur Bierle 760-749-2182

Board Member Emeritus

Thelma Balbes

Newsletter

Publisherpaul@video-fire.comPaul Dawson760-497-1200

Editor <u>ncpsgnl@gmail.com</u>

Rex McCoy 760-519-9588

Focus Interviewsscprphd@gmail.comSam Cooper520-820-0339

Printed Edition Distribution granny6mb@gmail.com
Madonna Bingham 760-757-7564

Wadonina Dingnam

Electronic Distribution carylparrish@gmail.com