NORTH COUNTY December 2020 www.NCPSG.org PARKINSON'S SUPPORT GROUP



NEWSLETTER for La Costa-Carlsbad, Fallbrook, Oceanside, and Rancho Bernardo Support Groups

Your NCPSG Board of Directors is asking for your help.

The challenges we face in our Parkinson's Journey are many, pandemic or not. You take action against these challenges by joining groups like NCPSG. But sometimes you find yourself saying, "I just wish there were some way to...". You get the idea. We are searching for out-of-the-box ways we could help you on your "Parkinson's journey", ways that could help you, say, navigate the healthcare system, access transportation or the internet, or access exercise and social opportunities, or deal with the other challenges that Parkinson's can bring. Is there anything that comes to mind where NCPSG could possibly help? PLEASE LET US KNOW IF YOU HAVE THOUGHTS, IDEAS, OR SUGGESTIONS. Email, phone or write us at our contacts listed on the back page.

Parkinson's Association of San Diego Website: A Wealth of Information

There is a rich resource at your fingertips. The PASD website: https://www.ParkinsonsAssociation.org is both comprehensive and current. Spend a few minutes checking it out, and see the great resources they have assembled for you. You'll find a box labeled "Click here for all the resources" in which you will find an amazing list of over seventy 2020 webinars from across the nation separated into thirteen categories. The list shows the topic, speaker and length. All you have to do is click the thumbnail title.

The website includes an up-to-date list of all the Movement Disorder Specialists in the county including their affiliation and contact information. Another part of the website lists current research projects and opportunities to participate in studies.

Most recently PASD added a discussion by Rasheda Ali, Muhammed Ali's daughter, talking about how PD affected her dad and the family. She is joined by Sherry Gould, Nurse Practitioner, on the importance of exercise, and Dr. Abagail Lawler, MD, and MDS discussing new treatments and research. Ms. Ali is hosting PASD'd 100% matching fundraiser, so there's good information and a good cause.

Come Back! We miss you!

Before COVID, (remember a time, long, long ago?) we had in-person meetings with stimulating speakers and discussions, and refreshments too. We are now confined in so many ways. For the time being we're limited to Support Group Zoom meetings on computer screens, and that's clearly not the same as being together. We have expert speakers on pertinent topics, and interesting discussions, albeit with occasional screen freezing. BUT WE DON'T HAVE YOU! We've lost more than half our usual attendees, and we want you back. Please give our temporary band-aid meetings a chance. You can join on computer, smart phone or just dial in using a rotary phone. Ask your leader for help if you have problems joining. Remember, you are not alone.

Purple Tier, Purple Tier

No, it's not a song by Prince. We continue to monitor the COVID situation, and almost every county in California is in the dreaded Purple tier, further restricting activities. The latest health order from the County of San Diego (as of this writing) is dated November 13th, and imposes additional restrictions on indoor activities. Even though we have seen the news about a vaccine, it will be months before it can be distributed in sufficient quantity for us to return to normal. So in the meantime, stay active, exercise and socialize even if it's online. See our events schedule on the next page for many opportunities. May we recommend our Support Group meetings as part of your schedule?

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Special Communications Insert

Support Group Meetings

Note: NCPSG Chapter in-person meetings are suspended until further notice. If you wish to attend any of the virtual meetings, contact the email address or phone number provided for a Zoom invitation.

Chapter Meetings

RANCHO BERNARDO - Online meeting December 7, 10:00 AM Speaker: Mina Nilchian, MSW. *Topic:* Things we can do to stimulate our brains. Host: Carol Maher hcmaher@cox.net or 760-749-8234

LA COSTA CARLSBAD - Online meeting **December 2, 1:00 PM** Speaker: Dr. Fernanda Penunuri Topic: Exercise: Your protection against Covid-19. Host: Sam Cooper NCPSGLC@gmail.com or 520-820-0339

OCEANSIDE - Online meeting December 9, 1:00 PM Double Header! David Higgins on CIRM refunding and David Miles on Progress for COVID 19 vaccine. Host: Paul Dawson paul@video-fire.com or 760-497-1200

FALLBROOK - No meeting in December Enjoy your Holiday! Host: Irene Miller NCPSGF@gmail.com or 760-731-0171

Breakout Groups

People with Parkinson's: two options;

New attendees: Please email the host to request the Zoom "Invite" details.

- Monday December 14, 10am, Bill Farrington, host email: billfarr48@gmail.com
- Thursday December 10, 10am, Paul Dawson, host email: paul@video-fire.com Care partners: Two options:

New attendees: Please email the host to request the Zoom "Invite" details.

- Monday December 14, 10am. Carol Maher, host. Email: hcmaher@cox.net
- Friday, December 18, 2pm, Sandy Miller, host email: sandy@greensails.net

Webinars to Keep Current

Michael J Fox Foundation

Free live webinars on various Parkinson's topics https://www.michaelifox.org/webinars

NCPSG Board of Directors

Wednesday December 16th 1 - 3pm Board meets on third Wednesday. Board meetings are conducted online. Paul Dawson 760-497-1200

Notice!

Public gatherings are restricted in California. Alternate listings are provided for online groups until normal activities are resumed.

Physical Exercise (Fees May Be Charged)

ROCK STEADY BOXING - Virtual Programs available Check their website for more information. https://www.rocksteadvboxing.org/

ONLINE EXERCISE CLASS - Classes for strength, agility and balance. Various times via Zoom. Christina Dinh cdinh@yadinneurowellness.com

PD Connect Various times and dates. www.pd-connect.org/#calendar

Dance for PD Music and dance at various times www.danceforparkinsons.org

SmartXPD Live Online Exercise with Patrick

An online exercise community. Contact: patrick@smartxpd.com

Coach Me Strong Informational meeting Monday December 7, 11am. Learn about this exciting new program! Register at

https://us02web.zoom.us/meeting/register/ tZMlcuugrzkvHtE1pxVSh8Yljdnp21lZ1TF9

Vocal Exercise

Tremble Clefs -Therapeutic Singing with chapters in Encinitas and Rancho Bernardo

Virtual practice Wednesdays at 10:00 AM and Thursdays at 1:00 PM

Melodi Denton at 619-363-0814 or check website: https://www.trembleclefs.com/

AudAbility - Online activities available free or discounted.

Music therapy program offering numerous music related activities for People with Parkinson's. Lindsay Zehren 858-457-2201 or lzehren@musicworxinc.com.

Small Social Groups

Virtual Meetings 3rd Mondays at 1:00 PM Monday December 21, 1pm. Our small social groups are meeting online until restrictions on gatherings are lifted. Contact Social Chairperson Sam Cooper scprphd@gmail.com or 520-820-0339

In Focus: Bob DeWinter



Bob DeWinter was born October 16, 1946, in Davenport, Iowa. His family moved to San Diego in 1962 and he graduated from El Cajon Valley High School in 1964. "I attended Grossmont College from 1965-66, with an emphasis on accounting. From February 1967 to January 1971, I served in the United States Air Force. This was during the Vietnam War and I spent my entire military career in San Antonio, Texas,

as an accounting specialist.

I met my wife, Sue, there
and we married in
November of 1968. During
our 52 years together we

raised three sons. After I got out of the Air Force, I returned to college and graduated from San Diego State University in 1972 with a degree in accounting. As a certified public accountant (CPA), I had a long career as an auditor and Chief Financial Officer retiring in 2006."

Bob's favorite hobby is wood working. "I enjoy the entire process of making something useful from wood and have a complete woodworking shop. There is just something about working with wood that is very special. I also play golf and enjoy the competition with myself trying to improve my score and the camaraderie of the other golfers."

"We have been involved with NCPSG, Rancho Bernardo since its inception and find the support and information available to us and the support of so many folks invaluable."

"My wife, Sue, is my rock. She reminds me to breathe and celebrate each day that is given to us."

"The only thing any of us can do is keep going. This is especially important when we really don't want to keep going. Every day is a new gift."

"I was diagnosed with Parkinson's in 2005. Without realizing it, I held my arm in an awkward position, parallel to the ground. When I attempted to correct the arm position, it would return to the same position within seconds. Going into my 16th year with Parkinson's, symptoms are becoming more prominent including loss of smell, freezing at any time, and orthostatic hypertension which causes my blood pressure to drop significantly upon standing. I am also experiencing stress and anxiety which is a trigger. I continue to exercise and am involved with Rock Steady Boxing and a moderator for a Parkinson's fighters support group in Rancho Bernardo. We have been involved with NCPSG, Rancho Bernardo since its inception and find the support and information available to us and the support of so many folks invaluable."

"My wife, Sue, is my rock. She reminds me to breathe and celebrate each day that is given to us. A positive effect of having Parkinson's is I can spend more time with her and our sons. I don't know what I would do without them. The only thing any of us can do is keep going. This is especially important when we really don't want to keep going. Every day is a new gift."

NCPSG Notice

We provide information in our newsletter and chapter meetings on a broad array of Parkinson's-related topics and perspectives. Please recognize that **a presentation should not be interpreted as our endorsement**. Do your own research, and talk with your neurologist before taking action.

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. If you find a broken link, contact Rex at micheline.allen@cox.net.

A Biomarker for Parkinson's?

Almost every one of us has a story of the difficulty getting the initial diagnosis for Parkinson's. It often happens years after the onset of some symptoms. This delay adds to our frustration, fear, and the lack of a plan to address our condition. To date the only diagnosis is clinical: how do our symptoms display, and do we respond to medications. The only biological test is obtained by an autopsy, which is more than a little inconvenient.

What if there were a simple biological test that were easily accessible? Well, there may be. Researchers at the lowa State University have published the results of a clinical trial in which alpha-synuclein protein clumping may be detected in the patient's skin. The results of the blinded random trial was published in the peer-reviewed journal Movement Disorders in September 2020. Fifty samples were tested, 25 from Parkinson's patients, and 25 controls. The test detected the clumping in 24 of the 25 PD samples.

Of course additional work must be done, but this may be a significant step towards early diagnosis of Parkinson's, leading to earlier and more effective interventions. The lowa State news release may be accessed at https://www.news.iastate.edu/news/2020/10/21/parkinsonsskinsample

Passings

Jeanette Shields
 Our thoughts and prayers go out to family and friends

Changes - Changes - Changes

If you have changed your phone, email or mailing address, or if you no longer want to receive our Newsletter, 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/

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