

NORTH COUNTY PARKINSON'S SUPPORT GROUP

September 2020
www.NCPSG.org



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

Let's Talk About the Newsletter: Recent Changes

Recently you may have received duplicate emails from NCPSPG distributing this monthly newsletter. (Check your spam/junk folder if you didn't see the second copy.) We are in the process of transitioning between providers of our website and email services. You will continue to receive a duplicate email for the next couple of months to ensure that you get your copy. For now, please open both copies until the transition is complete. Please make sure that you add info@ncpsg.org to your contact list, as that will be the only one we use in the near future. Just click on the link in that email to get access to your newsletter.

Newsletter Distribution

You have the option of receiving this newsletter by email or by postal mail. But we would like to make a serious appeal for you to consider using the email option. There are a lot of reasons:

- The postal mail option is considerably more expensive. Although we receive some generous postage assistance from The Neurology Center, we must still cover the costs of printing and envelopes. This is a significant budget item for NCPSPG.
- The physical newsletter requires volunteers to assemble and distribute. Now of course if you would like to volunteer for some of these activities, please contact us!
- You receive it early! As soon as it is published, the email version is sent out. You don't have to wait for snail mail.
- In the email version the links work! If an article has a link to a web resource, just click it and it will take you there.
- It's in color!
- And don't forget that if you want a hard copy, you can still print it out. That saves us the cost of printing and distribution. And did we mention that you can print it in color?

Please consider shifting your newsletter subscription to email. That will save us dollars and volunteer hours that can then go directly to our programs. Contact Micheline Allen at micheline.allen@cox.net if you would like to make that change.

Virtual Walk a Great Success!

Thanks to all who walked in the Parkinson's Association of San Diego's Virtual Walk on August 22. We had a great response from teams across north county. PASD raised more money for their services – thanks to your participation. Accolades to Madonna Bingham, who has raised over \$100,000 for PASD over the last decade! Awesome! You can see a plethora of video clips from the Virtual Walk broadcast on their website, www.ParkinsonsAssociation.org.

Stem Cell Research – Proposition 14

The grass roots effort to re-fund the California Institute for Regenerative Medicine CIRM research program, continuing research with a particular focus on brain disorders, is moving ahead. Thanks to those who circulated petitions to put it on the ballot. It will be on our November 3 ballot as Proposition 14. Read up on it. Take a position. **Vote!!!**

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Support Group Meetings

Note: NCPSTG 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

September 8, 10:00 AM *Speaker:* Lindsey Unger, Speech-Language Pathologist . *Topic:* Speech and Parkinson's. *Host:* Carol Maher hcmaher@cox.net or 760-749-8234

LA COSTA CARLSBAD -Online meeting

September 2, 1:00 PM *Speaker:* Sherrie Gould, NP, *Topic:* Treating Movement Problems In Parkinson's Disease. *Host:* Sam Cooper NCPSTGLC@gmail.com or 520-820-0339

OCEANSIDE - Online meeting September 9, 1:00

PM Join us for a timely topic and discussion. *Host:* Paul Dawson paul@video-fire.com or 760-497-1200

FALLBROOK - Online Meeting September 25,

10:00 AM *Speaker:* Patrick LoSasso, Trainer, CSCS, CES . *Topic:* How is Exercise for Parkinson Different? *Host:* Irene Miller NCPSTGF@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 September 14, 10am, Bill Farrington, host email: billfarr48@gmail.com
- Thursday September 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 September 14, 10am. Carol Maher, host. Email: hcmaher@cox.net
- Friday, September 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.michaeljfox.org/webinars>

NCPSTG Board of Directors

Wednesday September 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.rocksteadyboxing.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

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 1-619-363-0814 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 online until further notice.

Our small social groups normally gather in rotating private homes in months that we don't have a large group activity. In the meantime virtual meetings are being organized. If interested contact Social Chairperson **Sam Cooper** scprphd@gmail.com or 520-820-0339

Christ Presbyterian Church La Costa, Oceanside First Presbyterian Church, Christ the King Lutheran Church Fallbrook, and San Rafael Catholic Church, RB provide their facilities at no charge. We Thank You!



Sue DeWinter was born in Waukesha, Wisconsin. “Dad was career Air Force so we moved about every three years. I remember living in Livorno, Italy, as a teenager. During World War II, he flew a B24 and nicknamed his plane ‘Susie’. After my dad retired during my Senior year in high school, we moved back to Wisconsin where I graduated from his alma mater, Pewaukee High School. We then moved to San Antonio, Texas. I really didn’t want to go at all, but it ended up being the best move of my life as I met my husband, Bob, there.”

“After Bob was diagnosed with Parkinson’s I realized that although I did not know it at the time, my journey as a caregiver began in 1985 when I was diagnosed with stage three melanoma. Going through that I understand somewhat the emotional issues that Bob is dealing with now. I am fortunate in that Bob has always been very active. We did CrossFit together for some 5 years and that discipline has helped both of us. There are many challenges being my husband’s caregiver. There are times it seems like there is nothing wrong and I get complacent then Bob falls. I get very upset with myself as I feel I should be watching him more closely. I have learned Parkinson’s is sneaky that way. You never know when it will raise its ugly head.”

“My biggest joy of being a caregiver is being able to help my husband. I don’t see this part of our life together as being a burden. When I get short with Bob-and oh yes, I do get short with him-it’s really my getting mad at the disease and what it has done to him. He received a card one time that said ‘The Number One Rule is never give up. The Number Two Rule is always refer to Rule Number One’. I have it framed and it is one of the first things we see every morning. Our three sons are a huge part of my strength and are all very supportive. I know all I have to do is call them and they will be there for us. Our neighbors and friends are wonderful and they have come to my rescue more times than I can count.”

Bob and Sue attend the Rancho Bernardo chapter of our North County Parkinson’s Support Group. “Our friends Carol and Howard Maher have just been wonderful. The information provided by the group is incredibly invaluable and the many new friends we have met help so much. Being able to share with other caregivers is very helpful. It really is true that we are not in this alone. Even though we have to meet virtually now I feel like that support has never been stronger. It’s very comforting knowing that other people are going through this as well and we can lean on each other and learn from each other.”

Sue offers this advice to fellow caregivers. “Make laughter part of your daily routine. Admit there will be bad days. Cherish even the bad days. And always remember Rule Number One: Never give up. If you find yourself giving up, refer to Rule Number Two. I always knew that Bob is strong and stubborn and resilient. Now I know I am strong and stubborn and resilient too. We are on this journey together.”

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“Make laughter part of your daily routine. Admit there will be bad days. Cherish even the bad days. And always remember Rule Number One: Never give up.”

NCPSPG 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.

Coach Me Strong

We are constantly encouraging the benefits of exercise at NCPSTG. The Parkinson's Association of San Diego has brought to our attention a program called "Coach Me Strong". This program is designed to be customized to your specific needs. Fees are charged.

- You work with a coach specifically tailored to meet your needs.
- Your coach will create a structured exercise program just for you.
- Your coach will be your accountability partner.
- Workouts are posted to your private calendar and emailed to you daily.
- You have daily communication with your coach.
- You will become stronger

See the website <https://www.coachmestrong.com/> for more information. This announcement does not constitute an endorsement. You must decide if this is right for you.



Passings

- Mary Hjalmarson
- Thomas Reed
- Robert J. Grenus
- Nancy Moramarco
- John Hubert

Our thoughts and prayers go out to family and friends

Our mailing address :

NCPSTG
PO Box 230566
Encinitas CA 92023

Our Website: (Donations accepted)

NCPSTG.org

Our Facebook page: (Donations accepted, no fees)

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

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Our continuing thanks to the
Neurology Center of Southern California
for our Newsletter postage.



Serving San Diego County with four locations:
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