

NORTH COUNTY PARKINSON'S SUPPORT GROUP

November 2020
www.NCPSG.org



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

Meeting in an age of COVID-19

Health Orders

We are all painfully aware of the restrictions on physical contact, both voluntary and ordered, caused by the current pandemic. As an organization NCPSG is bound to comply with the orders of county health officials. San Diego county's current order can be found at their website at https://www.sandiegocounty.gov/content/sdc/hhsa/programs/phs/community_epidemiology/dc/2019-nCoV/health-order.html. As of this writing all gatherings are prohibited, with certain exceptions, to include single families and religious or cultural ceremonies. (Note that restaurants are not considered "gatherings" for this purpose.) The order may be modified at any time and may become more, or less, restrictive as circumstances change. Your Board is monitoring the situation and will advise you of any changes. Our current planning assumes that restrictions will continue for the next few months. Also note that the Parkinson's Association of San Diego (PASD) has adopted policy guidance that was prepared by leaders of the independent Parkinson's Support Groups (PSG). This guidance adds the requirement that an FDA-approved vaccine be widely available. Though not binding on NCPSG this guidance will also be considered. So, what does all this mean?

Social Meetings

Our pre-Covid social program included monthly small groups, and four large group opportunities including the July Summer Social with a buffet, Madonna's Weinie Roast, the potluck in Fallbrook, and the December Holiday Luncheon. All these events are cancelled, even though Sam Cooper, our Social Director, tried to save the annual Holiday Luncheon. But, as noted above, such gatherings are prohibited.

Until the pandemic has subsided, we will continue to meet socially via Zoom the third Monday of the month from 1:00-2:00. Anyone interested in joining the virtual small group is encouraged to contact Sam Cooper. There will be no large group events at all.

In planning for the future and assuming restrictions are lifted, our post-Covid social program will include our ongoing small groups and two large group events at the centrally located Shadowridge Golf Club: the July Summer Social, Wednesday, July 28, 2021, and the December Holiday Luncheon, Saturday, December 4, 2021. Details on these events will be provided as they approach.

Group meetings

The centerpiece of our past activities has always been the Group meeting. We have one each in Oceanside, La Costa, Fallbrook, and Rancho Bernardo. These meetings gave us a chance to gather information, and to share our journey with others in like situation. We are meeting online until we can meet in person again. (See page 2 for our meeting schedule.) The group leaders have maintained our relationships with the facilities where we met in the past. We hope that when restrictions are lifted that we can pick up where we left off, at the same locations. Your Board will monitor the situation and keep you advised.

We are as anxious to return to in-person meetings as you are. Restrictions on meetings will be modified based on progress of the disease, and the state of treatments and vaccines. As knowledge grows about how the disease is spread, and how that spread may be controlled, new orders will be issued. But each of us will make personal choices on whether to meet based upon our own unique circumstances and tolerance for risk. If you would like to share your thoughts on reopening please contact us at info@ncpsg.org or call Paul Dawson at 760-497-1200.

Inside This Issue

- Events Calendar Page 2
- IN FOCUS: Susan Rubio Page 3
- Legislative updates Page 4

Support Group Meetings

Note: NCPSPG 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

November 2, 10:00 AM Speaker: Dr Michael Okun.
Topic: Living with Parkinson's & Ending Parkinson's. Note: *The speaker is on a tight schedule, so please log in early!* Host: Carol Maher hcmaher@cox.net or 760-749-8234

LA COSTA CARLSBAD -Online meeting

November 4, 1:00 PM Speaker: Marty Acevedo
Topic: Potential Issues Related To Hospitalization For People With Parkinson's. Host: Sam Cooper NCPSPGLC@gmail.com or 520-820-0339

OCEANSIDE - Online meeting November 11, 1:00

PM Speaker: Dr. Mindy Bixby, Scripps Clinic, Movement Disorders Specialist Topic: Sleep issues in Parkinson's Host: Paul Dawson paul@video-fire.com or 760-497-1200

FALLBROOK - No meeting in November Enjoy

your Thanksgiving! Host: Irene Miller NCPSPGF@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 November 9, 10am, Bill Farrington, host email: billfarr48@gmail.com
- Thursday November 12, 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 November 9, 10am. Carol Maher, host. Email: hcmaher@cox.net
- Friday, November 20, 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>

NCPSPG Board of Directors

Wednesday November 18th 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 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 November 16, 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

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!



A California girl, Susan Rubio grew up in Riverside where she met her husband, Armando, in 1982 at the Harvest Christian Fellowship. Married in 1987, they blended families with Susan's two boys, Ruben and Macario, and Armando's two youngest Chris and Ryan. "I worked for Riverside County from May, 1975, until I retired in June, 2010, as Regional Manager In Social Services. My favorite thing to do is travel. We have been to Israel three times and Europe twice with the first trip being for two months visiting fifteen countries. We

have also been to Mexico and Canada several times as well as almost all the states here in America."

"I had surgery for malignant melanoma in May of 2010 followed by a year of Interferon treatment. That's when I realized that in this life you have to be a warrior. My theme song is "Warrior" by Hannah Kerr. I was diagnosed with Parkinson's in September of 2019 having developed multiple symptoms. I have learned that a person who has melanoma is four times more likely to develop Parkinson's. I am currently struggling with left side weakness in my arm and leg, left side tremors, blurred vision, and UTI's."

"I really enjoy our support groups and learn so much from the wonderful people I have met. It really does make a tremendous difference to know you're not on this journey alone and other people can help and share that journey if you'll only reach out."

"We all need to stay physically active and socially involved. It really does make you feel better."

"My theme song is "Warrior" by Hannah Kerr. Make "Warrior your personal anthem too."

"I attended the San Diego Good Start Program, Day of Empowerment, and the Parkinson's IQ program. I also started attending the Parkinson's exercise class at TriCity and through the Michael J. Fox Foundation, I am involved in four research studies. I attend the Oceanside chapter meetings as well as the small social group each month. I really enjoy our support groups and learn so much from the wonderful people I have met. It really does make a tremendous difference to know you're not on this journey alone and other people can help and share that journey if you'll only reach out. We all need to stay physically active and socially involved. It really does make you feel better. And make "Warrior" your personal anthem too.

'Staring down the face of fear,
Gotta keep breathing.
When the negatives is all you
hear,
Gotta keep believing.

Cause in the dark there is a light.
Your truth it keeps on burning
bright.
Brave enough to fight the fight
And shout the battle cry.

You'll never stop me,
I'm a warrior.
When I fall down I get stronger.
Faith is my shield,
His love is the armor."

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.

We take photos and videos at our live meetings and events and may use them in our Newsletter, website and other promotional materials. Please tell the Support Group leader at the start of every meeting or event if you do not want your image to appear.

Legislative updates-Vote!

California Parkinson's Disease Registry

Last month we advised you that Assembly Bill (AB) 2821, authorizing an extension of the Parkinson's Disease Registry had passed the legislature, and had been forwarded to the Governor for his signature. We are pleased to announce that Governor Newsom signed the bill prior to its expiration.

Funding Stem Cell Research, Prop 14

Your ballot this year includes Proposition 14, funding for stem cell research. The measure authorizes \$5.5 billion in bonds to fund grants, and dedicates \$1.5 billion to brain diseases such as Parkinson's and Alzheimer's. NCPSPG and PASD have not officially endorsed the measure, but many members are active supporters. To hear a debate on the measure between PASD's own David Higgins and Jeff Sheehy go to station KPCC's Airtalk at <https://www.scpr.org/programs/airtalk/2020/10/02/21238/>. Scroll down to "Debating Prop 14" and click the play button.

Exercise your voice! Be informed and vote!

Passings

- Arturo Andrade
- Patti DeLuna
- John Garrahy
- Al Henderson

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 :

**NCPSPG
PO Box 230566
Encinitas CA 92023**

Our Website: (Donations accepted)

NCPSPG.org

Our Facebook page: (Donations accepted, no fees)

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

CONTACTS

Rancho Bernardo Support Group Leaders

Carol Maher hcmaher@cox.net
760-749-8234
Brigit King bkicedancer@gmail.com
858-354-2498

La Costa Support Group Leader

Sam Cooper NCPSGLC@gmail.com
520-820-0339

La Costa Co-Leader

Eva Zamora 760-814-3479

Oceanside Support Group Leader

Paul Dawson paul@video-fire.com
NCPSPG Board President 760-497-1200

Oceanside Co-Leader, Library

Madonna Bingham granny6mb@gmail.com
760-757-7564

Fallbrook Support Group Leader

Irene Miller NCPSPGF@gmail.com
760-731-0171

Fallbrook Support Group Co-Leader

Carly Bonnell cbonnell@ucsd.edu
858-534-3708

Treasurer, Recording Secretary & Webmaster

Caryl Parrish carylparrish@gmail.com
760-753-5004

Corresponding Secretary

Micheline Allen micheline.allen@cox.net
760-631-0649

Parkinson's Association Advisory Board Liaison

Thelma Balbes 760-918-9887

Social Director

Sam Cooper scprphd@gmail.com
520-820-0339

Video Documentation

Arthur Bierle Google: [Arthur Bierle on Vimeo](#)
760-749-2182

Newsletter

Publisher paul@video-fire.com
Paul Dawson 760-497-1200

Editor rmcco@cox.net
Rex McCoy 760-519-9588

Focus Interviews scprphd@gmail.com
Sam Cooper 520-820-0339

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

Electronic Distribution micheline.allen@cox.net
Micheline Allen 760-631-0649

Message Line 760-201-5773

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



Serving San Diego County with four locations:
Carlsbad, Escondido, Poway, La Jolla
760-631-3000