

NORTH COUNTY PARKINSON'S SUPPORT GROUP

April 2019



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



Just Around the Corner. PASD “Step-by-Step” 5K Walk - April 7

It's almost here! The Parkinson's Association San Diego's (PASD) “Step-by-Step” 5K Walk is a major fundraiser for PASD's services to people with Parkinson's county-wide. We all benefit from some of those services, and your assistance with the fundraiser is truly appreciated.

If you can't make the Walk, become part of our “**NCPDG Virtual Team**”. Your donation to the Parkinson's Association of San Diego is important for their ability to continue county-wide services like the *Good Start Program*, *FACT* transportation resources, PASD website, educational resources, and *Empowerment Day*.

Donate on their website: ParkinsonsAssociation.org



Sidekicks - Kicking Off Davis Phinney Foundation

Sidekicks brings youth (students) and people with Parkinson's disease together through art. Students gain an appreciation for the wisdom of the adults, learn about PD and, in many cases, develop relationships that benefit themselves and their PwP partner. The person with Parkinson's disease is energized by the kids, develops a newfound appreciation for their past and future and gains better understanding of their disease.

We will hold the **Sidekicks program** here in two sessions at Tri-City Wellness Fitness Center, Carlsbad on May 11 and May 18. Refreshments will be provided. Our cohort of 10-15 people with Parkinson's will be volunteers from NCPDG and from the MI-Neuro/Parkinson's program at TCWFC.

We had very positive reactions from our first program in Pacific Beach last Fall, and know that both people with Parkinson's and youth participants will gain understanding and perspectives. If you are interested please contact **Marty Acevedo**, Davis Phinney Foundation Ambassador, by email at martyandace@gmail.com or by phone at 760 522-8145.

Inside This Issue

- Events Calendar Page 2
- In Focus: Willa Burns Page 3
- UCSD Online Research
- Summer Social July 24th Page 4

Support Group Meetings

RANCHO BERNARDO - Monday, April 1st

10 am - noon (NCPG Sponsored) (first Monday of each month,) San Rafael Catholic Church, 17252 Bernardo Center Drive, San Diego (RB)

Speaker: Attorney **Kimberly McGhee**

Subject: Estate and disability planning. Breakout groups follow. Call **Brigit King 858-354-2498**.

LA COSTA CARLSBAD – Wednesday April 3rd

1pm - 3 pm (NCPG Sponsored) (first Wednesday of each month) Christ Presbyterian Church, 7807 Centella St, Carlsbad, CA 92009

Speaker: **Sherrie Gould**, NP, Scripps Movement Disorder Clinic.

Subject: Discussion of Duopa, a medication used to treat major fluctuations in advanced PD. Breakout groups follow. Call **Rex McCoy 760-519-9588**.

OCEANSIDE - Wednesday, April 10th (NCPG Sponsored) 1pm - 3pm

(second Wednesday of each month) at **Oceanside First Presbyterian Church** 2001 S. El Camino Real, Oceanside.

Speaker: **Tremble Clefs** - Matt Ignacio, TC leader

Subject: **Concert** by Tremble Clefs demonstrating fun singing therapy for the Parkinson's community. Breakouts follow where people with Parkinson's and care partners meet separately to discuss issues and successes. Call **Paul Dawson 760-497-1200**.

FALLBROOK – Friday, April 26th 10 am - noon (NCPG Sponsored)

(meets fourth Friday of each month) at **Christ The King Lutheran Church**, 1620 S. Stage Coach Lane, Fallbrook.

Speaker: **Ana Kanilenko**, - Boston Scientific Representative

Topic: New Developments in the technology of DBS (Deep Brain Stimulation) - Use of MICC (Multiple Independent Current Control) Breakout groups follow. Call **Irene Miller 760-731-0171**

ATYPICAL Parkinson's (PwP & Caregivers)

Monday, April 15th 1pm - 3pm (third Monday of the month) at UCSD, East Campus, 9423 Health Science Drive, Medical Center Modular 1, Room 140, La Jolla. Contact **Darlene Gerow 619-806-9649** darlene.gerow@gmail.com

ATYPICAL Parkinson's (Caregivers only)

Wednesday, May 1st 11am - 1pm

(first Wednesday of every other month) at Tri-City Wellness Center, 6250 El Camino Real, Carlsbad. Contact **Darlene Gerow 619-806-9649**

darlene.gerow@gmail.com

Physical Exercise

CARDIFF LOCATION - Tuesdays & Thursdays

11am - noon (NCPG Sponsored) Encinitas Elks Lodge, 1393 Windsor Rd., Cardiff. Take I-5 to Santa Fe exit east to Windsor Rd. and turn right. (Fee charged). Call **Betty Byrd 760-635-1144**.

OCEANSIDE LOCATION - Fridays 11am - Noon

Tri-City Hospital, 4002 Vista Way, Oceanside, Lower level Assembly Room, (Free) Confirm room location at lobby info desk. Valet parking available. Call **Tracy Park, PT, 760-940-3617**.

MEDICAL INTEGRATED PROGRAM – Mondays & Wednesdays, or Tuesdays & Thursdays

- a variety of Parkinson's related individual and group exercises, including *Dance for Parkinson's*. Tri-City Wellness & Fitness Center, 6250 El Camino Real, Carlsbad. Parkinson's exercise classes (Fee charged.) Call **Susan Webster 760-931-3171**.

PERSONALLY FIT - Tuesdays & Thursdays 2pm - 3pm Parkinson's exercise classes at Personally Fit in Rancho Bernardo. (Fee charged.) Call **858-485-6706**

Vocal Exercise

Tremble Clefs -Therapeutic Singing **Tuesdays 1pm - 2:30pm** St. Andrews Episcopal Church, 890 Balour Dr., Encinitas. New members always welcome. (Free) Call **Deanna Hastings at 619-363-0814** or check website: www.trembleclefs.com/san-diego

AudAbility - This music therapy program offers numerous music related activities for People with Parkinson's. (Fee charged) For more information, call **Lindsay Zehren at 858-457-2201** or email lzehren@musicworxinc.com.

Small Social Groups

Our small social groups gather in rotating private homes on the third Monday of each month that we don't have a large group activity. Come and join us in Oceanside or Rancho Bernardo in a safe environment where we all understand and support each other. Contact **Sam Cooper**, Social Chair, scprphd@gmail.com or call/text **520-820-0339**.

NCPG Board of Directors

Wednesday April 17th 1pm - 3pm

Tri-City Wellness Fitness Center, large conference room, 6250 El Camino Real, Carlsbad. Contact **Paul Dawson 760-497-1200** paul@video-fire.com

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. Thank You!



In Focus: Willa Burns

By Sam Cooper

Willa Burns was a wide-eyed 17 year old with a long reddish ponytail when she left her home in Southern California to study at UC Berkeley. Her best friend introduced her to "a handsome 20 year-old engineering student on a Navy scholarship". Four years later in 1964 Willa finished her degree. Gene was a USMC 2nd Lieutenant assigned to the First Tank Battalion at Camp Pendleton. They married and made their first home in San Clemente.

During Gene's 21 years in the Corps, he was on unaccompanied assignments in

Okinawa and Vietnam for 3 years. Other assignments took him to family-friendly locations for about 3 years each: Carmel Ca., Boulder, Co, Quantico, Va., Northern Virginia suburbs, then "Oceanside in 1977 where we still live in the same house today!"

For two years towards the end of his Marine Corps career, Lt. Colonel Gene Burns commanded the 1st Tank Battalion at Camp Pendleton, the same unit he was first assigned to as a Second Lieutenant. "After he retired in 1984, Gene took an engineering job in Orange County and commuted for 20 years as we didn't want to take our son and daughter out of school here. I had a small photography business and taught black and white photography in the Art Department at Mira Costa College for 25 years."

In the 1970's, the family discovered Las Gaviotas in Baja, California. "It's a beautiful, seaside community, affordable for a military family to rent a vacation house, and it served as an inspiration for many of my photographs. We bought a house there in 1994, and continue enjoying wonderful times there, just the two of us, and with family and friends."

Gene was diagnosed with Parkinson's in 2014. "His mother had Parkinson's so we were already familiar with the symptoms. A newsletter at the neurologist's office alerted us to the North County Parkinson's Support Group. "We came away from our first meeting with relief and gratitude that this excellent group exists."

The Burns attend our Oceanside Support Group where they volunteer with set-up and greeting people. "Coming to one of our meetings for the first time can be a little overwhelming, so I want to make sure our new folks feel particularly welcome. We have so much to offer. I look forward to our meetings and the breakout sessions for caregivers. We really like all of the social activities, especially the small groups. You can really get to know people in this kind of a no-pressure setting. We host a small group each year, usually in March. I am just so thankful that all of this is available to all of us here in our beautiful North County."

Willa also wants folks to know that veterans from any branch of the military who have Parkinson's and had even the slightest contact with Vietnam during the war may be eligible for financial compensation from the VA due to exposure to the defoliant Agent Orange. "Gene found it easy to make an application and we encourage anyone else who might have been exposed to apply to the VA as well."

"Nobody wants to have Parkinson's. But it's not the end of the world. Stay active. Stay involved. Stay positive. Tell yourself Parkinson's is not going to define who I am."

Willa and Gene volunteer at the Oceanside meetings.

"Coming to one of our meetings for the first time can be a little overwhelming, so I want to make sure our new folks feel particularly welcome. We have so much to offer.

"I look forward to our meetings and the breakout sessions for caregivers. We really like all of the social activities, especially the small groups. You can really get to know people in this kind of a no-pressure setting.

"Stay active. Stay involved. Stay positive. Tell yourself Parkinson's is not going to define who I am."

NCPSG NOTICES

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

Online Research Opportunity

CAREGIVERS NEEDED FOR

RESEARCH STUDY (UCSD) – Up to \$200

Do you provide care for a family member who has Parkinson's Disease, Lewy Body dementia, or other dementia? Do you find caregiving stressful? Are you at least 40 years of age?

You may qualify for a research study examining ways to help caregivers cope with stress.

If you qualify for our study, you will receive at no cost to you:

- Access to our internet-based caregiver program designed to teach coping skills that may reduce caregiver stress or improve emotional well-being.
- Access to our web programs for up to 15 months
- Monetary compensation for your participation
- Feedback about your progress during your participation

If you are a caregiver and are interested in learning more about our research program, please visit psychiatry.ucsd.edu/research/alzcare or contact our friendly staff at (858) 534-9479.

For additional opportunities to participate in research, check out our website:

<https://www.ncpsg.org/research-opportunities>

Then click on "PD-related research opportunities"

Spring is Here!

Summer can't be far away!

This year, instead of our popular NCPSPG Annual Picnic, we're trying something a little different.

We've changed the name to "**Summer Social**".

We've found a nice clubhouse in Oceanside.

And we've already ordered the food! (They're keeping it warm for us.)



Save the date:

Wednesday July 24

Thanks to **Sam Cooper**, Social Director, for his creative planning. More details will follow in later Newsletters.

Getting hungry yet?

CONTACTS

Rancho Bernardo Support Group Co- Leaders

Carol Maher hcmaher@cox.net
760-749-8234

Brigit King icedancer@san.rr.com
858-354-2498

La Costa Support Group Leader

Rex McCoy rmcco@cox.net
NCPSPG Board Vice President 760-519-9588

La Costa Co-Leader

Eva Zamora 3evazamora@gmail.com
760-814-3479

Oceanside Support Group Leader

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

Oceanside Co-Leader

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

Fallbrook Support Group Leader

Irene Miller imiller4jc@gmail.com
760-731-0171

Fallbrook Support Co-Group Leader

(vacant)

Treasurer, Recording Secretary & Webmaster

Caryl Parrish cparrish@prodigy.net
760-753-5004

Corresponding Secretary

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

Parkinson's Association Liaison

Thelma Balbes (PA Board member) 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

Library

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

Newsletter

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

Focus Interviews

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

Printed Edition Distribution

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

Electronic Distribution

Micheline Allen micheline.allen@cox.net

Passings

◆ Dan Foley

Our thoughts and prayers go out to family & friends

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