

NORTH COUNTY PARKINSON'S SUPPORT GROUP

February 2019



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

Oceanside's recent speaker was Pete Fronte, President and CEO of Altura – enabling patients and healthcare professionals to participate in clinical studies of all types. Pete introduced the Michael J. Fox Foundation **"Fox Insight"** online clinical study for people with Parkinson's and others to periodically answer a series of questions regarding symptoms, personal perspectives. The goal is to have 100,000 participants. They currently have 22,000. Here are key points:

YOUR EXPERIENCE FUELING RESEARCH

Fox Insight is an online clinical study that empowers patients, control volunteers and researchers to work together toward Parkinson's breakthroughs.

Fox Insight makes participating in research easy. Every three months, participants log in to www.foxinsight.org for a *virtual study* visit and fill out a series of questionnaires. The information gathered in each study visit provides critical insights on:

- ❖ Symptoms ❖ Physical function ❖ Medications ❖ Quality of life
- ❖ Unmet needs ❖ Healthcare preferences

Questionnaires vary from study visit to study visit. There are no "right" or "wrong" answers. Only your experience

PATIENT-POWERED RESEARCH

Fox Insight enables collection of data from tens of thousands of individuals.

Participants' answers will be used by researchers to understand: ❖ How and why Parkinson's differs from person to person, ❖ How treatments affect disease in a real-world setting, ❖ The costs of living with Parkinson's, ❖ And much more.

Fox Insight is designed to collect information in a variety of ways including ❖ Health-related surveys ❖ Optional, activities including genetic testing* ❖ Future remote data collection* (e.g., wearables and other objective measures of disease such as keyboard tapping and voice recognition)

Optional activities: As a participant in Fox Insight, you can choose to contribute more to research by participating in "add-on" studies and surveys that look at additional information from a smaller group of individuals.

THE GENETICS RESEARCH REVOLUTION

By participating in genetics research, you can help create a more holistic understanding of Parkinson's disease.

Participants with Parkinson's may be invited to choose to share valuable genetic information through a collaboration with **23andMe**.

Combining genetic information with other self-reported information can help researchers:

- ❖ Look for trends between genetic profiles and patient perspectives,
- ❖ Shed light on poorly understood or unknown aspects of Parkinson's disease, and
- ❖ Open new avenues of research toward precision medicine.

IT'S GOING TO TAKE ALL OF US, WORKING TOGETHER.

Fox Insight is currently enrolling anyone who meets the following criteria:

- ❖ Is 18 years old or older ❖ People with and without Parkinson's disease
- ❖ Is able to complete health questionnaires in English
- ❖ Has access to the internet

Fox Insight needs your voice to fuel patient-powered research. Join over 22,000 participants contributing information about their experience with PD. Sign-up at www.foxinsight.org/group.



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Support Group Meetings

RANCHO BERNARDO - Monday, February 4th
10 am - noon (NCPSTG Sponsored) (first Monday of each month,) San Rafael Catholic Church, 17252 Bernardo Center Drive, San Diego (RB)
Speaker: Lindsay Zehren
Topic: “Audability – Music Therapy Programs for People with Parkinson’s”. Breakouts follow where people with Parkinson’s and care partners meet separately to discuss issues and successes. Refreshments. Call **Brigit King 858-354-2498**.

LA COSTA CARLSBAD – Wednesday February 6th
1pm - 3 pm (NCPSTG Sponsored) (first Wednesday of each month) Christ Presbyterian Church, 7807 Centella St, Carlsbad, CA 92009
NEW LOCATION!
Speaker: Christina Dinh
Topic: A Parkinson’s walking program. Breakout groups follow.
Call **Rex McCoy 760-519-9588**.

OCEANSIDE - Wednesday, February 13th
(NCPSTG Sponsored) 1pm - 3pm (second Wednesday of each month) at **Oceanside First Presbyterian Church** 2001 S. El Camino Real , Oceanside.
Speaker: Anchi Wang, MD, Movement Disorder Neurologist
Topic: Parkinson’s Disease and the Management of “ON” Time with Xadago. Breakout groups follow. Call **Paul Dawson 760-497-1200**.

FALLBROOK – Friday, February 22nd **10 am - noon (NCPSTG Sponsored)** (meets fourth Friday of each month) at **Christ The King Lutheran Church**, 1620 S. Stage Coach Lane, Fallbrook.
Speaker: Roshan Shadravan DOMP, PhD
Topic: Functional Medicine - Alternative Therapies
Call **Irene Miller 760-731-0171**

ATYPICAL Parkinson’s (PwP & Caregivers)
Monday, February 18th **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, March 6th **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 (NCPSTG 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**.

DANCE FOR PARKINSON’S - Suspended until further notice Although our Thursday program in Encinitas has been suspended, Dance for Parkinson’s is being presented by **Cheryl McIlhon** at Tri-City Wellness/Fitness Center. See the following...

MEDICAL INTEGRATED PROGRAM – Mondays & Wednesdays, Tuesdays & Thursdays 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 lzhren@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**.

NCPSTG Board of Directors

Wednesday February 20th **1pm - 3pm**
Tri-City Wellness 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: Eva Zamora

By Sam Cooper

Eva Zamora grew up in Los Angeles. After studying Fashion Design at UCLA, she worked on Rodeo Drive for two years before being offered a design position for a Moroccan company in downtown L.A.. "My father owned several Mexican restaurants in Los Angeles and, pretty much hating the restaurant business, I found myself taking another direction. But I later moved to Mexico and what did I do? I opened a restaurant which my girls run to this day 18 years later! Life is so funny like that, isn't it?"

"I have always been physically active and after my father died of colon cancer in 2005, I completed the LA Marathon in his honor. I competed in indoor rowing and our team came in second place in the Nationals in Guadalajara. I was also a Spin instructor and kickboxing instructor for many years. My doctor told me I couldn't do any of this because of a heart murmur, but I guess I proved him wrong!"

After moving to Encinitas in 2008, Eva continued her physical activities while managing a Swami's Cafe. "I began suffering from vertigo and when my left hand began to tremble I was diagnosed with Parkinson's in 2013. I remember refusing to accept my diagnosis, but stress related issues aggravated my symptoms so I decided to leave my job. I am also finding that I stumble on my words during a conversation and sometimes am forgetful."

Eva attends the La Costa Support Group where she facilitates the PWP's breakout group. She also attends the Oceanside small social group and will be hosting a small group this year. "Finding this group has been very helpful to me. I am just grateful that such a vibrant organization exists here in North County." She credits her "wonderful and very supportive husband" and six daughters for all of their help. "I try and stay very active. I am a photographer now and while my symptoms sometimes make it difficult to hold the camera still I am finding ways to cope. I exercise every day, I do yoga, I bake, I cater, I make jewelry, and I am learning to play the guitar. Once a month my husband and I volunteer to build houses in Tijuana. I am now a lead builder."

"I believe in herbology so in addition to my Parkinson's meds, I take CBD oil which helps with my tremors. I try and eat well and do a cleanse once a month. It makes a big difference."

"I have learned that Parkinson's is different for everybody, but we have got to continue to challenge ourselves mentally and physically. Get moving! Learn something different! Try something extraordinary. I went skydiving! We already possess our greatest fear. Just do it! Tell Parkinson's that, just for today, I am going to win. I have my days when I don't, but I pull myself out of the glass of water I am drowning in. If I start to feel depressed I go for a walk or get myself moving in some other way. Life is an adventure. Drink from the cup deeply. Make those memories for yourself."

"Challenge yourself to challenge Parkinson's."

"I have learned that Parkinson's is different for everybody, but we have got to continue to challenge ourselves mentally and physically.

**Get moving! Learn something different!
Try something extraordinary.
I went skydiving!**

**Life is an adventure.
Drink from the cup deeply.
Make those memories for yourself.**

**Tell Parkinson's that, just for today,
I am going to win.**

**Challenge yourself to
challenge Parkinson's."**

Save the Date **April 7 - PASD 5K Walk** - Liberty Station **Join the NCPSTG Team!**

NCPSTG provides information to keep you informed of promising research, new medications and procedures. Although we present a variety of subjects, we do not **endorse** any of them - except for close communications between you and your neurologist - movement disorder specialist
...and exercise, **exercise, exercise!**

“Good Start” Program February 13

The Parkinson's Association of San Diego is hosting its next “Good Start Program” seminar on Wednesday, **February 13** at the **Tri-City Wellness and Fitness Center in Carlsbad 9:30-noon**. Designed for newly diagnosed Parkinson's patients and their care partners, the seminar is a 2-hour session including a 90-minute presentation followed by Q&A. There is no cost to the participants.

Registration is Required by February 8

Visit www.ParkinsonsAssociation.org
or call (858) 999-5671

“Sidekicks”™ Combines Youth, People with Parkinson's and Art

“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.



Our own Marty Acevedo, the Davis Phinney Foundation and Parkinson's Association San Diego piloted the program with great success in Pacific Beach last fall and plan to follow up with the next program in late April/early May. Our cohorts of 10-15 people with Parkinson's will be developed as volunteers from NCPSPG and from the MI-Neuro/Parkinson's program at Tri-City Wellness/Fitness Center.

We will have more information in the next Newsletter. Does this sound interesting to you? Can you think of youth who might want to take part? Call Marty at (760) 522-8145 or email: martyandace@gmail.com

Letters Acknowledging Donations to NCPSPG

As a 501(c)3 “Public Charity”, NCPSPG is required to send acknowledgement letters on receipt of single donations of \$250 or more. Those letters are sent shortly after receipt of those donations.

Although not an IRS requirement, our NCPSPG Board of Directors decided to send donation acknowledgement letters for ALL gifts received throughout the year. Those letters are being prepared and will be mailed by the end of January.

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- ◆ Tom Copeland
- ◆ Lori Mandelbaum

Thoughts and prayers to families & 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