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



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

Will CIRM Stem Cell Research Continue? Will Funding be on the Ballot?

I don't know about you, but I go out of my way to avoid those folks with clipboards outside Vons or Target, who are gathering signatures for some ballot measure. I know that the clipboard people usually get paid by the signature, and usually have little real personal interest in the ballot measure itself.

One ballot measure that's really important to us, first adopted by voters way back in 2004, created the California Institute for Regenerative Medicine (CIRM). CIRM invested \$3 billion in stem cell research here in California, attracting another \$4 billion in funds from other sources: a more than 100% return on the investment financially. More importantly, there's also been a huge ROI in terms of research progress as well. Much has been accomplished by that substantial investment over those 16 years, but much remains to be discovered, through numerous health-related research projects.

Supporters of a new proposed ballot measure are currently trying to gather the 623,212 voter signatures needed to place it on the November 2020 ballot – a measure that would, if passed, make \$5.5 billion in funding for continuing the research effort. Of great interest to us is the dedication under the new initiative of \$1.5 billion enceificelly for a system of \$1.5 billion appears of the place it on the November 2020 ballot – a measure that would, if passed, make \$5.5 billion in funding for continuing the research effort. Of great interest to us is the dedication under the new initiative of \$1.5 billion appears of the place it on the November 2020 ballot – a measure that would, if passed, make \$5.5 billion in funding for continuing the research effort. Of great interest to us is the dedication under the new initiative of \$1.5 billion appears of the place it on the November 2020 ballot – a measure that would, if passed, make \$5.5 billion in state general obligation bonds to fund grar ative Medicine to educational, non-profit, and private entities for any evelopment, and therapy delivery: (2) medical training; and (2) are provided in the passed of the passe of \$1.5 billion specifically for support of research and development of treatments for diseases and conditions of the brain and central nervous system, "such as Alzheimer's disease, Parkinson's disease, stroke, dementia,

on the ballot, and making your own personal decision on whether to support or oppose it.

TO BE SUBMITTED DIRECTLY TO THE VOTERS repared the following circulating title and summary of the chief purpo

epilepsy, depression, brain cancer, schizophrenia, autism and other conditions of the brain." Under IRS rules as a 501c3 non-profit organization, NCPSG is not permitted to give a "substantial part" of our resources to lobbying for – or against – a ballot initiative. But as individuals we certainly can. We strongly recommend that you read the entire proposed initiative, consider signing or even circulating a petition to place it

In a time of declining research grants available from federal sources, it is encouraging that the people of California have committed years of funding for stem cell research into the causes and cure of the diseases like PD that have so deeply affected our lives. If each of us as individuals becomes involved, perhaps California voters will continue that commitment. Its critically important to discovering the cause and cure for PD.

First Saturday Seminar Complete - What Would You Like to See Next?

Our first "Saturday Seminar" took place in Torrey Pines on Saturday January 18th. Almost 150 attended to hear experts discuss the pros and cons of DBS, Deep Brain Stimulation. "Saturday Seminars" are the brainchild of Support Group leaders from around the County to bring to you topics of importance to people with Parkinson's, Care Partners, and others directly concerned. We hope to bring "Saturday Seminars" quarterly to different sites around the County, focusing on a variety of related subjects.



We invite you to suggest possible topics to your support group leader, who will bring them to the County SG leaders. Our thanks to the support group leaders



who put this program together, and particularly to David Higgins and David Miles who designed a structure for handling the many behind-the-scenes details of presenting these seminars. Finally, our thanks to the medical community and to the panelists who shared their expertise and perspectives.

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Events Calendar

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PASD 5K Step-by-Step 4/4/2020

Support Group Meetings

RANCHO BERNARDO - Monday, February 3rd 10am - noon (NCPSG Sponsored) (meets first Monday of each month) San Rafael Church, 17252 Bernardo Center Drive, RB (San Diego) Speaker: Vanessa Leschak, Certified Nutritionist and Cook

<u>Topic:</u> "Healthier Lives for People with Parkinson's through Diet, Nutrition and Education" Refreshments and breakouts follow.
Call **Carol Maher 760-749-8234.**

LA COSTA CARLSBAD – Wednesday, February 5th 1 - 3pm (NCPSG Sponsored) (meets first Wednesday of each month) Christ Presbyterian Church, 7807 Centella St, Carlsbad, CA 92009 Speaker: Lisa Stinchcomb, Acadia Pharmaceutical Topic: Medication to control PD hallucinations Call Rex McCoy 760-519-9588.

OCEANSIDE - Wednesday, February 12th (NCPSG Sponsored) 1pm - 3pm (meets second Wednesday of each month) at Oceanside First Presbyterian Church, 2001 S. El Camino Real, Oceanside.

Speaker: Kindra French, 101 Mobility Center Topic: "Mobility and Safety Solutions to help People with Parkinson's Gain Freedom and Independence". Break-out groups follow. Call Paul Dawson 760-497-1200.

FALLBROOK - <u>Friday, February 28th</u> (NCPSG Sponsored) (meets fourth Friday of each month) Christ The King Lutheran Church, 1620 S. Stage Coach Lane, Fallbrook.

<u>Speaker</u>: **David Higgins**, PhD, CIRM Board member, Michael J. Fox Foundation, Public Policy Council <u>Topic</u>: "**CIRM**" California Integrative Regenerative Medicine & its importance to person's affected by Parkinson's, and Parkinson's Research Updates. Call **Irene Miller 760-731-0171.**

ATYPICAL Parkinson's (PwP & Caregivers)

Monday, February 17th 1pm - 3pm (meets 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 4h
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

NCPSG Board of Directors

Wednesday February 19th 1 - 3pm Board meets on third Wednesday at Tri-City Wellness Fitness Center, Carlsbad, in the small conference room. Call **Paul Dawson 760-497-1200**

Physical Exercise

CARDIFF LOCATION - <u>Tuesdays & Thursdays</u>
11am - noon (NCPSG 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. Ask at entry desk for the meeting location. Class and Valet parking are free.

Call **Tracy Park**, **PT**, **760-940-3617**.

MEDICAL INTEGRATED PROGRAM – Mondays through Saturdays - a variety of Parkinson's related individual and group exercises. Tri-City Wellness & Fitness Center, 6250 El Camino Real, Carlsbad. Parkinson's exercise classes (Fee charged.) Call Susan Webster 760-931-3171.

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

ROCK STEADY BOXING - various North County sites and days Check their national website for a location near you, along with contact information.

https://www.rocksteadyboxing.org/

Vocal Exercise

Tremble Clefs -Therapeutic Singing
North Coastal Chapter Encinitas
Tuesdays 1pm - 2:30pm - St. Andrews Episcopal
Church, 890 Balour Dr., Encinitas.

North Inland Chapter Rancho Bernardo
Wednesdays 10 am - noon - San Rafael Catholic
Church, 17252 Bernardo Center Drive, San Diego (RB)
- Parish Center.

(Free) Call **Melodi Denton** at 1-619-363-0814 or check website: www.trembleclefs.com/san-diego

AudAbility - Music therapy program offering numerous music related activities for People with Parkinson's. (Fee charged) Call **Lindsay Zehren 858-457-2201** or email lzehren@musicworxinc.com.

Small Social Groups

Our small social groups gather in rotating private homes in months that we don't have a large group activity. Meeting are held on the coast and in the RB area. For this month's locations Contact **Sam Cooper**, Social Chair, scprphd@gmail.com or call/text **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!

In Focus: Stephanie Wu-Lester





Stephanie Wu-Lester was born in Shanghai, China. When the Communists assumed power, the family left China for Hong Kong. There she went to Catholic School and learned to speak English. "Life was good except we kept on moving around this tiny colony since it was difficult for my dad to find a permanent job. When President Kennedy opened the immigration quota for trained technical personnel, my dad applied as he was a pilot during World War II." Her dad was

sent to Austin, Texas, to study aeronautical engineering. From there the family arrived in San Francisco on Labor Day, 1964.

"I attended Berkeley High School, then the Optometry School at UC Berkeley. There were lots of challenges for me as a teenager coming to a different culture. I also got thrust into the role of the head of the family. I was running the everyday life of a family of seven as my parents spoke no English and was also caregiver to my younger siblings, Looking back, I think God used this opportunity to help me be the caregiver for my husband, Stephen, years later.

Stephen and Stephanie met in school and were married in 1972. "We were able to enjoy traveling and visited most of the places that we were only able to dream about. Then in the course of back surgery in 2012, Stephen was diagnosed with Parkinson's Disease. As we all know, Parkinson's is unique to each person. There is not pattern to his

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"Stephen and I are on a journey with a lot of unknowns.

But we are very grateful we have found this North County Parkinson's community to walk with us."

illness. Stephen's symptoms keep changing even though there are underlying commonalities-sudden onset fatigue, mood changes, and three TIA's (Transient Ischemic Attacks) which may indicate a future stroke."

The Lesters moved to Lake San Marcos three years ago from the Bay Area and heard about our North County Parkinson's Support Group. "We attend the Oceanside chapter group and find the monthly meetings very informative and appreciate the camaraderie with the fellow 'Parkies' support group for Stephen and the caregiver support group for me. It is very inspiring to learn how other caregivers support their loved ones. I also belong to the Southern County Caregiver Support Group This group provides respite care, regular support meetings, and workshops. The facilitator of this group is a social worker and emphasizes the importance of self-care for us caregivers."

"We also recognize the danger of being isolated. It's easy to stay in the Comfort Zone at home, but socializing is so important. We enjoy the small groups and will be hosting our group again this April. We also go to the large group activities as well."

"Stephen and I are on a journey with a lot of unknowns. But we are very grateful we have found this North County Parkinson's community to walk with us."

NCPSG Notices

We take photos and videos at our 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.

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.

PASD 5K Step-by-Step Walk **Saturday April 4**

We are working with other support groups and community organizations to make this year's PASD 5K Walk the biggest ever!



There's a healthy competition brewing between teams. And we've got a "ringer" in our midst: Madonna Bingham has raised more than \$90,000 over the years, and shares her best techniques with you.

This competition will benefit all of us in several ways:

- It's a fun event in a beautiful, historic location.
- Great way to gather friends and family together.
- Exercise itself is important to us all.
- Opportunity to show friends and family of your openness about your Parkinson's, and demonstrate you're taking control over the disease.

One of Madonna's secrets is to send a letter to friends, family, even distant relatives, updating them on her Parkinson's journey, and requesting their support of team "Bingham's Bunch". She encourages those who can walk to join her, and those who can't to donate. She encloses a self-addressed envelope which seems to increase responses. It really works!

YOU could form your own team - think of a catchy team name - and follow Madonna's suggestions. Or join another team. You could encourage your church, your service club, your neighbors to join you. You will see that teams can align with larger organizations like NCPSG, to sharpen the competition.

All proceeds benefit the Parkinson's community of San Diego County - that's us - through the excellent programs of the Parkinson's Association.

Our mailing address for all donations and correspondence:

NCPSG PO Box 230566 Encinitas CA 92023

Donations to NCPSG are now possible on our website www.NCPSG.org and on our Facebook page. Your gifts are truly appreciated! Thank you!

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 McCov rmcco@cox.net NCPSG 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 NCPSG Board President 760-497-1200

Oceanside Co-Leader granny6mb@gmail.com 760-757-7564 Madonna Bingham

Fallbrook Support Group Leader

Irene Miller imiller4jc@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@cox.net

Micheline Allen 760-631-0649

Parkinson's Association Advisory Board Liaison

Thelma Balbes (PA Advisory Board member) 760-918-9887

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

Video Documentation Google: Arthur Bierle on Vimeo Arthur Bierle 760 749-2182

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

Newsletter

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

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

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

Electronic Distribution micheline.allen@cox.net

760-631-0649 Micheline Allen

Passings

Art Mandelbaum

Our thoughts and prayers go out to Art's family and friends

