NORTH COUNTY February 2024 www.NCPSG.org PARKINSON'S SUPPORT GROUP



A NEWSLETTER FOR EVERYONE AFFECTED BY PARKINSON'S IN NORTH SAN DIEGO COUNTY

Focused Ultrasound –An Alternative to Deep Brain Stimulation

The majority of this content is from *Insightec website*

For many Parkinson's patients, the primary symptom is tremor according to the National Institutes of Health. These patients initially have tremor, and as the disease progresses, they may experience the onset of other symptoms. However, tremor remains the symptom with the most severe impact on their daily activities.

A number of our members have Deep Brain Stimulation (DBS), which is a surgical procedure in which an electrode is carefully positioned in the exact portion of the brain where tremors originate. Signals transmitted through the electrode can have a positive effect on controlling tremor symptoms. The FDA approved DBS in the early 2000's, and Medicare generally covers the expense.

More recently, another treatment called **Focused Ultrasound** has been developed and approved by the FDA which addresses the same tremor-producing portion of the brain. Magnetic Resonance-guided focused ultrasound (MRgFUS) provides an incisionless treatment option for tremor dominant Parkinson's patients



who do not respond to medications. During treatment, ultrasound waves heat and eliminate or erode the deep brain target with no surgical incisions. Treatment is guided by MRI for patient-specific planning, real-time temperature monitoring as well as immediate assessment of treatment outcome. The result for many patients is immediate improvement of tremor with minimal complications.

The procedure is currently available at six sites in California, with Sharp Grossmont Hospital the only San Diego County location.

Dr. Vamsidhar Chavakula, neurosurgeon from Sharp Grossmont, will discuss the procedure and the evaluation process at the NCPSG Oceanside chapter meeting Wednesday, February 14, 1 pm. (See page 2 of this Newsletter). All are welcome at the Oceanside SG meeting. This discussion may not be available at other NCPSG chapters in the immediate future. If you usually attend LC, RB or FB, please let Paul Dawson know (paul@video-fire.com or 760 497-1200) by Tuesday 2/13 so we can relocate to a larger room.

As always, we present a variety of topics. This does not represent an endorsement of our NCPSG Board. Review any subject with your Movement Disorder Specialist.

Mark your Calendar

SPRING SOCIAL - Monday, March 18, at the Oceanside Broken Yolk Reservation form on page 5 must be <u>received</u> by Thursday, March 14

NCPSG CRUISE - 3/30/24 - 4/5/24 Two Staterooms available Contact Liliana at AAA - (619) 397-6434

ANNUAL WALK - Parkinson's Association San Diego Saturday, April 6, Liberty Station San Diego. See page 6

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Support Group Meetings

RANCHO BERNARDO

Monday, February 5, 10 am to noon

Speaker: **Chris Buscher**, Exec Director PASD Topic: "Guided Tour of PASD's Amazing Website"

San Rafael Catholic Church 17252 Bernardo

Center Road, San Diego, 92128

Host: Brigit King bkicedancer@gmail.com.

858-354-2498

LA COSTA CARLSBAD

Wednesday, February 7 1 to 3:00 PM

Speaker Lisa Tataryn

Topic: "Advancing Care With Technology"

Christ Presbyterian Church 7807 Centella St Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

OCEANSIDE

Wednesday, February 14 1:00 to 3 PM

Speaker: Dr. Vamsidhar Chavakula,

neurosurgeon, Sharp Grossmont

Topic: "Focused Ultrasound for Tremors" *Insightec* **Oceanside First Presbyterian Church** 2001 S. El
Camino Real, Oceanside 92054, at Fire Mountain

Rd

Host: Paul Dawson paul@video-fire.com

or 760-497-1200

FALLBROOK

Friday, February 23, 10 AM

Speakers: **Kindra French, Ben Marsh** - 101 Mobility; **Sam Bosboom** - Rollz Topic: "Home Safety for Aging in Place"

Fallbrook Wellness Center 1636 E. Mission Rd,

Fallbrook -

Host: Irene Miller NCPSGF@gmail.com

or 760-731-0171

Social Groups

If you are interested in joining our small groups, please contact Sam Cooper at scprphd@gmail.com or 520-820-0339. Our large group **Spring Social** is on March 18

NCPSG Board of Directors

Wednesday, February 21, 1- 3 PM The Board meets online on the third Wednesday of the month. Contact Sam Cooper NCPSGLC@gmail.com or 520-820-0339.

Volunteer!

All Board members, officers, support group leaders are volunteers as are our greeters, refreshment team, sound folks, and breakout facilitators. Is there a way you could help? Volunteering benefits our members; it's a fun and rewarding way to contribute. to our Parkinson's community.

Physical Exercise

In-person or On-line Options. Fees May Be Charged. For more information on Scholarships see NCPSG.org

Personally Fit (NCPSG Scholarships Available)
In-person and Zoom classes for Parkinson's.
Personallyfitonline.com or contact Doris Flood, PT at

dflood@personallyfitonline.com

LifeSpan Health (*NCPSG Scholarships Available*)
Drug-free program to enhance a healthy life span https://lifespanhealth.me/

NeuroLab 360 (*NCPSG Scholarships Available*) Neurologic physical therapy & wellness. www.neurolab360.com

Rock Steady Boxing (NCPSG Scholarships available for some affiliates) Improve Parkinson's quality of life through non-contact boxing-based fitness curriculum. In-gym and online classes available. https://www.rocksteadyboxing.org/

RX Ballroom Dance - Dance therapy, the best therapy for mitigating and reversing symptoms of brain deterioration. Classes in Oceanside, Fallbrook, Rancho Bernardo, Temecula. (no charge) Details at https://www.rxballroomdance.com/ or call Erin Angelo 310-938-1620

Vocal Exercise

Tremble Clefs -Therapeutic Singing & Socializing. Inland Chapter (Rancho Bernardo)
Wednesdays at 10:00 AM no charge
San Rafael Catholic Church in the Parish Hall,
17252 Bernardo Center Road, San Diego 92128

North Coastal Chapter (Encinitas)

Tuesdays at 1:00 PM

Bethlehem Lutheran Church, 925 Balour Dr, Encinitas, CA 92024

In-person participants should be fully vaccinated, or attend via Zoom. Contact Matt Ignacio for details.

Email: <u>matt.sdtrembleclefs@gmail.com</u> Website: <u>https://www.trembleclefs.com/</u>

Parkinson Voice Project - Speak Out home practice exercise Monday - Friday 8 AM PST online at www.parkinsonvoiceproject.org

MusicWorx for Parkinson's (Formerly AudAbility)

Music therapy is the use of clinical, evidence-based interventions to achieve clients' non-musical goals. See <u>MusicWorx.com</u>. Cassandra Richtsmeier 858-457-2201 or crichtsmeier@musicworxinc.com

In Focus: Richard Rappaport

By Sam Cooper



"I am the oldest of two children. My father was from Russia and my mother was from Philadelphia where my younger sister and I were raised. I am in my third marriage and have two daughters and one son from my first two marriages and five grandchildren. I have two stepchildren and two step granddaughters with my current wife, Laura. I left Philadelphia after college to attend Chicago Medical School and become an MD then a psychiatrist.

After selling my psychiatry practice, I moved to San Diego thrilled to get out of cold,

blustery, Chicago. My youngest son was 15 at the time. I met Laura here. We just celebrated our 24th anniversary.

Burned out from seeing psychiatry patients for so many years, I began to do forensic work as an Expert Witness. I transitioned into telepsychiatry helping with the evaluation of military veterans and their drug management. I was also able to travel the world on cruise ships speaking on many different subjects related to psychiatry.

The group really has confirmed that I am not on my Parkinson's Journey alone...You need to see the best doctors possible, take naps when needed, and stay involved."

I began having symptoms of Parkinson's approximately 4 years ago and was formally diagnosed about 2 years ago. Current symptoms include difficulty walking, getting up from a sitting position, poor posture, short term memory loss, and poor penmanship. I no longer drive. Giving up that independence was particularly difficult. Physical therapy has been helpful, but I struggle with motivation to do the exercises on my own. Laura and I have been attending the La Costa chapter support group for a year. The informational speakers are very valuable. The group really has confirmed that I am not on my Parkinson's Journey alone. I really enjoy the social activities and camaraderie. My family and friends have been caring, thoughtful, and understanding. You need to see the best doctors possible, take naps when needed, and stay involved."

NCPSG "Business Cards" for You to Pass Out

We have prepared simple card handouts the size of business cards which you could carry and hand to someone you know or meet who is dealing with Parkinson's: as a person with the disease, a care partner, or others affected by PD. It includes a list of our NCPSG services and the date, time and address of each of our chapter meetings. It's a low-key way to let them know that there are resources that they would find valuable – as we "Fight Parkinson's Together!" Contact your group leader to get your cards.

NCPSG Notices

We provide information in our newsletter and chapter meetings on a broad array of Parkinson's-related topics and perspectives. **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 and promotional materials. Please tell the event leader if you do not want your image to appear.

You may **click the links** in this newsletter to be taken directly to the referenced resource. If you find a broken link, contact the editor at ncpsgNL@gmail.com.

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

"End Parkinson's Act" bill progresses.

Exciting news! A bill was passed by the House of Representatives on December 14, 2023, and was sent to the Senate. The "End Parkinson's Act", if passed by the Senate and signed by the President, would "direct the Secretary of Health and Human Services to carry out a national project to prevent, diagnose, treat, and cure Parkinson's, to be known as the National Parkinson's Project, and for other purposes."

Irene Miller serves on the Michael J. Fox Foundation advocacy team, now preparing to meet with Senate representatives as the bill advances. Irene provided a link to join in to help with the cause... Tell your story to your Congressman.

https://www.michaeljfox.org/advocacy-campaign/house-passed-national-plan-senate-next

What can I do to help?

We're a non-profit with no paid employees. Everything that takes place (and there are lots of moving parts) is done by volunteers. We know you've got lots on your plate, but could you help with refreshments, or checking people in, or greeting newcomers? Perhaps you could help facilitate a breakout group, or assist with set-up and breakdown.

Let your support group leader know if you see something you'd like to do, or just want to know where there's a need. Remember how important it is with Parkinson's to always have a back-up. Same is true with our support group meetings and all the tasks involved. Thank you!

Newsletter Published Online

Our monthly NCPSG Newsletter is available on our website www.NCPSG.org. It is posted about one week before the end of the month. Archived editions are also available there. Challenged by computers? Lack online access? Speak with your Support Group leader or Micheline Allen.

To update or remove your contact info, please let **Micheline Allen** know. 760-631-0649 ncpsgCS@gmail.com

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Paul Dawson...... paul@video-fire.com..760-497-1200
NCPSG Past President - PASD Board member

Oceanside Co-Leader
Who is the new person??

Fallbrook Leader ncpsgF@gmail.com
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Our Website: (Donations accepted)

NCPSG.org

We are a 501(c)3 non-profit organization, dedicated to serving the Parkinson's community. Your donation of funds and of volunteer service are truly appreciated! Thank You!

North County Parkinson's Support Group

Spring Social Monday, March 18, 2024 11:30am

Oceanside Room, Oceanside Broken Yolk 2434 Vista Way, Oceanside

Ticket price: **\$17.50**

Menu Choice includes hot/cold tea, coffee, soft drink, or lemonade

- Hamburger with choice of French fries, onion rings, or side salad
- Club Sandwich with choice of French fries, onion rings, or side salad
- Grilled Chicken Caesar Salad
- Veggie Wrap with choice of French fries, onion rings, or side salad

Number of tickets ordered:	<u> </u>
Name	Menu Choice
	-
	-

Reservations must be received by Thursday, March 14

Mail ticket form and make check payable to:

NCPSG PO Box 230566 Encinitas, CA. 92023



Join us to Fight Parkinson's

Our 22nd annual 5K STEP BY STEP WALK

in support of the

Parkinson's Association of San Diego

Saturday, April 6, 2024 • 7:30am Check In • 9am WALK, Dog Friendly LIBERTY STATION, SAN DIEGO

Your support of Step by Step enables PASD to offer critical resources to thousands of individuals with Parkinson's here in San Diego County.

All contributions remain in the County and provide services, assistance, and education to people with Parkinson's, their care partners, and families.

Meet over 50 exhibitors.



REGISTER AS:
An Individual
A Team or
Sponsor a Walker

REGISTER AT:

parkinsonsassociation.org (858) 215-2570

Early Registration \$40
After February 1 \$50
Youth 12-17 \$10
Under 12 Free





In memory of **Madonna Bingham**, your NCPSG Board of Directors suggests that you register under the team name "**Bingham Bunch**", the team that she created. Her wish was that **Bingham Bunch** would be the biggest and highest fund-raising team this year! Thanks!