August 2023 NORTH COUNTY www.NCPSG.org PARKINSON'S SUPPORT GROUP

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

My Deep Brain Stimulation Journey



Stephen Lester

DBS or Deep Brain Stimulation is a device that has an electrode implanted in your brain at the level of the globus pallidus. A signal generator is implanted under the skin near the collarbone and is connected to the lead from the brain. A programmer then uses the electrode to transmit signals to the rest of your brain. A neurosurgeon implants the leads and the signal generator. The patient then returns to his/her neurologist for programming.

This surgery was approved by the FDA in 2002 for the treatment of Parkinson's and Parkinson's related symptoms. The procedure is covered by Medicare. Medtronics, Boston Scientific, and Abbott manufacture the units. While all three are comparable, there are differences. Your specific unit is determined by the surgeon. The main symptom addressed by the surgery is dyskinesia, involuntary movement.

I had DBS when my dyskinesia got to the point where it was severely impacting my quality of life. My surgeon was Dr. Ben Haim. I had an MRI prior to the surgery which allowed Dr. Haim to precisely place my leads. I was asleep during the surgery as my dyskinesia was too severe.

As is common with folks with Parkinson's, I had difficulty with the anesthesia. My recovery took several months and was a roller coaster of paranoid delusions, hallucinations, and delirium. I still have occasional anxiety attacks, but overall everything is back to normal.

Am I glad I had the surgery? Very much so. In spite of all the difficulties, my DBS is functioning well and has dramatically improved the quality of my life. For the most part my dyskinesia is totally gone and I am on half the carbidopa levodopa that I was taking before the surgery. Would I do it again? Yes, although I would have had a consultation with the anesthesiologist before the surgery.

Would I recommend DBS? Absolutely. DBS is a proven tool in dealing with Parkinson's related symptoms, and I am very glad it is available. It dramatically improved my life with Parkinson's.

Please join us for the Fall Social Potluck Monday, September 18, hosted by our Rancho Bernardo chapter support group.

Inside This Issue

Events Calendar

IN FOCUS:

Page 3

Potluck Flyer Page 5

Chapter Meetings

RANCHO BERNARDO

Monday, August 7, 10:00-Noon

Topic: "Living with Purpose"

Speaker: Jeff Seckendorf, PASD Operations Director

San Rafael Catholic Church 17252 Bernardo

Center Road, San Diego, 92128

Host: Brigit King <u>Bkicedancer@gmail.com</u>

or 858.354.2498

LA COSTA CARLSBAD

Wednesday, August 2, 1:00 PM

Speaker: Ben Marsh, 101 Mobility

Topic: "Mobility Solutions For Safety And

Independence At Home"

Christ Presbyterian Church

7807 Centella St., Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

OCEANSIDE

Wednesday, August 9, 1:00 PM

Speaker: Jeff Seckendorf, PASD Operations Director Topic: "World Parkinson's Conference (Barcelona)

and expanding Mentor program"

Oceanside First Presbyterian Church

2001 S. El Camino Real, Oceanside 92054 Host: Paul Dawson paul@video-fire.com or 760-497-1200

FALLBROOK

Friday, August 25, 10:00 AM to Noon

Speaker: Sydney Kennedy, CSA, C PRS

Topic: "Care Options with A Positive Approach" Fallbrook Wellness Center 1636 E. Mission Rd,

Fallbrook 92028

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.

NCPSG Notices

We take photos and videos at our events and may use them in our newsletter, website, and other promotional materials. Tell the event leader if you do not want your image to appear. We provide information in our newsletter and at events. Such presentation should not be interpreted as an endorsement. Always talk to your neurologist before taking action.

NCPSG Board of Directors

Wednesday, August 16, 1 - 3 PM The Board meets online on the third Wednesday of the month.

Contact Sam Cooper NCPSGLC@gmail.com

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.

<u>Personallyfitonline.com</u> 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 - Improve Parkinson's quality of life through non-contact boxing-based fitness curriculum. In-gym and online classes available. Find a class at: <a href="https://www.rocksteadyboxing.org/"htt

RX Ballroom Dance - Dance therapy, the best therapy for mitigating and reversing symptoms of brain deterioration. Tuesday & Thursday 11:15 AM McCann Studio Oceanside. (no charge)Tuesday and Thursday, 1:00 PM, Fallbrook Regional Wellness Center. Erin Angelo 310-938-1620.

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

Tremble Clefs -Therapeutic Singing & Socializing. *North Inland Chapter (Rancho Bernardo)*

Wednesdays at 10:00 AM

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, in the Youth Multi Use Center, 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>

MusicWorx for Parkinson's (Formerly AudAbility)

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

In Focus: Alan Rich



By Sam Cooper

Alan Rich was raised in Claremont,
California. He graduated from Webb School,
then Cal Poly with a BS in Accounting at the
age of 18 and subsequently married Penny. He
went on to earn his law degree and CPA license
from UCLA. The family moved to San Diego in
1971 where Alan started his own private law
practice while simultaneously teaching at
Palomar Community College and UCSD. An
avid sports fan, he was a longtime Chargers
season ticket holder journeying to Miami for the
1994 Super Bowl. "I enjoy travel, museums,

restaurants, golf, and nonprofit charity work, but family has always been my top priority."

...you need to remember the positives and the small wins, like waking up every day to the sun shining."

"I was diagnosed with Parkinson's in 1998. There have been ups and downs. Current symptoms include tremors, body stiffness, and

balance issues. I continue to train in the gym, box, golf, and get regular PT and massages. All of these help the physical effects. Reading, regular meals with friends and family, and ice cream runs with the grandkids help my mental fortitude. Penny and I attend the La Costa chapter support group regularly. The informational speakers have added new perspectives and knowledge for us. Sharing strategies with folks in the Parkinson's breakout group is particularly helpful. And we really enjoy the small group and large group social activities. All of it makes us feel like we are not alone on our Parkinson's Journey."

"If there is one thing I could tell people about my Parkinson's Journey it would be it isn't easy. My Parkinson's is always foremost in everyone's mind around me whether they admit it or not. That being said, I'm very lucky to have friends and family that constantly support me. This just isn't my journey, it's our journey. Parkinson's has slowed my life down and given me a new perspective. I am very grateful for everything. If I could give advice to someone with Parkinson's it would be this. There will be days you struggle and want to give up, but you need to remember the positives and the small wins, like waking up every day to the sun shining."

"To all of you who are supporters and Care Partners, friends and family, you are the ones giving us the energy, life, and success we need. We can't thank you enough."

Michael J. Fox movie "STILL"

https://m.imdb.com/title/tt19853258/



Follows the life of beloved actor and advocate Michael J. Fox, exploring his personal and professional triumphs and travails, and what happens when an incurable optimist confronts an incurable disease.

The Michael J. Fox Foundation Parkinson's Podcast

Our 2023 Budget

Our Board of Directors has made available a summary of our annual budget. Our fiscal year is the calendar year. We are a 501(c)(3) non-profit and truly appreciate your donations.

Mailing address:

NCPSG PO Box 230566 **Encinitas CA 92023**

Website: (Donations accepted)

NCPSG.org

Passings

Lillian McGee Lee Woodcook

Our thoughts & prayers go out to family & friends

Scholarship Opportunities

We offer scholarships so you can try several feebased services, and then decide if you want to continue at your own expense. See our website NCPSG.org for the current options and the application form.

Parkinson's Association Of San Diego **Mentor Program**

Need help dealing with diagnosis or care giving? Find help by watching this video from the Parkinson's Association Of San Diego Mentor Program https://mentors.parkinsonsassociation.org/

Use the search filters to choose mentors who work with people with Parkinson's or who work with care partners. Click on the mentor's photo to read their bio. Everyone brings something a little different to the table, so take your time choosing. All mentors have completed the PASD Mentor Training.

Newsletter

We recognize that some readers may have no internet access. In that case, please contact Micheline Allen at 760-631-0649 or ncpsqcs@gmail.com for a printed copy. Otherwise, the newsletter will be available on our website. To update or remove your contact information, contact Micheline.

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 ncpsqnl@gmail.com.

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NORTH COUNTY PARKINSON'S SUPPORT GROUP

POTLUCK LUNCH

Main Dishes provided by NCPSG Rancho Bernardo
-Oceanside Members (Side Dishes)-La Costa/Fallbrook Members (Salads or Desserts)-



WHEN: Monday, September 18th, 2023 Starts at 11:30 AM

WHERE: San Rafael Church (Parish Hall) 17252 Bernardo Center Dr. San Diego, CA 92128