# NORTH COUNTY PARKINSON'S SUPPORT GROUP

July 2025 www.NCPSG.org



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

## **Paying it Forward**

Medical equipment can be expensive! Sometimes insurance or Medicare pays for most of the cost, but sometimes you are on your own. When we need a piece of equipment, or when equipment we have is no longer useful to us, wouldn't it be great to discover an "Exchange" - a place to pass it on, or conversely, to find equipment that has been donated and is available. "Paying it forward" is an awesome concept!





North County Parkinson's Support Group (NCPSG) does not have a formal "equipment exchange." Our recommendation is for you to go to the Parkinson's Association of San Diego's (PASD) website (parkinsonsassociation.org) where you can see photos of donated equipment that's available, and reserve it. Harmony Home Medical, a mobility sales and repair business in Kearny Mesa, has agreed to make available used devices that have been donated to PASD.

Here's how it works. PASD displays available new or slightly used equipment on their website where you can view and select from those currently available, and reserve the item. To reserve an item, just "click" on the photo on the PASD website page, add it to your "shopping cart," then pay a small processing charge for the item - generally \$10 to \$20.

ParkinsonsAssociation.org website



You will receive an email regarding pickup or delivery. Pickup is free at their store in Kearny Mesa. If you choose the delivery option, a small delivery fee is charged, which you will pay directly to Harmony Home Medical.

This program is a service of the Parkinson's Association of San Diego. Neither PASD, NCPSG nor Harmony Home Medical assume any responsibility or liability from the use of any item.

#### Thank You VOLUNTEERS!

There are lots of folks who volunteer for NCPSG, at support group meetings, at social events, and anywhere they can find an opportunity to serve. In fact, our organization **depends** on volunteers.

At our June NCPSG Board of Directors meeting (and all Directors are volunteers), our Corresponding Secretary Micheline Allen suggested that we ask support group leaders to identify a faithful volunteer every once in a while, and we'd add a short acknowledgement on our Page 4, where, by the way, you'll see leadership volunteers listed under "CONTACTS".

Well, Micheline, we're starting with you! Besides handling Board correspondence, Micheline prints and mails newsletters to those among us who struggle with computers and internet service, enters new member



information into our database, keeps that up-to-date, and provides valuable insights at our Board meetings.

Micheline brings her "eagle eye" to our publications, including this newsletter, scanning for punctuation and grammar errors. And she ALWAYS finds them. (Not this time, 'cause we added this article without telling her! So this may have a spieling airer or to.)

Thank you so much Micheline!

#### Inside This Issue

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### **Support Group Meetings**

#### **RANCHO BERNARDO**

#### No July meeting

Usual meeting location: **San Rafael Catholic Church** 17252 Bernardo Center Road, San Diego, 92128 *Hosts*: Brigit King <u>bkicedancer@gmail.com.</u> 858-354-2498 & Carol Maher <u>hcmaher@cox.net</u> 760-518-1963

#### LA COSTA CARLSBAD

#### Wednesday, July 2, 1:00 PM to 3 PM

Speaker: Dan Sweiger

Topic: "Parkinson's And Healthcare Options"

Christ Presbyterian Church 7807 Centella St. Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

#### **OCEANSIDE**

#### Wednesday, July 9, 1:00 PM to 3 PM

Speaker: TBA Topic: TBA

#### Oceanside First Presbyterian Church

2001 S. El Camino Real, at Fire Mountain Rd

Oceanside 92054

Host: Paul Dawson paul@video-fire.com

or 760-497-1200

#### **FALLBROOK**

#### Friday, July 25, 10 AM to Noon

Speaker: Matt Ignacio - Tremble Clefs

Topic: "Fighting Parkinson's One Note at A Time"

#### **Fallbrook Regional Wellness Center**

1636 E. Mission Rd, Fallbrook 92028 *Host:* Irene Miller <a href="mailto:ncps/ncps/ncps/">NCPSGF@gmail.com</a>



#### Wednesday, August 6, 2025

1:00 pm – 3:00 pm Sharp Prebys Innovation and Education Center 8695 Spectrum Center Blvd San Diego, CA 92123

#### **REGISTER HERE – SPACE IS LIMITED**

**Directions & Parking Information:** Will be provided to attendees. Registration is required by August 3, 2025.

#### **NCPSG Board of Directors**

**Wednesday, July 16, 1-3 PM.** The Board meets online on the third Wednesday of the month. Contact Sam Cooper <a href="https://www.ncpschipe.com">NCPSGLC@gmail.com</a> or 520-820-0339.

#### **Physical Exercise**

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

#### **Tri-City Hospital - Parkinson's Exercise**

Led by a Physical Therapist and an Occupational Therapist. Every Thursday, 3 - 4 pm. (no charge) Check in at hospital main desk.

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 and occupational therapy, and wellness sessions. <u>www.neurolab360.com</u>

**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. <a href="https://www.rocksteadyboxing.org/">https://www.rocksteadyboxing.org/</a>

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

**Tai Chi - Temecula -** (*NCPSG Scholarships Available*) Physical exercise & wellness. www.oyd-ca.com

#### **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 (no charge)

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 <a href="MusicWorx.com">MusicWorx.com</a>. Cassandra Richtsmeier <a href="mailto:858-457-2201">858-457-2201</a> or crichtsmeier <a href="mailto:musicworxinc.com">musicworxinc.com</a>

#### In Focus: John Milam

By Sam Cooper



"In 1984 when I was 18, I suffered a traumatic brain injury (TBI) at work in a factory in Orange County. I was in a coma for ten days and spent six months in the hospital followed by two years of cognitive and speech therapy. I was left with a speech impediment and balance, coordination, cognitive, and mental health issues. My parents and I moved back to our former home in the Detroit area. Despite my new health challenges, I completed a college degree in Computer Aided Design/Manufacturing. I worked in the field for a few years liking the job, but not the amount of overtime that seemed unavoidable in Detroit's automobile industry. Having had the ambition to write a book about my life, I left the Manufacturing arena and published the book on Amazon in 2022.

"In about 2016 I began to notice some of my residual symptoms from the TBI were getting worse. As I was about 50 at that point, I chalked it up to what I thought was normal aging. But over the next several years, the symptoms quickly got worse. In 2021, my mother passed away and my father and I moved to North San Diego County to be close to my sister and her family. I was diagnosed with Parkinson's in 2022. After learning to live with my TBI, I was familiar with physical and occupational therapy and dealing with the medical bureaucracy.

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Take action."

"I learned about the North County Parkinson's Support group and began attending the La Costa chapter meetings. Here I found others dealing with the same life circumstance. I wasn't alone as I'd felt after the isolation and depression of the TBI. The informational speaker is always very helpful and I find the breakout sessions for people with Parkinson's particularly helpful. I feel comfortable with other people who are going through the same thing I am. Social interaction and the support of friends and family has made all the difference. You need to be proactive. Instead of letting health issues get you down, take action. There are things you can do. Exercise, be social, stay involved in life I don't know what the future holds, but I will take it as it comes. I have always been spiritual and Faith makes a huge difference. Faith in something is essential. Even if it's just as simple as the faith in human goodness."

## **Social Gatherings**

We hope you join in our NCPSG large and small socials, where no one blinks an eye at a spilled drink or tremoring hand, or soft voice. Contact Sam Cooper NCPSGLC@gmail.com or 520-820-0339.

Save the date: Fall Social Potluck, Monday, September 15. Location TBA.

#### **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 <a href="mailto:ncpsgNL@gmail.com">ncpsgNL@gmail.com</a>.

#### **Parkinson's Media Mentions**

In February, 2025, the FDA approved an algorithm developed by a UCSF researcher that provides calibrated electrical pulses to fend off stiffness and involuntary movements before they arise. This means this new treatment can adjust to Parkinson's symptoms in real time.

According to the study, the therapy, known as adaptive deep brain stimulation, or aDBS, uses an implanted device that continuously monitors the brain for signs that Parkinson's symptoms are developing. When it detects specific patterns of brain activity, it delivers precisely calibrated electric pulses to keep symptoms at bay.

The FDA approval covers two treatment algorithms that run on a device made by Medtronic, a medical device company. Both work by monitoring the same part of the brain, called the subthalamic nucleus. But they respond in different ways. A "fast" algorithm detects patterns associated with symptoms and immediately suppresses them. A "slow" algorithm provides stimulation that maintains the person's brain activity within a range where symptoms are reduced.

The fast approach was developed by UC San Francisco neurologist Simon Little, MBBS, PhD, in 2013, while he was a Wellcome Trust clinical research fellow at Oxford University with Peter Brown, MBBS.

aDBS is a significant advancement over a treatment called continuous DBS, or cDBS. which delivers constant stimulation to the brain. cDBS has been used to improve Parkinson's symptoms since it was approved by the FDA in 1999.

Patients and their health care providers will be able to choose which adaptive algorithm to use and be able to easily switch from one to the other using software that communicates with the device via Bluetooth.

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#### **Newsletter Published Online**

Our monthly NCPSG Newsletter is available on our website **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 <u>ncpsqCS@gmail.com</u>

#### Our mailing address:

**NCPSG** PO Box 230566 Encinitas, CA. 92023 **Our Website: (Donations accepted) NCPSG.org** 

## Annual Summer Social: "Americana Barbeque" in Rancho Bernardo



















Thanks to our hosts - the Fallbrook chapter!