

NORTH COUNTY PARKINSON'S SUPPORT GROUP

December 2024

www.NCPSG.org



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



We are sad to announce the passing of Thelma Balbes who has had an amazing impact on NCPSPG over many years. Her approach to life and PD, as we reported in 2015, still resonates.

Thelma Balbes

What do you enjoy most?

The fact that I've been able to help people adjust to it (PD)....

And helping is fun, watching the way they looked at the illness, helping them be better prepared for what is coming, and also become more relaxed.

They can go through life happier and relax and enjoy the moment

Our 2015 interview with Thelma is on Page 5

HOPE and CURE

Our NCPSPG logo, the lighthouse in our banner above, has two beams of light streaming out "HOPE" and "CURE".

HOPE is the primary service that we provide through our four North County chapters and to the Parkinson's community beyond. It is what we offer through Support Group meetings and Social events, sharing our challenges and what we've learned to make life with Parkinson's more fulfilling, more meaningful. HOPE is what we gain from feeling our progress through exercise – consistent, challenging exercise – regardless of the type. And HOPE comes too, one-on-one, through friendships we make and mentoring we give and receive.

The **CURE** beam of light has been more elusive. Lately we've learned more about what scientists and physicians are uncovering about the disease in its many forms. But until very recently, treatment has been solely in symptom control. Now progress is being made in identifying whether you actually do or do not have PD, and even whether in the future you will develop PD. More than that, the new tests eventually could indicate when a research therapy has actually "cured" a PD patient! Exciting times!

Here are two sites that point to a "CURE":

Parkinson's Progression Markers Initiative (PPMI) is Michael J Fox's landmark study. It gathers information over time to learn more about how brain disease starts and changes and how to stop it. PPMI scientists validated a biological test for Parkinson's, capable of objectively and reliably detecting the alpha-synuclein protein, a hallmark of Parkinson's disease. The discovery will transform clinical trials and rapidly revolutionize the development of treatments. You can participate! <https://www.michaeljfox.org/news/breaking-news-parkinsons-disease-biomarker-found>

Aspen Neuroscience - now in Phase 1/2a clinical trial for the treatment of sporadic Parkinson's. Dr. Jeanne Loring conducted earlier research at Scripps Research Institute, previously supported by "Summit4StemCells". <https://aspenneuroscience.com/aspen-neuroscience-announces-expansion-of-autologous-cell-therapy-manufacturing-in-san-diego/>



Almost too late for Winter Social

Reservations are due **December 2** for our **Winter Social**, held at the Shadowridge Golf Club in Vista, **Saturday, December 7**.

It's a great meal, but the best part is meeting and sharing with others, old friends and new!

The Reservation Form is on Page 7.

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Support Group Meetings

RANCHO BERNARDO

Monday, December 2, 10:00 AM to Noon

Speaker: Erin Angelo

Topic: "RX Ballroom Dance-exercising with dancing"

San Rafael Catholic Church 17252 Bernardo

Center Road, San Diego, 92128

Host: Brigit King bkicedancer@gmail.com

or 858-354-2498

LA COSTA CARLSBAD

Wednesday, December 4, 1:00 PM to 3:00 PM

Speaker: Lindsey Unger

Topic: "Voice And Swallowing"

Christ Presbyterian Church

7807 Centella St. Carlsbad 92009

Host: Sam Cooper NCPSGLC@gmail.com

or 520-820-0339

OCEANSIDE

Wednesday, December 11, 1:00 PM to 3 PM

Speaker: Jamie Bolane

Topic: "What are QR codes, and why are they important to you"

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 December

No meeting in Lieu of Holiday Social Event - Contact Irene at email ncpsgf@gmail.com

Host: Irene Miller NCPSGF@gmail.com

Social Gatherings

We hope you join in our NCPSPG large and small socials, where no one blinks an eye at a spilled drink or tremoring hand, or soft voice.

If you are interested in joining our small groups, please contact Sam Cooper at scprphd@gmail.com or 520-820-0339.

Passings

- Kevin Taggart
- Thelma Babes

Our thoughts & prayers go out to family & friends

NCPSPG Board of Directors

No December Board meeting. The Board normally meets online on the third Wednesday of the month.

Contact Sam Cooper NCPSGLC@gmail.com or 520-820-0339.

Physical Exercise

Check with provider for possible changes around the holidays.
In-person or On-line Options. Fees May Be Charged.
For more information on Scholarships see NCPSPG.org

Parkinson's Exercise - Tri-City Hospital - Led by Physical Therapist and Occupational Therapist. Every Thursday, 3 - 4 pm. (no charge) Check in at hospital main desk.

Personally Fit (NCPSPG Scholarships Available)

In-person and Zoom classes for Parkinson's.

Personallyfitonline.com or contact Doris Flood, PT at dflood@personallyfitonline.com

LifeSpan Health (NCPSPG Scholarships Available)

Drug-free program to enhance a healthy life span.

<https://lifespanhealth.me/>

NeuroLab 360 (NCPSPG Scholarships Available)

Neurologic physical and occupational therapy, and wellness sessions. www.neurolab360.com

Rock Steady Boxing (NCPSPG 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. (no charge) Details at <https://www.rxbalroomdance.com/> or call Erin Angelo 310-938-1620

Tai Chi - Temecula - (NCPSPG Scholarships Available) Physical exercise & wellness.

<https://schools.oomyungdoe.com/temecula/>

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: matt.sdtrembleclefs@gmail.com

Website: <https://www.trembleclefs.com/>

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. (fee charged) See MusicWorx.com. **Cassandra Richtsmeier** 858-457-2201

or crichtsmeier@musicworxinc.com



Nancy Rathgeber grew up in a family of 5 kids. "Plus my Mom's youngest sister, so a family of 8 overall". She holds degrees in Spanish and French. Joining the Marine Corps in 1985, she retired in 2014 as a Colonel. She then worked for the Corps as a Department of Defense civilian from 1995 to 2024 helping in the development and acquisition of computer based command and control systems. She has raised Samoyed dogs for more than 40 years and shows her dogs competitively in AKS shows finishing many Champions and Grand Champions including top winning dogs commenting "I don't have any human kids. My dogs are my kids."

"My husband, David, was diagnosed with Parkinson's in 2019. I do everything I can to try and support him and keep him going even when he doesn't want to keep going. We participate in the Rx Ballroom Dance together and really enjoy it. It is both a social activity and a physical activity. David has been attending the Fallbrook chapter support group for about a year now and finds it very helpful which is great. Early on, we learned that exercise and intense physical activity is one of the best things for folks with Parkinson's. David is very involved in Kettle Bell activities which provides intense weight training that challenges him physically, mentally, and emotionally. He does several sessions a week."

"All of our friends and family members are aware of David's Parkinson's. They are all interested in his progress and are very supportive. In some ways, Parkinson's has brought David and I closer together. We are more in tune to one another's challenges now. We have and continue to improve our communication. Don't give up and don't give in. Don't sit and let life pass you by. Find a support group. Find physical activities. Push yourself. Engage with friends and family. For those of us caring for a loved one with Parkinson's, be a confidante, a friend, a coach. Be there for them, but don't provide an artificial crutch. The more your loved one can do for themselves the better."

"...exercise and intense physical activity is one of the best things for folks with Parkinson's..."

Read the Latest Research about Parkinson's Disease on [Medscape](#)

Medscape is the leading online global destination for physicians and healthcare professionals worldwide, offering the latest medical news, expert perspectives, and essential point-of-care drug and disease information. Patients are allowed to access the site and registration is free but required. Once registered, users can download the free App.

Free Mobility Devices from PASD

For many years the Parkinson's Association of San Diego has offered free mobility devices – walkers, rollators, wheelchairs, canes, and much more – to people in San Diego County impacted by Parkinson's. This donated equipment is generally lightly used, although some are new. They also accept donated equipment. Recently, management of the program was taken over by Harmony Home Medical and we now have an online catalog of the equipment. Click here to view the [catalog](#).

NCPSPG 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 ncpsqNL@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!



Dealing with Holiday Stress

The Michael J. Fox Foundation offered this valuable and timely advice:

Holiday time is here and for many of us this can mean extra stress, particularly for those of us with Parkinson's and those who have lost a loved one. There is often an increase in activities that overwhelm us and increase anxiety.

Parkinson's may change aspects of your Holidays, but you can still have an enjoyable and meaningful celebration. The following tips can help you.

Share your anxieties with a trusted person: Explain what you are feeling and how they can help.

Communicate your needs: Don't be afraid to say no, maintain healthy boundaries.

Choose your social events: Consider the dynamics of the event, prioritize the most important. Interacting with others is a benefit boosting your mood.

Be flexible: Don't try to do everything, it's okay to say "I can't do that, but I can . . ."

Suggest alternatives: if you can no longer travel consider a video chat such as Zoom. If family traditions no longer work for you discuss other ways.

Adjust your expectations: Let go of the illusion of the perfect holiday, accept that each year will be different and enjoy the present.

Allow extra time: A cushion of time to get ready and reach your destination prevents worry and worsening of symptoms.

Put yourself first: Make yourself and your health a priority. Exercise, eat and sleep well. Enjoy holiday treats in moderation. Find ways to reduce stress such as meditation.

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NCPSPG.org

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Newsletter Published Online

Our monthly NCPSPG Newsletter is available on our website NCPSPG.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

**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!**

We are sad to announce the passing of **Thelma Balbes**, who had a huge influence on NCPSPG in our formative years, and was honored as Director Emeritus by our Board of Directors. Let's revisit her thoughts expressed in our Newsletter nine years ago - August 2015.

Thelma Balbes - In Her Own Words

PRIOR TO DIAGNOSIS

Before Parkinson's, I had a really interesting job with a major communications company in the St. Louis area. I was doing customer satisfaction studies. Every time there was a purchase of another communications company, I was required to go out to the other company and see what they were doing in customer satisfaction surveys and try to come to consensus with their executives as to what we should be doing. That was what I was doing when I first starting having symptoms that something was wrong, but we didn't know what.

FIRST HINTS OF PD – AND MISSED DIAGNOSIS

I kept going to the doctor first with a frozen shoulder because I couldn't move my hand above shoulder height, and had physical therapy and medication, and it eventually went away. Then I had a backache that lasted about 10 months. The doctor was just getting ready to give me shots in the back when it went away. I was glad about that. Then when I starting having a tremor they said I had "essential tremor" and they put me on medication – the same medication they give people with epilepsy. I was really sick from that medication, so I stopped taking it – just lived with the tremor for about two years.

And then I asked the doctor to send me to a neurologist. And he did. The doctor was so sure of his diagnosis; he did it because I wanted him to, "not because I needed it". Because he said people your age don't get Parkinson's. I was 56.

So I went to the local neurologist, and he said that I had Parkinson's. It was difficult, because Parkinson's has no cure, but it was nice to know what was causing all my problems. I decided to get a second opinion – and I think everybody should do that. The second opinion was at Washington University in St. Louis, and that doctor said I had Parkinson's.

RESPONDING TO THE DIAGNOSIS

It took a little while, several months, to come to grips with it. I joined a support group which was very, very helpful, and I became very active in it. It's a shock the first time you see someone with dyskinesia in a wheelchair or sitting in a chair. I couldn't take my eyes off that person. I was sure he was going to fall off the chair. After a couple of visits to the support group I realized these people were just like me. They had Parkinson's and they were dealing with it.

PERSONAL JOURNEY

It is a journey, because you are always getting changes, and changes. You never know what the day will bring. It's like driving across the country. You never know what the traffic is going to be like, it might slow you down. You never know what the weather's going to be like. We have the same thing with Parkinson's. One day it's sunny and everything is great, and you can walk ten miles, and the next day you have trouble getting out of bed. That's the way the illness is. You just have to keep up with it.

The fact is that I've been able to help people adjust to it, and I really like helping people – watching the way they look at the illness, helping them be better prepared for what is coming, and also become more relaxed. They can go through life happier and relax and enjoy the moment. I think people should do as much as they can for themselves. I think you're happier when you do that.

Thank you, Thelma



Parkinson's Association of San Diego's

EMPOWERMENT DAY

December 4, 2024 Wednesday

- ◇ **New Topics**
- ◇ **New Speakers**
- ◇ **New Venue** **Four Points by Sheraton** 8110 Aero Drive, San Diego 92123

An all-day event filled with important discussions and updates on research, treatment, and services critical to everyone impacted by Parkinson's.

Register at <https://parkinsonsassociation.org/>





Saturday, December 7, 2024, 11:30 A.M

Check-in 11:00

Shadowridge Golf Club

1980 Gateway Drive, Vista

All choices include water, iced tea, or coffee, rolls with butter, salad, and dessert.

1. Honey Glazed Salmon with mashed potatoes and vegetables
2. Lemon Roasted Chicken with mashed potatoes and vegetables
3. Butternut Squash (vegetarian)

We must receive your reservation by Monday, December 2, 2024

\$32.00 per ticket. Number Of Tickets _____

Name

Menu Choice

Your phone number _____

Make your check payable to "NCPSG" and mail this form and your check to:

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