

Volume 28, No 5 May 2024

Movers & Shakers

The Santa Cruz County Parkinson's Group Monthly Newsletter

Wednesday, May 1st at 2 pm

"Questions & Answers about PD"

With Michael Gansauer, MD

Dr. Michael Gansauer will join us to answer our many questions about Parkinson's Disease. Come prepared!

Dr. Gansauer received his medical degree from the University of Cologne, then spent three years in training in a residency in Psychiatry in Germany. He did his Neurology residency at UC Davis, followed by a fellowship in Clinical Neurophysiology at UC Davis. He is board certified by the American Board of Psychiatry and Neurology in the field of Neurology. Dr. Gansauer has been in practice at PAMF Santa Cruz since 2004, and is the Director of the Stroke Center at Dominican Hospital.

My Philosophy of Care

All of Neurology is of interest to me. I started my career in psychiatry, and many of the areas of overlap between Neurology and Psychiatry are of special interest to me. We often evaluate and treat patients for medication side effects and many of the medications used in Neurology are also used in Psychiatry, just to mention the fields of dementia, Parkinson's disease, brain injury, epilepsy etc. I find the complex interactions of those fields of medicine and the medications used very interesting, and a field where I can often change my patients' life for the better.

Location in person:

Parrish Hall of the Congregational Church of Soquel 4951 Soquel Drive, Soquel, CA

Zoom Link for virtual participation <u>here.</u> Meeting ID: 823 0935 4550 Passcode: 164784 The church is located between Main Street, (where there is a traffic light) and Center St. A large parking lot is located behind the church, and can be accessed from either street. Parrish Hall is easily accessed from the pkg lot.

Upcoming Wednesday Meetings in 2024

Wednesday, June 5th, 2 pm "A Parkinson's Disease Research and Therapy Update from The Michael J. Fox Foundation" with Kristen Kovaletz

Wednesday, July 3rd, 11:30-2:30 Annual Picnic at Blue Balls park

Wednesday, August 7, 2 pm Nicolle Nelson—"Practical Estate Planning: Peace of Mind for You; a Gift for Your Survivors"

Anatomy of MY Fall (NOT the Oscar nominated film)

-"with 8 falls, where's my Oscar for Best Stunts in a Series?"

My first bad fall, October 2023, dislocated my clavicle. X-rays showed it *dented* my shoulder bone! (The quartzite counter didn't move.) In Sacramento I fell 5 times in December while visiting our first grandchild (born 10/28). Culprits: an unfamiliar place, planter boxes in a parking lot, muddy ground, loose rug, "dark & stormy night." The "pièce-de-resistance" falls, #7 & 8, taken together are comedy divine. #7 was falling backwards at my Parkinson's exercise class and hitting my tailbone! Ironically, #8 was on the ramp to Radiology Lab to get an x-ray of #7! Happy New Year!

How did I get to here? How is this happening, changing our life SO FAST! I'm 73. Young-at-Heart. I was in fairly decent shape, taking exercise classes, enjoying our grandson, and BAM! BAM!...these falls seem to come out of nowhere! What was different? Body is so banged up, I can hardly move! Every exercise hurts. How can I build up strength? Without exercise, I'll be stiffer. My Parkinson's will get worse, more freezing. You've read this somewhere too: seniors who fall and are hospitalized have a 25% chance of dying within a year, 75% never regain their prior level of functionality. One fall increases chances of falling again. But what about ME? Where do I fit in with 8 falls? BAM! I feel like 80. At a recent medical visit, I filled in the number of falls I'd had in the paperwork. That was it. No comment. No follow up. How about a training on how to fall?" My mind spirals down—I will *never* recover. My neurologist told me that using my rollator just bumped me to Stage 4 Parkinson's! BAM! I not going to make it to 74. Several times while at my daughter's, I caught myself-barely-from another tumble. I had kept these "almost fallens" to myself. No more.

My husband's world has changed dramatically. He's doing EVERYTHING: cooking, shopping, driving, and laments we will never travel again. He's terrified I'll fall again. He lovingly fixes my morning tea. Time to face today, think deeply, and take on my next project: Recovery Me.

Ann-Marie Mitroff served as the first water conservation coordinator for the City of Santa Cruz Water Department (1987-1994). Over the last 20 years, her work has directly supported urban river and environmental justice organizations around the country. Diagnosed in 2015, she and her husband re-settled back in Santa Cruz in 2020. She can reached at mitroff.annmarie@gmail.com. Just *reading* "Fall Prevention Month" recommendations won't cut it. *Doing is key!* Think of me and my falls to get you inspired. Your life might change for YEARS or be shortened in YEARS, if you don't pay attention to correcting or changing things to keep yourself safe.

Adopt "Act Your Age" as a critical and positive safety mindset when it comes to falls. We just don't "notice" getting older. But your body is changing, slowing down—you need to think differently as well. Pace yourself. Pay attention to your surroundings. Disclose "almost fallen's." If you fall, stop and go through "Anatomy of a Fall" to make needed changes to keep yourself safe.

Why get a rollator *after* a fall? Let's make rollators fashionable for those 65 and older to *prevent* more falls. And the Oscar for *"Best Marketing Photo Campaign"* goes to...



PD News

The City of Santa Cruz has declared April as Parkinson's Awareness Month, thanks to Board member Helena Fox's efforts!



The Steering Committee needs your help! REMINDER

The question of housing is an important one for seniors and people with Parkinson's. Our Steering Committee is planning to schedule two panel discussions on this topic in the fall of 2024 and we need your help in identifying speakers for these programs.

The September "Should I Stay?" program will focus on keeping people in their own homes. Some possible speakers could include: people from our own group who have opted to *STAY*; an architect addressing elements of universal design; a person, such as an OT, who can look at people's homes to determine what modifications should be made; a person from an organization such as Helping Hands who can make these modifications at low or reasonable cost; and an aging in place specialist.

The October "Should I Go?" program will focus on alternative housing for people whose homes no longer meet their needs. Some possible speakers could include: people from our own group who have opted to *GO*; a person who specializes in downsizing; a real estate agent who helps find suitable housing for seniors or those with disabilities; a person who can provide a broad overview of senior housing, both subsidized and not subsidized, in Santa Cruz County. These could include senior residential communities, independent living, assisted living facilities, nursing homes, and care homes.

If you know of people who could fill the bill for either of these programs, please contact Karen Williams, preferably before the end of April (williamk@union.edu; 831-708-2906).

Erik's Deli "Dine for a Day"

This year's 'Dine for a Day' fundraiser was another great success, **donating \$1,350 to our organization.**

Dine for a Day Aptos participants, from the left: Mike & Grace Terauchi, George & Karen Williams, Steve Hatton, Mari Fernandez-Wong, Phil Prsha, Paul Neuman, Linda Neuman (kneeling), Lou Prsha, Barry Marks & Julie Lorraine.

EasePD News

Moving Day 2024

"Moving Day San Jose, a Walk for Parkinson's was a huge success! SCCPG teamed up with the Monterey Support Group (MPSG) as Waves of Hope and on Saturday, April 20th we participated in this fundraising event and shared information about our Central Coast groups. It was a beautiful sunny day for an array of activities including a group exercise led by the San Jose RSB coach. Special recognition was given to the fundraisers, individuals and a special Volunteer Service award from the Parkinson's Foundation was given to our very own Helena Fox. The presentations were concluded with demonstration of Bollywood dancing which was a great warmup for the grand finale of the group walk.

Our team successfully raised over \$6700 with the entire event raising an impressive \$126K all in support of PWP. Thank you to those who supported us, cheered us on, and walked beside us whether in person or in spirit!

Ida (SCCPG) and Naomi (MPSG)"



EasePD Classes

The classes and activities listed on this page are supported by donations from EasePD. Several are also supported by NextStage Productions, and individual donors. Participate in activities based upon your ability to do so safely with respect to your own health as well as Covid-19 criteria. Classes are open to all levels of ability and Parkinson's - from beginner to more advanced.



Taiko Drumming

When: Mondays 10 – 11 am, current session continues through June 10th
Location: Trinity Presbyterian Church Fellowship Hall
420 Melrose Ave., Santa Cruz (Corner of Poplar & Melrose Ave. Enter Hall on Poplar)
To register, contact Bonnie Barisof 426-6575 or email: <u>bonniesb2020@gmail.com.</u>

Tremolos



Even if you have never attended a Tremolos session before, we welcome you to join in the fun. Singing is an essential activity as it strengthens the voice and muscles that control articulation, smiling, and swallowing. Singing also strengthens community and connection.

When: Tremolos will meet in person on Thursday May 9th, 16th, and 23rd from
1-2:30pm at St. John's Episcopal Church, 125 Canterbury Drive, Aptos.
Contact Camille Couture, Song Leader at <u>Camille.Couture@gmail.com</u> for details.
A \$5.00 donation is suggested. Please bring your water. Masks are optional.



Climbing out of Parkinson's

When: Saturdays 10:00 - 12:00pm. The cost for use of equipment, walls, and belayers is \$10 for those with PD, and \$20 for others, thanks to support from EasePD. Gym is at 104 Bronson in Santa Cruz (near harbor).



Pickleball

When: Wednesdays from 10 am – 12 noon except when courts are wet. Where: Brommer Park dedicated pickleball courts, 1451 30th Ave in Santa Cruz Donation: \$5 Contact: <u>htpower@me.com</u> if you have questions. We'll provide paddles, pickleballs, and instruction.



Sand Volleyball at Main Beach Location change! When: 11 am-12 pm Fridays, through May 3rd

Come join us Fridays for outdoor sand volleyball at Main Beach (Court 8) this spring, at a court near the intersection of Main Street and Beach Street. There's a variety of volleyball drills, activities and we end with a volleyball game on the sand. **There will be no volleyball May 10-September 13th.** Call Liz at 831 818-9248 or email Lizzyfowler@aol.com

Peer Counseling Support Group for those with Parkinson's

This ongoing group provides an opportunity for connection and caring while keeping a virtual distance. The group will meet **May 3rd and 17th** (the 1st and 3rd Friday of each month.) The meetings are via Zoom. If you would like to attend, contact Steven Barisof at (831) 426-6575 or <u>sbarisof@pacbell.net</u>. An email with a link will be sent to you 2 or 3 days before the meeting. Don't worry if you can't make it at 1pm, or if you need to leave before 2:30pm. This is a support group, and we'll do whatever we can to support you! Check us out, we always have room for one more person on the Zoom screen.

Caring Partners Support Groups

Our Caring Partners group meets to share experiences, speak, laugh, listen – give each other a helping hand. All care partners, both men and women, are warmly welcome to join us from the comfort of your home! If you'd like to join us, send email to Sue at <u>rday@aol.com</u> or call (408)623-4466.

We have two groups:

CP group 1 is for ongoing members – **meeting May 8th and 22nd from 2:00-3:30** (2nd and 4th Wed of month) *CP group* 2 is open to new members – next meetings are May 9th from 4-5:30 (2nd Thursday of the month) and no Wednesday meeting in May. Julie will send out links and reminders before meeting.

Women with PD

Each month, we meet at a different restaurant for tasty lunches and lively conversation—whether about our experiences with Parkinson's or other aspects of our lives. Lunches are scheduled for the third Thursday of each month. Our next lunch will be at Laili Restaurant on Thursday, May 16th at 1pm. Details and RSVP to <u>aura@easepd.org</u>

Flying Solo with Parkinson's continues May 9th and 23rd from 4-5pm NEW!

We are a group of PwP's living with Parkinson's experiencing unique issues and challenges of living alone or in a community that does not understand our personal needs. You may be in a family unit, partnered, or involved at your church or synagogue; but you are still feeling like you are "Flying Solo," on your Parkinson's journey. Flying Solo now has a private Facebook page. It's a closed group-people join and post only seen by members https://m.facebook.com/groups/1110203840164513

Email Helena at <u>Helenafx@aol.com</u> or call or text 408-656-4763.

Highly recommended!

Premiering April 8th on KQED/PBS is *Matter of Mind: My Parkinson's* a documentary about three individuals living with Parkinson's, and how they're striving to live well. <u>https://www.pbs.org/independentlens/documentaries/matter-of-mind-my-parkinsons/</u>

Community Opportunities for those with PD

The Parkinson's oriented classes listed here have proved useful for many of us. We appreciate their commitment to serve our PD community. Participate in activities based upon your ability to do so safely with respect to your own health as well as Covid-19 criteria. Classes are open to all levels of ability and Parkinson's - from beginner to more advanced.



Dance for PD - Live + virtual classes

Dance for PD is a free class where participants are empowered to explore movement and music in ways that are enjoyable, stimulating and creative.

When: Wednesdays at 1pm (except 1st Wed of each month). All classes will be *hybrid* of in-person and virtual. Contact: <u>mekatzman@gmail.com</u>



PEP Classes – Classes are in-person and live online

Low-cost Parkinson's specific exercise classes taught by Karen Nauenberg, MPT, Physical Therapist, PWR! Certified. Call (831) 457-7099 to sign up. https://www.dignityhealth.org/bayarea/locations/dominican/classes-and-events



Rock Steady Boxing classes at Santa Cruz Boxing When: Monday - Thursday from 11:30 to 12:30 Cost is \$150/month Taco Tuesday after class, 1st Tuesday of the month Call Brian at 831-438-2697 or check the website for class schedule and more information



IN MEMORIAM

at https://www.santacruzboxing.com

Private family services will be held for Louis "Lou" Florimonte who passed away on March 18th, he was 86 years old. Lou was born in Old Forge, Pennsylvania, to Italian-American parents. A playwright, producer, director, and writer, Lou was a beloved teacher and mentor, and he would often see more in a student's work than the student would ever recognize themselves.

Lou was an avid, operatic cook, particularly of Italian cuisine, and usually turned the kitchen into a dramatic whirlwind of barely contained chaos. Anyone arriving at Lou's home at any hour with even a hint of hunger would soon be served a steaming plate of linguini with clams, or a pizza with homemade dough he just happened to have on hand.

He faced the challenges of Parkinson's with courage, grace, and defiance, supported by Alex's love and her generous, meticulous caregiving. Lou left this world better than he found it in every way that matters, and his family remembers him with an abundance of gratitude. Alex cherishes the memories of golden afternoons in Italy's piazzas and the many road trips they took. His sons, Arik and Cory carry on Lou's creativity, sense of humor, and confidence in taking on difficult challenges. Shane is inspired to continue his storytelling legacy. His daughters-in-law, Claire and Cynthia, have thrived in the light of his unconditional love. For the complete obituary:

https://scmemorial.com/tribute/details/2613/Lou-Florimonte/obituary.html

May 2024 Calendar

View this calendar at <u>easepd.org</u>. See class details in this newsletter or online. Schedules may vary from this calendar. Contact leaders for meeting information, Covid criteria and to sign up.



| MON | TUE | WED | THU | FRI | SAT |
|---|---|---|--|--|-----------------------|
| | | May 1 11am Pickleball 11am PEP Mov 11:30am Boxini 2pm Monthly M1 | 2 9am PEP Movei 10am PEP Comr 11:30am Boxinç | 3 • 10am PEP Card • 11am Parkins-B • 1pm Peer Suppc • 1pm PEP Yoga | 4 • 10am Climbing |
| 6 10am Taiko Druı 11:30am Boxinı | 7 9am PEP Movei 10am PEP Movi 11:30am Boxing | 8 11am Pickleball 11am PEP Mov 11:30am Boxin; 1pm Dance4PD 2pm CP Grp 1 | 9 9 9am PEP Movel 10am PEP Comr 11:30am Boxing 1pm Tremolos 4pm CP GP2 9 4pm Flying Solo | 10 10am PEP Card 1pm PEP Yoga | 11 • 10am Climbing |
| 13 10am Taiko Druı 11:30am Boxinı | 14 • 9am PEP Mover • 10am PEP Mov • 11:30am Boxinç | 15 11am Pickleball 11am PEP Mov 11:30am Boxini 1pm Dance4PD | 16 9am PEP Movel 10am PEP Comr 11:30am Boxinç 1pm Women's L 1pm Tremolos | 17 10am PEP Card 1pm Peer Suppc 1pm PEP Yoga | 18 • 10am Climbing |
| 20 10am Taiko Drui 11:30am Boxini | 21 9am PEP Movel 10am PEP Mov 11:30am Boxing | 22 11am Pickleball 11am PEP Mov 11:30am Boxini 1pm Dance4PD 2pm CP Grp 1 | 23 • 9am PEP Movei • 10am PEP Comr • 11:30am Boxinç • 1pm Tremolos • 4pm Flying Solo | 24 • 10am PEP Card • 1pm PEP Yoga | 25 • 10am Climbing |
| 27 10am Taiko Drui 11:30am Boxins | 28 9am PEP Movei 10am PEP Movi 11:30am Boxing | 29 11am Pickleball 11am PEP Mov 11:30am Boxing 1pm Dance4PD | 30 9am PEP Movei 10am PEP Comr 11:30am Boxing | 31 • 10am PEP Card • 1pm PEP Yoga | |

The SCCPG is led by a group of caring volunteers who are not medical professionals. Please use your discretion before making any decisions based on the information in this newsletter. The opinions found in this newsletter are those of the contributors and do not necessarily reflect the opinions of EASE PD, Inc. and its directors and officers.

General questions about the Parkinson's Community and monthly meeting programs? Contact Karen Williams at 831-708-2906 or <u>williamk@union.edu</u>

Visit <u>www.easepd.org</u> for more information about the Santa Cruz County Parkinson's Group.

We respect your privacy and will never sell, trade or give away your information (name, address, email, etc.) to any third party.