



Movers & Shakers

The Santa Cruz County Parkinson's Group Monthly Newsletter

Volume 28, No 4 April 2024

Wednesday, April 3rd at 2 pm

“It’s your turn!”

This meeting will provide an opportunity for you to provide feedback on the symposium, then meet in small groups to explore ideas for future monthly meetings, future symposiums, and possible future fundraisers.

Monthly Meetings

The Steering Committee schedules two social events each year—a picnic in the summer and a holiday party in December. Other programs are primarily educational in nature.

For example: **Recent past programs** have featured presentations by an ophthalmologist, a cardiologist, and a nutritionist; swallowing & communication issues; Hospice; an Arts Showcase; dementia, a “silver linings” panel; depression; fall prevention; service dogs; dental health, a “getting to know you” program; and a presentation by a PMD specialist (Dr. Peter Lin) What else would you like to hear about?

Symposiums

Our group has organized day-long symposiums in 2010, 2017, 2019, and 2024. Should we have another one, perhaps in 2-3 years? What should the focus be? What speakers, topics, and program elements should we be looking at?

Fundraisers

In addition to our annual Eriks’s Dine for a Day event, we could be thinking about a fundraiser which could bring the message of Parkinson’s to the community at large.

Location in person:

Parrish Hall of the Congregational Church of Soquel
4951 Soquel Dr.

There will not be a Zoom component to this monthly meeting.

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

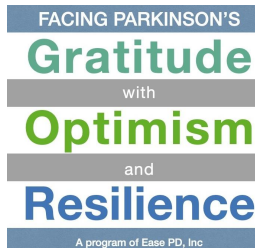
Wednesday, May 1st, 2 pm "Questions & Answers about PD" with Michael Gansaeuer, MD, neurologist

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

2024 Symposium

Our recent symposium, on March 16—“Facing Parkinson’s with Gratitude, Optimism, and Resilience” was the fourth such event which our group has organized. Eleven presenters, thirteen exhibitors, and two hundred attendees participated in the event. The day was sunny and warm, and the mood was reflective of the symposium title. In addition to two in-depth presentations about managing the Parkinson’s journey, by Drs. Lin and Wang, Dave Iverson shared a heartfelt account of living with and caring for his mother for the last ten years of her life (she lived to 105), and Molly Katzman had everyone on their feet, dancing. Later, members of Tremolos, Taiko Drumming, and Dance4PD performed a PD-inspired rap song. The afternoon session was capped with four breakout sessions that expanded on the main presentations.



Video links to the main presentations, along with video interviews with all the exhibitors can be found on our website: <https://www.easepd.org/2024-symposium>

Many thanks to Karen Williams and the Symposium Committee for all their hard work to make the symposium such a success, and the 25+ volunteers who supported their efforts, leading up to and during the day of the event.



Scenes from the 2024 Symposium: clockwise, from upper left: Dave Iverson, Steve McGee and Helena Fox, both ambassadors for the Parkinson’s Foundation, Mark Grantham and Mike Tossy, Artistic performance by members of our PD community.

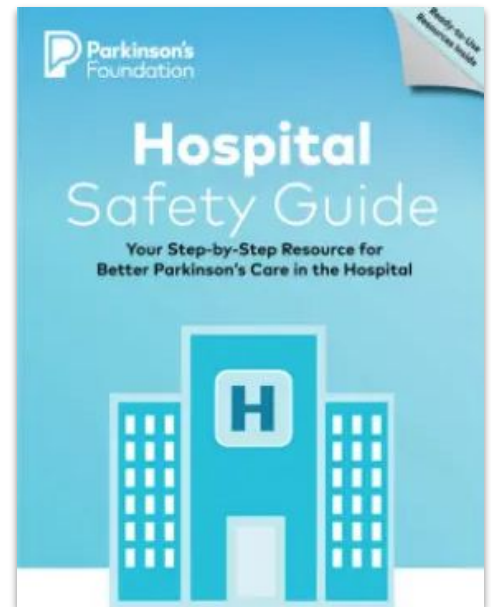
April is Parkinson's Awareness Month and the Santa Cruz Parkinson's Group is joining the Parkinson's Foundation to launch their New PD Awareness Campaign.

The ABCs of PD

It's been said that if you know one person with Parkinson's disease, you know one person with Parkinson's. Everyone's Parkinson's experience is unique. And that's why we're joining the Parkinson's Foundation as they share the **ABCs of PD this April for Parkinson's Awareness Month.**

The Parkinson's Foundation has created the **ABCs of PD** featuring 26 different aspects of the disease. They're going to share each of these on social media throughout the month with links to resources to learn more. To check out their #ABCsOfPD campaign and see how you can participate, visit Parkinson.org/Awareness.

While there, you can click on any letter and read the educational bullet for each letter of the alphabet. The site reminds me a little of Jeopardy! It's actually FUN! For Example: click on the letter "E" is for Exercise! **You will also find a printable worksheet of the ABC's of PD.**



As you read through the list, all of the **PD- ABC's** are important, but when clicking on the letter "H" you can learn about and order the **NEW Hospital Safety Guide**, an important addition to the **Aware In Care Kits**.

One of the topics in the Guide addresses is **The Five PD Care Needs of PwP when in the hospital**, in simple language that allows for empowerment and self- advocacy while in hospital.

Please order your FREE guide today by calling the Parkinson's Foundation Helpline at 800-473-4636 or order online at Parkinson.org/Library. You can also download the E-book. There are many other resource materials available for Free at the Library site. Stay informed and Stay Safe.

Helena Fox is Board member of EasePD, and a Parkinson Foundation Ambassador.

Age Well Santa Cruz County is an initiative by the Santa Cruz Human Services Department, in partnership with the Seniors Council and local cities. As part of the initiative, the county will be developing a Master Plan for Aging for implementing strategies and partnerships that promote healthy aging for all. This 10-year plan will aim to ensure people of all ages and abilities in Santa Cruz County are afforded equitable opportunities to thrive as they age, how and where they choose. Your survey feedback will help inform this plan. The deadline for completing this survey is March 31st, 2024. **Click below to complete the survey!!**

<https://thealliance.health/take-the-survey-santa-cruz-countys-plan-for-aging/>

“Shall I Stay?” or “Shall I Go?” Our family’s story

My parents, while in their early 90’s, decided to GO. In February of 2004 my 93-year-old father (who was diagnosed with PD the following year) turned to me and said, “It’s time.” I understood immediately that he was ready to move from the home in upstate New York where he and my mother had lived for more than 55 years and which he had built, quite literally, with his own two hands, in the winter of 1947-48. I spent the next few weeks researching four senior residential communities within 10 miles of our home near Schenectady, NY, and then took my parents to visit and have a meal at all of them. In the process I compiled a list of “25 Questions to Ask about Retirement Communities” which I would be happy to make available to anyone who wants it. In the end it was *their* choice to move to a community just 15 minutes from our home, and having them nearby was a blessing for me as I provided care and advocacy for them when my father was diagnosed with Parkinson’s in 2005, and my mother suffered a stroke in 2007. Both of them lived happily in this senior community for the remainder of their lives.

George and I decided to GO and then STAY! When my sister passed away in 1994, we inherited her one-story house where we now live in Aptos. After renting it out for more than 10 years, and after we had retired and all of our parents had passed away, we decided to move here in 2009, i.e., our decision was to GO. Before doing so, however, we worked with a contractor to renovate the house, keeping in mind that this is where we expected to live for the foreseeable future. Some of the modifications included widening doorways to the master bedroom and bath, enlarging the step-in shower to include a seat, and installing lever door handles, rocker switches, and grab bars. Since the house is all on one level with just one step into it, it would take very little to make it fully handicap accessible. As long as we are physically and mentally capable of living here, this is where we plan to STAY.

The message to be gleaned from both my parents’ story and our story is the importance of being pro-active rather than having to make serious decisions in the midst of a crisis. We recommend strongly that you *plan ahead!*

Karen Williams



Karen Williams is on the EasePD Board, where she leads the Steering Committee, and organizes the Monthly meetings. Karen has also led the program committees for four symposia, so far.

If you’re interested in writing a “My Two Cents” column, please email Aura @ aura@easepd.org.

The Steering Committee needs your help!

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" Sample Fundraising letter/email: please consider sending one to your friends and families (see flyer on next page)

Dear Friends,

Our non-profit organization EASE PD, Inc (Exercise, Activities, Support and Education for People with Parkinson's Disease) is benefiting from Erik's Deli "Dine for a Day" fundraiser program. We are on their schedule for **Sunday April 7.th April is National PD Awareness Month.**

Attached is the flyer which details how, by ordering menu items from the Aptos, Capitola or Soquel locations, a portion of the proceeds will help our organization.

EASE PD provides many activities and services including a monthly newsletter, monthly educational meetings, a singing group, and small support groups for people with Parkinson's and care partners. Please visit our website EASEPD.org for more information or donate online if you can't come to Erik's in person. www.easepd.org/donate

Our all volunteer group greatly appreciates your support. Thank you!



Dine for a Day Fundraiser

April 7, 2024
National Parkinson's Month

Erik's DeliCafé
Order.EriksDeliCafe.com

Aptos
102 Rancho Del Mar
(831) 688-5656

Capitola
1475 41st Ave
(831) 475-4646

Santa Cruz
1664 Soquel Dr
(831) 462-1919

A portion of your order will be donated to:



The Santa Cruz County Parkinson's Group, in existence for close to 30 years, and EASE PD (easepd.org), our more recently established non-profit organization, provide many activities and services including a monthly newsletter, monthly educational meetings, a singing group, and small support groups for people with Parkinson's and care partners.

Dine-in or order online at order.eriksdelicafe.com and choose any location listed above.



Moving Day San Jose



A WALK FOR PARKINSON'S



Saturday, April 20, 2024

Lake Cunningham
2305 S White Rd
San Jose, CA 95148

Our team name is: **WAVES OF HOPE**

Join our team or donate at
www3.parkinson.org/goto/WavesOfHope2024



Representing the CENTRAL COAST (MONTEREY and SANTA CRUZ COUNTIES).

Please join our team and walk with us to help raise awareness, End Parkinson's (get the End Parkinson's Act bill passed), and give **HOPE** to all who are or will be impacted by Parkinson's.

Thank you, Co-Captains: Naomi (Monterey County) and Ida (Santa Cruz County)



LOCAL PARTNERS



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, **new session starts April 15th - 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: bonniesb2020@gmail.com.



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, April 11th, 18th, and 25th from 1-2:30pm** at **St. John's Episcopal Church, 125 Canterbury Drive, Aptos.**

Contact Camille Couture, Song Leader at Camille.Couture@gmail.com 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 11 am – 1 pm except when courts are wet.

Where: Brommer Park dedicated pickleball courts, 1451 30th Ave in Santa Cruz

Donation: \$5 Contact: htpower@me.com if you have questions.

We'll provide paddles, pickleballs, and instruction.



Sand Volleyball at Main Beach **Location change!**

When: 11 am-12 pm Fridays

Come join us Fridays for outdoor sand volleyball at Main Beach 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. Come one, come all!

If you have any questions, call Liz at 831 818-9248 or email Lizzyfowler@aol.com

EasePD Support Groups

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 **April 5th and 19th** (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 sbarisof@pacbell.net. 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 rday@aol.com or call (408)623-4466.

We have two groups:

CP group 1 is for ongoing members – **meeting April 10th and 24th from 2:00-3:30** (2nd and 4th Wed of month)

CP group 2 is open to new members – **next meetings are April 11th from 4-5:30** (2nd Thursday of the month) and **April 17th from 1:30-3:00** (3rd Wed of month). 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 **the Hideout in Aptos on Thursday, April 18th at 1pm**. Details and RSVP to aura@easepd.org

Flying Solo with Parkinson's continues April 11th and 25th 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. The loving folks in your life just don't "get" or "relate" to your needs and wants as they are now.

Email Helena at Helenaafx@aol.com or call or text 408-656-4763.

Save the Date!

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.

<https://www.pbs.org/independentlens/documentaries/matter-of-mind-my-parkinsons/>

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.

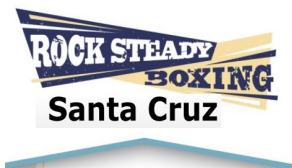
When: Wednesdays at 1pm (except 1st Wed of each month). All classes will be *hybrid* of in-person and virtual. Contact: mekatzman@gmail.com



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 at <https://www.santacruzboxing.com>

IN MEMORIAM



Anthony Tomasso passed away peacefully at home February 25th, 2024 with hospice care and his family: Dorothy (his loving ex-wife), children and grandchildren. Anthony was active in Rock Steady Boxing, Taiko drumming, and PEP fitness classes.

Anthony Tomasso had been beekeeping for over 30 years. What began as a hobby became a business when Anthony left his work as a contractor behind. Building his own hive boxes and frames, Anthony was drawn to beekeeping as an essential aspect of farming. He came from a family of farmers and spoke of a time when everybody had four or five hives on their property for the sake of honey and pollination.

There will be a memorial Sunday, April 21st at 3:00pm, at the Women's Club in Corralitos. Members of Taiko Drumming will perform.

April 2024 Calendar

NEW! View this calendar at easepd.org. 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 Apr 1	TUE 2	WED 3	THU 4	FRI 5	SAT 6
<ul style="list-style-type: none"> 11:30am Boxing 	<ul style="list-style-type: none"> 9am PEP Movement 10am PEP Movement 11:30am Boxing 	<ul style="list-style-type: none"> 11am Pickleball 11am PEP Movement 11:30am Boxing 2pm Monthly Mtg 	<ul style="list-style-type: none"> 9am PEP Movement 10am PEP Community 11:30am Boxing 	<ul style="list-style-type: none"> 10am PEP Cardio 11am Parkins-Ball 1pm Peer Support 1pm PEP Yoga 	<ul style="list-style-type: none"> 10am Climbing out
<ul style="list-style-type: none"> 11:30am Boxing 	<ul style="list-style-type: none"> 9am PEP Movement 10am PEP Movement 11:30am Boxing 	<ul style="list-style-type: none"> 11am Pickleball 11am PEP Movement 11:30am Boxing 1pm Dance4PD 2pm CP Grp 1 	<ul style="list-style-type: none"> 9am PEP Movement 10am PEP Community 11:30am Boxing 1pm Tremolos 4pm CP GP2 4pm Flying Solo 	<ul style="list-style-type: none"> 10am PEP Cardio 11am Parkins-Ball 1pm PEP Yoga 	<ul style="list-style-type: none"> 10am Climbing out
<ul style="list-style-type: none"> 10am Taiko Drum 11:30am Boxing 	<ul style="list-style-type: none"> 9am PEP Movement 10am PEP Movement 11:30am Boxing 	<ul style="list-style-type: none"> 11am Pickleball 11am PEP Movement 11:30am Boxing 1pm Dance4PD 1:30pm CP Grp 2 	<ul style="list-style-type: none"> 9am PEP Movement 10am PEP Community 11:30am Boxing 1pm Women's Lur 1pm Tremolos 	<ul style="list-style-type: none"> 10am PEP Cardio 11am Parkins-Ball 1pm Peer Support 1pm PEP Yoga 	<ul style="list-style-type: none"> 10am Climbing out
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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 williamk@union.edu
 Visit www.easepd.org 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.