

**Wednesday, January 4th at 2:00pm**

## "Parkinson's Disease and Speech Therapy: addressing swallowing and communication"

**Eileen Balian, Speech Language Pathologist**



Eileen Balian, MA CCC-SLP attended San Jose State University, obtaining a masters degree in Communication Disorders. She completed her internship at Dominican Hospital, and was asked to join the rehabilitation department. She has worked at Dominican since 1996 in the departments of neuro rehabilitation, acute care, and home health.

Eileen lives with her husband Alexander in Santa Cruz. He is retired and a volunteer with Habitat for Humanity building homes. They enjoy walking and birding in the hills and along the coast. Prior to becoming a speech therapist, Eileen catered for the Grateful Dead.

**Location:** Parish Hall of the Congregational Church of Soquel, 4951 Soquel Dr.

The church is located between Main St. (where there is a traffic light) and Center St. The large parking lot is located behind the church, and can be accessed from either street. Parish Hall can be accessed easily from the parking lot.

### 2023 Upcoming Wednesday Meetings

#### **February 1 at 2PM**

"Getting to Know You—Again"--An opportunity for us to appreciate each other, not just as people affected by PD, but also as *people*.

#### **March 1 at 2PM**

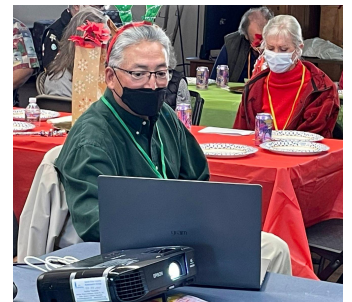
"Graceful Endings: Hospice and Family Roles" --a presentation on end of life care by Annelise Schinzingler and Mary Dixon

## *Holiday Party! It all began with songs led by Glenn and Ellen.*



Left. As head of Steering Committee, Karen and members schedule 1st Wednesday events such as this.

David, on right, displays words to songs on the screen.



Above. Candace and Stephen arranged the party. They send many *Thank You's* to volunteers who worked to create the festive day and also do the clean up.

Below. Candace learned from Lynn and Ron, who did the same for many years.



Left. Susan, Julie, Risa, and Barry. They work to bring you *Tremolos, Taiko*, and today, *Glenn and Ellen*.

Below. Charlotte, who designed our brochure, and Andrea, who mails these newsletters to those without email.





## Newly Diagnosed Group PickleBall - January 7th

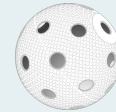
If you've ever enjoyed badminton, ping pong, tennis, and/or smash ball, you may love playing pickleball. There is no pressure to play well. It's a fun way to keep moving and meet others who understand Parkinson's.

There were torrents of rain and blustery wind at the recent Newly Diagnosed meeting. After discussions where Barry, Carol, and Ginger shared their experiences with PD, the pickleball net came out. Anne Berne taught some basics and everyone played - in the cozy carpeted room.



**Who:** Those diagnosed with Parkinson's in the last 3 years, those with mild symptoms, and those having experience playing pickleball or tennis are appropriate for this activity. Players need to be steady on their feet with minimal fall risk. If unsure, please speak with your physician.

**When:** Saturdays from 11am – 1 pm, January 7 – March 25



**Location:** Brommer Park dedicated pickleball courts, 1451 30<sup>th</sup> Ave in Santa Cruz.

**Cost:** No cost for the 1<sup>st</sup> month. *EasePD* has authorized funding to get us started. Possibly a small cost for instructors in February and March.

### How will it go?

We'll provide paddles, pickleballs, and instruction. Tony Marcopulos, PickleBall instructor at Cabrillo, Anne Berne, Helen Power, and other volunteers affiliated with the Santa Cruz Pickleball Club will be there to get you started. No one will be too-good or too-bad to fit in. Wear shoes suitable for tennis. Care partners are encouraged to play.

**RSVP** to [audreyT@easepd.org](mailto:audreyT@easepd.org) is appreciated, but not necessary. Allows us to contact you if there are changes due to the weather. Basically, a chilly day won't stop us from playing, but wet courts will.

The following link shows how the game is played. [Let's Play Pickleball](#)

## Self Efficacy for the Newly Diagnosed

PD SELF is a national program for Parkinson's patients who have been diagnosed within the last 3 years. Program provides patients with the motivation, confidence, skills, and knowledge needed to improve quality of life. Will introduce you to ways of better managing this disease throughout its progression over time. Having a care partner is not required. However, they do encourage care partners to participate as they provide you with educational tools to make you more effective.

To learn more, visit [PD Self Efficacy video](#) <https://www.pdself.org/>

### Update from the Symposium Planning Committee—we need your help!!

The committee has been working for more than a year to plan another central coast Parkinson's symposium and has been met with delays resulting in part from the pandemic but also from the lack of a suitable venue. The symposiums we held at Twin Lakes Church in 2017 and 2019 were extremely successful but, unfortunately, the church is no longer in a position to host this event. Committee members have been unsuccessful in identifying another venue, and need your help. Requirements include:

- An accessible meeting place which can accommodate up to 240 attendees seated at tables.
- Accessible restrooms which can accommodate the needs of this many people:
- Parking for 150+ cars (including handicap spaces)
- Experienced AV support staff (would be helpful if presentations from speakers from outside the area could be livestreamed; the possibility of a hybrid event could also be explored)
- Tables for check-in, exhibitors, and refreshments
- Access to the facility for at least 2 hours of the day of the event or previous day for setup
- Other things which would be useful but not required would be:
- 3-6 smaller rooms for breakout sessions
- Access to a piano (to accompany the Tremolos)

Although our primary audience would be residents of Santa Cruz County, we could also consider holding the event in a surrounding county such as northern Monterey County. If you know of a place which meets these requirements (and ideally have a contact there), **please contact Karen Williams ([williamk@union.edu](mailto:williamk@union.edu); 831-708-2906)**. If you do contact venues which may work for us, please emphasize that EASE PD is a 501(c)(3) organization and has liability insurance.



### In Memoriam Tom Pelio 1941-2022



Tom lived a vibrant full life despite battling Parkinson's for over 22 years, thanks to the love and support from his wife Marcia, together with his family and friends.

A gifted athlete, he competed in volleyball, golf, racquetball, squash, tennis, softball. He also loved surfing, sailing, kayaking, mountain biking. Tom followed through with his love of exercise by participating in exercise activities offered by the Santa Cruz Parkinson's group. Tom's wife Marcia played critical roles in planning the previous Symposiums and creation of the non-profit EasePD.

Learn more at: [Tom Pelio](#)

## 2022 Highlights of the Year By Julie Lorraine, Board President of EasePD

We have so much to be proud of! For a small county, there are many available opportunities for PwPs to participate in these ongoing classes. Some are sponsored by EASE PD and others are available within the community that focus on PD specific activity.

**Tremolos**  
**Taiko Drumming for PwP**  
**Voice and Movement classes**  
**2 Care Partners groups**  
**Women with PD group**  
**Peer Support group for PwPs**

**Newly Diagnosed group**  
**Dance for PD**  
**Rock Steady Boxing**  
**Beach ParkinsBall**  
**Ping Pong Palace**  
**PEP classes through Dignity Health**

### Monthly highlights:

#### January thru August - Our speakers were still on-line

We gained knowledge from topics ranging from Restful Sleep, Pedaling for PD, New Research, Heart Health, Vision updates, and Quality of Life for all stages of PD.

#### April - National Parkinson's Awareness Month

Erik's Deli Dine for a Day Fundraiser raised money for EASE PD.

#### May

*Climbing out of Parkinson's* begins at Pacific Edge Gym

#### August

Return of the Annual Picnic was a joyful event connecting with old friends, meeting newcomers, and playing group games.

#### October/November

We resumed in person meetings, still masked, but another step toward normalization with talks about new treatments and nutrition.

First meeting of a group for people who were diagnosed within the last 3 years. And plans for PickleBall activity beginning in January.

#### December

Our wonderful in-person Holiday party resumed with food, sing-a-long with Glenn and Ellen, and happy socialization!

**We thank all our volunteers including members of the Steering Committee, Symposium Committee, Support group facilitators, and our EASE PD Board of Directors.**

### Michael J. Fox receives the Jean Hersholt Humanitarian Award from the Academy of Motion Picture Arts and Sciences

Michael received the Oscar statuette, at the Academy's 13th Governors Awards in Los Angeles, California, for his tireless advocacy and boundless optimism to change the future for millions of people and families in the Parkinson's community.

Introducing Michael to the stage to accept the award, actor and friend Woody Harrelson shared a powerful introduction: *"Michael J. Fox never asked for the role of Parkinson's patient, disease advocate. But make no mistake, it is his greatest performance. Michael J. Fox sets the ultimate example of how to fight and how to live. Vulnerable? Yes. Victim? Never. An inspiration? Always."*

Accepting the award with a standing ovation, Michael reflected candidly on living with Parkinson's three decades and his determination even during life's challenges: *"Parkinson's disease is the gift that keeps on taking. But it truly has been a gift."* He played a crucial role in the Michael J Fox Foundation's tremendous impact for Parkinson's research progress with over \$1.5 billion funded since inception in 2000.

His inspiring acceptance can be see here: [MJF Acceptance speech](#)



### Online Voice Group for PwPs in Santa Cruz County

In collaboration with *NextStage Productions* and *EASE PD*

Ninety percent of those with PD will have voice issues. The inability to swallow effectively can lead to aspiration which is food or drink going down into the lungs. This online Voice class will harness the benefits of targeted specific activities to improve vocal clarity, breath control, and loudness. Techniques for effective swallowing will be addressed.

Class is led by Jocelyn Lagier, Speech-Language Pathologist - licensed with the state of CA and certified in LSVT training. A Speech and Language intern will assist in some of the activities.

**Dates: Tuesdays, January 24<sup>th</sup> - March 7<sup>th</sup> (No Class on Feb 21<sup>st</sup>)**

**Times: 11 am – 12 noon Online**

**Cost: \$30/per participant** including one caregiver, if needed.

Once registration is completed, participants will receive instructions for accessing the meeting on ZOOM and a meeting link/password. Class is open to new and continuing students.

Click on link below to fill out registration form:

[Sign Up for Parkinson's Voice Group](#)

Please fill out contact information for the Parkinson's Voice - 6 week Class via Zoom

Dates: Tuesdays - January 24th - March 7th (No Class on Feb 21st )

Time: 11:00 AM

# EasePD Classes

## Tremolos

Tremolos will meet **in person** on **Thursday January 12 and 26, from 1-2:15 pm** at St. John's Episcopal Church, 125 Canterbury Dr., Aptos, and online via Zoom.

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.

All participants must show proof of 2 Covid vaccinations and a booster. Everyone will wear a mask inside and we will be socially distanced. Bring your water. Email [ellomar@sbcglobal.net](mailto:ellomar@sbcglobal.net), text to (831) 239-5286 or call (831) 688-0888 with questions. Thanks to Steve Barisof for monitoring the zoom.

We have created a zoom component for our Tremolos sings. If you prefer to sing virtually, please click on this link at 1 pm: [Tremolos Link](#) If necessary: meeting ID 817 9019 2197 Passcode **742277**

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## Taiko Drumming for People with Parkinson's

Evidence suggests that participation in Taiko can result in improved mobility and cognitive functioning through patterning and vocalization. Taiko drumming was found to be a community building activity that can increase energy and positivity. We are so fortunate to have our Taiko classes led by **Watsonville Taiko Group**, Sensei Ikuyo Conant. She brings her knowledge, energy, talent and kindness to each class and we are so very grateful.

**New session: January 16 – March 13, 2023**

**Time: 10-11 am (please arrive 10 minutes early so class can start on time)**

**Location: Trinity Presbyterian Church Fellowship Hall 420 Melrose Ave., Santa Cruz**

The entrance to Fellowship Hall is on Poplar

To register, contact Bonnie Barisof 426-6575 or email: [bonniesb2020@gmail.com](mailto:bonniesb2020@gmail.com) Maximum class size is 20. We will start a wait list if the class is full. This is not a drop in class; please plan to attend every week. Drummers must show proof of Covid 19 vaccination. Masks required.

**No fee to participate.** This class is supported by NextStage Productions with grants from St. John's Helpful Shop, EASE PD and Omega Nu who make these classes possible along with generous gifts from Harriet Mainis, Ellen Mazaika and kind donations from class members. We are grateful for the support of these donors and all of who make these classes possible. Donations to NextStage or [EASEPD.org](http://EASEPD.org) earmarked for this class are always welcome, so we may continue to offer these classes to everyone.

December Recital



# 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 **January 6 and 20**. (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](mailto: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.

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## 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](mailto:rday@aol.com)

### We have two groups:

*CP group 1* is for ongoing members – **meeting January 11, 25 at 2-3:30** (2nd and 4th Wed of month)

*CP group 2* is open to new members – **meeting January 18, 1:30-3:00** (3rd Wed of month). Julie will send out a link and reminder before meeting.

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## 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. Monthly online TeaTime sessions provide the women with PD in our community an opportunity to share with, learn from and support each other.

### Monthly Lunches

The January lunch is scheduled for **Thursday, January 19th** at 1pm. Please email Aura at [aura@easepd.org](mailto:aura@easepd.org) for details.

### TeaTime

Teatime will be **Weds, January 11th at 4pm** (2nd Weds of month). All are welcome. Email Aura at [aura@easepd.org](mailto:aura@easepd.org) for login details.



# 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 refreshing, enjoyable, stimulating and creative. Due to the recent increase in Covid-19 cases, this class is being held online via Zoom. **Wednesdays at 1pm** (except 1st Wed of each month). Third Wednesday of month will be *hybrid* of in-person and virtual. Contact: [mekatzman@gmail.com](mailto: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>

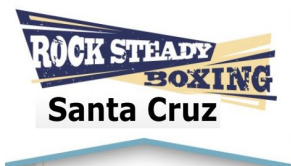


## Climbing out of Parkinson's

December 3, 10, 17, from 10 to 12

**The cost for use of equipment, walls, and belayers has changed from \$20 to \$10 for those with PD, thanks to support from EasePD.**

Gym is at 104 Bronson in Santa Cruz (near harbor).



## Rock Steady Boxing classes at Santa Cruz Boxing

Call Brian at 831-438-2697 or check the website for class schedule and more information at

<https://www.santacruzboxing.com>

**Monday - Thursday from 11:30 to 12:30**

Taco Tuesday after class, 1st Tuesday of month



## Beach Parkins-Ball at Seabright Beach

Contact: [Lizzyfowler@aol.com](mailto:Lizzyfowler@aol.com)

**Friday mornings at 11am.**



# January 2023 Calendar



See details in newsletter or at [easepd.org](http://easepd.org). Schedules may vary from this calendar. Contact leaders for meeting information, Covid criteria and to sign up.

Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
2 PEP? 11:30-12:30 Boxing	3 PEP 11:30-12:30 Boxing Taco Tuesday	4 PEP 11:30-12:30 Boxing <b>2:00 – 3:30 PD and Speech Therapy</b>	5 PEP 11:30-12:30 Boxing	6 PEP 11-12 Parkins-Ball <b>1-2:30 Peer Support group for PwP</b>	7 10-11:30 Climbing out of Parkinson's is now \$10/session. <b>11-1 Pickleball4PD</b>
9 PEP 11:30-12:30 Boxing	10 PEP 11:30-12:30 Boxing	11 PEP 11:30-12:30 Boxing <b>1-2 Dance for PD</b> <b>2-3:30 CP group 1</b> <b>4:00 Women with PD teatime</b>	12 PEP 11:30-12:30 Boxing <b>1-2:15 Tremolos</b>	13 PEP 11-12 Parkins-Ball	14 10-11:30 Climbing out of Parkinson's <b>11-1 Pickleball4PD</b>
16 PEP <b>Taiko 10-11</b> 11:30-12:30 Boxing	17 PEP 11:30-12:30 Boxing	18 PEP 11:30-12:30 Boxing <b>1-2 Dance for PD</b> <b>1:30-2:00 CP group 2</b>	19 PEP 11:30-12:30 Boxing <b>1:00 Women with PD luncheon</b>	20 PEP 11-12 Parkins-Ball <b>1-2:30 Peer Support group for PwP</b>	21 10-11:30 Climbing out of Parkinson's <b>11-1 Pickleball4PD</b>
23 PEP <b>10-11 Taiko</b> 11:30-12:30 Boxing	24 PEP 11-12 Voice 11:30-12:30 Boxing	25 11:30-12:30 Boxing <b>1-2 Dance for PD</b> <b>2-3:30 CP group 1</b>	26 PEP 11:30-12:30 Boxing <b>1-2:15 Tremolos</b>	27 PEP 11-12 Parkins-Ball	28 10-11:30 Climbing out of Parkinson's <b>11-1 Pickleball4PD</b>
30 PEP <b>10-11 Taiko</b> 11:30-12:30 Boxing	31 PEP 11-12 Voice 11:30-12:30 Boxing		<b>Note</b> Items in <b>bold</b> type are at no cost to participant.		

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](mailto:williamk@union.edu)

Visit [www.easepd.org](http://www.easepd.org) for more information about the Santa Cruz County Parkinson's Group.

Editor – Audrey Trautwein [AudreyT@EasePD.org](mailto:AudreyT@EasePD.org) Contact editor to unsubscribe.

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