



# Movers and Shakers

October 2019  
Volume 23 No. 10

*Monthly meeting: Wednesday, October 2, 2:00 - 3:30*



## *"Non-Motor PD Symptoms"*

*Salima Brillman, MD, Movement Disorders Specialist*

"There is a wide variety of possible non-motor symptoms of Parkinson's, ranging from physiological effects like trouble swallowing, pain and fatigue, to mental and emotional impacts, such as mood changes, cognitive challenges and anxiety. Just as Parkinson's affects everyone differently, the type, frequency and severity of non-motor symptoms each person experiences vary. Remember, just because something is listed as a non-motor symptom of Parkinson's does not mean you will experience it. Non-motor symptoms also tend to cause more stress and frustration in everyday life than the motor symptoms of Parkinson's. Recognizing and discovering how you can best manage your non-motor symptoms are critical for learning to live well with Parkinson's." (Quotation from the [Davis Phinney Foundation](#).)

Dr. Brillman identifies the fact that no two people have exactly the same disease states, therefore will not have identical therapeutic regimens. She emphasizes the importance of taking the time to meet the specific needs of each person and their family.

She has extensive experience in diagnosing and treating all forms of movement disorders and is proficient in DBS, Duopa and Neurotoxin therapies. She is not only interested in the motor aspects of movement disorders, but the vast non-motor elements that accompany each disease state and recognizes the importance of following those as well.

In her current practice, Dr. Brillman does not contract with third parties such as HMOs or PPOs in an effort to provide medical services without the restrictions they set forth. Dr. Brillman is among the first to offer concierge services for neurodegenerative conditions in the Bay Area. She is excited to have the opportunity to provide exceptional care with easy, direct access to herself.

Dr. Salima Brillman is a board certified neurologist with a fellowship in movement disorders, which include Parkinson's Disease, Atypical Parkinsonism, Drug Induced Parkinsonism, Essential Tremor, Dystonia, Lewy Body Dementia and other Neurodegenerative disorders.

**Location:** Congregational Church of Soquel, 4951 Soquel Dr in Soquel village. Parking and entrance to meeting hall are easiest when approached via Main Street.

*Dots!*

We have gone dotty on our monthly meeting name tags! A blue dot means you filled out a 2019 Contact Form - thank you!

No blue dot means we haven't received your 2019 Contact Form. Contact forms allow you to update of your contact information, indicate interest areas for future meeting topics, your desire to volunteer, and to make a voluntary annual donation.

If you'd like your blue dot, ask greeter for a Contact Form at next meeting. Thanks!

*FUTURE MONTHLY MEETING PROGRAMS:*

November 6      Brian Reedy, Ambassador from the *Davis Phinney Foundation*, will teach us about "Laughter Yoga."

December 4      Holiday Party

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*Save date -*

Monday, November 4. Taiko drumming performance.



*EasePD Survey*

Are we meeting your needs for PD support in Santa Cruz County?

The EasePD Board would like to hear from you! We'd like to better understand whether our existing programs meet the needs of patients and care partners in our community. It'll take no more than 5-8 minutes to complete the survey. Look for an email with a link to the survey on October 6th.

If you receive the monthly newsletter by mail, we'll mail the survey to you with a return envelope.

## *Volunteer of the Month ~*

### *Aura Oslapas*



About three years ago, my husband and I transitioned from weekenders to full time residents of Bonny Doon—in a pastoral setting surrounded by meadows and majestic redwoods--where we enjoy working on the house and in the gardens, and hosting family and friends.

As I explored Santa Cruz, I discovered the monthly PD meetings, and attend whenever my work schedule allows. With Karen Williams encouragement, I joined the Symposium Planning committee, and really enjoyed working with them to put on that awesome event this past March. In September 2018, I started a monthly luncheon for women with PD in our community. We meet at a different restaurant each month to enjoy it's cuisine, share our experiences, and to laugh and work our smiles (lots of facial exercises). And, this past spring I joined the EasePD Board—such a truly dedicated group of Care Partners and PwPs whose hard work is reflected in the size, the activities and the engagement level of this PD community. I also serve on the Board of New Way Homes, a unique investment fund focused on creating the most need types of housing from Santa Cruz to Salinas, and am an Arts Commissioner for Santa Cruz County.

My Parkinson's journey began in 2011, with a tremor in my left leg, and rigidity in my back. I was quite sure it was Parkinson's because my father lived with PD for 10 years. I was finally diagnosed at 54, while commuting to Minneapolis most weeks for a demanding corporate job--yikes! I never revealed my condition, and left 2 years later to refocus, and to incorporate some complementary approaches to PD that I'd read about but just couldn't fully embrace in my crazy lifestyle: Qigong, meditation, dietary changes, exercise, etc. Not only did I feel better, but I was able to reduce my medications.

Although I made peace with my Parkinson's journey years ago, the daily roller coaster ride would get me down---so I channeled my frustrations and my designer's need to 'make things better' for people towards creating something to help us. The result is a mobile app called StrivePD.

### *StrivePD*

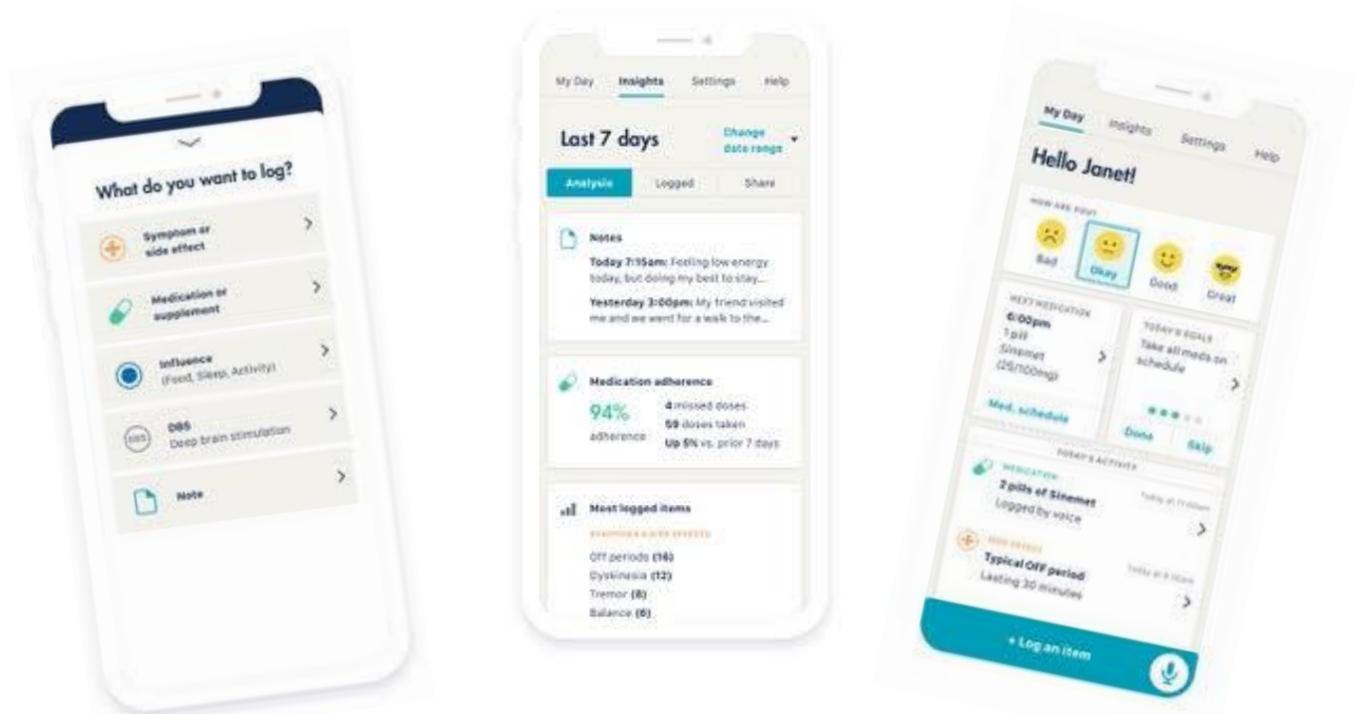
Being highly sensitive to medications, I tried all sorts of worksheets, spreadsheets, and generic medication apps to track my side effects and learn from any patterns. Conversations and testing with fellow PwPs and Movement Disorder Specialists confirmed my suspicion that many others could benefit from a better way to manage and learn from the daily interplay of symptoms, medications, side effects and other influences that make us feel better or worse...so I decided to create a mobile app to support our needs.

This month, after 2 years of development, 3 pilot programs (including testers from this PD community), and an acquisition, we launched StrivePD. With this app, you can

- set up a medication schedule, and be reminded when to take your meds
- adjust your day's schedule if you take your levodopa earlier or later than normal
- log and track symptoms and side effects
- log and track influences such as exercise, sleep and other triggers, such as stress
- log and track DBS settings and get reminders to recharge your battery
- log and track your mood
- set and check off daily goals
- receive weekly or monthly printable reports
- view everything you've logged
- see visual patterns of when your OFF periods occur

We've seen different ways PwP use the app: from those who “set it and forget it” until their med schedule or dosage changes to those who are “all-in” logging and tracking everything to do with their wellbeing---PD and beyond. Care givers have found StrivePD helpful for setting medication schedules and reminders, tracking what makes their patients feel better or worse, and for taking notes (you can also record notes by voice).

Check out the website at [strivePD.com](http://strivePD.com) which includes a link to the Apple App Store, where you can download the app (it's free), and a detailed User Guide to get you started. Try it out if you have an iPhone or iPad (though not optimized for the iPad). If you find it useful, spread the news, and direct your PD friends to [strivePD.com](http://strivePD.com). Let me know what you think!            Aura



## *Caring Partners Corner*



### *Support group*

This group was the brainchild of Ginger, Alex, and myself (Audrey) about 4 years ago. Though it started off small, we have steady grown in numbers and come to treasure our times together. We learn and gain strength from each other, sharing both laughter and tears.

Now I'm running out of space for chairs in my living room so, it's time to begin a second group. It will be same as existing group, but on a different day -- with a new mix of members and more ability to participate with it being a smaller group.

### **New group –**

When: **Monday, November 4, 2:00 – 3:30** (1<sup>st</sup> Monday of each month)

Location: 119 3<sup>rd</sup> Avenue in Santa Cruz

Members of original group can switch over to this new group if they wish. Because of the cohesiveness which develops within a group, we ask that you not switch back and forth between the two. Contact Audrey to sign up for Monday group. [atrautwein@gmail.com](mailto:atrautwein@gmail.com)

### **Original group – open to continuing members only**

When: **Wed, October 16, 2:00 – 3:30** (3<sup>rd</sup> Wednesday of each month)

Audrey will be out of town, and October meeting location is undecided. An email will be sent to group members once we finalize who will be hosting. For more info, contact Ginger at [gingeranderson@sbcglobal.net](mailto:gingeranderson@sbcglobal.net).

### *Care Partners Walking group*

We will meet at Seascape Park and then walk together along the cliffs until the path goes down to the beach. Then, back up. **Wed, Oct 9, 1:00 – 3:30**

Sign up for Alex's email list - [alex.florimonte@gmail.com](mailto:alex.florimonte@gmail.com)

### *Del Mar Caregivers in Santa Cruz*

They offer services for family caregivers of adults living with impairments such as PD.

Care planning

Counseling and Support Groups

Education Workshops Trainings

Information and Referral

Legal and Financial Consultation

Respite Care

Learn more at <https://www.delmarcaregiver.org/>

## *Women with PD Luncheon*

The next Women's lunch will be **Wednesday, October 16th at 1:30**, at Gabriella Cafe  
If interested in joining in, contact Aura at [auraoslapas@gmail.com](mailto:auraoslapas@gmail.com) or (415) 527-7855.

### *Peer - Support Counseling Group for Those with Parkinson's*

A gathering of PwP to share the experience of having PD, problem solving, improving interpersonal skills and mutual support for those with Parkinson's. A wonderful way to have meaningful conversations with those who understand your issues.

Group meets on Fridays **October 4, 18 from 1:00 to 2:30**. David Zimmerman co-leads October 18 meeting. **Meetings will be in new location, beginning Oct 4 -- the Kenny Room at the Episcopal Church of St John, 125 Canterbury, Aptos.** Contact Mavel Armijo to RSVP: 462- 9415

## *Pool at Fast Eddy's*

**Wednesday October 23, from 3 – 5.**

*Fast Eddy's* is a pool hall located at 4300 Capitola Road (Next to Dharma's restaurant). Cost is \$12 per hour/table. (About \$5 per person total.) Care partners welcome.

No experience, nor steady hands required. Only the desire to have a good time!

Contact [heleng@baymoon.com](mailto:heleng@baymoon.com) or Robert and Helen at 426-1972.



## *Tremolos at Westwind*

The Tremolos traveled to Westwind Memory Care to sing for residents, including some members of our Parkinson's community. The audience responded warmly to their uplifting music and spirit.

Join them in singing cheerful songs. No need to have a good singing voice. It's about having fun, making friends, and exercising voices.

**Thursday October 3, 10, 17, 24.  
1:00-2:30**

St John's Episcopal Church 125 Canterbury Dr. Aptos.  
More info: Call Julie or Barry at 688-0888 or 239-5286.





## *Parkin's~Ball*

Exercise outdoors while enjoying the sand beneath your feet, the smell of the ocean air, the sound of the waves lapping or pounding on the shore, and the support of others with Parkinson's. Each week, students work on communication and coordination skills through learning basic volleyball. Fun drills and games

enhance the weekly classes. This class is designed for people with Parkinson's.

Contact Liz for more information or to attend class. [lizzyfowler@aol.com](mailto:lizzyfowler@aol.com)

Parkins~Ball is held 10 to 11 am Monday mornings October through December 6, at 3rd Ave Beach, Santa Cruz. Cost is \$10.00 per session

*Hope to see you at the beach! Liz*

## *Rock Steady Boxing for those with Parkinson's*

The Santa Cruz Boxing and Martial Arts gym offers *Rock Steady Boxing* classes. **Tues & Thurs from 11:30 to 1:00. Monday & Weds from 11:30 to 12:30.**

Cost is \$150/month for classes and gym membership. Gym located at 208 Mount Herman Rd in Scotts Valley. Call Rick Hill, a member of our group, for information. 818-6599

## *DANCE FOR PD*

Moving to music is a wonderful way to get exercise while having a good time.

Motion Pacific Studio, 131 Front Street in Santa Cruz, on Wed **Sept 11, 18, 25 1-2:15.**

Classes are free to participants (PwP and partners), thanks to a grant from ComForCare.

For information, write Damara Vita Ganley, [wedanceforparkinsons@gmail.com](mailto:wedanceforparkinsons@gmail.com)

or, see <http://danceforparkinsons.org>

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.

That said, the Parkinson's oriented activities listed above are offered by businesses and others in our community. We appreciate their commitment to serve our PD community. Participate in activities based upon your ability to do so safely. Check with your physician if uncertain.

General questions about the Parkinson's Community and monthly meeting programs? Contact [President@easepd.org](mailto:President@easepd.org)

Visit [www.easepd.org](http://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.*

# October 2019

For details, see Movers & Shakers newsletter at EASEPD.org, or in your email.



Monday	Tuesday	Wednesday	Thursday	Friday
	1	2	3	4
	10-10:50 PEP PD3 1130-1 RSB 1-1:50 PEP PD2	11 PEP PD 1, aquatic 11:30-12:30 RSB <b>2-3:30 Main Meeting, Non-motor Symptoms, Dr. Salima Brillman</b>	11:30-1 RSB <b>1-2:30 Tremolos</b>	<b>1-2:30 PwP Peer support</b>
7	8	9	10	11
10-11 PB <b>10-11 New Taiko</b> <b>11:15- 12:15 Continuing Taiko</b> 11:30-12:30 RSB	10-10:50 PEP PD3 1130-1 RSB 1-1:50 PEP PD2	11 PEP PD 1, aquatic 11:30-12:30 RSB <b>1-2:15 Dance for PD</b> <b>1:30-3:00 CP walk at Seascape</b>	10-10:50 PEP PD3 11:30-1 RSB <b>1-2:30 Tremolos</b>	
14	15	16	17	18
10-11 PB <b>10-11 New Taiko</b> <b>11:15- 12:15 Continuing Taiko</b> 11:30-12:30 RSB	10-10:50 PEP PD3 1130-1 RSB 1-1:50 PEP PD2	11 PEP PD1, aquatic 11:30-12:30 RSB <b>1-2:15 Dance for PD</b> <b>1:30 Women w/PD lunch at Gabriella Cafe *</b> <b>2-3:30 CP group</b>	<del>Vets w/ PD breakfast</del> 11:30-1 RSB <b>1-2:30 Tremolos</b>	<b>1-2:30 PwP Peer support with Zimmerman</b>
21	22	23	24	25
10-11 PB <b>10-11 New Taiko</b> <b>11:15- 12:15 Continuing Taiko</b> 11:30-12:30 RSB	10-10:50 PEP PD3 1130-1 RSB 1-1:50 PEP PD2	11 PEP PD 1, aquatic 11:30-12:30 RSB <b>1-2:15 Dance for PD</b> 3:00-5:00 Pool	11:30-1 RSB <b>1-2:30 Tremolos</b>	
28	29	30	31	
10-11 PB <b>10-11 New Taiko</b> <b>11:15-12:15 Continuing Taiko</b> 11:30-12:30 RSB	10-10:50 PEP PD3 1130-1 RSB 1-1:50 PEP PD2	11 PEP PD 1, aquatic 11:30-12:30 RSB <b>1-2:15 Dance for PD</b>	11:30-1 RSB <del><b>1-2:30 Tremolos</b></del>	

**Bolded** items are no cost

\* Cost for your meal

PwP = Person with Parkinson's  
PEP = Dignity Health PEP classes

CP = Care Partners    PB = Parkin's~Ball  
RSB = Rock Steady Boxing