

## **HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER February 2019**



### **February 2019 Activities on Hawai'i Island**

**Hilo PD Support Group**-- February 22 from 2-4 pm at Hawaii County ADRC. Special topic & speaker to be determined. Please contact the ADRC or Fran Calvert at [fcalvert@hawaiiantel.net](mailto:fcalvert@hawaiiantel.net) for more information

**Hilo PD Exercise**—every Wednesday from 9:30-10:30 am at the Hilo YMCA. Contact the Y at 935-3721 for more information.

**Rock Steady Boxing**--every Monday & Friday from 8:30-9:30 am in Hilo at the Waikeae Recreation Center. They may meet on February 18<sup>th</sup>. Current participants will be contacted or contact Marlene Goodwin at [buckup1952@gmail.com](mailto:buckup1952@gmail.com) for more information.

**Kona PD Support Group**—Debra Dellinger from the Southeast Parkinson's Disease, Education, and Clinical Centers, located in Richmond Virginia, is scheduled to attend and provide an update on the latest research and participate in a Q&A discussion including such topics as medications and non-motor symptoms. Contact Tom St. John at [tomstjohn1@gmail.com](mailto:tomstjohn1@gmail.com) or 925-785-609 for the specifics of date, time and location of the meeting.

**REMINDER!! February 13<sup>th</sup> from 12:30-3 PM: A Focus on Relationships at Tutu's House** with healthy lunch salads provided. Looking forward to seeing PWP's with their care partners, close friends, adult children—anyone with whom you have a close relationship from all 3 PD Support Groups. Potluck pupus or dessert if can, but just come!! Car pooling encouraged. This is an opportunity for members of the Hawai'i Island Parkinson's community to come together, share a community meal and talk story about the changing nature of relationships with Parkinson's. Special guests from Honolulu—Pat Bemis, HPA Board member (& care partner) with husband Gardner.

**Kona Dance for PD**—February 5<sup>th</sup> through March 5<sup>th</sup>, Tuesdays @ **10-11:15 am**. Classes are held at Kona Dance and Performing Arts, 81-973 Haleki'i St, Kealahou. Drop Ins are encouraged and welcome. No dance experience necessary. Caregivers/Family/Friends are welcome to join in the fun! Donation based. Classes are taught by Dr. Marie Snyder who is a Stanley J Wertheimer Fellow of Dance for PD®, a program of the Mark Morris Dance Group. The class empowers those afflicted with Parkinson's disease, their partners, their caregivers, and friends to enjoy movement, music and dance. Participants will explore elements of modern dance, ballet, social dancing and repertory from various choreography in an enjoyable, non-pressured environment. The classes are inclusive of all abilities. For more information please contact [marie@isnyders.com](mailto:marie@isnyders.com) or call (609) 577 2349.



Dance for PD

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### **Tutu's House**

Every Friday at 9:30 am-- Chair Yoga  
February 6--Caregiving conversations at 11am  
February 7 and 14-- Zumba Gold  
February 11- -Tai Chi/Chi Kung at 1:30pm

See full schedule of programs/activities by  
going Tutu's House.org

### **January 9<sup>th</sup> Waimea PD Support Group Meeting with special guest, Dr. Bill Code, MD**

Bill, as he prefers to be called, from Vancouver Island joined the January meeting and encouraged lots of questions as he described some of the key parts of his recent book of interest to PWP's: "Solving the Brain Puzzle." Besides being a physician for 40 years, he was diagnosed with the neurological condition, Multiple Sclerosis (MS) over 20 years ago, and many of his words of wisdom are based on a combination of his extensive research and his own experiences dealing with his MS symptoms.

Twenty-two years ago, he began to experience symptoms that interfered with his general practice. After a period of frustration, he was diagnosed with MS. After some time he had to end his medical career as an anesthesiologist, but he has continued private practice as a pain specialist.

It's been his personal journey to find ways to deal effectively with his MS. This includes extensive research and the writing of books relating to the wide scope of neurological diseases including Parkinson's. His research led him to the Integrated Medicine approach. Much of which is included in his new book "Solving the Brain Puzzle."

Dr. Code briefly summarized his background and personal experiences. This led to a lively Q&A discussion covering a variety of Parkinson's challenges including the importance of recognizing the gut brain

connection and having a healthy diet, the positives and negatives of prescription drugs, helpful supplements, dealing with sleep issues, and the critical importance of regular exercise.

"Solving the Brain Puzzle" covers a wide scope of topics in words intended to be a complete guide to achieving brain health. With Bill's permission, you can receive an electronic PDF copy of the book by contacting Joel Cohen at [jcohen8@hawaii.rr.com](mailto:jcohen8@hawaii.rr.com).



1/9/19 Waimea PD Support Group Meeting

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### **Lindsey Sutton's Yoga Breathing Exercises**

The key to breathing better is to make it a daily practice or routine. Try out the following practices each daily (morning and evening) for the next 3 weeks and see if it helps improve your breathing! If you notice better breathing after the 3 weeks, continue these practices as part of your health routine on a regular basis – such as daily or every other day.

#### Belly Breathing – Practice #1

This practice is to help with deeper breathing and can be used for relaxing the body and mind. Try to breathe through the nose if possible for both the inhale and exhale.

1. Sit comfortable with the spine relatively aligned in a neutral position (avoid slouching). Lying down in a neutral position is also possible for this exercise.
2. Place a hand over the heart and the other hand over the navel.
3. Breathe easily (comfortable for you) and see if you can count up to 5 seconds on both the inhale and exhale. Practice a 5 second inhale and 5 second exhale. (Work up to this if not possible just yet – trying out a 3 or 4 second count).
4. Now begin to notice that there is more movement in the belly on both the inhale and exhale rather than at the heart/chest. When you inhale the belly needs to rise/expand and when you exhale the belly needs to draw in slightly/contract.
5. Time yourself for one minute again, practicing the 5 second inhale and 5 second exhale as well as expanding the belly on the inhale and contracting/drawing the belly in on the exhale.
6. Remove your hands, and once again practice a 5 second inhale and 5 second exhale for one minute while feeling with your body (even try closing your eyes so you don't rely on seeing this) the belly rise on the inhale and the belly draw in on the exhale.



**Lindsey Sutton**

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### **Michael J Fox 3<sup>rd</sup> Thursday Webinars**

The Michael J. Fox 3<sup>rd</sup> Thursday webinars provide a wealth of information that is helpful to people with Parkinson's. You can easily register to tune in on the current and previously presented panel discussions by going to the MJF 3<sup>rd</sup> Thursday website. These monthly webinars are available for CME credit for practicing health care professionals.

**The January 17** webinar focused on gait and balance issues as Parkinson's progresses including the ever-present danger of falling in 70% of the PD population. It included commentary on how gait and balance challenges can be treated and new therapies that are being developed.

A discussion on Deep Brain Stimulation and Focused Ultrasound is on tap for the up and coming **February 21** webinar beginning at 7am HST. You can participate with a question by registering prior to the program.

The panelists will discuss who should consider these treatments and when, and what someone may expect after surgery.

### **Why You Are Important**

**By Leimomi Shearer (Hilo PD Support Group)**

Aloha

I was diagnosed with PD in March 2018. I noticed tremors in my left hand in November of 2016 but was busy taking care of my Mom until her passing in 2017.

Going through the grieving process was challenging and I still didn't "take care" of me. Finally after months of being depressed, and tremors escalating, I googled "tremors" and information led to PD.

I finally went to my PCP, got a referral to the neurologist and basically asked him if there was a test to determine a PD diagnosis. The next referral proved positive.

So now I knew, so now, what do I do? Further research on the internet led me to you, the PD Support Group.

From day 1, my daughter and I felt comfortable, informed, empowered and cared for. My medical team didn't know this Support Group existed. When surfing the web and reading your newsletter on line, I knew this was where I needed to be. This is the resource I needed.

When I first walked into the room, I felt comfortable, warm, and the smiles and welcome I received opened the door to learning more about PD from you.

Mahalo. Each of you are important. Each of you are an Ambassador of Aloha. Each of you are a ray of hope to someone else.

Mahalo.



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### **From a Person with PD's Perspective**

By Joel Cohen



Valentine's Day is approaching. Is it my time to truly recognize what is the highest priority and most important part of my life? Of course, as you would expect, my highest priority is having a loving relationship with my wife, Phyllis.

Saying this, having PD is challenging to a healthy relationship. This is not as simple and easy as I want for us. It is important to stay the course of continually being conscious of our love, sharing, and mutual support. Excuses can come easily due to my physical and emotional challenges. So, it is really tough to say this out loud and know for certainty that I have to walk my talk each day

I have learned over my long period of dealing with PD that my life and its challenges are shared with Phyllis. It's so easy for everything to become complicated and overwhelming! The list for us includes: common symptoms of sleeplessness, lack of mobility, and a host of aches and pains. Add to the list, the need for many of us to travel to Honolulu for medical treatment. All of these challenges can lead to anxiety, frustration, and if not careful...misunderstanding, and at least temporary breakdowns in communication. So, if my relationship with my beloved is so important, what do I need to be conscious of today, tomorrow, and the unforeseeable future?

First and foremost, I need to slow down and be in tune with my limitations. That is hard for me, and I hazard to say, for most men my age. Impulsive behavior is a symptom of PD. Why does it take me so long to get this and that done? I need to get this column completed. The computer doesn't seem to be working right. Can you help me now!

Life is an ongoing changing process. Adjustments are needed by everyone as we grow older. Having PD just adds to the equation. So, without being taken care of 24/7 and feeling like a victim of circumstance, asking for help when needed in a kind way without demands, is best.

If this commentary is about healthy relationships, it's also important for me to recognize the challenges of my partner who has her own personal life obstacles to hurdle in addition to mine.

So, there are some simple words of wisdom that I need to remember each day. "I recognize that my partnership with Phyllis goes both ways and requires to the best of my effort, mutual support, understanding, and the utmost of love that we can share. Life is good, and I am grateful for what I have."

### **Newsletter Submissions**

This is **YOUR** newsletter!! This Newsletter will not be sustainable without your participation. We **NEED** your personal stories about your PD experiences (e.g. affects from a medication or supplement, how certain forms of exercise has benefited you, how you've recognized and possibly, overcome, a challenge, etc.) – from **YOUR** perspective, whether you're a PWP, a care partner, a member of the medical community, or friends/family!! Please email your stories to Joel Cohen at [jcohen8@hawaii.rr.com](mailto:jcohen8@hawaii.rr.com) and Phyllis Tarail at [Phyllis.tarail@gmail.com](mailto:Phyllis.tarail@gmail.com) by **February 22** for inclusion in the March/April edition. Mahalo to Leimomi for her article in this month's edition.

Joel Cohen & Phyllis Tarail, writers/editors