

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER January 2019

We start out this newsletter wishing everyone as much joy and happiness as possible in the coming year and quoting an icon of college basketball history with his words of wisdom.

"Things turn out best for the people who make the best of the way things turn out".

John Wooden

January 2019 Activities on Hawai'i Island

January 9 1-3:00 pm Waimea PD Support Group talk story at Tutu's House. In addition to our usual format, our special guest participant will be Dr. Bill Code, MD, who will speak briefly about parts of his new book, "Solving The Brain Puzzle." Bill, who has MS, has done extensive research on neurological disorders and has tried numerous therapies, some of which he feels may be helpful to PWP's.

Multiple interesting things happening at Tutu's House this month:

January 2 11am-noon: Caregiving Conversations with Karyn Clay.

January 10 5:30-7pm: A talk on Health and Healing with Dr. Bill Code, MD.

Every Monday 1:30-2:30 pm (Except January 21): Senior Fit Club--Chair movement on DVD

Every Friday 9:30-10:15am(except January 25): Chair Yoga with Kit Hill

Thursday, January 17 and 31, 10:30-11 am: Zumba Gold with Renee Moninaka

Saturday, January 19, 10:30-noon: Harmony for Health with Richard Adoradio. Singing for fun and all abilities

January 25 from 2-4 pm Hilo PD Support Group at Hawaii County ADRC. A video from the recent Parkinson's Foundation Caregiver Conference will be shown. Please contact the ADRC or Fran Calvert at 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 Waiakea Recreation Center. Contact Marlene Goodwin at buckup1952@gmail.com for more information.

Kona PD Support Group meets at the West Hawai'i Community Health Center on Kuakini. Date for January to be determined.

Dance for PD restarts in Kona on January 8, 10am at Kona Dance and Performing Arts in Kealahou. Contact Tom St. John at tomstjohn1@gmail.com or 925-785-609

Rock Steady Boxing Hilo



SAVE THE DATE!
Wednesday, February 13 12:30-3PM:

Special focus will be on Relationships at the Waimea PD Support Group meeting just in time for Valentine's Day. Inviting PWP's, their care partners, and family members from all over the Island to join together for lunch and talk story. Special guest will be Care Partner extraordinaire and HPA Board member, Pat Bemis. Please bring a pupu or dessert to share. The Waimea group will provide a healthy main course lunch.

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Sleeping Well With PD

Michael J. Fox December webinar
Summary by Joel Cohen

Getting a good night's sleep prior to facing the next day is a very common challenge with Parkinson's. It is important to clearly define your sleep issues and have open discussion with your treating physician knowing that your PD may make things more complicated than other patients that they see.

Originally broadcast in October, 2017, the webinar panel discussion, moderated by Dave Iverson, included PWP Michael Sweet Sr., Dr. Carlos Singer, Professor of Neurology at the University of Miami; and Dr. Alexander Videnovic, Associate Professor of Neurology at Harvard Medical School.

General topics discussed included sleep disorders especially associated with the variety of symptoms associated with PD including: daytime sleepiness, pain and rigidity issues, acting out dreams, multiple trips to the bathroom, and bringing feelings of anxiety from past and present events to bed with you.

Use of medications can become complicated especially as your PD symptoms increase and age and reduced capabilities become factors. Changes in the dosage and timing of taking your meds may be necessary.

Dr. Singer suggested that low levels of dopamine during the night might cause your tank to run low and contribute to disruptive sleep. The duration between taking your last levodopa/carbidopa pill and the next morning could be too long. Anxiety may also be a symptom of low dopamine. You may want to discuss the use of dopamine agonists as a possible cause of sleep issues with your doctor.

Dr. Videnovic pointed out the need for lifestyle changes including ensuring adequate exercise and a healthy diet. Saying this, exercising earlier, well before bedtime is best. Liquids, especially those containing alcohol or caffeine, and drinking large amounts of water before bed, are to be avoided.

Summarizing Michael's remarks relating to what he has learned over time, is to go to bed as relaxed as possible. Exercise and having a healthy lifestyle is important, and being patient with yourself knowing that sleep issues will continue to some extent.

The next MJF 3rd Thursday webinar is scheduled for January 17. The topic of discussion is "Addressing gut and balance issues with PD." You can participate with your questions for the 7am start time by registering at the easy to find MJF webinar site <http://www.michaeljfox.org>, or tune in later. Past webinars are also found at the site.

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Breathe Better to Live Better

by Lindsey Sutton, PhD

HPA Board of Director Secretary and Exercise
Committee Chair

Most of us have likely heard or read information about the importance of breathing for our daily health. And, if we haven't yet, it is time to integrate this knowledge into our everyday health routine. Taking deeper, slower breaths, and breathing into the body rather than just into the top of the chest will improve overall bio-psycho-social health (a fancy way these days of saying mind-body health). This is the case, no matter what our health circumstances are. However, if we don't normally breathe deeply or if we find ourselves taking shallow breaths, it may feel challenging to take in a deep breath. Practicing over time though will help to strengthen the muscles in the body that support breathing. This will help you draw O₂ into the lower parts of the lungs and get the old air, CO₂, out. In this way, breathing better creates a more efficient exchange of O₂ and CO₂, and overall more effectively revitalizes and replenishes the body's organs and tissues.

Of course, there is an abundance of research literature studying the many ways better breathing improves health, but we can actually be our own research case study. Take a moment to pause here and notice how you have been breathing while reading this newsletter. When you breathe, can you see the collarbone area rise or do you feel tension in your shoulders? Even if we already know how to breathe better, we still may forget throughout our day to practice a better breath. So, again, pause and take a fuller breath. Does your body feel better, or did it feel stressful to breathe deeper? Did you breathe through the mouth or the nose? Sometimes when we focus on breathing deeper it may feel awkward or difficult.

Or if we are out of practice, breathing deeper can contribute to tension and stress both in the body and in the mind. Also, if we breathe through the mouth, we are not using the most efficient pathways to breathe. Breathing in and out through the nose (especially in) cleans and moistens the air we take in as well as more effectively uses our body's respiratory system.

Lindsey Sutton



The February PD Newsletter will include some of Lindsey's breathing exercises.

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Parkinson's Foundation Caregivers' Summit December 1, 2018 By Fran Calvert

The Summit was a wonderful event with speakers who addressed many issues that come up for us as caregivers. Communication is the key! The main talks were on *Collaborative Caregiving*, *Intimacy and PD*, and *Building Stronger Caregiving Partnerships Through Better Communication*.

You can access these talks through the link below. The Hilo group is going to watch one of the videos at our January meeting.

<https://event.netbriefings.com/event/parkinson/Archives/caregiversummit/>

We learned about the "Aware in Care" kit which you can order at no charge from the Parkinson's Foundation. This is a kit which you take to the hospital should you have to go for any reason. It lists your medications and has cards to suggest to your nurses, doctors, etc. how important it is for you to receive your PD medications and on time. Apparently some folk with PD have had serious setbacks when they were not given their meds when in hospital for other reasons. We encourage everyone to order one!

This was our best Christmas present ever. A delightful labradoodle yearling pup to work with for advanced training as a service dog. It's Glen and I that need the training now. The dog is quite talented.

Fran & Glen with Service Dog & Friend



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From a Person With PD's Perspective

By Joel Cohen

It's a new year, and my resolution is to appreciate and enjoy life to the utmost. Saying this, I need to be "real" about my everyday challenges. Some will literally continue on a daily basis. Some come and go depending on my discipline to adhere to my vow to walking my talk regarding lifestyle changes, and other challenges are just plain unpredictable as I continue to get older.

So, being "real" let me talk about some of the PD challenges that I, and likely others, face and continue to try and figure out. Being as open and vulnerable as possible--enough of the intellectual approach as is clearly represented in this newsletter's efforts to educate and inform. There are subjects that just need to be discussed in a personal way, hopefully that hits home for the readers.

I'll somewhat reluctantly start with one of the least discussed challenge--constipation. Have I ingested enough fiber into my gut today? Can I concede to the fact that I need to take stool softeners prior to bedtime to get things going the next day?

Is it possible, to sleep through the night without having to get up to go to the bathroom somewhat bewildered and a bit unbalanced?

Do I recognize my limitations and abilities to deal with stress while writing this column, and get up and stretch periodically?

Am I honest when my wife asks me if I am falling asleep in my chair while both of us are watching what is a truly hysterical comedy in the early evening?

How many times do others ask me to speak up and be clear when trying to get a point across?

And most of all, in an effort to protect my personal desired image, do I mask my limitations by denying that they are happening?

Well, I guess that some changes are needed for me to be real about my challenges and maybe even accept them as real in the coming year--hopefully, years. I'll do what I need to do, knowing that acknowledgement works best for me and hopefully for others too.

Davis Phinney Foundation

The Davis Phinney Foundation is an icon of the worldwide Parkinson's community. Please contact this newsletter editor, Joel Cohen at jcohen8@hawaii.rr.com, if you wish to order a copy of "Every Victory Counts" manual. It contains all the essential information and inspiration for a lifetime of wellness with Parkinson's Disease.

You will also be able to receive valuable information immediately by going to <http://www.davisphinneyfoundation.org/blog/> and you can sign up for receiving periodic messages by completing the form at the bottom of the page.

Parkinson's News Today

Readers of this newsletter can find the latest news regarding research relating to Parkinson's by going to the Parkinson's News Today website at <http://www.parkinsonsnewstoday.com>. You will be able to receive regular updates delivered to your e-mail. Highly recommended!

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PD Celebrity of the Month



Jesse Jackson

The Rev. Jesse Jackson, age 77, only revealed in late November, 2017 that he had been diagnosed with Parkinson's Disease in 2015 after having suffered symptoms for some time. As he stated in 2017, "Recognition of the effects of this disease on me has been painful, and I have been slow to grasp the gravity of it." He says that he is doing all that he can to slow the progression through physical therapy and life style changes. "This diagnosis is personal but it is more than that. It is an opportunity for me to use my voice to help in finding a cure for a disease that afflicts 7 to 10 million worldwide."

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 and Phyllis Tarail at Phyllis.tarail@gmail.com by **January 25** for inclusion in the January edition.

Joel Cohen & Phyllis Tarail, writers/editors