

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER May/June 2018

Important May/June Activities on Hawai'i Island

May 14 & June 11 from 1:30-2:30 Tai Chi/Chi Kung with Maddy (Madeline Sofranac DPT). Come join people from the community at Tutu's House. Take a seat and come away feeling positive and optimistic the rest of the day.

May 7 & 28; June 4, 18, & 25 (Mondays) from 1:30-2:30 PD Exercise with Maddy at the Allstar Crossfit Gym next to Tutu's House—same routine every class in the month with a mix of BIG & PWR moves, Tai Chi/Boxing and a version of Dance for PD. Minimal cost--\$5 or more per class or pay \$20-\$40 per month. *We need more attendees to keep these classes going, so please join us on Mondays!*

May 9 from 1-3:00 Waimea PD Support Group talk story at Tutu's House. Madeline Sofranac (Maddy) will be leading this month's talk story while Joel & Phyllis are traveling off Island. Maddy will share her expertise on how to improve your PD symptoms and what classes she offers.

Mahalo nui to Lorraine and Tutu's House for hosting our support group for the past 4 years.

May 25, from 2-5 pm Hilo PD Support Group at Hawaii County ADRC. Yoga for PD teacher and HPA Board member, Lindsey Sutton will be the speaker at the May meeting. Speaker at the **June 29** meeting will be past HPA Board President & physical therapist, Kevin Lockette who will share his knowledge about PD and exercise. Please contact 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.

WHAT!!!???

by Phyllis Tarail

So, there are 2 kinds of WHAT!!!?? The first is you telling your PWP to speak up, that you can't hear their super quiet voice. The second is if you're a PWP whose family & friends keep having to repeat themselves a lot, talk much louder than before, or come closer to you when they are speaking to you. If the second is you, then you are experiencing some degree of hearing loss. And, if you're the care partner who lives with a PWP that keeps saying WHAT!!!?? to you, then you, too, are dealing with the frustration of living with someone who is getting farther and farther out of communication with you.

Hearing loss can easily lead to serious cognitive issues, including dementia, for the person losing their hearing, as well as serious relationship issues between you and your partner. For the sake of your emotional health, please do yourself and your loved ones a big favor and have your hearing checked if it's at all suggested to you that you are missing out on some key communications.

If the audiologist advises you that hearing aids would benefit you, then please take their advice. And, after you receive your hearing aids, give them a fair chance to help you. It may take a month, with multiple tweaks, for you to adjust to hearing really well for the first time in a long time. If you are patient, you will find your world, AND your relationships, greatly enhanced. And maybe, just maybe, you'll start saying the word "WHAT!!!???" a lot less often.

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER May/June 2018

Hawaii Parkinson's Association Symposium, April 28

Joel & I were fortunate to attend this year's symposium in Honolulu. Keynote speaker was Amy Lower, Educational Coordinator and instructor at UH Manoa's Department of Communication Sciences and Disorders and speech and language pathologist. Her presentation entitled "Keeping Connected: Maintaining Meaningful Communication with PD" was very informative. Amy opened her talk listing the common speech changes in PWP: reduced loudness, hoarseness, imprecise articulation, unsteady rate, monotone, masked face. She then described how we physically create speech: via respiration, phonation, resonance, and articulation.

A panel consisting of 4 neurologists, Drs Webb Ross, Mel Yee, Michiko Bruno, and Stuart Pang plus 2 care givers, Pat Bemis, and Mel Hayase each spoke briefly on prepared topics, including research and clinical trials, how to prepare for your medical appointment, and quality of life issues. They then answered a range of questions that attendees had sent in advance and also from the floor. Soon you will be able to watch a video of the whole symposium on the HPA website, www.parkinsonshawaii.org and we highly recommend that you check it out.

HPA Award to Rep. Jarrett Keohokalole



Amy Lower



HPA Panel



L-R, Pat Bemis, Amy Lower, Webb Ross, Mel Yee, Michiko Bruno, Stuart Pang, Mel Hayase

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER May/June 2018

From PD Patient's Perspective

by Joel Cohen

There are days that are memorable. Attending the Hawaii Parkinson's Association annual symposium is likely to be one for me. So, I feel it's important to share my experience in a personal way.

Getting good sleep the night before traveling is a challenge for me. However, I really looked forward to the day ahead in Honolulu this time. So, with a positive eagerness to proceed and a nudge from wife Phyllis, I opened my eyes and in a pre-programmed manner, rolled out of bed, took my first in the morning pills (including my ever important Sinemet), splashed some water on my face, brushed my teeth, slowly but methodically climbed into my clothes, checked myself out in the mirror, and was ready to get out door at Phyllis' predetermined time for a 50 minute pre-sunrise drive to the Kona Airport.

Worry, unfortunately, is a regular symptom of my Parkinson's. It's going to be a tight squeeze between the Hawaiian Airlines arrival time in Honolulu and being in time for the first symposium speaker. Well, fortunately, the full plane arrives prior to the scheduled time and touches down 10 minutes early. So just a brisk walk, rather than a run, to catch a taxi ride to the Aloha Tower Marketplace meeting location. Good start to an anticipated anxiety-free day of learning and subsequent meeting with my fellow HPA Board members for lunch, socializing, and scheduled discussion about the organization's future.

The Aloha Tower Marketplace meeting room is set up for 200 people. The first thing in mind is to find our reserved seats up front—fortunately helped in by fellow Board member, Pat Bemis. After taking a short breath to settle in, I turn around to look toward the entrance and see the remaining attendees entering. Many of them are in wheel chairs or using walkers moving slowly,

and deliberately with their dedicated caregivers assisting them. I say to myself, "This requires a whole lot of courage and personal strength for them to come to this event." I am so fortunate and blessed to still have my mobility relatively intact with my caregiver sitting beside me. This moment of recognition was reflected in what happened later in the morning.

The formal program begins with welcoming remarks by HPA president Jerry Boster, and includes an excellent presentation on communication and the ever-common voice challenges faced by people with PD by UHM speech pathologist instructor Amy Lower. All goes well, and now it's break time with a trip to the restroom prior to the second part of the program.

Phyllis tells me that it is not all that far away and gives me directions. "First go right at the corner. Go up a ways and look to the left. You will see the restroom sign." I easily find the restroom. There is a bit of a crowd including "Parkies" who obviously had much more difficulty getting there. I do my business and head back to the meeting room. So, it's just retracing my steps. Let's see, I went left. So, now I go right and so on. Five minutes later, moving on what I thought was the pathway back to ground zero, I actually was not. Worse yet, I'm finding myself confused, literally lost, frustrated, and honestly, a bit scared. On a list of symptoms that I have experienced literally years ago, there has been nothing worse than feeling this way.

After 10 minutes of wandering, I eventually found my way back to the original starting point—shaken, and with an emotional sense of relief. Phyllis finally found me after hunting for me for quite awhile, so she also experienced a sense of relief.

So what happened? The early wakeup, travel to the airport, and excitement related to attending the event, accepted at the time

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER May/June 2018

proved to be stressful. Plus, I'm not the young stud physically or mentally that I once was. And likely much more important, not recognizing that I had gone almost 6 hours without taking my regular dosage of levodopa/carbidopa (Sinemet), which proved to be a BIG mistake.

I made it back to the meeting room initially in a state of bewilderment and self – consciousness. This was momentary, however. It took only a minute for me to look around the room once again to view those much less fortunate than me. This turned into a moment of truth for me.

So what have I learned on this memorable day? I have Parkinson's. This requires continual recognition of potential challenges including the effects of stress and taking my meds on time. More important, however, and saying this with some emotion: I am so grateful for still having the capabilities that I possess. In comparison, there are others not so fortunate as me who attended this event with challenges significantly greater than mine.

Marijuana & PD: What Do We Really Know

From an April 18 webinar by Benzi Kluger, MD.
Dept. of Neurology University of Colorado on the
Parkinson Foundation website www.parkinson.org
(section, Living With PD/Library)



Medical cannabis is now more common in Hawai'i as more statewide dispensaries are opening. This webinar includes food for discussion, both pro and con. Dr. Kluger talks about current research trials and his personal experiences as a medical practitioner. It's credible information that will add to discussions at future support group meetings.

According to Dr. Kluger more studies are needed on the affects of cannabis properties, especially the THC content on PWP's, particularly on the cognitive symptoms. There are continuing studies on animals. However, human studies have included only small numbers of participants and precaution is needed regarding research bias and motives.

There are a number of other archived webinars and presentations on medical cannabis and PD that are available on this website that are worth checking out.

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER May/June 2018

Constipation--A Movement Disorder

By Joel Cohen

Constipation is an all too frequent symptom endured by people with Parkinson's.

The Mayo Clinic defines chronic constipation as infrequent bowel movements or difficulty passing stools that persists for several weeks or longer. It is generally described as having fewer than three bowel movements per week.

As has been previously discussed regarding ongoing research relating to the gut brain connection, there is this bottom line to consider. Having a problem in one part of the body inevitably affects another part of our holistic being, including the brain and the way it is dealing with our other motor and non-motor symptoms.

So, here are some tips from a medical resource website called UpToDate (www.uptodate.com), on ways to deal with this common PD challenge.

- For starters, exercise gets everything in the body moving. As continually stated, so important for people with PD.
- Diet is very important, particularly foods high in fiber. The recommended daily intake for the general population is 20-35 grams. I would shoot for the higher number, because of my PD.
- Fiber will work for you only if you accompany it with "lots" of water to allow it to flow through the intestinal system.
- Fiber found in citrus and legumes stimulates the growth of colonic flora thereby increasing fecal mass. Probiotics also help with this.

- The sugar components of fresh apples, peaches, pears, grapes, cherries, grapes, and nuts will help do the job
- Then, and foremost, there is what my wife, and now my doctor, recommends --(the shriveled plum) **prunes**.
- Adding 2-6 tablespoons of raw bran with your meal may help. Just make sure that you follow it up with a glass of water or other liquid.
- You can't go wrong with fiber supplements such as Citrucel or the one recommended by my doctor, Metamucil, if the latter suggestions are not accepted fully. Read the bottle first before taking them, however.

According to the website, patients who respond poorly to the fiber approach may require laxatives other than bulk forming agents. Caution is given, however, to not take these on a regular basis.

Stool softeners can be helpful to soften the load for movement, however be careful not to rely on them too much.

It should also be noted that you should be careful when you are just getting started, before you take large amounts of fiber. Consuming too much fiber at a time can cause bloating or likely embarrassing flatulence. So there is a limit to everything.

Newsletter Submissions

This is **YOUR** newsletter!! We seek your input on any subject related to PD—written by PWPs, care partners, or friends/family—for future editions of this newsletter. Please email them to Joel Cohen at jcohen8@hawaii.rr.com and Phyllis Tarail at Phyllis.tarail@gmail.com by June 20 for the July edition.

Joel Cohen and Phyllis Tarail, Editors