

# **HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER Sept./Oct. 2018**

## **Important September/October Activities & News on Hawai'i Island**

**September 10 from 1:30-2:30 Chair Tai Chi/Chi Gung** at Tutu's House. Maddy (Madeline Sofranac) is back and we highly recommend this great class.

No date has been set yet to resume **PD Exercise classes**. We need more participation in order to restart the classes.

**September 12 & October 10 (Wednesdays) from 1-3:00 pm Waimea PD Support Group talk story at Tutu's House.** On 9/12 Joel will lead the discussion on the increasing challenges of PD. October meeting focus TBD.

**September 28 & October 26 from 2-5 pm Hilo PD Support Group** at Hawaii County ADRC. Please contact Fran Calvert at [fcalvert@hawaiiintel.net](mailto:fcalvert@hawaiiintel.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** is scheduled to begin on **10/12** in Hilo at the Waiakea Recreation Center every Monday & Friday from 8:30-9:30 am. Contact Marlene Goodwin at [buckup1952@gmail.com](mailto:buckup1952@gmail.com) for the details.

**October 17 from 1-3 pm Kona Support Group's first meeting!** At the West Hawai'i Community Health Center. They will be meeting the third Wednesday of every month.

## **Kona PD Support Group Starting Soon**

Great news for people living in the Kona area. Here is an opportunity to join a newly formed PD support group. It will be led by Tom St. John, care partner, with his PWP wife Donna at his side. Both previously participated in PD support group activities in California.

Monthly meetings are scheduled to start on Wednesday, October 17 at the West Hawaii Community Health Center, 75-5751 Kuakini Hwy #104, Kailua-Kona. Meetings will continue on the 3<sup>rd</sup> Wednesdays of the month from 1-3pm.

Tom has been in a leadership capacity in many community service programs. He's also an avid deep-sea fisherman. Tom provides caregiving support for Donna who was diagnosed with PD in 2001. She stays active with Dancing for PD, chair yoga, physical therapy and water aerobics.

You can contact Tom at 925-785-6093 to talk story.



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## **HPA Fundraising**

By Joel Cohen, HPA Board Member

The 2018 Hawaii Parkinson's Association fundraising walk is scheduled on September 16 from 9-Noon in Honolulu. As a relatively small non-profit, fund raising donations now are critical to both continuing and planned programs and activities for the coming year.

HPA is currently in a transitional phase re-evaluating how we do business. We are a relatively young organization. Board members have a lot of passion to provide the highest level of service possible now and into the future. We continue to seek funding through private sector support with a greater emphasis on receiving non-profit grant funding, and doing whatever we can to find the money to carry out our long term mission in support of people with Parkinson's and their caregivers.

Our donations currently provide funding for our island's support groups and exercise classes. This includes keeping class fees to a minimum and providing scholarships for people unable to pay. Funds are needed to pay travel expenses for neighbor island participants in a new partnership research project with Hawaii Pacific Neuroscience (HPN). Patient care kits including important information for newly diagnosed patients and their caregivers are now being provided. Perhaps at the top of our island's priority list is HPA's continuing joint efforts with HPN to provide certification training and travel expenses to provide a much needed part-time movement disorder healthcare professional who will be available for appointments locally as an alternative for the many Hawaii Island patients who currently have to travel to Oahu.

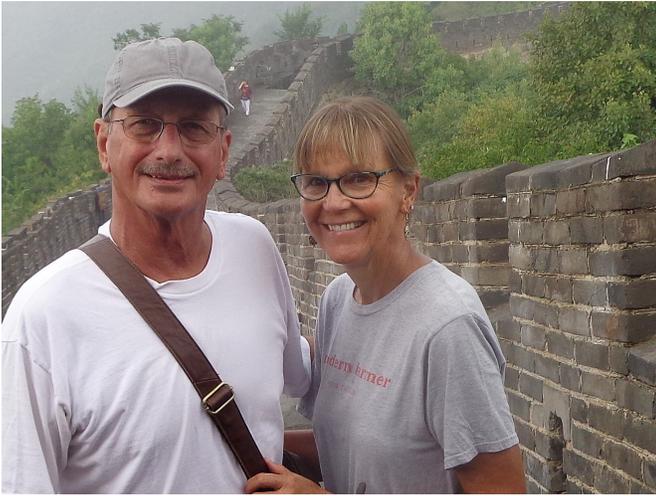
You can go to the HPA website at [www.parkinsonshawaii.org](http://www.parkinsonshawaii.org) to make your donation, or as Phyllis and I are doing, send your check directly to HPA at PO Box 1312, Kailua HI 96734. If you write a check, please indicate on the memo line that your check is from Hawai'i Island.

Be assured that your donation will be well spent in the cause of providing increased opportunities for our island's Parkinson's community.

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## **My DBS Saga, Part 2**

By Marlene Goodwin



Part 2 of my story began in the first week of July this year. We took the long plane ride to San Francisco to have the necessary surgeries to install a Deep Brain Stimulation (DBS) device. We arrived at our rented one-bedroom apartment to set up house for the next month. Having a kitchen, washer and dryer was a blessing as restaurant costs could have been astronomical to say the least. Also, the close proximity to UCSF was a real plus.

July 11<sup>th</sup> was my pre-op appointment and I was still upbeat and feeling no fear, although my husband was worrying enough for both of us. 5:00 am the next day was the first of three surgeries. It went very well and I spent the next two days in the hospital. My semi-private room was anything but. People in and out at all hours. Recommended sleep was a figment of someone's imagination.

My wonderful Doctor team lied to me. They told me my hair would only need to be shaven just a tiny bit. I had visions of a slight "comb-over" as my new hairdo. Not so. Friar Tuck's hairdo looked better than mine, so I asked the Doctors to go all the way and shave my head prior to the next surgery to better resemble Telly Salvalas.

My husband also lied to me. He kept telling me I "look just fine."

The next surgeries (head and chest) were two weeks later. They installed the Pulse Generator in my chest and ran and connected the wires to the implants in my brain they had placed in the first surgery. Again, everything went as planned and I was still upbeat.

Two nights later while recovering in our apartment, which was built on the site of the old Winterland Ballroom, the fire alarms went off and we had to evacuate the building. I must have been a sight in my nightgown, shaved head and staples in my head. A fashion statement for sure!

Our last visit at UCSF was to turn on the Pulse Generator and begin the tuning process, which I continue to do at home with my own programming device.

All-in-all, I am glad I underwent DBS surgery, but if one thinks you are going to be cured, you are going to be disappointed. I do feel like I have more energy, less tremors, and I am walking much better, and farther too. I would do it all over again, but this is probably not for everyone. And if you do not have a really strong caring partner to be with you, you may want to think twice.

### **Tutu's House Programs**

The Waimea Parkinson's Support Group has met monthly at Tutu's House for the past 4 + years. In addition to being an essential partner for us, they also provide a home for other community health and wellness organizations free of charge and a host of classes, educational and special programs that may be of benefit to you and family members. You can contact Tutu's House at 885-6777 and check out their website that includes their entire program schedule at [www.tutushouse.org](http://www.tutushouse.org).

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Here are some examples that may be of special value to people with PD and caregivers:

Powerful Tools for Caregivers (6 weeks)  
Mondays, September 10, 17, and 24. October 1, 8, and 15. Sponsored by Hawaii Community Caregiver Network. Space limited. Call Paulette Chang for information and registration.

Chair Yoga with Kit Hill. Every Friday.. 9:30-10:30

Zumba Gold (In chair) with Rene Morinaka  
Thursday, September 6 and 20 from 10:30-11 am

Harmony for Health with Richard Adoradio  
Group singing for your health and happiness  
Saturday, September 22 from 12:30-2 pm

### **MJF 3<sup>rd</sup> Thursday Webinar Urinary Tract Disorders and PD**

Urinary tract problems are common for PWP's-- maybe in the neighborhood of 80% of people diagnosed.

This disorder is connected to other problems such as constipation, sexual dysfunction, and hypotension (low blood pressure). If those issues are not seriously recognized and at least partially controlled, they can lead to urinary tract infections and serious illness.

The August 16 Michael J. Fox 3<sup>rd</sup> Thursday webinar focuses on this subject. Moderated by Dave Iverson, panelists included Marie DeLeon, a retired movement disorder specialist diagnosed with PD in 2008, Professor of Medicine and director of the movement disorder program at the University of Alberta-Edmonton, Janis Miyasaki, and Dr. Jorge Juncos of Emory University School of Medicine.

Like many PD symptoms, questions come up regarding cause. Is it PD or other factors including the ever-increasing factor of aging? According to the panel, developing dialogue with your primary care physician and/or treating neurologist is the place to start. Prior to any changes or additions in medication,

exercise, diet, and determining frequency and patterns need to be determined. PD medications, in fact, can be contributing to your problem. Working with your physician, it is important to determine the root cause prior to figuring out the best course of action.

Your current medications can complicate your problem. For example, a significant number of PD patients experience hypotension. Meds can contribute to this condition, causing you to get up frequently during the night. Other prescription medications such as anti-depressants, diabetes meds, and calcium blockers should also be on the agenda for discussion with your physician.

How much water should a person with PD drink daily? According to Dr. Juncos, "just normal intake around 6, 8 ounces glasses should work for most people." Regarding those who have to deal with frequency issues, it's tough for some, however, it may be necessary to limit or totally avoid caffeine, alcohol, and diuretics.

As previously mentioned, most people with PD experience some form of urinary control challenge. The hour of discussion is worth your time. You can easily Google Michael J. Fox webinars to access this and past webinars.

The next webinar "Cramping More Than Your Style- Dystonia Causes and Care" is scheduled on September 20 at 6am HST, if you want to be an active participant and submit a question for the panel you need to register in advance. Otherwise, you can tune in any time.

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### **August 31 Hilo PD Support Group Meeting**

Two couples recently returned home after attending a 6 day PD "Bootcamp"/ "School" held at Bastyr University in Seattle, a naturopathic college. Kathe & Charlie, Iris & Rick were full of information about what they learned from this intensive week of classes, lectures, workshops and a field trip. Kathe promised to write an article for our November issue that will cover more of the details. The 30 people in attendance were most interested in what they learned and had experienced, with several people expressing interest in attending next summer.

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

By Joel Cohen

Life altering events appear to happen more often as I get older. One definitely occurred upon starting my day early on Saturday August 25. The day began, as I will describe, with a likely avoidable serious accident.

My initial thinking in writing this column was to inject some humor into what happened. I often begin our support group meeting in Waimea to help facilitate open discussion by asking others... "Are you feeling upbeat or beat up?" My wish is to hear positive responses from most of the circle.

On second thought, trying to lighten up what could have created a major change in my life is not funny nor a good idea. So, I will share what I learned in a more serious manner.

The preceding week had been both physically and emotionally challenging in a number of ways. I hit the sack on Friday evening with a sense of discomfort hoping for a good night's sleep to regroup and move on the next day.

My sleep fell short around 1am with the remainder of the early morning in a state of restlessness and what I literally hate doing...thinking about the "what if's" and "what to do's."

I hesitated getting out of bed at 6am, sitting on the edge of my bed in a somewhat unstable and confused state and eventually, somewhat painfully, made my way to my favorite living room chair to contemplate the day ahead. "Okay, let's get on with it.

Moving way too quickly and clearly unfocused, I went to pull up the window blind across the room.

Then, somehow, (what I still don't clearly understand), I tripped and catapulted at some imaginable speed at least 6 feet away into my metal radiator style heater looking downward in a state of temporary shock at small pools of blood caused by the serious cuts on the right side of my face and neck and on both forearms.

Care partner Phyllis hears the thud of contact to the floor from the kitchen and immediately reacts to the potential tragedy. My initial thinking is that I need to get up and assess the damage. I did not feel that much pain and still had, however limited, a sense of mental clarity.

Phyllis' response, to her credit, in a relatively calm manner, is "don't move. I am calling 911." We both kept our cool for the paramedics to arrive, assess the damage to my body and state of mind, and administer first aide by wrapping my wounds. They offered transport to the hospital, and I refused. I survived the remainder of the weekend, and went to the Kaiser Waimea clinic first thing Monday morning for complete and thorough assessment and bandaging.

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Aside from the right side my face being all cut up, having 2 weeks of scraggly beard growth, and feeling, at least initially, hesitant to be seen in public, I will be okay.

So, what have I learned from all of this?

First and foremost, I have a care partner who remained calm at the time of the accident and has methodically replaced bandaging to ensure no additional damage occurs.

I need to handle tasks at hand with all deliberate speed, making a conscientious effort to stay focused, and aware of my surroundings.

This accident is a message to me that not being careful in performing daily tasks can potentially lead to serious, if not catastrophic, injury.

Sleep is important for me to recover from the last day and for starting a new one. I need to be conscious of my state of mind and condition of my body.

Low blood pressure is a common PD symptom that I, and many people of my age, have that can cause instability, dizziness, and disorientation.

I have Parkinson's and limitations come with the playing field. My limitations will undoubtedly increase over time.

Avoiding accidents like this one will allow me to be able to live the highest of quality of life possible including going on vacation and enjoying it for most of September.

Take care (saying it literally) and try to the best of your ability to stay present in the moment.

**Wounded Joel August 2018**



Note from Phyllis: Joel's spirit shines through as he smiles through his trials and tribulations.

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### **PD Celebrity of the Month**

**Leslie Stahl, Care Partner**



It's Leslie's husband, Latham that actually has PD, as she tells Brain & Life magazine in its August issue (available online at [www.brain&life.org](http://www.brain&life.org) ). Now 74, Latham was diagnosed 11 years ago after he developed a series of symptoms. Leslie states, "He's very tall, and when he fell, it was awful. We have a flight of stairs in our house, and he fell down them. He hit his head on the street when he was walking the dog. He was fainting."

The article about Leslie and Latham is a long one and a very good read about their pursuit of quality medical care for his PD symptoms and their struggles with medication, etc. Please read it and see for yourselves.

### **Newsletter Submissions**

This is **YOUR** newsletter!! We continue to seek your input on any subject related to PD—written by PWP's, care partners, members of the medical community, or friends/family--for future editions of this newsletter.

Please email them 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 October 24th for inclusion in the November edition.

Joel Cohen & Phyllis Tarail, writers/editors