HAWAI`I ISLAND PARKINSON'S COMMUNITY NEWSLETTER March/April 2019

March/April 2019 Activities on Hawai`i Island

<u>Waimea PD Support Group</u>—Wednesdays, March 13th & April 10th from 1-3 pm, at Tutu's House. Focus in March & April will be on dealing with transitions and change. Contact Joel Cohen at jcohen8@hawaii.rr.com for more information.

<u>Kona PD Support Group</u>—Wednesdays, March 20th & April 17th from 1-3pm at the West Hawai'I Community Health Center on Kuakini near Hualalai Rd. Contact Tom St. John at tomstjohn1@gmail.com or 925-785-6093 .

<u>Hilo PD Support Group</u>—Fridays, March 29th & April 26th 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 for more information

<u>Hilo PD Exercise</u>—Every Wednesday from 9:30-10:30 am at the Hilo YMCA. Contact the Y at 935-3721 for more information.

<u>Rock Steady Boxing</u>--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.

<u>Tutu's House March Upcoming Activities</u>

<u>March 6</u> at 11am- Caregiver Conversations with Karyn Clay

<u>March 7 and 21</u> at 10:30am- Zumba Gold with Renee Morinaka

<u>March 8, 22, & 29</u> at 9:30am- Chair Yoga with Kit Hill

<u>March 20</u> at 10:30 am- County Office of Aging and Disability Center regarding their available support services

2/13 Opening the Waimea Talk Story Gathering After Lunch

February 13th--A Focus on Relationships

Nearly 40 members of our Hawai'i Island PD community from all over the Island came together for a healthy lunch and fellowship at Tutu's House in Waimea. Representing Kailua-Kona, Puna, Hilo, and Kohala, we welcomed Pat Bemis, HPA Board member (and care partner) with her husband, Gardner from Honolulu. It was a lovely afternoon of sharing, celebrating a birthday, and connecting between PWPs, care partners, adult children, close friends, and caring members of the support community. We mahalo and appreciate all who attended.

Jim Riley's & 83rd Birthday Cake

Photos of the February 13th PD Gathering

Lisa's Message on the 2/13 Gathering

Lisa Bollinger, a graduate student in Social Work at University of Hawai`i Manoa attended the February 13th bash as an observer. She subsequently sent us this message reflecting on what she observed at the event.

"What an incredible inspiration it was to experience the honesty and support that attendees have cultivated in navigating life with Parkinson's. It was beautiful to see the loving and non-judgmental way in which everyone shared, both those living with Parkinson's and those caring for someone with the disease. There is no greater way to encourage one another and create soul healing than through listening. Your group facilitated listening in a special way. It is not every day that you find such inspiration amid a challenging illness, and I was deeply touched by the strength and tenderness in the group."

HPA Symposium in Honolulu

The 2019 Hawai`i Parkinson's Association Symposium is scheduled on Saturday, April 6th in Honolulu at the Aloha Tower Marketplace. The free event kicks off with breakfast at 8am, the formal program goes from 9am until noon.

This year's theme is "Exploring nutrition, exercise, and wellness for Parkinson's." It will feature guest speakers and a Q&A from audience participants. The program will be videoed. So, if unable to attend, you will be able to view what happened at a later time.

The final program schedule is still in progress. You can get up to date information by going to the Hawaii Parkinson's Association website, www.hawaiiparkinsons.org .

MJF 3rd Thursday Webinar: Beyond Medication-DBS and Focused Ultrasound

The February 14th webinar included moderator Soania Mather MD, co-chair of the MJF Patient Council, Richard Rothenberg, a Council member diagnosed with PD 16 years ago and a DBS patient since 2010, Paul Fishman MD-Professor of Neurology, Pharmacology, and Neurobiology at the University of Maryland School of Medicine, and Joohi Jimenez-Shahea-Director of the DBS program at Baylor University.

DBS surgery has evolved over the past 30 years. According to Dr. Fishman and Dr. Jimenea-Shahea, it is recommended for people who initially get a good response to levodopa, but progressively experience complications such as dyskinesia and "off time." Dr. Fishman refers to this lessening of the drug's effect as "fluctuating responses."

DBS is not an alternative for people with significant cognitive and psychological problems. It may, in fact, worsen these conditions. That is why it is critical to have a thorough patient assessment, including consideration of these symptoms, prior to moving forward with the surgery.

According to Dr. Fishman, PD meds normally work well in the early stages of PD. Fluctuating responses normally don't begin until a few years after diagnosis, but with some people this happens much more quickly. People in a later progressive stage of PD will likely experience more non-motor symptoms such as increased cognitive challenges, balance issues, and falling, thus making them less likely candidates for DBS. By and large, he feels that the middle phase, usually 3-4 years after diagnosis, is the best time to consider DBS as an alternative.

Dr. Jimenez-Shahea's contribution to the discussion placed emphasis on the importance of thorough assessment and patient/doctor conversations to determine not only eligibility for DBS, but also to an open discussion of the pre and post surgery psychological impacts of undergoing DBS.

There was also discussion about **Focused Ultrasound** as a way to lessen PD symptoms. This incision-less procedure is done in a MRI machine targeting a specific part of the brain that can contribute to alleviating a symptom. As with DBS, it too is something to consider when the patient is not responding as desired to meds.

Beams of energy converge to permanently destroy cells interfering with motor functions. According to the doctors, the important thing to know is that this procedure is irreversible. Also, at this point, it can only be done on one side of the brain. Saying this, Focused Ultrasound may be an option for people who are not candidates for DBS or basically don't see DBS as the way to go.

The last comments came from Richard Rothenberg who pretty much summed up the positive effects from undergoing DBS, by emphasizing how much it has personally made life better for him. He still has his challenges with PD, however he can cope with them, and he feels that he can continue to have a fulfilling life ahead of him.

You may want to tune into the next 3rd Thursday webinar on March 21st . The subject is "Better Conversations and Care--How Patients and Doctors Can Work Together." It is easy to register by going to the MJF 3rd Thursday link on the MJF website, www.michaeljfox.org .

Parkinson's Foundation Summit

Fran Calvert, leader of the Hilo PD Support Group & care partner, attended the Parkinson's Foundation Caregivers' Summit held in Arizona this past December and shared the following link: www.parkinson.org/Summit .

Brain Fog

By Toni Bernhard J.D.

This is a summary of an article in Psychology Today magazine. Toni Is a retired Professor of Law at the University of California, Davis. For over 17 years, Toni has been dealing with a mostly undiagnosed and not totally treatable illness that expresses itself primarily in extreme exhaustion—more than ordinary fatigue. She took to writing as a way to continue living a productive life and has written several books as well as regular monthly articles published in Psychology Today.

Toni relates her issues with brain fog as one of the many serious cognitive challenges that she has had to deal with. Her illness also prevents her from participating in strenuous exercise as is the case with people dealing with PD. As Toni is a person who believes in finding ways to deal with her issues, in this article she shares some of the things (maybe solutions) that help her get through her brain fog experiences.

Brain fog is sometimes defined as a lack of mental clarity due to the inability to focus on or remember things. You may have trouble concentrating on the task at hand or comprehending what you are reading, finding yourself going over the same paragraph several times. You may have trouble remembering things big and small--from where you left your cell phone to what you watched on TV the night before, to the task you decided to do just moments before.

Her 6 strategies and suggestions in dealing with these challenges are:

#1 Don't beat yourself up if you're experiencing cognitive difficulties. It's not your fault. They are part and parcel of your human condition. Being sad and engaging in self-blame are different mental responses to chronic illness and its consequences. Sadness, hopefully, can give rise to self-compassion. Self-blame cannot.

#2 Start keeping a record of when your cognitive difficulties are the worst. See if you can detect any patterns when problems kick in or become more intense. Is it at certain times of the day or engaging in certain activities? It has been extremely important to her to learn what triggers these challenges. This helps relieve frustration, because she can point to a cause that prevents her from performing the task.

#3 If you are experiencing brain fog, don't try to memorize things or figure them out in your head, write them down. Your best friend becomes your pen and pencil. She feels that writing down her thoughts immediately actually improves her cognitive abilities, because it calms her mind enabling her to see things more clearly.

#4 Write down pros and cons before making decisions. As a teacher, Toni felt the best way for a student to make a decision was to take a piece of paper, draw a line down the center separating pros and cons. For example, staying in school or not. She feels that this works for her dealing with brain fog in making important decisions.

#5 Break down big tasks into a series of tiny ones. Don't try to do something that requires a lot of concentration all at once. Create a list of what is needed, and spread it out over a period of time as long as you can. If you are having a bad day, it's okay to move it forward to another day. Eventually, you will have a day when your brain is clear enough that you can make up for the lost days.

#6 Find a game that's fun and gently challenges your mind. Toni has started playing a game called Wordscapes. She is shown letters and has to continue to make words that fill in crossword squares. She accepts the fact that she has difficulty playing the game on some days. However, playing it helps reduce the frequency and intensity of cognitive dysfunction by gently exercising the mind in the absence of ability to exercise physically. According to her, it comes under the heading of "use it or lose it."

From a Person with Parkinson's Perspective

By Joel Cohen

As many of you who attend one of the support groups on our island, you have heard that I and my co-editor and wife, Phyllis, will be moving to Tucson, Arizona at some undetermined time later in the year. So, I have limited time to recognize and extend my personal appreciation to those who have been part of my Parkinson's world here on Hawai'i Island.

Before I get going on this subject, it's important to me, and somewhat of an emotional task for me, to identify some of the people who have had special impact on my life here in Hawai`i. There have been many people who have personally helped me in my quest for living as healthy a physical and emotional lifestyle as possible.

My focus this time, will be on someone who stands out in the crowd, knowing that there will be more to come in the next, and also last issue, of this newsletter.

It started in early 2015, the beginning of what has become Waimea's Parkinson's Support Group. Phyllis found out that a movement class for people with neurological disorders was being started at Tutu's House. Being self conscious of my day to day PD challenges, frankly I was initially reluctant to participate. However, it didn't take me all that long to check this program out.

Phyllis, not me, called Tutu's House and spoke with the long-term program coordinator, Lorraine Urbic. A relatively new and what she called enthusiastic and motivated physical therapist, had hit town and volunteered her time and energy to start the class. Her name is Madeline Sofranac--later, with some personal hesitation, to be known by me and pretty much everyone else, as "Maddy".

Within six months of starting the movement class it became clear that the PWPs and their care partners were looking for more than a movement class. They (we) were looking for movement PLUS. So, starting with a small group of four plus our leader Maddy, the first classes morphed into a support group plus movement.

Those who attended the first classes got to know Maddy quickly. She had/has a special spark of undeniable energy and enthusiasm. Add to the mix her professional expertise and education that includes an achievement of her doctorate in Physical Therapy with specialization in Parkinson's and related neuroplastic disorders. We have in our community someone special who definitely has made a difference in my life and, as I can say with a whole lot of confidence, in the lives of others. What makes Maddy extra special though, is that she REALLY CARES, particularly when she is working with her PD people.

The first class meetings were just a start in her contribution of time, energy and expertise. Our first year turned into a collaborative effort between Maddy, Phyllis and me as the group, which initially started with focus on specialized exercise, moved to a place where folks like me and their care partners who yearned for more time for open discussion talk story got their wish.

Without hesitation, Maddy, who Phyllis calls our "physical therapist extraordinaire," continued separate specialized PD weekly exercise programs for 3+ years until it became evident only recently that the numbers of participants attending did not meet expectations. North Hawai`i is a large area and it's been difficult to attract enough people willing to travel to make the program work.

So, by mutual agreement, the many other commitments on Maddy's plate including other special exercise classes particularly her much loved aquatics therapy program/s activities, increasing number of Parkinson's physical therapy clients, the exercise program came to an end this past summer. Maddy continues to play a significant part in the local PD community in other ways including her physical therapy rehabilitation practice.

It is inappropriate for me to promote her current professional endeavors. However, if you want to know more, you can check out her website, www.waimotionmadeline.com or contact her at masofranac@gmail.com .

My plan is to create the most complete recognition list that I can for the next (last) edition of this newsletter. I have thoughts of my own. My hope is that the other Hawai`i Island support groups will provide us with more names of folks to add to the list.

Newsletter Submissions

This is **YOUR** newsletter!! 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 **April 26th** for inclusion in the May/June (last) edition.

Mahalo nui
Joel Cohen & Phyllis Tarail, writers/editors