

**HAWAII ISLAND PARKINSON'S
COMMUNITY NEWSLETTER March 2018**

**Important February Activities on
Hawai'i Island**

March 12 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.

March 19 & 26 (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!*

The possibility of scheduling new exercise classes is being explored, if enough interest is shown—such as, Yoga and Rock Steady Boxing.

March 14 from 1-3:00 Waimea PD Support Group talk story at Tutu's House. It's a time for sharing, caring, and receiving with occasional humor thrown in that enables participants to leave the gathering with optimism looking forward to the next get together. New participants are always welcome. Time has been extended, so we can talk longer if we want.

March 30 from 2-5 pm Hilo PD Support Group at Hawaii County ADRC for the Hilo PD Support Group's monthly discussion, possibly with a speaker.

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

Kona PD Support Group Needed?

Currently, there is no talk story support group in Kona. Are you or someone you know interested in starting or being in a Kona PD/Neurological support group? It's a missing piece in providing opportunities for the Hawai'i Island Parkinson's community as a whole. Please contact Joel Cohen at 769-4490, if you are interested.

**Editors Note On Building the
Parkinson's Community**

At last count, the number of people receiving this newsletter has climbed to 99. It's been more than a year since we started this venture. Our mission is not limited to providing information regarding special programs such as exercise, talk story discussion gatherings, and current research being conducted related to Parkinson's and other neurological diseases. Perhaps, even more importantly, our goal is to expand and create a Parkinson's community on our island that, in last analysis, will benefit all who participate.

Whether it be people with PD (PWP's), caregiver partners, or medical professionals, WE are all part of this advocacy community. We're encouraging all who receive this newsletter to help spread the word of support when the opportunity arises...whether it be discussing the challenges of PD in open conversation with friends and family or encouraging your personal physician or physical therapist to join our email list. This will help build the community and create a new level of consciousness of what PD is all about. Working together in common cause we can create a new feeling of awareness of community and help spread positivity to others who may need our support.

Phyllis Tarail and Joel Cohen, Editors

**MJF February 15 Webinar
Dealing with Depression and Anxiety**

Approximately 50% of diagnosed PD patients experience depression and 40% show anxiety as a continuing challenge. The February Michael J. Fox 3rd Thursday webinar narrated by David Iverson focused on this topic. Panelists included Dr. Laura Marsh from the Michael E. DeBakey Veterans Affairs Medical Center, Dr. Gregory Pontone from John Hopkins School of Medicine, and MJF Board member, a 20 year PD patient Israel Robledo.

In addition to these mood disorders, other non-motor symptoms such as the all too common chronic fatigue, including sleep issues, are likely to occur well before tremors and a confirmed diagnosis. In the case of Israel, this included feelings of helplessness and hopelessness. According to Israel, "it was like looking through mud colored glasses." In the beginning, prescribed anti-depressant drugs did not work for him, which caused him much frustration. It was a trial and error process to find the right medication. Even when one was found, it took months to finally take effect. In fact, the initial dosage "made things worse before making it better."

According to Dr. Pontone, his patients begin on medications with the least possible side effects, knowing that side effects are likely to occur prior to considering stronger drugs. So, finding the right medication with the right dosage requires a whole lot of patience with continual monitoring by the physician.

Phyllis and I watched this webinar together and we found it extremely helpful. We had a better understanding of how PD was affecting me emotionally and we highly recommend watching it with your care partner.

The Michael J. Fox 3rd Thursday webinars cover a wide scope of topics in a clear and easily understood manner. You can easily access this one on depression and anxiety as well as past topics in this monthly series by going to Michael J. Fox 3rd Thursday webinars. It only takes a moment to register. The next webinar is scheduled on March 15. Scientists predict the number of people diagnosed with PD in the world will double by 2042 to more than 12 million. The panel will review some reasons behind this increase and strategies in what is being called "The Parkinson's Pandemic."

2018 HPA Symposium

The annual Hawai'i Parkinson's Association symposium will be held in Honolulu at the Aloha Tower Marketplace on Saturday, April 28 from 8am until noon. You can register for this free event by going to the HPA website at www.parkinsonshawaii.org. Arrangements are being made for neighbor islanders to connect electronically to the panel discussion part of the program. Stay tuned. More information will be available in the April newsletter.

Gut Brain Connection

Numerous studies have shown a connection between gut issues and a host of neurological disorders. A community presentation is scheduled at Tutu's House in Waimea on Saturday, March 10 from 3-4:30pm. This is a subject that may be helpful in understanding progression of Parkinson's and it is likely to be a topic of discussion at future support group meetings.

Natural Therapies for PD

By June Kiyabu & Phyllis Tarail

A large group of us gathered for the February 16th Hilo PD Support Group meeting and talk by Laurie Mischley ND, PhD, MPH. We sat quite enthralled for the almost 3 hour detailed talk and Q & A by the passionate, extremely knowledgeable and very enthusiastic Laurie Mischley. She covered wide-ranging recommendations for PWP's in the areas of supplements, diets, and exercise. We are briefly covering some of these recommendations, but we suggest watching one of her videos, "Food for Thought, Diet & Nutrition in PD" ([https://vimeo.com/Parkinson Society BC Videos](https://vimeo.com/ParkinsonSocietyBC/Videos)), checking out her article "The Best Nutrition for Your Parkinson's" (<https://nwpf.org/media/308142/Mischley-Best-Nutrition-91514.pdf>), or her book, "Natural Therapies for PD" to get way more of the details.

Laurie's research focused on 2 particular deficiencies in PWP's--Lithium and Glutathione. So in the area of supplements, these are two that are inexpensive and that she highly recommends be taken daily. Her suggested dosage for Lithium is 5-20 mgs. Low dose Lithium is very helpful in dealing with depression and anxiety. Her research also noted that PD patients make too much of a gut virus that causes intestinal inflammation. This inflammation then travels up the vagus nerve to the brain and is the probable causative factor of PD. Therefore, she recommends various anti-inflammatories such as liquid forms of fish oil and of Coenzyme Q10 as well as turmeric. Recommended pharmaceuticals include the prescription drugs Rasagiline (Azilect), or Selegiline, plus levodopa/carbopoda (Sinemet), which she believes are disease modifying.

Recommended diets are vegetarian or Mediterranean (olive oil, non-fried fish, fresh fruits and vegetables). A low protein diet is the most beneficial. Non-progressors of PD include these foods plus nuts & seeds, coconut oil, and moderated amounts of wine. Natural glutathione is found in raw fruits and vegetables—particularly avocado, potatoes and asparagus, which also can be cooked. She highly recommends eliminating dairy products and fried foods altogether, as much as possible.

Laurie has been conducting a long-term survey that she invited everyone to participate in. Just go to www.CAMCAREPDBastyr.edu to sign up. The 1½ hour surveys are conducted twice a year.

Yoga(#1), Tai Chi, and dance are her most recommended forms of exercise. She believes that exercise for PWP's must be intense and cognitively demanding. "You should be flirting with humiliation and stink at the thing." Pushing yourself emotionally is positive!

You can find Laurie on Facebook "Education is Medicine."

Laurie Mischley



From a PD Patient's Perspective

By Joel Cohen

Dealing with symptoms of Parkinson's is not only a challenge for me but also for my wife Phyllis, family, close friends, and, as I will focus on shortly, my medical providers.

Parkinson's is challenging and complicated. The physical part for me is actually easier to accept. The emotional side, however, is much more complex, and I need to understand my emotions much better. This goes both for how others react to me and how I react to them.

For me, there is a difference between "fixing" and much needed support. Parkinson's can take a toll on my sense of self worth. So, "fixing" me goes outside my desire to figure it out for myself. My response to those who try to "fix" me can be counterproductive. It can lead me to feeling self protective and wanting to fend off their advise with a "give me some slack" reaction.

So, how do these feelings relate to the medical community? What can I do to ensure that the system works for me? How do I develop positive relationships with my personal physicians?

My expectations regarding hospitals are minimal. Realistically, a hospital stay is about fixing the patient, whether it is surgery or a temporary emergency. For the most part, I am sure that medical staff care. However, it comes down to fixing the patient and returning him/her back to the real world. Those of us who have experience in being confined bedridden during a hospital stay can describe the best and worst scenarios. The bottom line is hospitals are for fixing and not for healing.

So, let's go to the important relationship with my personal doctor/s. Diagnosing and treating Parkinson's can be, and was, tricky, for my primary care physician many years ago, and it can even be tricky for my specialized trained movement disorder neurologist.

The list of possible symptoms is long. It's a challenge to distinguish between the body part and the human entity as whole in the usual 15 minute medical appointment. Knowing this, it's important to develop and nourish a partnership of healing with your doctor. I recognize that I have a responsibility to be prepared for the medical visit. I also may need to question, if necessary, if PD may be a factor in dealing with the problem or symptom that I am seeing the doctor for on that given day.

One last thing before this month's self-described words of wisdom come to an end. The human side of medicine goes both ways. I am so fortunate to have doctors who really recognize my health challenges and keep me as a healthy as possible. So, given this opportunity...I thank them for their support. I truly appreciate it very much.



Caregivers/Carepartner's Corner
By June Kiyabu

Our neurologist told us that Parkinson's Disease has no cure and it will get worst with time and the medication will lose its effectiveness so we accepted that. Our family MD told us that he has never seen a Parkinson patient decline so quickly as Herb. He said that it usually is a very progressively slow disease but Herb was getting worse every week. We felt that we had to hurry up and do things before Herb got too disabled to travel. We were prepared to expect the worst for Herb's Parkinson prognosis for the next few years.

However, Laurie Mischley's lecture gave us so much hope and optimism that we could do things to slow the progression of Parkinson disease. We are trying our best to follow her instructions on delaying the progression of Parkinson disease. I thought that it was such an inspiring and hopeful lecture. We can all do something positive for Parkinson disease by following a proper Parkinson diet and challenging your brain to learn new things by adding new activities and exercises.

Laurie Mischley has given us valuable information and new insight on how we can delay Parkinson disease. We are more hopeful now.

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 March 21st for the April edition.

We also encourage you forward this newsletter on to anyone who might be interested.