

Getting to Know Your PD Support Group Facilitators

We are fortunate to have volunteer facilitators in the North Hawaii and Hilo areas that keep those two support groups going, so we thought it would be helpful to get to know them a bit. We encourage those of you who haven't attended to come and meet them in person!



Fran Calvert—Hilo
In Her Own Words

Overview--We lived in British Columbia (BC) for 35 years before moving here. I conducted honeybee research there and had a healing center, which focused on biokinesiology as a way to test for natural supplements and therapies to bring the body back into balance, acupuncture, and energy healing. We have lived here for 15 years. We bought an acre of land in Leilani Estates in 2001 and planned to build a cabin to come and escape from the dreary rain of BC winters. We bought a home in Hawaiian Paradise Park (HPP) and moved here in 2004 after our youngest son started university. Although we both worked here for about 10 years, we are now retired.

Symptoms--About 3 years ago, Glen's gait changed and at that time we sought medical advice. After learning that PD was a probable diagnosis we started researching everything we could and realized that he had had non-motor symptoms for many years--stiffness, rigidity and loss of sense of smell (more than 20 years ago), and REM sleep disorder (15 years ago). He does not have visible tremors.

Diagnosis-- He was diagnosed here and our experiences with doctors at Kaiser have been good. He had not seen a neurologist that was a movement disorder specialist until he saw Dr. Pang in Kona last year--he confirmed the PD diagnosis. Glen has not been pushed by the doctors to take prescription drugs and at this point in time he is doing as many natural treatments and exercises as possible: Tai Chi, QiGong, EFT (Emotional Freedom Technique or "Tapping"), Fast conscious walking (John Pepper--*Reverse Parkinson's*) and the oriental medicine teachings of Dr. Janice Walton-Hadlock DAOM (*Recovery from Parkinson's*). The latest book we have come across in our search for natural treatments is *Road to Recovery from Parkinson's Disease* by Robert Rodgers, PhD.

Hilo PD Support Group--When Glen was diagnosed I started looking for a support group in Hilo and was told there was none. No one I called knew the HPP group was still going and maybe that was a good thing because we would have joined it and not branched out. After a year of asking the Hawaii Parkinson's Association (HPA) via email about a Hilo group, they suggested that if we wanted one we could facilitate it and they would help us. And they have!

Future of PD Support Groups--We hope that more people with PD will find out about us and join both the support group and exercise group. The YMCA exercise group has been going for a month and it is excellent and very well received by all who attend. We look forward to having interesting presentations at

our group meetings about ways we can help ourselves with this challenge.

HPA (Hawaii Parkinson's Association)--HPA encouraged and helped us start our support group in Hilo. Their commitment in 2015 to support people with PD on the neighbor islands made this possible. The president at that time, Kevin Lockette, came over several times to help us get started and make presentations. He recently came to Hilo to train the teachers at the YMCA for our newly formed exercise class.

Through my participation on the HPA Board, I hope to help others in our community find the information and support that has been so helpful to us. We know there are many people with PD in East Hawaii that don't come to our meetings or exercise group and we hope to find ways of reaching out to them or helping them form their own support groups. We plan to have a Rock Steady Boxing Group start here in the Fall and that may appeal to others in a way that our regular support group doesn't.

My own training in natural medicine encourages us to seek treatments outside the normally prescribed drugs until such time as they are necessary. I will encourage the Board to assist other groups in finding speakers and information along this vein. However, we have no aversion to the use of prescription medications.



Joel Cohen--Waimea

By Phyllis Tarail

Overview--Joel and his wife, Phyllis, moved to Hawai'i Island on October 1, 2001 to start a new chapter in their lives in a place they had visited a number of times. They felt lucky that they were able to retire from paid work in their 50's after they fell in love with the home in Kukuiahaele that they had rented on vacation. After 7 years in that home, they moved to a single story house right in Waimea town, close to everything that they need.

Symptoms--Thinking about it, in retrospect, Joel realized that he had been misdiagnosed with familial essential tremor over 30 years ago. His symptoms included tremors, heavy sweating, high levels of anxiety, and serious fatigue that required daily napping. He worked for at least 10 years with these undiagnosed PD symptoms, which finally caused him to retire early.

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Diagnosis— In June 2004, his Kaiser primary care physician referred him to a neurologist suspecting that Joel actually had PD. He has continued to see the same Kaiser neurologist every 4-6 months at the Kona Kaiser Clinic. Dr. Stuart Pang has guided Joel's journey to a healthier place. However, Joel recognizes that his PD symptoms affect his other health issues.

Waimea PD Support Group--About 3 years ago Joel attended a new PD movement class in Waimea, at Tutu's House taught by physical therapist, Madeline Sofranac. After speaking with Maddy, as Joel explained, "I expressed a desire to take the lead in the talk story part of the monthly gathering. I was looking for a challenge." Soon, the monthly support group at Tutu's House separated from a weekly PD movement/exercise class, which Maddy taught.

Future of PD Support Groups-- Joel states that his wishes are "to reach out to more PWP's and their caregivers/care partners to encourage them to participate in our support groups and exercise classes in order to become as healthy as possible. He wants to see the attendance grow and see "this recognized as an Island-wide PD community."

HPA (Hawaii's Parkinson's Association)—Joel learned about HPA and the past president, Kevin Lockette, from Maddy. In April 2017, Joel became the Waimea representative on the HPA Board of Directors. He wants to work closely with the other Board members to bring resources to our Island in order to expand our programs. As he states, Joel's vision is "helping bring the PD community together—including doctors and other medical professionals, caregivers/care partners, and PWP's." He strongly believes that "PWP's must be members of the HPA Board so that they, too, can be involved with decision making."

Waimea May Talk Story

Medical marijuana was the subject of the day at the Waimea May 3 talk story. The lively and open discussion focused on the experiences of participants who are using cannabis to relieve symptoms of PD. A number of issues were discussed including its benefits, availability, and the quantity taken to be effective. In the absence of cannabis dispensaries on our island, some experimentation is needed to determine the strain and amount.

According to participants, cannabis is benefiting their ability to get a good night's sleep. Concerns were expressed regarding possible effects for other purposes. The quantity, including the amount of THC, is difficult to determine. The amount, like other drugs and prescribed medications, is determined on a trial and error basis.

We learned that there are local medical providers who will sign off on the paperwork required for an individual license by the State. Invitations will be sent to those providers to attend future support group meetings.

I have received a number of e-mails regarding the use of medical marijuana, all in support of the benefits. Mahalo to all those who submitted these articles and research information. Look for more information in future newsletters.

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Waimea PD Schedule Changes

REMINDER--Looking ahead, the Waimea Parkinson's Support Group **meetings will change** from the 1st Wednesday of the month from 1-2:30 to the **2nd Wednesday effective July 12.**

Madeline Sofranac's Wednesday PD exercise classes beginning at 2:30 pm at Cross Fit Gym will be temporarily limited to once a month during the summer (June through September) right after the Waimea Support Group's talk story.



Hilo YMCA PD Exercise Class

The YMCA PD exercise class is off to a successful start and continues every Wednesday morning at the Hilo YMCA. All levels of capability are encouraged to participate. This is an opportunity, as seen above, to get moving and share your experience with others. Please call the Hilo YMCA at 935-3721 for more information.

May 26 Hilo Support Group Meeting

Communication between people with PD and their care partners is so important. Challenges for both exist. In this spirit, at the May 26 meeting, Hilo Support Group leader, Fran Calvert, did something new. We started off all together and then the people with PD and the care partners met separately to discuss their special challenges. Both groups came back together at the end of the gathering with positive responses indicating that the open confidential dialogue was very beneficial. The consensus is periodic separate supportgroup meetings of this type will be scheduled.

Michael J Fox Article

You may want to check the April/May AARP newsletter. It includes Michael's 6 rules for surviving adversity. Many of you know about his history of depression when initially diagnosed with PD-- how he learned to accept limitations, move on with his career, and become a major contributor of hope and research for folks with PD.

In summary, MJF's 6 rules are (1) exercising to operate positively in the world, (2) pacing yourself, (3) accepting limitations that help create change, (4) making himself happier by being honest with others about his illness, (5) being hopeful about the future in what he calls "informed optimism", and (6) laughing at his involuntary movements and the scenes that they create loving what he sees.

A Patient Perspective by Joel Cohen

Merriam-Webster Dictionary defines a support group as "a group of people with common experiences and concerns who provide emotional and moral support for another." Are our island's PD support groups doing this? Can I say that participation in one of our groups is for everyone? Well it's working for me.

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Saying this requires some explanation, however. Learning from others with PD, their care partners, and invited guest speakers are clearly of benefit. Regular exercise, some just plain essential and others just for fun, are a no-brainers. For me, participating in support group gatherings is more. They also provide me with the opportunity to socialize and learn from others who have similar challenges, and find positive ways to deal with them. I know that our open dialogue happens with heart as well as mind.

I am learning from others in the group--some of this learning is needed to recognize my limitations. For example, my voice and occasional words of wisdom are not always heard and clearly understood. So, I continually hear, "Joel, please speak louder". Although my ego defenses say "I'm really trying," I am grateful to others for ringing my bell. Madeline Sofranac, my exercise guru, encourages me, in an empathetic, however clear concise direct manner, to stay the course with regular exercise.

We talk story about a lot of serious topics, and occasionally we are distracted from lengthy serious dialogue with some Polish style commentary from Mike Schrieber. Some humor, at times, is needed to lighten things up for real listening. So, as stated in the dictionary, all of this is good for me to grow emotionally, physically, and intellectually. It's working!

June 7 Waimea Talk Story Topic

Research indicates a relationship between gut issues and PD occurring prior to and after diagnosis. This will be the primary subject of the day at Tutu's House beginning at 1pm on June 7. Conversation, as always, will focus on Q&A dialogue learning how others deal with their challenges.

Madeline Sofranac's exercise class follows next door at Cross Fit Gym at 2:30.

Care Givers/Care Partner Corner

By Phyllis Tarail

Participating with 7 others in the care partner breakout group in Hilo on May 26 was extremely beneficial to me. Learning about how other care partners are dealing with PD in their homes including various coping and planning mechanisms for the future did my heart and mind good. I really look forward to the next support meeting of the care partners and I encourage others to attend.

Newsletter Items From You

Since we are all part of a Hawaii Island Parkinson's community, we continue to look for short articles-- information that may be helpful to others, particularly personal stories "from the heart" written by YOU!--PWP's (people with Parkinson's), care partners, friends, medical folks--to include. Please send your item not to exceed 200 words to Jcohen8@hawaii.rr.com and ptarail@hawaii.rr.com for the next edition no later than the 3rd Friday for consideration in the up and coming month's edition.

"KEEP MOVING, KEEP SMILING"

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June

2017

Hawaii Island

Parkinson's Monthly Activities

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
				1	2	3
4	5 58	6	7	8	9	10
	11:00 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:30 am Deep Water Aerobics with Maddy at HPA Pool 1:00-2:30 Talk Story—Tutu's House 2:30-3:30 pm PD Exercise—Crossfit Gym	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 8:30 am Chair Yoga at Tutu's House	
11	12	13	14	15	16	17
	8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:30 am Deep Water Aerobics with Maddy at HPA Pool	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 8:30 am Chair Yoga at Tutu's House	
18	19	20	21	22	23	24
	8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:30 am Deep Water Aerobics with Maddy at HPA Pool	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 8:30 am Chair Yoga at Tutu's House 2:00 Hilo PD Support Group Meeting	
25	26	27	28	29	30	
	8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:30 am Deep Water Aerobics with Maddy at HPA Pool	8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 8:30 am Chair Yoga at Tutu's House	