



A PD Patient Perspective by Joel

Are you looking for easy ways to cure your PD symptoms? Unfortunately we cannot find them. There is nothing generic about PD. We all, to at least some extent, differ in our symptoms. Definitely different strokes for different folks.

For me, my challenges can only be resolved by viewing my life as a long-term journey doing what I **have** to do. It's adjusting and hopefully, transforming them from frustration and despair to discovering positive ways to move forward.

I have learned to understand that becoming as healthy as possible, for me, requires the following (1) patience, (2) perseverance, (3) acceptance, and (4) the courage to hang in there and do what has to be done. This includes regular exercise, ingesting food and drink that nourishes me, and listening to the guidance of my loving care partner.

Over what has turned into at least a quarter of my life, I have learned that on the long haul, only **I** can create change. So, in a hopefully humble manner, I recognize my accomplishments and reward myself with a personal *atta boy*. This not only makes me feel better, but hopefully, also does the same for other characters in my lifelong play.

New Exercise Classes in Hilo

Experts agree that regular exercise is important both physically and emotionally for people with PD to stay as healthy as possible.

Thanks to HPA's Kevin Lockette, weekly, specialized exercise classes began on April 26 at the Hilo YMCA, located at 300 Lanikaula Street. The classes will continue every Wednesday from 9:30 to 10:30 am. Hilo Support Group leader Fran Calvert strongly encourages your participation. An initial membership/application fee of \$50 is required. The monthly class cost is \$32, which allows you to participate in all activities and services that the YMCA provides. Hawaii Island Kaiser will cover the cost. Other insurance carriers may also provide financial incentives.

Please call the Hilo YMCA at 935-3721 with your questions.

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April Hilo Support Group

Ride with Larry is an inspiring story of Larry Smith's 5-day cycling trip across South Dakota through rain and shine.

The award winning film, was scheduled for their March talk story meeting, however, the around the circle check in proved to be so beneficial to those attending that there was not enough time to show the documentary, so, it was postponed and shown on April 21. The Hilo group will return to their 4th Friday schedule in May at the ADRC building, 1055 Kinoole St. starting at 2pm. Please contact Fran Calvert at fcalvert@hawaiiintel.net for more information.



Hawaii Parkinson's Association Annual Symposium



HPA held their annual statewide gathering in Honolulu on April 1. According to Waimea participant, Rob Shallenberger, most of the 200 attendees were members of support groups from all over the state.

The keynote speaker, Dr. Webb Ross, focused his comments on updating the crowd on the latest research being conducted, including many studies that are happening in Hawaii. He was joined in the second half of the program by a panel of Parkinson's medical practitioners including Drs. Melvin Yee, Ami Gupta, Pat Borman, Michiko Bruno, and Leo Maher. You can view Dr. Ross' speech, and the Q&A questions from the audience at parkinsonshawaii.org

**May Waimea PD Support Group Topic
Medical Marijuana as an Alternative**

The subject of medical marijuana (MM) and its potential benefits is a big one, so our May 3 meeting will narrow the focus to discussing the subject on the effectiveness of marijuana in treating symptoms of PD. Therefore, we encourage as many PWP's (people with Parkinsons) who are using or have used, medical marijuana to attend this meeting. With this in mind, we have created the following questions for users:

1. How long have you used MM and when did you start?
2. How do you take it? Eat, drink, smoke or?
3. How much do you use? How did you determine how much and how often?
4. What else are you taking for your PD? Prescription drugs? Supplements? Treatments—e.g. acupuncture, special diets, etc.?
5. How do you feel that MM helps you?

We are pleased that our Hilo PD Support Group facilitator, Fran Calvert and her husband Glen, will be attending and we look forward to seeing many of you. We'll not only get answers to the above questions, we'll all have an opportunity to ask our own questions.

Waimea PD Support Group Schedule Changes

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**. There is

no change in the June meeting time. The primary topic for June will be "gut and related issues."

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.

Dance for PD Community Class Video

Here's a link to a clip of a Dance for PD instructor David Levinthal's community class. It will likely at least put a smile on your face. The video is of an hour-long class. You'll start from the beginning and may not stop. Go to capture.nbs-enb.ca/27/watch/1250.aspx

Dance for PD in Kona

People with PD and their care partners are encouraged to join West side PD participants on your next shopping trip to Kona. The Spring series of Dance for PD classes are led by certified instructor Marie Alonzo Snyder. Classes continue every Wednesday through June 14 from 1-2:30 pm at Hale Halawai, 75-5760 Alii Drive. The class is by donation. You can RSVP and get more information by e-mailing Marie at marie@isnyders.com.

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Visit to the Tucson Arizona PWR Gym

Madeline Sofranac leads a variety of exercise classes that play an important role in the Waimea Support Group's overall programming. She is a certified Parkinson's Wellness Recovery (PWR) instructor. The PD specialized program, developed by Becky Farley, is based on moving "Bigger and Faster every day."

Phyllis Tarail and Joel Cohen stopped by the Parkinson's Wellness Recovery (PWR) gym in Tucson on March 29. The gym has a membership of 150 including people with PD. A wide variety of daily classes and special activities are scheduled based on levels of ability.

The structured exercises that help retrain the brain are designed to deal with both the wide scope of PD physical limitations and also with non-motor symptoms such as depression, anxiety, apathy, and fatigue...all too common challenges facing people with PD.

You can order Becky Farley's exercise guide booklet by going to www.pwr4life.org

May calendar highlights:

May 3, 1-2:30 pm--Waimea Parkinson's Support Group at Tutu's House. The focus will be on specific questions about medical marijuana as used by people with PD.

May 3, 10, 17, 31; 9:30-10:30 am—specialized PD exercise at the Hilo YMCA

May 26, 2:00-4:00 pm—Hilo PD Support Group at the Hawaii County Department of Aging, ARDC building

Madeline Sofranac's classes:

- Deep Water Aerobics at the HPA Pool in Waimea Mondays 8:30am, Wednesdays 11am
- Mauna Lani classes on Tuesdays and Thursdays-- Ai Chi (warm water meditative motion) 8:30am at the Spa & Shallow Water Aerobics 10am at the Resort Pool

Contact Madeline at masofranac@gmail.com for more info, including cost of the pool classes.

Parkinson's Disease Foundation

This foundation offers a variety of free booklets that are helpful to people with Parkinson's and their care partners. The brochures and booklets are concisely and easily read and include a host of topics. The Waimea and Hilo support groups have a limited supply for distribution at our meetings.

Davis Phinney Foundation

Every Victory Counts is their all-inclusive publication covering the full spectrum of helpful information including PD symptoms, treatments, effects of medications, diet, and emotional health. The publication differs from others as its emphasis is on the patient and care partner perspective. You will find many personal quotes that likely will hit home including from Davis and his wife, Connie Carpenter.

"We wake up in the morning expecting a good day. That's where it starts-every day".

You can order Every Victory Counts by going to their website, davisphinneyfoundation.org

Words of Wisdom from Sue

Depression, at least as a short-term challenge, commonly occurs with People with Parkinson's. Sue Lifschiz shares the following suggestions that help her get her through these times.

1. Make a list of at least 5 things you can do easily that make you happy. Examples of her personal approaches include baking cookies, listening to music, making jewelry, exercising in the water, soaking in a bubble bath, and making a gift for a friend.
2. When you are feeling down, go to your list and pick one activity from it. Try to put all your energy into that activity, and see if that alleviates your down and discouraged feelings.
3. You do not want to make this a habit for obvious reasons, however, scooping a fair share of your favorite ice cream (mocha almond fudge in Sue's case), may help too! I

Caregivers/Care Partners Corner

By Phyllis

In last month's piece I talked about Joel's challenges. Well, he and I still have those, but I am happy to report that his pain and discomfort are much reduced—enough that we will both be back to the gym at least twice a week beginning this month! That's a big plus for both of us, because we've been away from the gym for the past 2-3 months and we know how important exercise is for us. Joy and gratitude continue to be guiding us to find fun, somehow, every day and appreciate all that we have.

I continue to encourage care partners to write a piece on your challenges, your feelings, your thoughts, your suggestions that we can include in this section of the newsletter!

Newsletter Items From You

We are all part of a Hawaii Island Parkinson's community. We are looking for short articles-- information that may be helpful to others, particularly personal stories "from the heart" written by YOU!—PWPs (people with Parkinson's), care partners, friends, medical folks—to include. Please send 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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May

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Hawaii Island

Parkinson's Monthly Activities

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
	1	2	3 11:00 am Deep Water Aerobics with Maddy at HPA Pool 1:00-2:30 Talk Story—Tutu's House 2:30-3:30 PD Exercise—Crossfit Gym	4 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	5 8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay	6
7	8 11:00 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	9 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	10 11:00 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 PD Exercise—Crossfit Gym	11 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	12 8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay	13
14	15 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	16 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	17 11:00 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 PD Exercise—Crossfit Gym	18 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	19 8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay	20
21	22 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	23 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	24 11:00 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 PD Exercise—Crossfit Gym	25 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	26 8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 2:00 Hilo PD Support Group Meeting	27
28	29 MEMORIAL DAY	30 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	31 8:30 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 PD Exercise—Crossfit Gym			