



A PD Patient Perspective by Joel

Researchers estimate that 60% of people diagnosed with Parkinson's Disease fall into depression at some point. Many, if not most, experience serious symptoms for a lengthy period prior to diagnosis. I definitely fell into this group creating significant changes in how I felt about myself and how I dealt with day-to-day challenges.

My past life prior to diagnosis included working as a Human Resources Management analyst, trainer, and someone who continually put on a face of positivity at the worksite. Literally, years went by as I felt life-

altering changes in my health. Organizing, solving problems, and staying as cool under pressure as possible, once my signatures, became challenges-- slowly and progressively lessening how I viewed myself.

My symptoms included unexplained fatigue, anxiousness, frustration, inability to speak concisely and clearly, and worse of all--feelings of being lost and bewildered. Finally, in May 2001, I recognized that my professional life was over. I left my job with both a sense of relief and one of self-doubt.

Retirement in Hawaii became a blessing. However, my symptoms continued to get worse until finally, in June 2004, my primary care physician referred me to neurologist who diagnosed me with PD--actually something positive, finally knowing that there was an explanation for my decline. I continued to be depressed at times. However, at least I began to realize that PD was a cause.

Life is a journey for sure. New challenges occur with age and advancement of the disease that require adjustments in my lifestyle. Physical activity, although progressively difficult, staying as positive as possible, and acknowledging limitations are part of my daily routine. I am a member of a local PD support group, and I am able to share my thoughts with others. Challenges yes--however, there is joy in my life. Let the journey continue for me and for you!

Waimea March Support Group Meeting

16 people attended our March meeting, including Sue Lifschiz' daughter, Jill, also a PWP, visiting from Tacoma, Washington. Jill is an Ambassador of the Davis-Phinney Foundation and she gave us lots of info and handouts about what the Foundation is doing. We also discussed "Challenges of Daily Living with PD," a topic that surely will come up again over the next months.

Ride With Larry in Hilo

Waimea Wellness Support Group members had the opportunity to view the award-winning documentary on February 23. Sue Lifschiz describes it "as a moving inspiring story of courage, determination, hope, and love". Ride with Larry will be shown again in Waimea if enough people show interest. The Hilo PD Support Group will show the film at their **March 24** meeting at **2pm** at the Aging Disability Research Center (ARDC) in Hilo. Please contact Fran Calvert for more information at fcalvert@hawaiiintel.net

Hawaii Parkinson's Association

HPA is holding their annual symposium on April 1 from 9am until noon at Queen's Hospital in Honolulu. Rob Shallenberger is representing the Waimea PD support group and Fran Calvert will attend on behalf of the Hilo group. You can send your questions to the conference speakers via an online form available on

the HPA website. In addition, HPA is working with Queens' Hospital to create a way for you to view the gathering on neighboring islands. We'll update you if arrangements are made.

Joel and Fran will be representing Hawaii`i Island on the HPA Board effective April 1st and the other neighbor islands will also have representation as of that date. It will be great to have the opportunity to provide input and feedback directly to HPA!

Medical Marijuana as an Alternative

Hawaii Island support groups are now discussing the subject of the effectiveness of marijuana in treating symptoms of PD. Research is occurring relating to marijuana as viable alternative or an addition to the current treatment of PD.

According to Zvi Loewy, immediate Past Dean at Touro College of Pharmacy in California, there is good evidence that marijuana, binding with dopamine receptors may help with the effects of dwindling dopamine, and may affect motor symptoms such as tremors and rigidity, and also can reduce pain, insomnia, and depression. You can go to academicminute.org/2017/zvi-loewy-touro-college-of-pharmacy-cannibis-and-parkinsons-disease/ for more details.

Also supporting this conclusion is a February 16 article in the New York Times relating to use of marijuana for the elderly. According to the article, the drug is commonly used successfully in retirement communities for chronic health issues including PD. It also states that more research is needed to provide data on the efficiency and safety of marijuana and what molecular components are the most effective.

Stay tuned. The Hilo and Waimea PD Support Groups plan to explore medical marijuana in more detail at future meetings.

Mucuna Research

Our "Dance for PD" instructor, Marie Snyder, is supporting a student who is researching the benefits of the plant mucuna on PD. Tanya Denne made a presentation at the World Parkinson's Congress regarding the research she is doing with Amula Soumyanath, Phd at Oregon Health and Science University. Mucuna has been used in India for centuries for "Kamptvata" a disease she says is similar to PD. You can find more information regarding her efforts for funding by going to indiegogo.com/projects/new-avenues-for-Parkinson-s-treatment/.

Every Victory Counts

The Davis-Phinney Foundation provides quality information that is helpful to people with Parkinson's and care partners. They publish a free manual, "Every Victory Counts" that can be ordered on their website. It covers a wide scope of information including daily challenges that we face and suggestions relating to your approach to medical professionals. Go to davisphinneyfoundation.org to get your free copy.

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER

March/April 2017

Sonoma Parkies

Sue Lifschiz suggests that we check out the website of her mainland support group, the volunteer led Parkinson's Support Group of Sonoma County (parkinsonsonomacounty.org). They meet monthly with special activities including a PD men's group, and Dance for PD and singing classes.

Staying Regular

How to Make Homemade Sauerkraut in Mason Jar

Here is the "end" article. Thanks to Sue Barton, we likely have a remedy for constipation. Go to the.kitchen.com website for the recipe. You will find what is needed to ferment raw cabbage into a form that's probiotic. It's time tested by Madeline Sofranac and Phyllis Tarail. You can also buy it at the natural food store for \$12. Buying a cabbage with some inexpensive additives is cheaper.

March/April calendar highlights:

March 1, 1-2:30 pm--Waimea Parkinson's and Neuroplasticity Wellness Support Group at Tutu's House. This meeting already took place. We briefly touched on the subject of the use of medical marijuana, particularly as it was used and seen in "Riding with Larry."

March 24, 2-4 PM--Hilo Support Group:

Showing of the documentary Ride with Larry. The Waimea group saw this film on February 23rd and found it very moving and evocative of several subjects close to the hearts of the viewers.

April 5 1-2:30 PM—Waimea Parkinson's and Neuroplasticity Wellness Support Group at Tutu's House—**Topic will be Gut Health and PD.**

April 28. 2-4 PM—Hilo Support Group

Madeline Sofranac's classes:

- **Empowerment Through Movement (PD Exercise)**—every Wednesday, from 2:30-3:30 pm at Crossfit Gym, Waimea (next to Tutu's House). Every month has the same schedule: Week 1—PWR Moves; Week 2—Martial Arts (Tai Chi, Chi Gung & boxing); Week 3—Dance for PD Inspired; Week 4—Circuit Training
- 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.

Caregivers/Care Partners Corner

By Phyllis

Every day sometimes brings new challenges for me as Joel's care partner—watching him deal with pain and discomfort—most of which is unrelated to his PD. I have 2 words that have been guiding me the past few months—joy and gratitude. Whew!—some times it's hard to see either one, but I come back to my breath and look to what WE can do to find some fun in that moment and appreciate what we have together. I encourage care partners to write a piece on your challenges, your feelings, your thoughts that we can include in this section of the newsletter!

Attention Writers and Would-be Writers!

We are looking for short articles “from the heart” written by YOU!—PWPs (people with Parkinson's), care partners, friends, medical folks—to include in upcoming newsletters. Plus, if you see an article online, briefly describe it and include the link and we'll post the description and the link. Now we want to hear your perspective.

Thank you for being part of the Hawaii Island Parkinson's community. The next edition of the newsletter is scheduled to be out by May 1. We'd love to consider your submittal. There is a limit of no more than 200 words. Please include your name, e-mail address and phone contact number--deadline is April 17.

Here's how to contact us:

Madeline at masofranac@gmail.com

Editors:

Joel Cohen at jcohen8@hawaii.rr.com

Phyllis Tarail at ptarail@hawaii.rr.com

“KEEP MOVING, KEEP SMILING”



HAWAII I ISLAND PARKINSON'S COMMUNITY NEWSLETTER

March/April 2017

March

2017

Hawaii Island

Parkinson's Monthly Activities

| Sunday | Monday | Tuesday | Wednesday | Thursday | Friday | Saturday |
|--------|---|--|---|--|---|----------|
| | | | 1 | 2 | 3 | 4 |
| | | | 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 | 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool | | |
| 5 | 6 | 7 | 8 | 9 | 10 | 11 |
| | 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 | 11:00 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 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 | | |
| 12 | 13 | 14 | 15 | 16 | 17 | 18 |
| | 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 | 11:00 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 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 | | |
| 19 | 20 | 21 | 22 | 23 | 24 | 25 |
| | 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 | 11:00 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 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 | 2:00 Hilo PD Support Group Meeting "Ride with Larry" documentary showing | |
| 26 | 27 | 28 | 29 | 30 | 31 | |
| | 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 | 11:00 am Deep Water Aerobics with Maddy at HPA Pool 2:30-3:30 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 | | |