

**“Discipline is just doing the right thing the right way
whether any one’s watching or not.”**

Michael J. Fox

A Parkinson’s Patient Perspective

Joel Cohen

As I reach the ¾ of a century mark at 75, it's time to reflect on what I have learned about Parkinson's Disease since my diagnosis in 2004.

Nothing changes immediately. Evolution is a better way to describe my life at this point knowing that containing the inevitable progression of PD, and just getting older, requires patience, perseverance, and a real desire to smile and be grateful for what I have and what I can still do.

Being part of a support group began with personal apprehension and uncertainty about sharing my experiences with others about my PD. My wife, Phyllis, my caregiver and sometime nudge, strongly encouraged me in no uncertain terms to take a chance. So, I began on this positive path. Writing this newsletter is an example that it's working for both of us.

Here are some specific things that I have learned. I'm not sure that I have the personal discipline to regularly follow my self-proclaimed words of wisdom, however, I try.

I appreciate the fact that Phyllis really has my best interests in both heart and mind really supporting me in my efforts to do my thing. She sorta knows that I'd rather do it myself without too much of her support. Well, maybe being real about it, my ability to do everything I'd like to do is not so real.

I've learned that there are no easy or miracle cures for PD. So, I take ads and commentary regarding easy remedies with a grain of salt knowing that I am different from others in what symptoms I have and what ways are best for me to deal with them. For me, it's about taking my medications and supplements in a timely and regular basis knowing that it's really a process of trial and error, changing as I go, just figuring things out over the long haul.

Then there are the obvious and unquestionable lifestyle changes that are essential for all of us to stay as healthy as possible. The list is simple, however, realistically, challenging at the same time.....Drink lots of water. Eat a healthy diet without going crazy about it and indulge at least occasionally, and for sure exercise our bodies to the maximum we can handle, just to continue to make ourselves happy and hopeful-likely the bottom line for all of the above.

2017 HPA Walk

The Hawaii Parkinson's Association Walk 2017 will be held at Magic Island in Honolulu on Saturday, November 4 from 9am until noon. This is the major annual fundraiser for our organization.

This fun event attracts people of all ages and abilities. It features a 3k walk, live entertainment, a health fair, and an opportunity to join in doing special exercises with all who attend.

Proceeds from the event will go to support our island's support groups and special activities and programs.

The HPA Board of Directors, led by president Jerry Boster, is expanding its vision to reach out to provide more support for neighbor islands. The walk is an opportunity to highlight our Island's involvement in the statewide mission.

It's all about big picture ohana in supporting people with PD and care partners. You can go to the HPA website and make a donation, or better yet attend yourself and join the Hawaii Island Movers and Shakers Team OR sponsor a member of our team. Look for an email coming soon with information on how to do this.

Parkinson's Showcase



Linda Ronstadt—A PWP/Parkie

One of Joel's favorite all time singers with a bevy of hits over at least 4 decades, Linda Ronstadt had to stop her singing career when Parkinson's took her singing voice. Nevertheless, she perseveres with other activities, including becoming an author writing her memoir, "Simple Dreams," and occasionally making public appearances to promote the book and to talk about how her singing career interfaced with composers and other musicians and singers.

Madeline's Return

Specialized PD exercise classes, taught by Madeline Sofranac DPT, return to Waimea on Wednesday, **October 11 starting at 2:30 at the Allstar Cross Fit gym** immediately after our Waimea PD Wellness Support group gathering at Tutu's House. Future PD exercise classes will be scheduled based on your interest.

Wear comfortable clothing. Bring water. Have a desire to be as healthy in mind, body and spirit as possible.

It's a time not only to keep the body and mind in good shape but also a time just to have some fun with others who are experiencing the challenges of PD.

Madeline adapts exercises to your ability and pace level doing a variety of movement activities including tai chi and chi gung, PWR moves, and her personal take on boxing and Dance for PD.

Madeline also teaches other classes, including a monthly Tai Chi/Gung class at Tutu's House—next class is November 13th at 1:30 pm. Contact her at msofranic@gmail.com for more information.

Dance for PD in Kona

Our island is fortunate to have a specially trained Dance for PD teacher, Marie Snyder, EdD. Her passion for dance as a way to move the body, improve focus, and generally have some fun in the process is unquestionable.

Tuesday is generally a slower than average day at COSTCO. So, you may want to attend her November classes as part of your shopping trip to the West side. Her classes are scheduled on November 7-28 from 1:15 until 2:15 at Kona Dance and Performing Arts In Kealahue. Contact Marie at marie@synders.com



September 19 HPA Board Meeting

The HPA Board of Directors met on September 19 (Joel attended via conference call). Long term planning, partnerships with other organizations, and additional support for neighbor islands were the highlights of the meeting.

The Board welcomed a new member, Patricia Bemis. Pat, is a retired nurse who has extensive experience in organizing and leading PD caregiver programs and groups. She expressed a desire to visit our island, participate in meetings, and provide necessary support and guidance in our continuing development of caregiver support activities.

One of President Jerry Boster's plans is to contract with a neurologist to finance continuing education for specialization as a movement disorder specialist who concentrates his/her practice on the neighbor islands. This will benefit our island greatly, not having to travel to Honolulu.

The next HPA Board meeting is scheduled on December 5. You can provide input by contacting Hawaii Island board representatives Fran Calvert (at fcalvert@hawaiiantel.net) or Joel Cohen (at jcohen8@hawaii.rr.com.)

Hawaii Pacific Neuroscience Institute (HPN) Reps Coming to Our Island

The **Waimea PD Wellness Support Group** meets next at Tutu's House on **Wednesday, October 11th from 1-2:30 pm** and we will be greeting 2 researchers from HPN who will fill us in on the current PD research that they are conducting in Honolulu. The research team's mission is to develop working relationships with support groups on the neighbor islands and they are very interested in being involved in an open discussion. HPN specializes in advanced care and research treatment of a wide variety of neurological disorders. As always, we will also be sharing our thoughts on a wide variety of PD topics.

The **Hilo PD Support Group** will have the opportunity to hear from the HPN reps at the **October 27th meeting at the ARDC in Hilo from 2-4 pm.**

The Hilo YMCA PD exercise class continues meeting every Wednesday morning at 9:30 AM. Contact the Hilo YMCA for more information.

Preparing for a Visit with Your Doctor

Time with your doctor moves fast...Fifteen minutes goes by so quickly. We have a progressive medical challenge with new and increasing symptoms continually occurring. So, here are some suggestions of how to prepare for your next visit:

- Write a list of what symptoms are now bothering you, but focus on 2-3 that are the most troublesome.
- Be specific about what you are now doing to alleviate the symptoms and ask for specific help where you need it.
- Hand the list to the doctor.

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!--PWPs (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.

Joel Cohen—Writer/Editor
Phyllis Tarail—Writer/Editor

Care Partners/Caregivers Corner

Phyllis Tarail

On Friday, September 29th, members of the Hilo PD Support Group broke into 2 smaller groups—the PWP/Parkies (all men with 1 woman) together and the 7 care partners (all women) meeting in another room. This is the second time some of the care partners have met separately and as one who has been to both, I can't say enough about how helpful it was for me. Hearing others dealing with some of the same issues and, more importantly, getting their ideas on ways they work through, overcome, or deal with these issues, helps keep me going through my frustrations and challenges. These separate meetings will continue to be offered on a (mostly) quarterly basis, so stay tuned for dates of future gatherings, and I hope to see you there!