

## HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER

July 2017



### A Patient Perspective By Joel Cohen

**Humor.** There certainly is nothing funny about dealing with the symptoms of Parkinson's—e.g. pain, mobility issues, anxiety, depression, constipation, etc. So, how can I inject some humor into my life each day that will help me deal with the many Parkinson's symptoms in my daily life? Well, people's use of the term "Parkies" certainly lightens up the picture. This is okay and acceptable for me. It actually gives me a special identity that helps me not be so self-conscious and inordinately serious about my health challenges.

I have to do whatever I have to do to at least try to relieve my mind and body during my highly uncomfortable "crappy days," especially ones where my internal organs are literally in slow-mo with the continuing challenge of irregularity and constipation.

Stress is my biggest challenge. Tremors are relatively minor compared to others, however there are times when I become a bit disoriented, unglued and unfocused. My wife suggests (mildly put) to slow down, because I am experiencing tremors in my jaw and left hand. Being self conscious about this, I head off to the nearest mirror for a look-see focusing on my reflection coming off

the glass. This reveals nothing wrong except continuing view of aging. Hello, I have Parkinson's, and it's a resting tremor.

Cognitive issues have really affected me in the past. Where am I? Why am I here anyway putting myself in a near impossible, intolerable situation? Do, I want to be standing in a line at Foodland feeling like others are looking at me with a sense of avoidance and discomfort? Do I really want to get into a serious conversation with someone who is not understanding the importance of my well thought out opinion? As the leader of my support group, do I recognize that it's better to hand the ball over to someone else to continue the conversation when my well-intentioned facilitation skills go south?

The good news is I've learned to live with the Foodland wait. My Parkinson's is what it is and it's okay. I'm "right," at least most of the time, regarding the disagreeing conversation, and yes, I need to find a way to turn over the discussion in the meeting.

For sure, PD is a super bummer, and making fun of the symptoms is really not something that others may want to hear... especially the newly diagnosed and those who are experiencing a physically or emotionally bad day. So although it's important, humor must be appropriately timed.

Saying this with some emotion, my Parkinson's challenges come with the territory. It's important for me to understand that in spite of it all, life is better when my smile, laughter, and mindful sense of humor flows throughout my body. Possibly, this contributes to a mutually contagious feeling of joy that I can share with others.



**Steve Sakala**

**Cannabidiol & Its Medical Uses—7/15 Talk Story at Tutu's House**

Cannabidiol (CBD), one of the non-psychoactive cannabinoids found in cannabis and medical hemp, is the topic to be presented at Tutu's House in Waimea on July 15 at 2pm. The guest speaker is Steve Sakala, owner of HiCBD Organics and Honaunau Farm Wellness Retreat. Steve has been educating people about medical cannabis for nearly 20 years, the last 6 of those focused on high CBD strains. This is an opportunity to learn and ask questions regarding possible medical benefits of CBD.



**Tai Chi at Tutu's House**

Tutu's House also provides a variety of non-fee health related classes and programs including the Waimea PD Support group's monthly talk story, chair Tai Chi/Chi Kung, and chair yoga. You can contact Tutu's House at 885-6777 for more information.

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### **Schedule Change For Waimea PD support Group**

The Waimea Parkinson's Wellness Support Group talk story meetings move to the second Wednesday of the month, starting this month on July 12 from 1-2:30 at Tutu's House in Waimea. Participant sharing begins the meeting with the central topic of the day "Non-motor symptoms of Parkinson's." Possible items of discussion include cognitive decline, anxiety and depression, sleep disorders, chronic fatigue, compulsive behavior, and fear of socialization. Please come with your suggestions for future guest speakers. After the talk story, we'll continue the monthly gathering with Madeline Sofranac's exercise class next door at Cross Fit Gym at 2:30.

### **Suggested Home Work**

There is an excellent ½ hour video by Dr. Benzi M. Kluger, Assistant Professor of Neurology and Psychiatry at the University of Colorado at Denver on the Davis Phinney Foundation video library website related to non-motor symptoms worth watching prior to the gathering.

### **Policy and Legislation**

A number of national, regional and local Parkinson's organizations have banded together to strengthen their policies regarding federal legislation. This includes the following: Funding for the Centers for Disease Control and Prevention's (CDC) creation of data based systems that can be used for research promoted by Georgia Senator Johnny Isakson, a PD patient himself. The RAISE Family Caregivers Act is currently before the Senate that creates a policy council of state and local officials to promote

support to caregivers currently in the workforce. Part of tax and healthcare reform legislation that affects a cap on non-profits such as PD support organizations, as well as caps on pre-existing conditions, lifetime insurance, and Medicare for physical, occupational, and speech therapy. More information will be forthcoming as it becomes available. You can, of course, also contact your US senator or House representative for more information.

### **PD Exercise in Waimea**

**Reminder**--Madeline Sofranac's Wednesday PD exercise classes beginning at 2:30 pm at Cross Fit Gym will be temporarily limited to once a month after our talk stories 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 to get moving and share your experience with others. Please call the Hilo YMCA at 935-3721 for more information.



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### **Hilo PD Support Group 6/30**

Frances Moniz, trainer for Hawaii Fido Service Dogs, came with her dog, Bea, to provide valuable information about how service dogs can help people with Parkinson's along with many other types of disabilities. Frances put Bea through her paces picking up a variety of items, including keys, a pill bag and her phone—from the floor and from a chair. These service dogs can be trained with a special rigid harness that can be used to help people up from the floor or a chair and get them moving during a “freezing” episode. Frances is one of only two trainers on our Island, so she recommends applying for a dog at least two years in advance of anticipated need.

### **Hawai'i Parkinson's Association (HPA) Board Meeting**

On June 20th Hawaii Island HPA representatives, Fran Calvert and Joel Cohen, participated in a quarterly HPA

Board meeting via teleconferencing. Subjects effecting our island included grants that HPA is seeking, funds available for training, evolving partnerships, future discussion of providing financial support for specialized exercise classes, fund raising events, and the newsletter that you are now reading. The next Board meeting is scheduled on September 12. Look for more information at our talk story gatherings with Fran and Joel.

### **Care Givers/Care Partner Corner**

By Phyllis Tarail

Sometimes it's hard to tell the difference between my “Parkie” husband's behavior—is it related to his PD, or is it HIM?? In our situation, Joel had PD (undiagnosed) when I met him 28+ years ago, so I can't always tell. When I get impatient with him (all too frequently) and I have to repeat myself, I try to remind myself that it's not that he's not listening, it's his PD. This is not always easy for me. The next step is breathing deeply. I highly recommend breathing in all circumstances.

### **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](mailto:Jcohen8@hawaii.rr.com) and [ptarail@hawaii.rr.com](mailto:ptarail@hawaii.rr.com) for the next edition no later than the 3<sup>rd</sup> Friday for consideration in the up and coming month's edition.

**“KEEP MOVING, KEEP SMILING”**

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## Hawaii Island

## Parkinson's Monthly Activities

Sunday	Monday	Tuesday	Wednesday	Thursday	Friday	Saturday
30 11:00 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	31 11:00 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House					1
2 11:00 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	3 11:00 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	4 HOLIDAY	5 8:30 am Deep Water Aerobics with Maddy at HPA Pool	6 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	7 8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 8:30 am Chair Yoga at Tutu's House	8
9 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	10 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	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 8:30 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	13 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	14 8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 8:30 am Chair Yoga at Tutu's House	15
16 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	17 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	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 8:30 am Deep Water Aerobics with Maddy at HPA Pool	20 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	21 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	22
23 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	24 8:30 am Water Aerobics with Maddy at HPA Pool 1:30 pm Chair Tai Chi/Gung at Tutu's House	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 8:30 am Deep Water Aerobics with Maddy at HPA Pool	27 8:30 am Ai Chi with Maddy at Mauna Lani Spa 10:00 am Shallow Water Aerobics with Maddy at Mauna Lani Pool	28 8:00 am Beach Yoga with Maddy at Anaeho'omalua Bay 8:30 am Chair Yoga at Tutu's House	29