

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER

August/September 2017

"Acceptance doesn't mean resignation. It means understanding that something is what it is, and that there's got to be a way through it".

Michael J. Fox



**Jerry Boster—President of the Hawai'i Parkinson's Assn.
Parkinson's Community Profile of the Month**

Hawaii Island support groups are affiliated with the statewide-focused Hawaii Parkinson's Association (HPA). This edition introduces HPA's new president, Jerry Boster. With encouragement from a friend and his wife Janice, he sought medical treatment and was diagnosed with Parkinson's in 2013. This motivated him to research available information on the internet and in publications relating to available treatment of his symptoms. This included participating in a nicotine study conducted by Dr. Web Ross.

Jerry became a member of the HPA Board of Directors in 2005, and he became president of our organization on April 1. Jerry comes to the position with extensive leadership and management experience. A graduate of the U.S. Naval Academy, he is a retired commander in the U.S. Navy serving in a wide variety of leadership capacities over a period of 29 years.

In preparation for assuming the role of president, he was invited to (and participated along with other federal, state, and local representatives) in the Michael J. Fox sponsored National Parkinson's Policy Forum in Washington D.C. He subsequently became a member of the nationwide Unified Parkinson's Advisory Council.

Here are examples of how Jerry views HPA's long term mission: As the numbers of people diagnosed with PD increases across the state, he sees a need for HPA to increase support and expand the numbers of talk-based PWP support groups, exercise groups, as well as developing groups dedicated to caregivers. He feels that this vision will become a reality by creating more medical and non-medical business partnerships, securing more funding through available grants, donations from families and individuals affected by PD, and by encouraging more medical professionals to focus their careers on the neurosciences.

HPA Hawaii Island board members, Fran Calvert and Joel Cohen look forward to working with him to expand program opportunities available to people with PD and their care partners on our island.

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Rob's DAT Scan

A neurologist's initial diagnosis of Parkinson's Disease is generally correct. According to Dr. Thomas Davis of Vanderbilt Medical Center, the DAT scan is available to differentiate symptoms from other causes, specifically essential tremor and to confirm the initial diagnosis is correct.

Waimea Wellness Support group member Rob Shallenberger was initially diagnosed with PD in January 2016. He subsequently saw Dr. Michiko Bruno who determined that the diagnosis "was most likely correct." However, in view of the remaining uncertainty, they mutually agreed that a newly developed imaging procedure, a DAT scan, would help to confirm the diagnosis.

The DAT scan provides a visual indication of the density of the dopamine transporter in the brain. It involves an IV injection of a radioactive drug followed by a scan similar to an MRI. Rob's scan clearly showed a decrease in dopamine that is considered "abnormal", thus confirming the PD diagnosis. He states that "I would have preferred a normal result, however the test resolves the uncertainty of going forward."

You can get more information regarding the procedure by Googling "DATscan."

Steve Sakala--Cannabidiol & Its Medical Uses Phyllis Tarail

Steve Sakala, an organic farmer and owner of Hawaii Island CBD, provided lots of information about Cannabidiol (CBD) to the attendees of this most educational talk story. CBD is one of the many cannabinoids found in hemp, which, he explained, is actually a manmade designation based on a cannabis plant that has .03 THC or less. Early research on the uses and benefits of CBD was done in Israel.

CBD has been shown to very effective in reducing pain in and symptoms of a wide range of different ailments and a pharmaceutical company is in the process of obtaining CBD drug approval. CBD oil can now be purchased in all 50 states over the counter in the form of an extract or a salve/balm.

One of the most interesting pieces of information was that the human body has an endocannabinoid system. This was only discovered in 1992. This system has receptors for cannabis and was designed to bring bodies to homeostatis (balance). For information about this go to www.thehumansolution.org.

Steve recommended a number of Youtube videos to watch for more information on cannabis, especially the CNN Special by Dr. Sanjay Gupta called "Weed"—all 3 parts. For details on multiple studies on different ailments, he also suggested <https://www.ncbi.nlm.nih.gov/pugmed/>.

Fran Calvert from the Hilo PD group also recommended <https://www.projectcbd.org/ciencia/cannabis-pharmacology/cbd-and-parkinsons-disease>



**A Parkinson's Patient Perspective
Joel Cohen**

Receiving a diagnosis of Parkinson's brings reality into focus. Before finally being diagnosed most of us had a variety of preliminary symptoms long before, not knowing the cause.

Parkinson's is an evolving disorder with symptoms often occurring 10 or more years prior to diagnosis. They may show up in a variety of ways, including gastrointestinal related symptoms, inability to think straight, anxiety and sometimes downright depression, life altering daily fatigue and chronic sleep problems.

These symptoms may have come long before the more obvious tremors and non-motor challenges. Looking back, and now understanding Parkinson's, finally being diagnosed was/is really a blessing. I have an explanation for the craziness that was developing in my mind and body. I now have to continue to figure out ways to keep my Parkinson's symptoms relatively stable and at least somewhat under control.

For me, the word "motivation" is so important especially during times of illness and my body parts going into at least temporary disrepair. It is so easy for me to move into a plain and simple acceptance pattern not doing what I know needs to be done--including daily exercise, doing what makes me feel good so I can continue to be as healthy as possible for today, tomorrow, and at least the near future.

Author Steven Pressfield has a great line defining motivation..."At some point, the pain of not doing it becomes greater than the pain of doing it."

So, I hope that my personal, hopefully humble message is one that you will consider and embrace. Together we have opportunities to share our joy and optimism for continuing good times. I hope to see you all at our monthly talk stories and exercise classes.

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August and September Events

We are not providing a calendar for these two months as things are quieter this time of the year.

The Hilo PD Support Group will be meeting on Friday, August 25 and Friday, September 29 at the ARDC building from 2-4 PM.

The Hilo YMCA exercise class continues meeting every Wednesday morning at 9:30 AM.

The Waimea Parkinson's Wellness Support Group will be meeting on Wednesday, August 9 and Wednesday, September 13 at Tutu's House from 1-2:30 PM. There will be no PD exercise classes in Waimea until October, as Madeline will be away.

There will be an HPA Board meeting on September 12. Please email Ideas/thoughts to Fran and Joel. Look for more information at our talk story gatherings .

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.

Joel Cohen—Writer/Editor
Phyllis Tarail—Writer/Editor
Jerry Boster—Contributor
Rob Shallenberger--Contributor

"KEEP MOVING, KEEP SMILING"