

**A Patient's Perspective  
Joel Cohen**

It's Sunday morning, and another day looking forward to my life, wanting to believe that although my chronic health challenge with Parkinson's is progressive, it's moving slowly as I can make possible. At least I want to feel this is the case with the thoughts that I share in this column.

In the past, I have approached my quarterly visits to my to my neurologist sub-consciously making every effort to have him view me as healthy and positive as possible and hoping to have him say "It looks like things are stable Mr. Cohen. See you in 4 to 6 months."

Well, this week, with my wife Phyllis' encouragement, I went to my appointment with a list of ailments that are progressively bothering me. The fact is that health challenges, whether directly or indirectly relating to Parkinson's are limiting me in what I can do. It's becoming abundantly clear that my symptoms are slowly but surely progressing. This is my time with my doctor and this time, I used it in a real way--clear, concise, and honest.

It is important for me to be conscientiously aware of how I relate and interact with my doctor, and more importantly, with my care partner wife, close friends, readers of this column, and all people that I interact with.

In the past, emphasizing how well I am doing and how much I have learned over the many years dealing with my health challenge, I recognize that I may have come across too strongly with others as an expert on how to deal with Parkinson's. The truth is that I continue to have to approach each day with challenges, unfortunately coming more frequently with growing restrictions of what I can do.

I believe that recognizing my increasing limitations is actually good. Lowering the pressure of trying to go beyond my capabilities will allow me the freedom to openly listen to others perspective without that compelling desire to convey my self-proclaimed words of wisdom. Understanding, taking the time to listen before responding, and openness to learning from a different perspective is so important to me.

As is often repeated at our support meetings, we share common challenges, AND we are all in some respect different.

### **HPA 2017 Walk**

The Hawaii Parkinson Walk is **the** major fundraising event of the year for the Hawaii Parkinson's Association. It will be held this year on November 4 at Magic Island, Ala Moana Beach Park in Honolulu.

HPA's mission includes raising the awareness of PD in the community, and supporting those with PD and their caregivers. The Board of Directors' vision for our island focuses on patient care and more specifically, to help expand and create new programs.

Our island's team name is **Hawai'i Island Movers and Shakers**. Representing us will be Marlene Goodwin, Rob Shallenberger, Phyllis Tarail and Joel Cohen.

Mahalo to all those who have already donated in support of the walkers. As of October 31, \$710 has been raised in support of our team. Donations for the Walk are still being accepted up to the date of the walk, November 4. All amounts, however minimal, are appreciated and encouraged. The money raised will help toward fulfilling HPA's vision for our island. Some temporary problems with the website have been fixed. So, if you had a problem donating online at First Giving.com Hawaii Island Movers and Shakers or [parkinsonshawaii.org/walk](http://parkinsonshawaii.org/walk), please try again. You can also mail your check to HPA at P.O. Box 1312, Kailua HI. 96734.



Hilo PD Support Group Meeting 10/27/17

### **Waimea and Hilo October Talk Story Meetings**

At the October 11, Waimea, and 27, Hilo, meetings members of the Hawaii Pacific Neuroscience (HPN) research team, Ashley Chandler and Catherine Chao, came to listen in about our PD concerns. They also provided information regarding HPN's desire to reach out and provide support to neighbor islands.

Ashley and Catherine provided information about HPN's participation in a national clinical trial studying a new drug that deals with down time associated with the use of levodopa carbidopa. Eligibility criteria includes a minimum of 3 years of being diagnosed with PD including continual use of levodopa carbidopa and at least 1

other Parkinson's drug. Those selected will undergo an extensive review process including blood tests, medical evaluation and completion of survey documents. All costs to participate including travel and accommodations for both the PWPs and their care partners are covered by the study. Patient safety during the process is considered a high priority for a person continuing in the trial. See more details at [Study@HawaiiNeuroscience.com](mailto:Study@HawaiiNeuroscience.com) or by contacting Ashley at 808-564-6113 or 808-633-3690.

### **November 8 Waimea PD Support Group Meeting**

The next meeting of the Waimea Parkinson's Wellness Support Group is scheduled on November 8 from 1-2:30 pm. We will continue the discussion of ways to deal with the long list of non-motor symptoms including understanding emotional challenges for both the PWP and care partners, being real about limitations, and understanding the wide scope of symptoms that are likely to occur over time with PD.

### **Recommended Online Videos**

The Davis Phinney Foundation website houses many excellent videos of talks given by various experts on the wide variety of Parkinson's symptoms and their effects on PWPs and their caregivers. We have found that the videos that showcase non-motor PD symptoms are particularly beneficial. The 26 minute video presentation by Joanne Hamilton, Phd, called **The PD You Don't See** is one of the best. We feel that watching it with your care

partner and then discussing it together will contribute to your healthy relationship. It will also aid in facilitating more discussion at our monthly talk story gatherings. You can access the video at [davisphinneyfoundation.org/video/the-pd-you-don't-see](http://davisphinneyfoundation.org/video/the-pd-you-don't-see).

### **Parkinson's Meds Described**

Addie Patterson DO provided general information regarding current prescribed PD drugs at the 2017 University of Florida PD Symposium. Her YouTube presentation outlines pros and cons regarding these drugs. This video may be of particular value to newly diagnosed patients. Go to [www.youtube.com/watch?v=NIMB3gEEQwU](http://www.youtube.com/watch?v=NIMB3gEEQwU) OR for those of us less computer savvy, Google "Addie Patterson video".

**Movement Disorder Specialists**

A movement disorder specialist is a neurologist who has received additional training in Parkinson's disease and other movement disorders including dystonia, chorea, tics, and tremors.

The following movement disorder specialists are listed on the Hawaii Parkinson's Association website:

- Michiko Bruno MD--Queens Medical Center
- Allison Przekop DO--Hawaii Pacific Neuroscience Center
- Stuart Pang MD-- Kaiser Permanente, Moana Lua
- Webster Ross MD--Veterans Affairs
- Melvin Yee MD--Kuakini Office

All are based in Honolulu. Dr. Pang has regularly scheduled appointments in Kona.

The HPA Board of Directors is working on a plan to provide local neighbor island access to a movement disorder specialist in the near future.

**Support and Exercise Group Calendar- November**

Note: Classes open to all levels of ability.

**Waimea**

Wednesday, November 8, 1pm.- Waimea Parkinson's Wellness Support Group at Tutu's House.

No exercise class this month. More information on future classes to come.

Monday, November 13, 1:30 Tai Chi/Chi Gong with Maddy (Madeline Sofranac) at Tutu's House

**Hilo**

The regular last Friday gathering at the ARDC will not be held in November. Stay tuned for future meetings.

Exercise classes continue every Wednesday at the Hilo YMCA at 9:30 am

**Kona--Dance for PD**

November 7-28 from 1:15-2:15 at Kona Dance and Performing Arts, 81-973 Halekii St. in Kealahue. Taught by Marie Snyder. Contact her at [marie@isynders.com](mailto:marie@isynders.com) for more information.

**Caregivers/Care Partners Corner**

**Phyllis Tarail**

Joel and I are excited to be participating in the HPA Walk for the first time and to be doing it with fellow support group members. This is truly a great way to support each other, each with our own challenges. Mine was highlighted in the "PD You Don't See" video—thinking that Joel wasn't listening to me when he simply couldn't remember what I had said or asked him—yet another reminder of my need for patience!!!

**Maurice White--Celebrity of the Month with PD**



**Maurice White** (December 19, 1941 – February 4, 2016) was an American [singer-songwriter](#), [musician](#), [record producer](#), [arranger](#), and [bandleader](#)—and one of Phyllis' personal favorite singers. He was diagnosed with Parkinson's in the 1980s. He was the founder of the

band [Earth, Wind & Fire](#). He was also the older brother of current Earth, Wind & Fire member [Verdine White](#), and former member Fred White. He served as the band's main songwriter and record producer, and was co-lead singer along with [Philip Bailey](#).

He won seven [Grammys](#), and was nominated for a total of twenty Grammys. White was inducted into the [Rock and Roll Hall of Fame](#) and the [Vocal Group Hall of Fame](#) as a member of Earth, Wind & Fire, and was also inducted individually into the [Songwriters Hall of Fame](#).

**Newsletter Submissions**

This is **YOUR** newsletter!! We seek your input on any subject related to PD—written by PWPs, care partners, or friends/family—for future editions of this newsletter. Please email them to Joel Cohen at [jcohen8@hawaii.rr.com](mailto:jcohen8@hawaii.rr.com) and Phyllis Tarail at [Phyllis.tarail@gmail.com](mailto:Phyllis.tarail@gmail.com) by November 27 for the December edition.

Wishing everyone the best of health possible and a wonderful Thanksgiving holiday with gratefulness for all that we have.

Joel Cohen, editor writer  
Phyllis Tarail, editor writer