

HAWAII ISLAND PARKINSON'S COMMUNITY NEWSLETTER Nov./Dec. 2018

This is the last newsletter of 2018 so we want to wish everyone Happy Holidays with the hope for a kind, compassionate upcoming new year.

Important November/December 2018 Activities & News on Hawai'i Island

November 12 & December 10 from 1:30-2:30
Chair Tai Chi/Chi Gung at Tutu's House. Time with Maddy (Madeline Sofranac) is very beneficial & we highly recommend this great class.

November 14 & December 12 (Wednesdays)
from 1-3:00 pm **Waimea PD Support Group**
talk story at Tutu's House. November's focus will be "Dealing with What Is" otherwise known as "Acceptance VS Denial" during the ever changing challenges of PD. December topic TBD.

November 30 & December 23 from 2-5 pm
Hilo PD Support Group at Hawaii County ADRC. Please contact the ADRC or Fran Calvert at fcalvert@hawaiiantel.net for more information.

Hilo PD Exercise—every Wednesday from 9:30-10:30 am at the Hilo YMCA. Contact the Y at 935-3721 for more information.

Rock Steady Boxing--every Monday & Friday from 8:30-9:30 am in Hilo at the Waiakea Recreation Center. Contact Marlene Goodwin at buckup1952@gmail.com for more information.

November 21 & December 19 from 1-3 pm
Kona PD Support Group At the West Hawai'i Community Health Center on Kuakini. They will be meeting the third Wednesday of every month. Contact Tom St. John at tomstjohn1@gmail.com or 925-785-609

1st Meeting of the Kona PD Support Group

Tom St. John, care partner, with his PWP wife Donna at his side led the first meeting with 13 total attendees, including some newly diagnosed PWPs. The opening discussion was focused on issues with travel and then led to other topics of interest.

10/17/18 Kona PD Mtg



Valuable Information for the Newly Diagnosed PWP

The Davis Phinney Foundation has a wealth of valuable information that is helpful to both people with PD and caregivers. This includes podcast presentations including one from a person "relatively close" to the Waimea PD Support Group. **Jill Ater** is the daughter of Sue and Jule Lifschiz. Some of you may remember her, as a Davis Phinney Foundation ambassador, joining the Waimea group conversation with her parents a couple of years ago.

You can listen to Jill's October 17 words of wisdom by clicking on the following link: <https://www.davisphinneyfoundation.org/?s=valuable+information+for+the+newly+diagnosed>. As a young onset person with PD, Jill provides positive encouragement to the newly or relatively newly diagnosed.

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Valuable Information for the Newly Diagnosed PWP (continued)

Summarizing some highlights of her podcast:

- It's okay to make the choices that will make your life easier, whether it's about where you live, your work, or how you spend your time.
- Whatever it is you do, do it now. Don't wait. Don't put your dreams on hold.
- Be patient. It can take a long time to figure out how to treat your symptoms.
- Changing your mindset is critical. This is the new reality.
- Getting involved and giving back are great ways to live with PD.
- It's okay to feel lost. Shift your expectations, and make a new plan for your life.
- Tell people that you have PD. It will help you feel less isolated.
- Participate in support group activities.

You can also find a host of topics, both technical and personal, that will benefit PWP's and caregivers by going to the Davis Phinney Foundation podcast site.

Pat Bemis Hits the Front Cover

Pat is a member of the statewide Hawaii Parkinson's Association Board of Directors and her husband Gardner's care giver/partner. She is among five people who Generations magazine interviewed in their November front-page feature article entitled "Care- Giving in the Cycle of Life." You can read this article along with many others by going to the Generations magazine website www.generations808.com/issues. Pat told us: "I am blessed to have been asked to be a part of the Magazine. I continue to reach out as best I can to provide support and encouragement as we all move along the PD pathway. We all are just trying to put one foot in front of the other even if it freezes, or shuffles, or is slow we continue to try."

Here's a poem she shared from a Colorado PD Support Group:

THE INTRUDER BY Norma Wagner PWP & Support group leader

What is the beast that has taken hold of me?
What am I the one it chose?
The good life I've had is what I want it to be,
Is there a door on this intruder that I can close?

It saw my weakness, into my life it crept,
And when it was named, it was no surprise,
I had suspected, I hoped not, I never wept,
But hated the pain in my family's eyes.

My world is shaky, but the beauty is not gone,
The sun still comes up at the morning's dawn,
Springtime freshness, emerging blossoms,
Summer sunshine threatening gloom,
The autumn glory of changing leaves,
Winter and snow, the seasons please.

The tremor is here and will not go away,
But it will not conquer, as day after day,
I continue living the best I know how,
I don't wait for tomorrow, I do it now,
I thank God each morning for this life of mine,
I'm happy! I love! All will be fine.

Pat at a Hilo PD Support Group Meeting



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MJF 3rd Thursday- Off Time

The October 18 panel discussion focused on treating off times.... When, how, and why "off time" occurs.

This month's moderator, Brian Roberts, is an Associate Dean Of Communications at Ithaca College and Michael J. Fox Foundation Patient Council member who was diagnosed with Parkinson's at 30 years old. Other panelists include Barbara Howard, also a PD patient who is a retired Associate Dean of Business at the college, Dr. Sarah Horn, a Board certified movement disorder specialist and fellowship recipient at the University of Pennsylvania, and biotech entrepreneur and MJF Board member, Glenn Batchelder who provided input on the latest research relating to dealing with off time.

Glenn summarizes the crux of it all regarding dopamine replacement meds and off time. "It's a matter of paving the road smoother and filling in the pot holes."

Even if your PD related med/s are taken as prescribed, unexpected off time is not predictable. There are times between scheduled dosages when symptoms are not well controlled, and can happen gradually or suddenly. Also, as PD progresses, patients often become more sensitive to off time fluctuations.

Off time can result in the "long list" of PD symptoms. They can come in the form of both motor and non-motor symptoms including major fatigue, anxiety, balance problems, and of special note to caregivers...periodic grumpiness.

All of this said about off time, the dosage and timing of taking meds will likely change. Having regular conversations with your doctor about this is extremely important.

Much more was discussed that is of value to people with PD. You can access the October 18 webinar and previous programs on a host of important topics by going to the Michael J. Fox 3rd Thursday website. It's a simple process and a way to get the most reliable and current information possible.

The Davis Phinney Foundation is conducting a survey (1 per family) on the affects of off time on PWDs and their families. You can click on this link to take the survey <https://www.surveymonkey.com/r/HLQC9KL>.

The next MJF Foundation webinar is scheduled for November 15. The subject is "Research Year in Review and a Look Ahead."

Balance and Falls From WEBMD

Preventing Falls

- **Floors.** Remove all loose wires, cords, and throw rugs. Minimize clutter. Make sure rugs are anchored and smooth. Keep furniture in its accustomed place.
- **Bathroom.** Install grab bars and nonskid tape in the tub or shower. Use nonskid bath mats on the floor or install wall-to-wall carpeting.
- **Lighting.** Make sure halls, stairways, and entrances are well lit. Install a night light in your bathroom or hallway. Make sure there is a light switch at the top and bottom of the staircase. Turn lights on if you get up in the middle of the night. Make sure lamps or light switches are within reach of the bed if you have to get up during the night.
- **Kitchen.** Install nonskid rubber mats near the sink and stove. Clean up spills immediately.
- **Stairs.** Make sure treads, rails, and rugs are secure. Install a rail on both sides of the stairs. If stairs are a threat, it may be helpful to arrange most of your activities on the lower level to reduce the number of times stairs must be climbed.

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Preventing Falls (continued)

- **Entrances and doorways.** Install metal handles on the walls adjacent to doorknobs of all doors to make it more secure as you travel through the doorway.

Tips for Maintaining Balance With Parkinson's Disease

- Keep at least one hand free at all times; try using a backpack or fanny pack to hold things rather than carrying them in your hands. Never carry objects in both hands when walking as this interferes with balance.
- Attempt to swing both arms from front to back while walking. This may require a conscious effort if Parkinson's disease has diminished your movement; however, it will help you to maintain balance, posture, and reduce fatigue.
- Consciously lift your feet off of the ground when walking. Shuffling and dragging your feet may cause you to lose your balance.
- When trying to navigate turns, use a "U" technique of facing forward and making a wide turn, rather than pivoting sharply.
- Try to stand with your feet shoulder width apart. When your feet are close together for any length of time, you increase your risk of losing your balance and falling.
- Do one thing at a time! Don't try to walk and accomplish another task, such as reading or looking around. The decrease in your automatic reflexes complicates motor function, so the less distraction, the better!
- Do not wear rubber or gripping soled shoes, they may "catch" on the floor and cause tripping.
- Move slowly when changing positions. Use deliberate, concentrated movements and if needed, use a grab bar or walking aid. Count 15 seconds between each movement. For example, when rising from a seated position, wait 15 seconds after standing to begin walking.

- If you become "frozen," visualize stepping over an imaginary object, or have someone place their foot in front of yours to step over. Try not to have a caregiver or companion "pull" you, this may throw you off balance and even prolong the episode.
- If balance is a continuous problem, you may want to consider a walking aid such as a cane, walking stick, or walker. Once you've mastered walking with help, you may be ready to try it on your own again!

From a Person With PD's Perspective By Joel Cohen

As the co-editor of this Newsletter with my wife, Phyllis, I try my best to include information relating to PD treatment and research through credible sources such as the Michael J. Fox Foundation, the Davis Phinney Foundation, and other sources that come my way via e-mail and the internet. My intent is to help motivate people with PD and their care partners and to help motivate others to do their own research and build a better understanding of the physical and emotional challenges that they face.

I often state at support group meetings that I really appreciate the knowledge and sharing that others bring to the circle believing that I learn at least as much from participating in our open talk story discussions as I do during the long hours of listening to podcasts and reviewing the latest research updates from the medical community.

I often ask myself why are we doing this newsletter? What audience are we trying to reach? I asked myself these questions today. So, here are my general thoughts as spontaneously as possible.

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From a Person with PD's Perspective (continued)

Attendance at PD support group meetings in Hilo, Waimea, and now in Kona continue to increase. There are people, however, who cannot travel due to time, distance, lack of mobility, or just are not comfortable in being part of open discussion..some of which can be of a personal nature. Our hope is that the newsletter not only is of benefit to them, but also makes them feel a sense of being part of the big picture Parkinson's community that cares.

Parkinson's is usually composed of multiple symptoms with everyone having special individual profiles. Most of the research papers and webinars place more emphasis on motor symptoms and not enough emphasis on non-motor symptoms including depression and anxiety, (which is experienced by an estimated 50% of the newly diagnosed.) And then there are people--like many of us--who previously struggled with PD challenges and had not yet been diagnosed. Understanding this, I hope that people who receive this newsletter will act as knowledgeable advocates encouraging these folks to seek the professional medical help that they need.

So, what is my personal story behind this mission and vision? I continue to have increasing levels of challenges, both physical and emotional. AND by participating in support group activities, and helping build a community that promotes knowledge, I hope conveys my message of acceptance and a positive outlook. I wish for others to convey this message, too.

Please take care. Do your best. We are in this together!



PD Celebrity of Month- Kirk Gibson
By Joel Cohen

This is a story that long time baseball fans like me will remember about Kirk Gibson. The Los Angeles Dodger's outfielder, considered to be the best all around player on the team, injured his knee late in the 1988 season and was unlikely to be able to play in the World Series between the Dodgers and the Oakland A's. He could not run and likely did not have the strength and balance to hit a baseball.

So it's the bottom of the 9th inning in the first game of the series with the A's leading 4-3-- Two outs, a runner on base, and the Dodgers are on the edge of losing the game.

Gibson, literally, comes limping out of the Dodger dugout, to try to save the day. Future Hall of Famer, Dennis Eckersley was on the mound. He serves up a pitch, and Gibson's somehow remarkable swing launches the ball over the right field wall. It was a night to remember, and there are more stories to tell about him.

Fast-forward past his playing days, he became a coach with the Detroit Tigers manager of the Arizona Diamondbacks, and eventually offered the job as a broadcaster with the Tigers.

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PD Celebrity of Month- Kirk Gibson (continued)

During this period of time, Gibson had been seen by doctors for a variety of health issues for years. He and his doctors attributed many symptoms to the physical nature of his baseball career and to just getting older. Aside from an obvious limp when his left leg moved forward, other ailments included major fatigue, frequent anxious moments, and sticking his hand in his pocket so nobody would notice his tremors.

According to his bio, "Opening day 2015 in the Tigers broadcast booth is a day he will never forget. In preparation for the telecast, he was hit with great anxiety on camera that lasted throughout the entire game. During the postgame wrap up, he totally locked up and was unable to talk."

The time of acceptance of a progressing health challenge had come. With the encouragement of a good friend, the wake up call prompted him to see a neurologist two days later.

Gibson is now an advocate for others with Parkinson's. You can go to the Kirk Gibson Foundation website (www.kirkgibsonfoundation.org) to learn more about him and his Foundation's mission. There you will find more about his personal journey and the foundation's mission to educate others about PD and provide funding for research efforts to find a cure.

Newsletter Submissions

This is **YOUR** newsletter!! This Newsletter will not be sustainable without your participation. We **NEED** your personal stories about your PD experiences (e.g. affects from a medication or supplement, how certain forms of exercise has benefited you, how you've recognized and possibly, overcome, a challenge, etc.) – from **YOUR** perspective, whether you're a PWP, a care partner, a member of the medical community, or friends/family!!

Please email your stories to Joel Cohen at jcohen8@hawaii.rr.com and Phyllis Tarail at Phyllis.tarail@gmail.com by **December 21** for inclusion in the January edition.

Joel Cohen & Phyllis Tarail, writers/editors